October 2016

TBILOPE MAGAZINE

The Day our Lives Changed Forever

A Lifetime of Recovery

Turning the Tables on Brain Injury

AN ANNIVERSARY TO REMEMBER



TBI HOPE MAGAZINE

Serving All Impacted by Brain Injury

October 2016

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Welcome

Welcome to the October 2016 issue of TBI HOPE Magazine!

As we continue to move forward in our second year of publication, I marvel at how much the concussion landscape has changed over the last few years. Slowly, the Dark Ages, where concussion was rarely in the news, continue to fade.

We need look no further than our own back yard. When I was injured almost six years ago, my wife Sarah and I sought out a TBI Support group, only to find none in our local area. The nearest was over a hundred mile round trip away – a distance not practical in early recovery.

This past week, we attended one of our "regular" meetings and had the wonderful opportunity to support a new meeting across the border in Massachusetts. Both meetings were overflowing with survivors, caregivers, and family members with several first-time attendees. Support groups can and do save lives.

And I think about those new to this journey – and how more resources than ever are available. We still have a long way to go, but sometimes it's nice to look back for a moment – to see how far we've come.

David A. Grant Publisher

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"To live without hope is to cease to live." ~Fyodor Dostoevsky





Sacrifice. Strength. Courage. Hope. Struggles. Successes. Fear. Sadness. Those are all words that come to mind when I think about what it means to be a caregiver. It is a difficult role to take on, but I wouldn't change a thing. I wouldn't do one thing differently. I could have easily given up, thrown in the towel, let it be someone else's responsibility, and I was even told to do so by some very unforgiving family members. That is not me. That is not my way.

That was not an option. There was no way in this lifetime that I was going to leave him at a time when he needed me most. It just was not an option. My dedication, my loyalty...it never faltered, not once. I was painfully protective of him - I had to be his voice. I wasn't going anywhere, and I was sticking by him every step of the way. He was going to recover no matter what it took.

He spent six months in the hospital and I was by his side every single day. I spent countless hours researching and educating myself. I will admit I knew absolutely nothing about TBI until it abruptly entered my life and left me with no choice but to learn all I could, and that I did.

Below is a Facebook post that I made a few months after the accident, which best expresses how I was feeling at the time and how I still feel today.

Dated February 8, 2015:

What I have done and am doing is exactly what I was meant to do. The path I'm on wasn't in the original plans, just a different road now. If this is what God had intended for me and what is meant to be, then I wouldn't have it any other way. This journey I have been on has taken me places I never knew existed nor could I ever before imagine. It has been life's biggest lesson yet and God's true test. I am taking heed of your message.

At the time I was reading Healing Light on a daily basis to help me cope. This post I made was in response to a saying that I read and could completely relate to. "Today's Message — Did you know that regardless of what road you take...you're still going along your path? We may take different routes, but ultimately we end up exactly where we're supposed to be!" It completely resonated with me. For some reason, I found comfort in knowing that I was on the right path according to God. I didn't exactly understand where God was taking me nor did I like it. All I knew was that it just felt right in my heart and I had to trust that. As I reflect back on that time I have



no idea how I made it through or how I even survived. I know that I am not the same person that I was before the accident. I am still unable to describe it, but I am different somehow.

In the beginning, I was unsure of myself and of everything going on around me. This was new territory for me. I have always been in complete control of my life. But, not after the accident. I was no longer in control, and I did not know how to handle that. I felt so alone and isolated. No one could possibly know the fear and pain and shock that I was experiencing. I wanted to get off this roller coaster ride. I wanted to be on stable ground again. At the time, I had no idea of the severity of the situation, nor did I have a clue that it would be days, months, years, a lifetime of healing and recovery.

Researching all I could online and reading books made me feel like I was doing something. Hearing the stories of others experiencing a similar situation gave me hope. It gave me strength to keep going. I quickly put my 'big girl britches' on and learned what it meant to become his voice, an advocate. I jumped right in. I talked to as many people at the hospital as I could. I googled every medical terminology I did not understand. I learned

his daily routine, what all the machines were for, and asked what every nurse was doing to him. The hospital staff quickly realized my role and allowed me to be very much a part of his treatment. He did not have medical coverage at the time of the accident. I spent countless hours filling out forms, emailing, and making phone calls regarding Medicaid and disability. I had to speak with his social worker regarding placement. Choosing the right rehab facility was a scary and painful process.

I mistakenly believed that once he came home from the hospital that the storm was over. It wasn't. We held meetings regarding his discharge. That was scary. I relied heavily on the nurses and doctors to take care of him. Suddenly, that was going to be my responsibility. I was ecstatic to finally have him come home, but had no idea how I was going to do it. Prior to discharge, we arranged for a personal care



attendant who would be at the house with him while I was at work. We were also connected with a local agency that provides in-home therapy. Having all of those resources in place alleviated some fear, but not all. However, I could not have done it without any of them. They helped me navigate my way through uncharted territory.

