

January 2017

TBI HOPE

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MAGAZINE

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TBI HOPE MAGAZINE

*Serving All Impacted by
Brain Injury*

January 2017

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Welcome to the January 2017 issue of TBI HOPE Magazine!

Living life as a brain injury survivor means constantly evolving. New compensatory strategies are learned, and the lifelong process of recovery will continue for as long as there is a heartbeat.

Our publication continues its evolutionary process as well. From the introduction of our new cover design last year to this New Year's issue of TBI HOPE Magazine, changes abound!

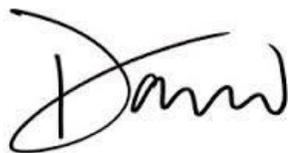
While first-time readers won't even notice, our regular readers will see many changes in this New Year's premier issue. We've introduced a more stylized look, easier to read text and an exciting new layout.

Of course, the features that have made TBI HOPE Magazine the largest publication of its type will remain. You can expect the same reader stories that you've come to love. Our cartoon mascot Hope with her occasionally present companion Faith will still grace our pages.

TBI Hope has grown to be bigger than any one person – it is a true community compilation and a reflection of where we are going as a community bound together by a shared fate- brain injury.

I'd love to hear what you think about our new look. Please feel free to email me personally at david@tbihopeandinspiration.com and give me your feedback.

It is our hope that this issue brings you a bit of hope and inspiration as we start a new year!



David A. Grant
Publisher

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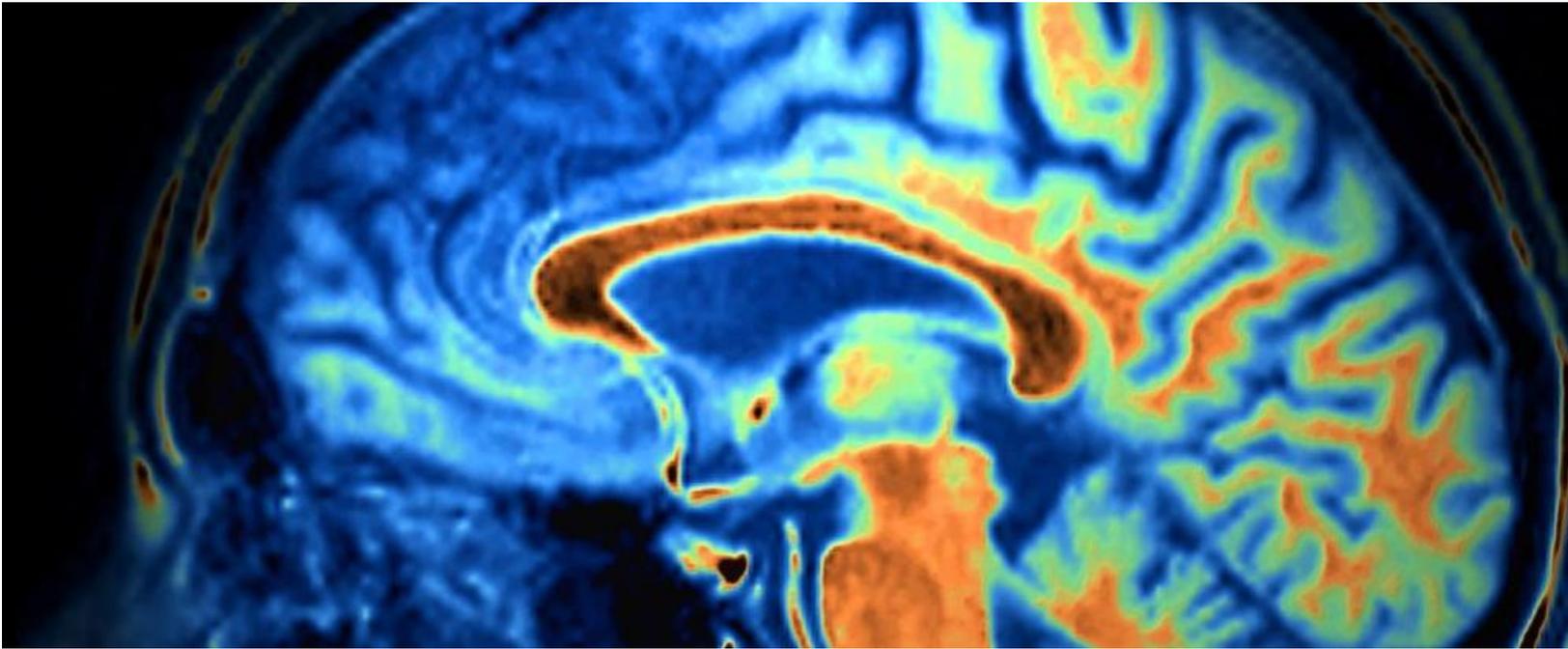
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*Brain Injury Recovery is
a Lifelong Process*



Touch your Nose

By Nancy Hueber



I first learned about neuropsychological testing more than a decade after my craniotomy in 1996 for a 6 cm meningioma (brain tumor). For twelve years following my brain surgery, my husband Tom and I would drive a four-hour round trip through northeast Missouri for an annual check-up with a neurologist. “How are you today, Nancy?” “Fine, thank you.” “Any new symptoms to report?” “Ummmm....no.” “Ok, touch your nose with your right index finger. Good. Now touch with your left. Now, walk a straight line and back.” (Then, the whacks below the knee for reflex testing, followed by the ticklish safety pin grazing the bottom of the feet.) “Okay, well, let’s have you come back in one year,” and so we’d begin the neurological “Lather, Rinse, Repeat” dance, which lasted for twelve years.

How was I to tell the doctor I saw once a year, that I had memory problems? I forgot to tell him! How was I to remember to show the doctor the bruises from bumping into things? I forgot I had them! Sometimes, depending on availability, I was seen by a

different doctor. Besides my memory issues, my family, particularly my husband, was too busy and exhausted from working and caregiving to notice the changes in me over time.