Marvin and I quickly established a routine, a routine that consisted of management of many medications, therapy appointments, and doctor appointments. The paperwork, emails, and phone calls on his behalf, continue at a steady pace. Being his caregiver is exhausting. I am also his legal guardian, which adds extra paperwork. It has been overwhelming at times as I continue to work full time. I do try to take care of myself the best I can. I have learned to accept things as they are and always remain hopeful. The storm is never truly over. It just becomes easier to live with. Not easy, just easier.

More about Tiffany Gross

Tiffany shares, "Marvin and I have been together 16 years. He is my best friend, my soul mate, and now my hero. On October 4, 2014 he was in a horrible car accident. It left him with severe head trauma along with many other injuries. He was in a coma for 2 weeks and remained in acute care for 9 more weeks before moving on to the rehab hospital. What he has accomplished is nothing short of a miracle. We were told that he had a 10% chance of waking up, and if he did wake up, he would be severely disabled. He has proven all of them wrong!"



Turning the Tables on Brain Injury

by Jeff Sebell



We all have been in a situation where other people don't understand us. Sometimes it's as if they are listening with half an ear. This thing we call brain injury is just so hard to communicate to others in an impactful way. Why do we get so upset when this happens, and what should we do about it?

Peoples' Words

One reason we get upset is that the way people react to us only amplifies that voice in our head that tells us we are worthless or not deserving. We take what they say personally, as an attack on our being, because they make us feel as though we don't even deserve human kindness or that we shouldn't exist at all.

When we take others' words to heart we are stopped from feeling better about ourselves, even when we are making positive strides and moving on with our lives. The truth is, much of our self-worth is derived from relationships with other humans: it is hard to overstate their importance to our well-being.

Rightly or wrongly the way we view ourselves is influenced by how others react and interact with us. And it's not just casual acquaintances. The people we expect to be the most understanding and compassionate, our close friends and relatives, can sometimes be the last ones to give us a break or to make an effort to understand.

Not only have we had our lives turned upside down by brain injury, we have to figure out a whole new way of relating to people and getting support; a tall order given what's going on with us. Often we are left asking ourselves this question, "Why?"

A Little Make Believe

Let's play a game of make-believe, so we can perhaps understand better why people react to us the way they do.

In this game of make-believe, you are walking down the street and you come upon a friend who is walking towards you. Now, what do you think your friend is thinking as he/she approaches you? Put yourself in this person's shoes for a moment.

This person might be uncomfortable. Maybe he has concern or pity for this friend he's approaching (you), who seems to be a little "off" since he was in car accident. Maybe he doesn't know what to say or do; he just doesn't know how to be a friend in this situation.

In his own mind, he really just wants to help but doesn't know how. At the same time, you, who experienced a brain injury, can't understand why things aren't the same as they used to be.

What we have in this situation, is two people, friends, who have good intentions but don't know how to interact with each other anymore.

"In his own mind, he really just wants to help but doesn't know how."

Helplessness becomes awkwardness. Sometimes, ugly things are said out of desperation or ignorance. Sometimes, things that are said are interpreted differently from how they are meant, or offhanded remarks are taken to have a great meaning. Often things escalate and get out of control.

Basically...

We all need to realize that while you have experienced a traumatic injury and your friend has not changed, the dynamics of the relationship has changed. The ground rules have changed for the relationship that was once there. In the back of your mind is some expectation that things will be as they always were, and your friend will be there for you and assist you in the transition back to normal life.

However, just as you have an invisible injury, your friend has an invisible conflict in his mind, and must deal with the confusion about how he is supposed to act. We would like things to be as they always were, but, whether we admit it or not, we have changed. Many times we blame others for not being there for us, forgetting about the role we play.

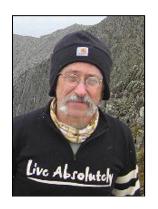
They are unable to see what's going on with us, just as we are unable to see that it is hard for others to adjust to the changes we have undergone. No one has been trained on how to live their life after brain injury, while at the same time, no one has been taught how to resume a relationship with someone who has had a brain injury.

This new reality is difficult on both sides, but perhaps we can make it easier by turning the tables and looking at it from their perspective. That is, instead of looking at what they can be doing for us, we can look at what we can be doing for them. Sounds kind of kooky, but we need to realize it is not all about us and our needs, it is about the two of you and what the relationship needs.

Nobody is right or wrong. We are all just trying to get by, the best we can, and perhaps the way for them to be more understanding is for us to be more understanding first.

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.