Much of brain injury, in terms of cognitive deficits, reveals its ugly head (pun unintended) over time. The disconnection between the lifesaving brain surgery and the “what-do-I-do-now” life after brain injury/surgery astounds me. But for those survivors and caregivers in the thick of it, simply surviving life characterizes the theme of most days. We’re too busy navigating through our obstacle course called “life” to recognize that we’re truly dealing with the road blocks called “deficits”, which we didn’t have before the injury.

My own story of surviving brain injury began with the development of that near baseball-sized meningioma which impacted my short-term memory, sense of space, peripheral vision, and sequencing--among other things. Most of these symptoms appeared AFTER the removal of the tumor. As a 35 year-old mom of a three year old at the time of surgery, I experienced such incredible relief to be rid of the tumor and on the path to wellness and life, that I didn’t even question why my preschooler would beat me every time we played the Memory Game. I thought I was absent-minded and dumb for not remembering all that she would tell me from day to day.

I gave birth to a son four years to the day after I was told I had a brain tumor, and the Forgetful Clumsy mom story continued (as did losing the Memory Game with another child). Brain Injury, folks, doesn’t announce itself with a marquee on your forehead. It can sneak up on you and bite you one nibble at a time in everyday life. I was forgetting numbers, faces, names, and directions. (This was maybe the normal outcome of being in my fifties, and

“

***I thought I was
absent-minded
and dumb for not
remembering...***

”

being assured by too many people that, “oh, that happens to me all the time!”)

The list went on: losing track of time and being late, much more than before the injury, and forgetting words much more often, needing to lie down and rest the brain, getting bruises on one side of my body from banging into furniture I didn't notice. Falling down inexplicably. Being overwhelmed by crowds or sounds or bright lights. Frequent headaches or overall head pressure (some have nicknamed it “barometer head”).

Eventually our own little town had its first neurologist. A brilliant man, who tested my memory and balance and went on to recommend a neuropsychological evaluation. Overwhelmed during that several hours-long testing, I cried and rested my head on the test administrator's desk. How was I supposed to remember all the stuff he just said to me? What's wrong with me? What's wrong with this test? Why must I be subjected to such humiliating testing?

Why? So that I didn't have to feel crazy anymore. So that my loved ones would realize, in fact and in print, that I was truly changed by brain injury, no longer just clutzy or forgetful, not intentionally lazy or late. So that my medical team would have all the information they needed. So that I would receive the proper medications. So that everyday life could be ordered according to more specific needs. So that our family could function and thrive on the same page.

Post-Its and white boards became central features in our home. I do believe we still live today in



“Post-Its and white boards became central features in our home.”

much of the same “pioneer days” of brain science through which I stumbled and crawled from 1996-2008. Technology has created tremendous, life-saving diagnostic equipment and surgical procedures since then; and yet, the sharing of information regarding SURVIVING brain injury hasn’t exactly advanced by leaps and bounds. At least it didn’t for me. I am thankful for the Internet and how it opened my eyes in recent years to the support groups which have sprung up, for the information disseminating in every direction concerning brain injury and where to find a doctor, medication discussions, and support groups or websites on just about any type of injury or tumor or stroke.

As a result of our own clueless decade and the confusion and isolation of never meeting other brain tumor survivors and their caregivers in our neck of Missouri woods, my



husband Tom and I established a brain injury support group four years ago, eventually affiliating with the Brain Injury Association of America. One of the astonishing things we discovered in the years since then was that many brain injury and surgery patients in our group (we average 20-25/month) had still not learned of neuropsych testing after years of living with their brain injuries. Our support group consisted of accident victims (TBI), post-concussion survivors, and acquired brain injuries (ABI), such as tumors, strokes, and aneurysms.

My husband, a college professor, had discovered that one of his university students struggled with concentration and memory issues, as well as fatigue, and that this same student had experienced multiple concussions as a soccer goalie and through an accident. Her doctor back home had treated her for ADD, not realizing her problem

stemmed from brain injury. He treated her symptoms, but in the cases of these group members and the college student, neuropsych testing eventually revealed post-concussive syndrome, memory impairment, and many other life-altering deficits.

Thankfully, brain-injury survivors and their families can be made aware that neuropsych tests are available and helpful for diagnosing and treating the problems related to brain injury. For the college student of my husband, the diagnosis of post-concussive syndrome brought educational allowances like extensions on homework, longer testing time, and more importantly, the realization that she wasn't crazy or "ditzy." For the woman in the group surviving from two brain cancer surgeries who didn't have a neurologist for several years after surgery, neuropsych testing provided proof of memory impairment for her caregivers, and showed them the need for household help and a walker for her lack of balance.

No one should have to live for years without a neuropsych evaluation following brain injury. Through my own struggles to find the help and support I was needing over more than a decade, I could clearly identify the lack of knowledge and help which these folks so desperately needed. My hope and desire will continue to be that the brain-injured community will be exponentially more informed of the help available to treat their symptoms and deficits, as well as their resulting emotions, and that they will no longer have to walk alone...or in a straight line once a year.

Meet Nancy Hueber



Nancy Hueber, a professional pianist, wife, mother, and frequent visitor to her couch and bed, survived a near baseball-sized brain tumor (meningioma) in the middle of her brain, and its removal by craniotomy six days later. In 2012, Nancy and her husband Tom established a brain injury support group in their town in northeast Missouri, now affiliated with the Brain Injury Association of Missouri. Their monthly meetings average 20 attendees, both brain injury survivors and their caregivers, with injuries received from brain tumors, strokes, aneurysms, accidents and/or concussions.

My Name is Gerry

By Gerry Parent



Hi, my name is Gerry Parent and I have a brain injury. A lot of people see brain injury as a negative thing in their life, but I see it as something positive in my life. Some people can't walk or talk or take care of themselves. Not only can I now take care of myself with my brain injury, but I have also become a better person, and it has really put things in my life into perspective.