I often wake and wonder, is today the day?
Will things fall back into place, to help me find my way?
You see, my mind has faded, my memories and words are tossed.
Some are mixed around, others completely lost.
My girls, they giggle and tease me, lightly joke at the comments and thoughts at the things they hear me say each day, some corrected, and at some they are lost.

If I don't think about my ailments, I can sometimes find the old me.

But if talking in crowds, or am shopping, it doesn't take too long to see.

There's something not right with the new me. She's tired, and aches, and is scared.

Scared of stumbling or saying the wrong thing, with the mixed up confusion she's shared.

I used to be so good with words, in sharing my heart of all hearts. A carefree and spirited woman, from the fun wished to never part. I aimed to bring joy and laughter, was never afraid of a crowd. Now I am quiet and guarded, afraid of the movement and loud.

Noises and lights and the movement, they all make my head spin so fast!

I've worked really hard now for ten months but have not learned to completely adapt.

My head aches as if someone has hit me, it throbs and stabs in my brain.

And no one can see what is happening, all they see is the old me by name.

The girl who mud bogged and kayaked, always just one of the boys.

She could hunt, fish, hike and make a mean whiskey, she loved nature and playing with toys.

She nurtured all children, and always encouraged others to call her place home.

And now she just naps and rests quietly, in the few memories left she will roam.

I want to show others I'm still here... that girl that they loved through their years. But how do I show them what's happening, when I am tangled within my own tears? Fear that she's trapped forever, in the ice of her TBI. Fear that her wings have been clipped, caged in the blink of an eye.

I get angry and ache for the girl I have grown to be for 35 years.

How can I get through the ice to embrace her, to prove wrong all of these haunting fears?

I see the sadness in my girls' faces when they are reminded that I'm not the same me.

It kills me to know they are growing to learn to live without me.

A mother should be with her children to support, always cheering, to guide.

But now I have to rest and plan often, after events I can get to, I hide.

My body, it aches and it quivers, my mind often gets lost in the noise.

There is no amount of makeup that can keep me cool and collected with poise.

Some, they see the shell of me sitting, they really cannot simply see how I am feeling so lost and different, they just want me to be the old me. I would give anything to shake this big weight that looms over my body these days. And run in the puddles, to be carefree... if only I could find the way.

I'm thankful for those that can see me, the ones who stuck by through my pain. The ones who have seen me through my healing, who do not just expect me and my name. There's so much that has changed and haunted, there's a long road ahead still to come and each day I get up and walk it... from TBI one cannot run.

My birthday is spent with the doctors, with therapists and those who help heal and every day before and after, right now it is part of the deal.

My life is surrounded by big words, clinical thoughts and scans to see if my brain will start working again with my body, my eyes and my hands.

The goal is to get me back working, to be independent and free. That's what all of the specialists' goals are, but I just really need me! I work towards all of the healing, watching her trapped in the ice waiting to see the melt come... oh my god, to be me would be nice.

So today as you ramble or work hard, or call me to shoot the shit remember it's not being lazy, why in my quiet home I sit.

I'm healing and struggling to get through this burden on me that was placed.

I know you get tired of hearing everything that I have faced.

It helps me to heal and to know though, that maybe you understand what is happening inside my body, to my eyes, memories and hands. I miss her, that girl that I once was, and I know that you do too. I hope that you can stick by me, while I find her for me and you.

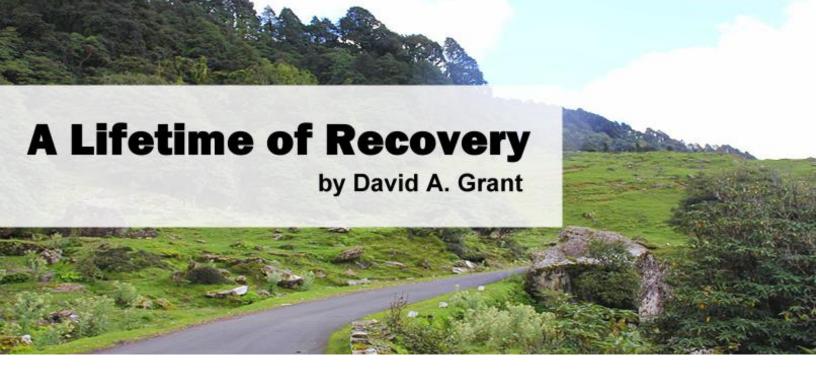
Meet Amanda Isley

Amanda is a first-time contributor to TBI HOPE Magazine. It is her hope that by sharing her own experiences as a brain injury survivor that she can help others to know that they no longer walk alone after traumatic brain injury. We are looking forward to future contributions by Amanda!





http://www.facebook.com/TbiCaregiverSupport



Early on, in the months after I sustained a traumatic brain injury, I heard a saying that I am now quite familiar with – recovery from a brain injury lasts a lifetime. While so many have found this to be encouraging, I did not. In fact, the very concept appalled me.