I am a poet. I wrote poems before my brain injury and still do after. I am the type of writer that writes about important issues people would like to see and read. I would like to share one of my poems with you. "Divine Intervention" is a poem explaining how brain injury people are.

What I would really like to happen is for people all over the world to be able to see and read my poetry because it would be a good way to help spread the word about brain injuries.

Divine Intervention

By Gerry Parent

Ever since my Divine intervention,
My life got saved with love and affection.

I don't remember what happened to me.
From what I was told, I had brain injury.

Between talking too much and being real loud,
My memory got worse as my vision went
down.

Brain injury People have a lot in common,
Like trying a new life without a problem.

Some of us are wheelchair bound.
While some of us are lost but not found.

People like me talk too much,
But the power of God gave us his touch.

When God and Jesus saved our lives,
They gave us faith we can't lose or buy.

Meet Gerry Parent



Gerry sustained his brain injury in November of 2008 when he was hit by a car while crossing the street.

He went through years of rehab and has learned to become independent again. It took a lot of hard work, but he now lives on his own in his own apartment. He is a poet, and likes to write about things that he thinks people would enjoy reading. He would really like to share his poetry with everyone and he thinks this would be a good way of doing so. "I think other people with brain injuries could relate to some of my poems," shares Gerry.
We agree!

Reaching Your New Year's Goals

By Donna O'Donnell Figurski



New Year's Day has passed. A new year is always a time of renewal – a time to look back on the past year and make positive commitments for the upcoming year. As humans, we seem to strive to improve and to make life better. The New Year is a good time to correct old mistakes and to look to the future to make new plans.

It feels like the whirlwind of the holidays happened eons ago, and yet it's just been a couple of weeks. If you are like most of the population, you probably made resolutions on New Year's Day - promises to yourself that you would do something to better your life. In the days after the New Year's celebration, you probably saw more people in the gym or running through the streets – maybe decked out in new running clothes to increase their motivation. You might have heard folks talking about the new diet they are trying, to help lose those unwanted pounds. Some folks vowed to stop smoking or drinking, or at least cut-down. Some folks promised to take more time for family or friends, save money, travel more. Usually, these resolutions are good intentions for the year that last maybe a week or two - perhaps even a month - but for whatever reason or reasons - time, lack of interest or motivation - many of these good intentions fall by the wayside.

Each new year, I usually make the resolution to exercise more. I start off okay, but not long after New Year's Day is past, my motivation starts to wane. Lack of time, or more like the "inability to properly manage time," is a big factor for me. I seem to be always too busy with tons of projects, most of them involving writing. I work daily on my blog. I spend hours preparing my radio show. I'm writing articles for publication, and, of course, I have to write a lot of query letters to agents and publishers as I try to sell my book, "Prisoners Without Bars: A Caregiver's Story." It seems like the only things that ever get any exercise are my brain ... and my fingers as they fly over the keyboard. Uh, did I say "fly"? I meant more like "stumble."

Most of my projects have deadlines - if not actual ones, then at least self-imposed ones. So, due to my over-commitments, this year I chose not to make any resolutions that I know I will not keep. Not keeping my resolutions only makes me feel like a failure, and that is not productive. I bet a lot of people fall into this category.

Folks with a brain injury are continually working to improve their lives, and New Year's resolutions may seem even more important. Brain-injured people are used to taking small steps, but the temptation for New Year's resolutions may be to try to do too much.

I'm going to discuss how to keep interest up and to make it possible to reach the goals of reasonable, responsible, and realistic resolutions - resolutions that are made and altered throughout the year.

“

Brain-injured people are used to taking small steps, but the temptation for New Year's resolutions may be to try to do too much.

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DO YOU ENJOY YOUR GOAL?

Don't make a goal you will never want to do. That's a recipe for disaster. Is your resolution such a chore that you can easily find any excuse to NOT do it? If you'd rather clean toilets than complete your resolution, then perhaps you should reassess your plan. I can pretty much guarantee that you will not be successful and that lack of success is certainly going to instill feelings of failure. I think a big part of being successful in keeping a resolution is to give the goal plenty of thought first.

DECIDE HOW YOU WILL IMPLEMENT YOUR GOAL

If you want to get more sleep and go to bed earlier, then set an alarm for 30 minutes before your desired bedtime so you can start your bedtime preparations. If you want to always remember where your keys are, put a hook on the wall and ALWAYS hang your keys there. You will never have to search your home again for keys. Following a routine makes life easier. That goes for anything. Also, use available tools (calendar, Post-It notes, smartphone, etc.) to help you keep organized.

KEEP A TRACK RECORD

By keeping a record of your accomplishments, you are setting yourself up for success. You could keep a record in a journal-like notebook. Simply write the date at the top of the page, and write what you accomplished that day (e.g., Sit-ups - 5 minutes; Meditated - 10 minutes). You could also simply use a calendar dedicated just to your resolution and write your activity under each day that you do it. If you are computer savvy, you could keep a spreadsheet. Place the days in the left column; list the activities across the top. Then just put a checkmark in the box corresponding to day and activity.

I like to see my progress. It motivates me. I enjoy seeing how well I am doing – or NOT doing so that I can readjust and improve. It may work for you too.

BE PATIENT – YOUR GOAL WILL NOT BE ACCOMPLISHED OVERNIGHT

Your success will not happen overnight. It will take time. You may even become lax at times, but don't worry. The record keeping that we spoke of above will help to get you back on track.

Before his brain injury in 2005, my husband, David, used to do a half hour of his version of Tai Chi every morning. He'd run twenty miles each week, and he'd regularly lift small weights to strengthen his arms. He was fit and healthy. He exercised not only for

his health but also to leave the stress of his laboratory behind. David's disabilities are all physical, including severely compromised balance, which makes him unable to run. He regrets this, but he has turned his attention to the treadmill - with its handrails - for exercise.