Before being struck by a teenaged driver back in 2010, I spent many years in Corporate America and went on to start and run a successful web design and business marketing company. I lived in the reality of hard and fast deadlines. Projects had a start date and a firm completion date. Always one to meet committed project completion dates, it was a safe bet to say that projects began and ended on time. My corporate clients counted on me – and I consistently delivered.

So this concept of something that had no end date, no date to circle on a calendar, something that would go on as long as I had a heartbeat was NOT something that I embraced. Taking it one step further, I made up my mind early on that I was going to be that one-in-a-million person who recovered back to 100%. I was going to get back to where I was before my accident.

Fast forward to today and time has shown this to be a fallacy. My 2016 reality is vastly different than my 2011 reality. Now well into year six as a survivor, I have found that I am a very average "TBI Guy." The challenges that I face today are in lockstep with the millions of Americans who live daily with the long-term effects of a concussion. Typical of so many, I have ongoing memory challenges, often more significant than most realize.

Word-finding challenges and aphasia are my constant companions. Add a splash of vertigo and half a cup of tinnitus and you have the perfect recipe for a pretty average post-concussive life.

And amazingly, today I am okay with that. All I really need to do is look around me to see that although challenging, the after-effects of my accident pale in comparison to those faced by other survivors.

I am able to work, albeit at a reduced pace. I can walk on my own and drive a car. My marriage survived – not always a guarantee after trauma strikes. I have a smaller circle of souls who love me unconditionally. When I take a step back to look at my life through the prism of this perspective, I can easily see that I am blessed beyond measure.

In a recent conversation, my wife Sarah and I discussed reaching out again to the medical community. My last experience with the medical community was less than stellar.

A well-intentioned doctor let me know in no uncertain terms that after the one-year mark, any meaningful recovery was over, and any gains to be had would be minimal at best. It was a harsh life sentence, it was discouraging, and it was wrong. I hold no



ill-will toward this doctor as he was doing the best he could, though he was part of the TBI old school of recovery, one that is quickly being replaced by new science-based treatment.

Over the last few years, there is an emerging body of hard data—factual information—that brain injury does indeed continue for a lifetime. New treatment protocols are evolving for what is called "late stage recovery," meaning recovery that is tangible even many years after an injury.

This brings me full-circle to our choice to reach deep into the medical community again. It is my hope that I'll be able to tap into some of the newest information available and use it to continue my own recovery.

Gone is that feeling that a lifetime of recovery is something to be dreaded. A new hope has emerged that I can continue to make more gains, like the gains that have already come to pass over the last five years. I fully understand now that the brain is plastic, and not elastic. It won't bounce back to where it was. Rather, as remapping continues, and neuroplasticity works its silent wonders, I will continue to grow, to evolve, and to become who I am supposed to be.

Meet David A. Grant

David A. Grant is a freelance writer based out of southern New Hampshire. He is the author of Metamorphosis, Surviving Brain Injury. David is also a contributing author to Chicken Soup for the Soul, Recovering from Traumatic Brain Injuries. David is a BIANH Board Member as well as a member of the Brain Energy Support Team Board of Directors. David is a regular contributing writer to Brainline.org, a PBS sponsored website.





'Let your hopes, not your hurts, shape your future."

~ Robert H. Schuller



Often times the worst part of dealing with TBI is my own thinking. I have been dealing with the effects of a motor vehicle accident for a little over a year and a half. Nineteen months is a long time past, "Take some Tylenol. You will feel sore for a few days, but are fine otherwise."

Lately, I have tried to stop my negative thought patterns BEFORE they get out of hand by practicing awareness and saying, "Reframe it."

For example, when I begin feeling sorry for myself for not being able to listen to music like I used to, especially while driving in my car, I reframe that thought into, "I am so lucky that I have been introduced to podcasts. Without my sensory issues, I never would have been introduced to such a variety of podcasts." I am hooked! I begin my day in such a positive way by listening to the upbeat messages, and many of the podcasts have led me to read books I never would have read otherwise.

My inability to socialize in large groups as often as I did in the past, has been reframed into, "I am fortunate that I am connecting with nature." I make it a point to walk on the beach more often. I have found different green spaces and have benefitted from forest bathing. I also have enjoyed putting bird feeders and a birdbath in my yard which I can watch while on my deck.

The reframe for "I can't take this migrainous head pain!" has been "My wellness journey has led me to getting massages and using supplements which have led to the best blood work in my life. I can't wait to see where better nutrition and exercise take me."

Not being able to accomplish all I used to be able to do at a constant pace has led to me to frame the question, "On what things will I spend my time and energy? What projects and people bring light into my life or are necessary, and what things can I let go?"

Increased anxiety has led me to reframe awareness of stress into, "My body is letting me know I need to create today!" I have found that making time for journaling and painting is a good release and I naturally relax as I create, just for the sake of creating.

Finally, one of my favorite reframes is, "I can't wait to go upstairs to my bedroom!" I was spending so much time sleeping and resting and hating every second of it. Once I purchased a fluffy mattress pad, new pillows, expensive sheets and new lamps, an experience viewed as a punishment is now seen as a treat.

Take the time to be more aware of your thinking. The next time you find yourself beginning to think negatively, try to reframe that thought into a positive one. The more you practice reframing your thoughts, the easier it becomes. Your brain will thank you!

Meet Amiee Duffy

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





It's taken me over four years and many hours of counselling to accept my new me (most days). I made a list of things that make me feel better and I am hopeful that some of these things resonate with you and might help you through those bad days.

Sunglasses and Headphones - Bright lights, glare and ambient noise became my instant enemies starting with the day of my injury. Bright light and ambient noise cause me physical pain.

I found my brain got tired very quickly in bright light/ambient noise environments. I began using sunglasses and headphones to go grocery shopping, because it was so hard for me to shop with the bright lights, many signs, and sounds of music and people. In my headphones, I play calm, soft music and it made trips to the grocery store easier. Then I started using the headphones at home and started feeling better too. Now I wear the headphones to watch TV too. I'm pretty much in headphones whenever I'm not speaking with someone. It helps to cut the ambient noise and I have less neuro fatigue and fewer and less strong headaches.

Alone Time - Even though I am a single mom of an adult son and I don't work anymore (I am on disability), I find that alone, unplugged time seems to evade me. Until, that is, those days that I have monster migraines. Then I am forced to unplug, turn off lights and spend some time alone with my thoughts.

What I learned from the bad migraine days is I need to unplug before the migraine happens. I do it at least once a week, and some days, once a day for an hour.

By "unplugged", I mean no TV, no phones, no tablet, no computer, no music - just sitting quietly for at least 15 minutes. This is different than my meditation time. This alone time is "me" time. If I choose to be sad, I cry. If I choose to be happy and wonder in the beauty of nature outside my window, I do so. It is 15 minutes to half an hour spent doing nothing. That could be laying in my gravity chair watching the clouds, or lying in my bed in the dark relaxing, allowing my thoughts and feelings to go where they go.

During my alone time, I never tell myself I am wrong to feel how I am feeling, I just try to feel it. If I have negative emotions, I tell myself it is ok to feel this way for 15 minutes, then I must let it go for today.

... And that is OK. - With my TBI life, I find the little things seem to bother me more and make my anxiety levels higher. I have learned to say "...and that's OK."

If I hear, "Mom, the car is making a strange noise." I say, "that's OK, I am sure it is not major. Let's take it in tomorrow." Somehow, by saying "that's OK", I feel better.

I can't walk well today ... and that's ok, tomorrow will be different. I'll just take it easy.

... And that's OK has changed the way I think. Instead of getting really upset because something bad has happened or because I can't do something, I say ...and that's OK, and somewhere in my brain, it is. I can't explain it. Try it ten times to see if it works for you. It truly has changed my life. My anxiety level is down, I'm not worrying as much, and believe it or not I'm actually sleeping better on the bad days.

Meditation - Guided meditation works incredibly well for me. I feel lighter, safer, and more in control.

Before my injury, I used to walk over 4 km to work and back every day. I have visual over-stimulation issues, balance and mobility issues, and now walk with a cane. I can't walk very fast or very far before the visual stimulation is too much for me and makes me dizzy.

I've worked up to about half an hour of walking very slowly which, for me, is about five blocks. By using the techniques I've learned through meditation, calming my thoughts and breathing, I'm able to walk farther, and I'm ok with the fact that I can't walk as far as I used to. I'm coming around to accepting my limitations. Meditation has taught me how to stay calm when I feel like I'm going to lose it.

Grounding / Earthing - When I first learned about grounding, I was skeptical. I didn't realize that through my whole life I had been grounding naturally. Grounding, in a nutshell, is the act of feeling our feet connected to the earth. There's plenty of information on the internet, if you're interested in studies and data.

From May to October as a child, I only wore shoes when I absolutely had to: going to school, during riding lessons or going into a store. Otherwise, I was always barefoot.

Now, as an adult, I am barefoot still, until it's too cold to go without socks and shoes. As soon as the weather warms up, I'm barefoot only wearing shoes when I go into stores, etc.

My physiotherapist suggested walking barefoot, while using my cane, on various different surfaces, to help my brain relearn my body's position on the earth. I have serious visual processing issues and balance issues, so as I understand it, that means my

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brain and my eyes are not communicating with my body to keep me upright in space.