He has also recently acquired a recumbent trike, which allows him to pedal away on his own with no danger of falling. None of this was possible when David first arrived home from the hospital. He was confined to a wheelchair and bed. He could not even stand unassisted. It was a slow process - one that he has worked on over the past eleven years, but with small steps and small increments of exercise, he is gaining his strength and his independence. No matter what your goal is, **BE PATIENT**. Reach for the stars, but remember, it will take time.



Be patient
Be flexible
Try something new

BE FLEXIBLE

If you choose a goal that you find is not appropriate - it's too hard, it's too easy, or you are not enjoying it - **QUIT IT!** It's your life, and you can make the choices. Because you are a brain-injury survivor, I am sure there are many goals you would like to accomplish. Make new resolutions. (It doesn't have to be a new year.) And, mix it up.

If you are not seeing the progress you want - for whatever reason, choose something else to work on. You can always come back and try again later. That's why I encourage you to make reasonable and realistic resolutions. You want success to be imminent.

Once David tried a form of therapy on the recommendation of a friend who insisted that it helped her greatly, and, in fact, it did help her. David tried it for quite a long time and dedicated himself to it, but found it tedious and boring. He soon quit and set his sights on something more enjoyable that was not going to make him miserable. That's where the flexibility comes in. Do what works for you.

TRY SOMETHING NEW

I mentioned earlier to “mix it up.” That's not a bad idea for anyone. If boredom sets in, your chance of success will fall greatly. You won't reach your proposed goal, and you will become disenchanted with the activity. The feelings of failure are right behind. So, don't put yourself in that position. Make a new resolution and try something different. It can be something different that is still familiar, or it can be something so different that you have never done it before.

I want to go back to the story of David's recumbent trike. In his adult life, he never rode a bicycle. As I mentioned, his preferred method of exercise was to run. When that was no longer a viable exercise mode, he turned to a recumbent trike. That has changed his post-brain-injury life. Before the trike, David was unable to leave the house alone. Now he can leave whenever he wants to. He is able to go to the garage, get on his trike, ride for several hours, and return. (The only thing he cannot do is get off the trike anywhere else because his balance issues do not allow him to walk freely outdoors.) So, try something you have never done before. Maybe you always wanted to draw or paint. Do it.

HAVE A BUDDY FOR SUPPORT

You may want to exercise with a buddy. Exercise can be much easier with a friend. I much prefer walking and talking or treading water in the deep end of a pool and talking or rotating through the machines in the gym and talking. Are you seeing a pattern here? I

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If boredom sets in, your chance of success will fall greatly.

”

find exercising with a friend much more enjoyable than exercising alone. No matter what your goal is, if you can do it with someone else, it makes the exercise easier. It also adds an element of accountability. If you have made plans with a friend, you are more likely to meet your goal.

For most survivors with brain injury, life has drastically changed. The kinds of resolutions that you may have made before your brain injury are now more than likely impossible to attain. But, that doesn't mean that you can't set goals that you can successfully achieve. The gym may be out of the question, but you can set aside some moments at home for leg lifts, small weights, push-ups, stepping-in-place, etc. You can do anything to keep your body fit.

Each brain injury is different. The disabilities that accompany each brain injury are wide and varied. For some folks, the injury entails only cognitive/learning disabilities or emotional issues. For others, the brain injury might include physical disabilities.

Basically, you want to assess what you can do to improve your life while not being miserable. You want to make resolutions that can fit into your lifestyle. You don't want to set your goals so high that they cannot be achieved. But, if you set your goals too high, change them. Make your resolutions reasonable, responsible, and realistic and make them any time of the year. Most of all, make them FUN.

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.

On January 13, 2005, Donna became the caregiver for her husband and best friend, David. Donna had never heard of "TBI" before David's cerebellar hemorrhage.

Donna spends each day writing a blog, called "Surviving Traumatic Brain Injury," and preparing for her radio show, "Another Fork in the Road," on the Brain Injury Radio Network.

The REAL Story about Mild Brain Injury

By Marilyn Lash, MSW



Confused About “Mild Brain Injury”? The term “mild brain injury” is a huge misnomer. It implies that it’s no big deal; it’s a minor injury; it has no serious consequences; there’s no need for immediate medical attention or follow up care. None of this is true. A popular public awareness campaign captures the critical fact about mild brain injury in the statement that there’s nothing “mild” about it. It is an injury to the brain.

Why No Diagnosis?

So why is mild brain injury so often undiagnosed and misunderstood? You can start with the terminology. Concussion is the more common term used to describe a mild brain injury and somehow that seems less serious to folks. In fact, when patients are questioned about a history of head trauma, they are more likely to respond positively when the term concussion is used rather than brain injury. Simply put, the idea that the brain has been injured is a scary thought.

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**The Centers for
Disease Control
report that at least
1.7 million traumatic
brain injuries occur
every year.**

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Loss of consciousness or coma is one of the landmarks of moderate and severe brain injuries. This brings immediate medical attention and specialized care. By contrast, most cases of concussion or mild brain injury do not involve a loss of consciousness.

Although the person may feel dazed, confused or disoriented, there may be no immediate dramatic signs that the brain has been injured. Most people who sustain a mild brain injury are not evaluated in an emergency department and are not admitted to the hospital. They may not even see a local physician.

The truth is that concussion is a type of traumatic brain injury and it changes how the brain functions, but there may be no evidence of damage on an MRI or CT scan. Even a standard neurological examination may not reveal symptoms. However, this does not mean that a mild brain injury has no consequences.

Numbers Reveal “The Real Story!”