When I was first injured, I was afraid to go without shoes, since my balance was bad and I felt safer with my shoes on. When I started seeing my physiotherapist, it was February and it was much too cold to walk outside without shoes, so I didn't start until approximately May. I definitely remember the first time I did it. It was a nice day and not too bright. I took off my shoes, went outside into my yard and walked around. I instantly felt better! The feeling of the grass between my toes, the earth under my feet, and the cool cement changed me somehow. I can't explain it. I actually felt better without shoes.

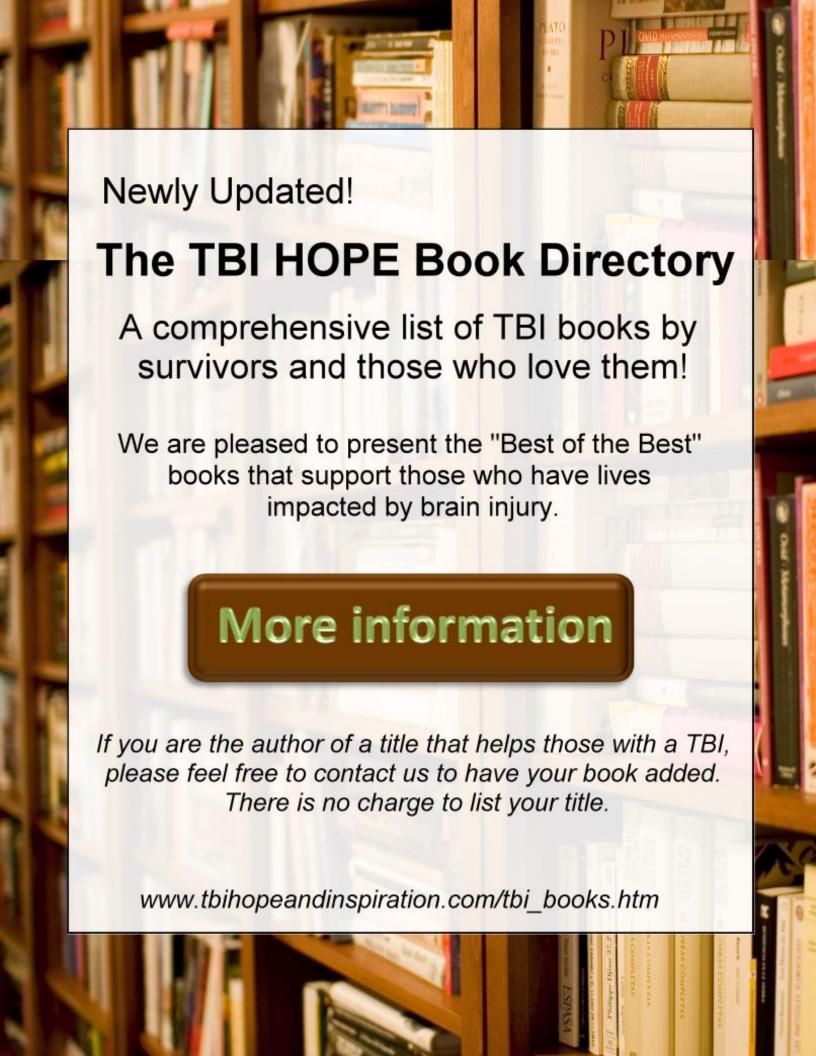
Now I am back to only wearing shoes when it's too cold not to. Try going barefoot and let your feet feel the ground.

Networking – Join a Facebook group or go to a TBI support group. As my dad always said, it could be worse. I get my motivation from those who were hurt worse than I, but overcame. All of our injuries are unique. I find solace in knowing others are in the same boat as I am, and are struggling or succeeding in a similar way to me. It helps me to not feel so isolated.

Meet Lori Lee

Lori Lee is an essayist and horsewoman having ridden both English and Western. She is hoping to get back in the saddle next year. She is currently on disability and working hard on her recovery. She is getting back to her writing and moving towards being a life coach and advocate for adults, children, and families with TBI or anxiety and depression.









"I don't believe people are looking for the meaning of life as much as they are looking for the experience of being alive." ~Joseph Campbell

Stories of Survivor Recovery

It has taken me a while to figure out in what context to frame why I wanted to pull this book together. Why, in the middle of my own survivor recovery from trauma, would I start to think that Concussion and Mild Brain Injury: Just Another Headline was a good idea at all? Over the last few years I have had many gifts bestowed on me. Yes, some are the kind you can hold in your hand.

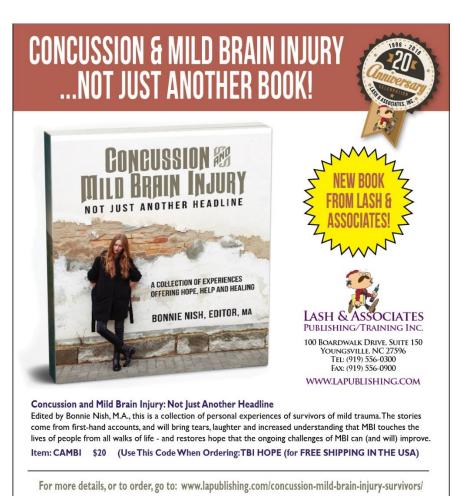
Others however, are more cerebral and the kind you hold in your heart. Tonight I couldn't find my keys, and for an instant I could feel my stomach turn when I remembered last week having left them in the door for hours. It wasn't that I was worried someone would walk away with them and use them later, it was that it was so reminiscent of a time in my life when I wouldn't even have remembered putting them in the door in the first place.

This knowing that I could remember something so small as leaving my keys in the door last week was a gift, something I am so grateful to have and something I will never again take for granted.

Not Taking on Every Problem

Sometimes as a writer working through survivor recovery, I think I need to write something so big that it takes on every problem that needs to be answered. I can forget that small things are just as interesting and of vital importance as well. While concussion and mild brain injury are not small subjects, they are injuries that affect not only the biggest but also the smallest of details in an individual's life. I know.

After sustaining two mild traumatic brain injuries in just over a year, my life was turned



completely upside down. For a writer, there can be nothing more frustrating than losing the ability to think creatively and not to be able to put pen to paper, or worse, not to be able to find words at all.

As someone pursuing an academic path, not being able to remember that I had even read certain books was absolutely terrifying. For nearly two years I couldn't even be in a room with more than a few people at a time. I couldn't eat anything other than grapes and mandarins for months. Every single aspect of my life, big and small, was affected.

In my time of crisis at the start of my survivor recovery journey there came many other gifts that I never

expected. There were the individuals who drove me to doctor's appointments weekly, or the friends who came to visit and ended up assembling a table.

There were the people who organized a food tree and then those who sent food. And the family who stuck by me whether I was crying, or hurting, or falling over. A whole community came together for me. I can never forget this. It helped me to remember I was alive and still in there somewhere, even in the darkest of times.

My Hope to Give a Gift

My hope is that <u>this book</u> becomes a gift for you in your survivor recovery journey. That if you are alone you can pick it up, thumb through the pages and get to know us a little better.

I hope that you find lightness here and community. Most of all, that even if it is just for a moment, you have the experience once again of 'feeling alive', and finding yourself.

Why did I do this? Simply put, because I could and that has to be the greatest gift of all.

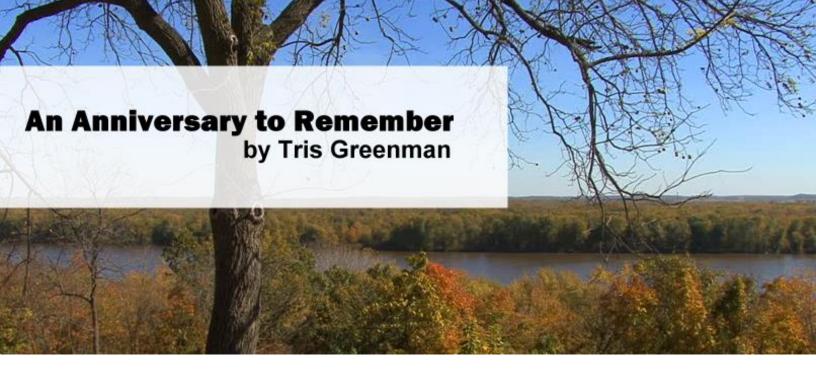
Meet Bonnie Nish

Bonnie Nish is founder and Executive Director of Pandora's Collective Outreach Society a charitable organization in the literary arts based in Vancouver British Columbia. She is also Executive Producer of the Summer Dreams Literary Arts Festival, an outdoor festival now in its tenth year. Bonnie's newest book, "Concussion and Mild Brain Injury: Not Just Another Headline," is now available.



Please Consider Sharing our Publication B H O P E

WITH A FRIEND OR COLLEAGUE



Tim and I recently passed our 11th wedding anniversary with little celebration. We were married 5/5/5 and always high-fived each other if we saw 5:55 on the clock, or other such nonsense. Our lives revolve around another date now: 6/22/13. This is the date Tim was struck by a utility vehicle that ran a stop sign. His injuries were so severe, he was not expected to live. By some miracle he did survive, but suffers from major TBI. We now measure our life together as 'Before accident' and 'After accident'.

Before the accident (BA): Hard working, fun-loving, friendly, joking, considerate, helpful, grateful, and happy.