The numbers are staggering. The Centers for Disease Control report that at least 1.7 million traumatic brain injuries occur every year. They estimate that 75% of these are concussions or other forms of mild traumatic brain injuries. Some estimates are even higher at 80 – 90%. The age groups most often injured are young children under 4 years, adolescents between 15 – 19, and adults ages 65 years and older. [1] The good news is that most of these people will have symptoms which will improve within hours, days or weeks and they will recover fully. This

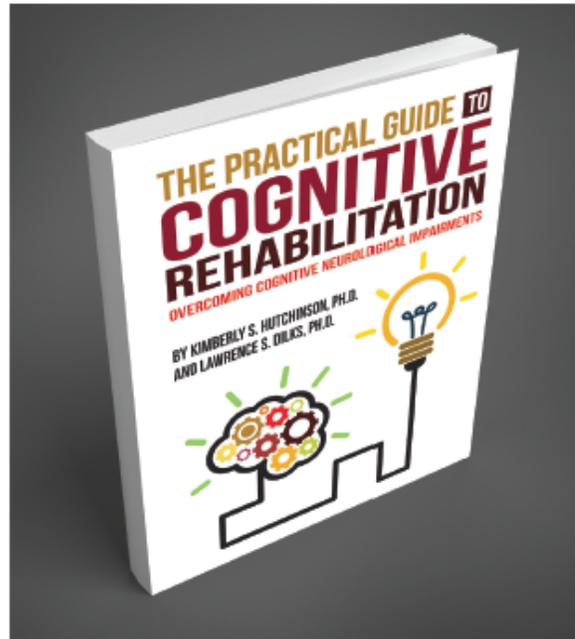
transient effect has often been described as feeling dazed, stunned, or just “out of it.” However, age does make a difference. Older adults, young children and teens generally have slower recoveries and thus need careful monitoring.

Despite these high numbers, mild brain injuries are too often not taken seriously because they are usually not life threatening. This attitude among the general public and even many health care professionals is now changing. This is partly due to new scientific evidence on concussions with the examination of brains of deceased athletes with long histories of multiple concussions, the settlement by the National Football League, and advances in brain imaging.

There are also the rare but too frequent stories of healthy young student athletes, typically high school or college players, who are injured during a game and then die within hours or days due to undiagnosed trauma and bleeding in the brain. These stories have directly contributed to the passage of concussion legislation in all 50 states requiring a concussion education and management program in schools to protect student-athletes.

PRACTICAL & ESSENTIAL.

THE PRACTICAL GUIDE TO COGNITIVE REHABILITATION: OVERCOMING COGNITIVE NEUROLOGICAL IMPAIRMENTS



**Dr. Kimberly S. Hutchinson
and Dr. Lawrence S. Dilks**

Authors Dr. Kimberly S. Hutchinson and Dr. Lawrence S. Dilks have developed a workbook filled with readings and exercises designed to assist persons with neurological impairments in the recovery process. Each section has activities and worksheets with a variety of visual and cognitive activities. Sections include orientation, attention and concentration, processing speed, memory, executive functions, language redevelopment, visual perception, anxiety and depression, and extra activities. This workbook is for individuals, caregivers, and clinicians.



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Athletes Aren't the Only Ones with Mild Brain Injury

But concussions do not occur solely in athletes. Traumatic brain injury has become known as the signature wound among veterans of the wars in Iraq and Afghanistan and most of these are classified as mild. These concussions are largely caused by the explosive blasts from improvised explosive devices (IEDs), rocket propelled grenades and landmines. The percussive wave that results from the explosion can be particularly damaging to the brain. Many of these injured service members have been exposed to multiple blasts and have incurred multiple concussions.



The Department of Defense has become increasingly vigilant about screening troops during and following deployments for symptoms of concussions and setting up treatment programs. Among wounded warriors, the combination of mild brain injuries and post-traumatic stress disorder or PTSD results in a very complex condition with both overlapping and distinct symptoms. The most common comment by families is that the service member who came home “is not the same person,” yet many service members consider treatment a sign of weakness and resist seeking help.

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No Discrimination When Brain Injury Happens

Sports and war are the scenarios that are receiving the greatest media attention these days. But a mild brain injury does not discriminate. It occurs to athletes, service members, and civilians. It happens to people of all ages, races, ethnic groups, and across all incomes. Falls, biking accidents, motorcycle and ATV accidents, car crashes, assaults – these are the most common causes of mild brain injuries among civilians. The sad part is that so many of them could be prevented with greater attention and use of safety devices – protective helmets, child safety seats, bath mats.

Greater Risk for More Concussion Injuries

We also know that people who have had one concussion are at a greater risk for having another concussion and they also face a longer recovery period. It is not just the number of concussions that pose greater risks but the time between concussions that is a factor.

If the brain has not recovered from the earlier concussion and sustains another, the damage to the brain may be more serious. For the unfortunate estimated 10% who have persistent and chronic symptoms that are described as “post concussion syndrome” the impact can be life changing and life altering.

Concussion Symptoms – A Quick Look

The symptoms of concussion fall into four categories of cognitive, physical, emotional, and sleep changes. You can readily see how they can alter not only a person's ability to get through life's daily activities, but to pay attention and concentrate in school, or to perform at work. Cognition is the clinical term for how you think, learn, process information, and remember. A person who has had



a concussion often complains of being unable to think clearly, of being in a fog, having a hard time concentrating, or remembering new information. Physical changes can range from headaches to fuzzy or blurry vision, nausea, dizziness, light or noise sensitivity, poor balance, and fatigue. Emotional changes can create additional stress on relationships as the person becomes more irritable, emotional, anxious, nervous, or sad. Changes in sleep are also very common but may have different effects including sleeping more or less than usual.

Brain Injury Is Unique to Each Person

The exact combination of these symptoms is different for each person because each injury to the brain is unique. But it's easy to see how exhausting, worrisome, and confusing these symptoms may be for the person and for family, friends, and colleagues. A concussion is an invisible injury. There is no outward sign like the broken bone covered in a cast that signals "Caution! This person is hurt." In fact, it is just the opposite. The person who has had a mild brain injury or concussion may look just fine – but that doesn't mean that all is well. Some symptoms may appear right away, others show up over time as people go back to school or work. As people return to more complex tasks, the brain has to work harder. People often describe how they feel in vague terms such as "not feeling like myself" to more alarmingly "thought I was going crazy." Obtaining an accurate diagnosis is the first step to getting treatment.