After the accident (AA): Tired, sore, suspicious, angry, distrustful, mean, unreasonable, and unhappy.

Surviving TBI is hard work, every day. Every day Tim must get up and face another day in pain and confusion. Early in the morning is a slow time. He often does not know me and asks for his mother. He needs help getting dressed and out to his shop with coffee, where he wakes up slowly. We review where we are, how we got here and what is going to happen today. Notes are made so Tim has reminders of things he can do throughout the day to stay busy and whether or not he has therapy or doctor appointments. We don't do well with surprises.

BA: NO PILLS. Both of us avoided taking medications. Sore muscles got Bengay, upset stomachs got soda water, and only bad headaches got an occasional aspirin.

AA: PILLS ARE OUR FRIENDS. Since Tim's brain cannot produce the right amounts of the various chemicals we all need to function, he takes a host of medications. Anti-convulsants, antidepressants, psych meds, pain meds and then all of the meds to combat the myriad of side-effects from the above meds, including nausea, dry mouth, sleepiness, insomnia, constipation, diarrhea. It has taken months to find the right combination of type dosage and to keep Tim functioning at a tolerable level.



Reconciling our lives from what they were to what they are now is

hard work as well. I believe I have a harder time of it than Tim, as I remember. He does not. He can remember very well up to about 1985, but then it becomes hit or miss. He does not remember most of our married life, including trips to Yellowstone, fishing tournaments, major home improvements we've made, or me finishing my degree two weeks prior to his accident. I didn't get to go to graduation. My diploma was sent in the mail and sat unopened on the table during his two-month-long coma. He helped me get that diploma. He took up my chores around the house and yard so I could study and write papers. It's as much his as it is mine. I miss him so much.

BA: BARRELS OF MONKEYS. We were truly goofballs. Practical jokes, April Fools, laugh-till-we-cried moments that I still chuckle over now.

AA: SILENCE OF THE LAMBS. Now we have to say what we mean, no sarcasm, no play on words, no puns intended. He cannot get jokes that are told and feels when someone laughs, they are laughing at him and at 'how stupid he is'. I have always subscribed to laughter being the best medicine, however, this is one med he cannot take.

I now get my laughter away from home with various friends and co-workers. Re-telling the stories of the hardships I have at home and 'laughing' about the latest Tim story. Tim putting on 4 sets of clothes to go to the doctor. Tim telling me I look like a clown after my hair appointment. Tim calling the police and accusing me of trying to kill him with my garden shears. Funny stuff? No, but it beats breaking down in tears every day. I get up each morning thinking today will be the day my husband finds his way over to me.

BA: I AM NOT A NURSE. I am an accountant by profession. Numbers make sense to me and can be filed away at the end of the day. I could never see myself having the patience and wherewithal to nurse someone through a lengthy illness. It takes special people to be in the healthcare profession.

AA: I'M STILL NOT A NURSE. I am a caregiver by fate. It's exhausting, stressful, limiting, and completely necessary if our household is to get through another day. Dressing, feeding, medicating, monitoring, bathing. Rinse, repeat.

To cope with this second profession, I am learning to let go. It is a big step for someone who has always thought of herself as strong and independent. There are agencies out there who will give respite breaks to caregivers, friends who want to help out, family members who are available to lend a hand and I take it. I get away. I try not to worry about what is going on back at home and I live. I am just now learning to lose the guilt factor that comes with seeking enjoyment in life without my husband. It is a necessity if I am to go on keeping Tim at our home. I matter. I do. Till death do us part. 5/5/5.

Meet Tris Greenman

Tris is caregiver to her husband, Tim, in Southwest Michigan. She finds writing down her experiences with Tim's TBI cathartic and hopes other TBI caregivers find hope and inspiration in knowing they are not alone.



TBI HOPE Back Page

A few weeks ago, a reader asked me about a topic that I had written about a several years ago. And while I do recall the piece that I wrote, I had a bit of a challenge recalling where it was published.

Over the years since my injury, I've written a lot about life with a brain injury. There are a couple of books that have my name on the cover, a compilation book that my wife Sarah and I produced earlier this year, as well as several hundred articles. From Chicken Soup for the Soul to my blog, from Facebook to many print publications, when I step back and look at how widespread my articles have become, it's just amazing.

This month, I started what I fondly call "The Inside-Out Project." Over the next couple of months, I'll be compiling all my written work online in a searchable database format. This is no small task.

Why is this important?

Try this: If you (like me) have occasional challenges with aphasia, you can search our new article database for "aphasia" and read only articles related to aphasia.



Want information related only to PTSD? You'll be able to find that. Our new search function will search ALL prior issues of TBI HOPE Magazine as well. You can read about others who share the same experiences.

I'll be posting updates as we move forward. It is our hope that this becomes a useful tool for the concussion/TBI community.

David