Most Common Treatment Regimen

Rest may be the most important treatment for a concussion – and it may be both the easiest and hardest instruction for patients to follow. Just as you would not expect to go out and run a marathon after spraining or breaking an ankle, you can't expect to work your brain too hard after a concussion. Just as your ankle needs physical rest after a sprain, your brain needs cognitive rest after a concussion. The “push through it” and “tough it out” philosophy so common among soldiers, athletes and teens just doesn't work here. It may worsen symptoms and slow down recovery.

How Important is Sleep?

Getting plenty of rest at night and napping and resting during the day is part of the healing process. It's not just contact sports that should be avoided while recovering from a concussion. Any activities that are physically demanding – whether it's housecleaning or working out at the gym, should be avoided. Likewise, lighten the cognitive demands – this is not the time to do things requiring lots of concentration, problem solving or organization.

Your brain needs a break. As you monitor the physical, emotional, and cognitive symptoms, you will be able to judge when you can resume activities. But there are some cautions here – alcohol and drugs can not only slow your recovery but increase your risk of another injury so talk with your health care professional first. By becoming more knowledgeable about mild brain injury, you can become an informed consumer of health services, effective health care provider, supportive family member, caring friend or colleague. It can happen to anyone.

Meet Marilyn Lash



Marilyn Lash has over 35 years' experience working with persons with disabilities and their families in medical, rehabilitation, educational and vocational settings. Author of many publications and a national speaker, her primary focus is supporting and educating families about brain injury. She is a founding partner and President of Lash and Associates Publishing/Training in North Carolina, a leading source of information on concussion and brain injury in children, adults and veterans.



Four Missed Calls

By Heidi J. Holdsworth

The meeting at the hospital where I worked was long. Anyone who has ever been in any meeting, anywhere, can relate to that. I have no recollection about the topic. To be honest, that would probably be the case even if the rest of the day had been uneventful.

My co-workers and I poured out of the conference room and I checked my ever present but set to silent, cell phone. I saw it. Four missed calls.

Odd. To have one would be strange. With the exception of the occasional person trying to sell me a new roof or a timeshare, I rarely get calls during the day. None of the numbers were in my contact list.

I listened to the first voicemail message as I was walking down the hall. It was the manager at the auto dealership where my fiancé works. My fiancé, Larry, was a New Hampshire State Trooper for over 23 years. He worked, primarily, the Interstate 89 corridor. He was a K-9 handler for 15 of those years. It cannot be overstated the danger he willingly placed himself in on a daily basis.

The dealership employs several retired troopers and his manager is one of them. I listened to the sound of his voice on the message he left. It was muffled and wasn't a great connection, but I heard him say I needed to call him ASAP.

That's never good.

The next message was from the owner of the dealership, again urging me to call. By now I was running through the hospital.



As I listened to the third voice mail, the manager again, I ran into one of the other nurses, almost literally. I remember gasping (clearly I need more exercise) that there was something wrong with Larry, but all I remembered was hearing he had been hit by a car. His head and leg were wounded but he was conscious.

I made it to my office and back out the door in under 30 seconds while I listened to message number four. This time it was the police and by now I was in a panic. Then I remembered I parked off campus and had to wait for the shuttle bus to bring me to my car. As I hyperventilated and paced, I listened to the officer.

In my state of mind, I could only focus on the words "accident" and "Concord". I rode the bus to Lot 9, while frantically calling the Concord police. They had no idea what I was talking about. I do remember saying something to the effect of "He's one of you. What do you mean you don't know anything?!" The dispatcher asked me what town Larry worked in, I told her Tilton. She suggested I try them.

By this point, Dana, the bus driver, had delivered me to my car. He caught most of what was going on. God love him, he wouldn't let me leave until I could breathe and speak. He even tried to give me money in case I needed it. He was an angel.

I reached the Tilton Corporal and he broke it down like this: Larry was on the side of the road in front of the dealership and was helping to move a disabled car. A Jeep came through the intersection and hit him. He was taken by ambulance to Concord Hospital. (Why I didn't call the hospital when the words accident and Concord came up is a mystery to me. Maybe denial.) Larry kept telling them he had to pick up his daughter. It was a Wednesday, he always leaves at 2:00 on Wednesdays to pick her up at school. He was hit at 1:15. I contacted her mother and made arrangements for her after-school care.

I drive a Dodge Dart. She gets an average of 38mpg. She is not overpowered. She tops out at 108mph (my next car will go faster). Along the way, I called my Mom. I remember crying and talking at a manic pace. The unknown was tearing me apart.

“

I remember crying and talking at a manic pace. The unknown was tearing me apart.

”





When I squealed into the hospital parking lot I saw several police cars along with trooper cars. Not good. Inside the emergency department, I didn't even need to ask where he was. No less than 14 assorted law enforcement officers surrounded his room.

And then I saw him: my love, the reason why I breathe. The one I finally

found after so many attempts. The man I would marry in July. And he was broken. His leg had been flayed open, his whole body beaten. The left side of his scalp and ear were peeled back away from his head. His eyes showed pain, fear, and love.

I managed to stay in nurse mode for a few minutes, doing a quick assessment, asking coherent questions. Then I broke. I sobbed. I almost lost him. I was surrounded by people I didn't know. I was terrified.

The nurse was talking and I don't know what she said. Troopers and officers and his co-workers all seemed to introduce themselves at the same time. Most gave me their cards and urged me to call if we needed anything. The owner of the dealership made me promise to call him if I needed help. I still didn't know what had actually happened.

He wasn't wearing a neck collar. The emergency room doctor had cleared him after a cervical CT scan, but he would not move. He was in pain, specifically, a neurological pain he was familiar with. Years ago, Larry had a neck injury and had cervical disks six and seven fused. The pain was the same and he feared the fusion had broken and was missed on the scan. The MD kept telling him it was soft tissue pain but he continued to refuse to move. Larry knew something was wrong because of the incredible pain he was in. Somewhat politely, I requested that the nurses give him the pain medications that were ordered. The MD finally relented and ordered an MRI.

“

I held his neck and head in traction when he was moved to the MRI table.

”

I held his neck and head in traction when he was moved to the MRI table. His scalp was still peeled backward and the gash on his leg remained open. The MRI felt like it took three days.

While I was waiting, I called the friend that had introduced us and who had obtained her Justice of the Peace license so she could preside over our marriage ceremony. She was in New York and about to get on her flight home. She arrived at the hospital early the next morning and spent weeks commuting over three hours a day to help care for Larry after he came home.

When Larry came out of the MRI, we transferred him to the stretcher when he vomited and his head started to bleed again. We went back to our emergency department cubby to await some news.

Within five minutes the transport team returned. Another MRI was needed because the radiologist thought he saw something wrong at the second cervical disk but needed further imaging.

After the second MRI, the doctor returned and told Larry he had three fractures of the second vertebrae; we later found out there were five in total and he would be in an enormous neck brace for twelve weeks.

The PA came in to stitch the wounds. The leg cleaned out easily and was stitched quickly but the scalp was a disaster. He was able to reattach most of the left ear and scalp.

Where do over 20,000 Members of the Concussion and TBI Community Come Together Every Day?

We'll give you one guess...

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We joke now that Larry looks like someone chipped with a two iron off the side of his head. I remember thinking I could manage the wounds, but the idea of keeping him reigned in for twelve weeks in a neck brace seemed impossibly difficult.

If I knew then what I know now, I would have relished that first week. Larry needed around the clock care for his injuries, his pain was difficult to manage, he was using a walker and we have a three story house. I thought I was tired. I had no idea what tired was.

Sometime between days seven and ten, I started to realize he was forgetting things. It was easy to chalk it up to the pain medication, but when he asked me if his daughters had been to see him I knew there was something wrong.

Thus began our TBI journey. Memory loss, debilitating PTSD, words that refused to cooperate and be spoken, stuttering, horrible balance, vertigo. Food tasted horrible and smells made him sick. He had headaches and shaky hands. Did I mention memory loss? There was also anxiety, fear, pain, and anger that go hand in hand with memory loss.

We have come a long way but haven't done it alone. We've been through a range of medical specialists including surgical trauma, neurology, psychology, occupational therapy, physical therapy, speech therapy, otolaryngology, endocrinology, care management, occupational medicine, orthopedics, and a new PCP. He endured videonystagmography, electromyography, and a comprehensive assortment of bio-neuro-psych testing.

More than anything was the incredible support we received from family, State and Local Police, his employer and co-workers and my incredible work family.

We have a new normal. We both wear Medic Alert bracelets. If anything were to happen to me I have explicit directions regarding his needs.

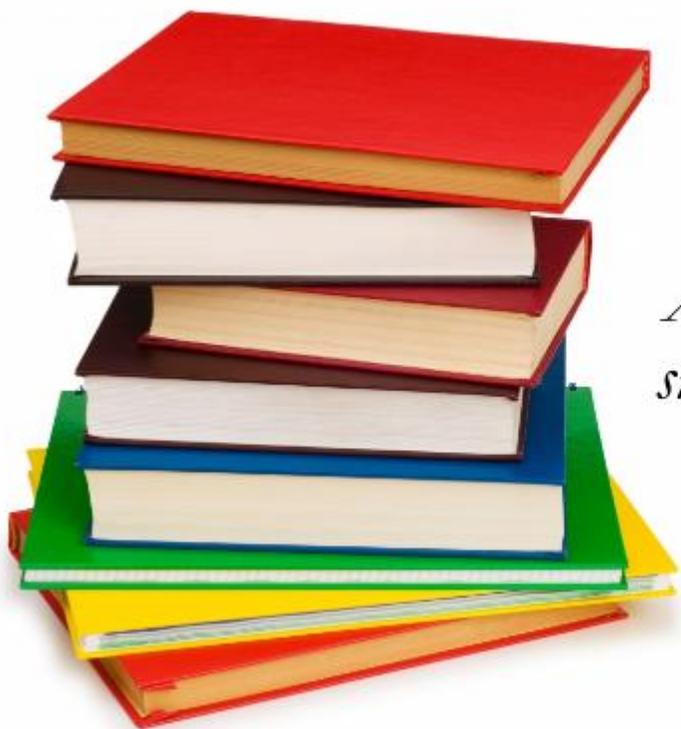
If something happens to him, it will alert me along with a list of trusted friends. He has a Psychiatric Support Dog. Some days there is despair but more often than not there is happiness.

Some days he remembers we were married in July, some days not. But he never forgets he loves me and never doubts that I love him.

Meet Heidi and Larry Holdsworth



Heidi has been a nurse for almost 25 years and has been able to use her skills to help Larry with his physical recovery. Larry is a retired NH State Trooper. He served over twenty-three years, fifteen of those was as a K-9 trainer and handler. He is now training his own Psychiatric Support Dog.



The TBI HOPE Book Directory

A comprehensive list of books by survivors and those who love them!

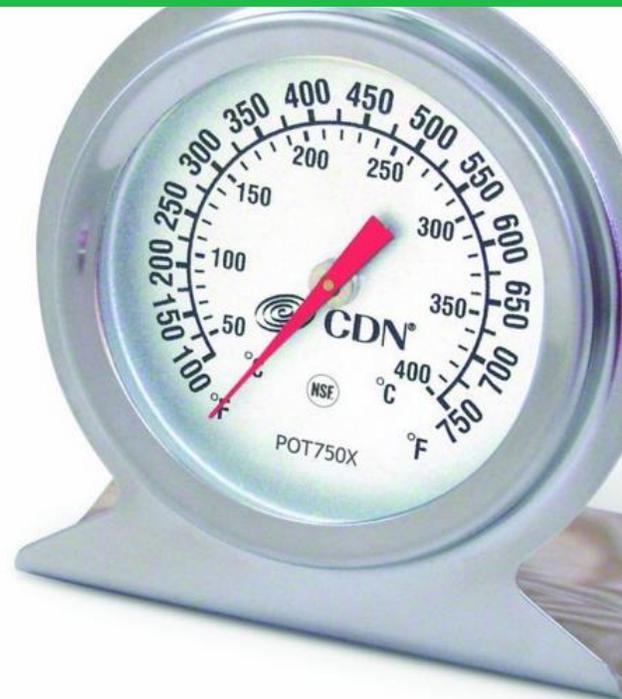
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Living Life at 350°

By Lori Harrison



I'm 53 years old. I've been cooking since I was tall enough to reach the counter.

I started cooking on a regular basis when I became a latchkey kid after my parents divorced. It was my responsibility to make dinners and my own lunches from when I was about 11 or 12 years old.

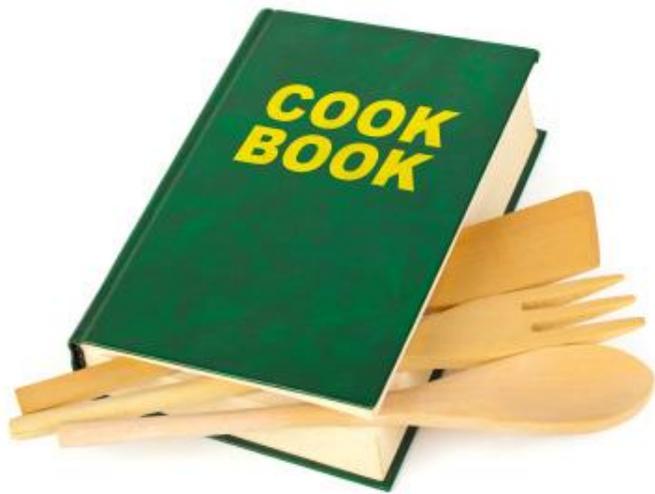
For my 17th birthday, my stepfather bought me the Time Life series of international cookbooks, the Joy of Cooking, and signed me up for Chinese cooking lessons. At the time I thought it was a purely selfish act.

At 350 plus pounds my stepfather was a connoisseur of fine foods, a good man, and he loved his food. At times he told me he liked my cooking better than my mother's. I really truly enjoy cooking.

It wasn't until I was married and on my own with my husband that I realized my stepfather had given me a huge gift by giving me cookbooks and cooking lessons. He found something I loved and turned it into a valuable and useable skill.

I still love to cook. Many people have told me I am a good cook and I believe it's because I love cooking and I know what tastes good to me.

My TBI has robbed me of several things, one of those being a short term memory, which made cooking very difficult for three or four years after my injury. This is especially important when you can't remember if you've already put in a tablespoon of salt, or a cup of sugar.



I eventually worked out a way that I could cook. At first, it was simple, chicken breasts and rice in those nice little pouches. And of course, all those wonderful convenience foods which are not really cooking, just heat and serve.

As I got further into my recovery and while working with my OT, I realized that by writing everything down, I remember things better.

To apply this to cooking, for example, I will write down a recipe from the Internet. As I add the ingredients, I cross them off the written list. I write down what time the chicken goes in and has to come out. I write down what time the vegetables need to start and will finish, etc.

I set several timers with labels on my phone and my iPad so everything is timed properly. My cakes rise now, my cookies aren't too salty, my chicken is tender again, and my pork apparently is to die for.

All this did not happen overnight. Thank God for smoke alarms, otherwise, I probably would've completely forgotten about the cookies that I left in the oven for almost an hour.

Or the time that I turned on the tap in the kitchen sink to do the dishes, put the soap in, got interrupted by the cat and walked into another room. I realized the carpet was dirty and needed a vacuum. I grabbed the vacuum and started vacuuming when my son came running into the living room ten minutes later to tell me I flooded our kitchen by leaving the tap on.

No, it was not a smooth transition. It was a comedy of errors. Sometimes even laughing in the middle of it. I truly knew everything was going to be OK when, in the middle of the flooding of my kitchen, my son looked at me and said: "at least the floor is clean."

You see, I used to cry to my physiotherapist, literally, with tears streaming down my face, that I couldn't clean my floors because bending over made me dizzy or nauseous or both. I felt so helpless and useless.

I've learned the workarounds and work-throughs that help me do some of the things that I used to love doing before my TBI. I know now I'll never be able to cook the same way I did before my TBI.

I know there are a lot of things that I won't ever be able to do again, and there are a lot of things I need to learn how to do differently.

Currently, I'm living my life at 350°F. Most cakes, cookies, meats and chicken cook well at 350°F. I'm hopeful that someday I'll be able to broil again without setting the house on fire.

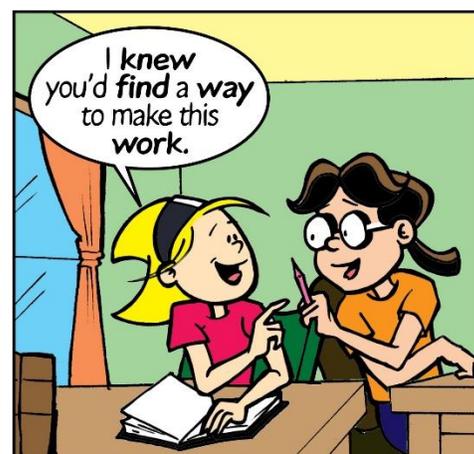
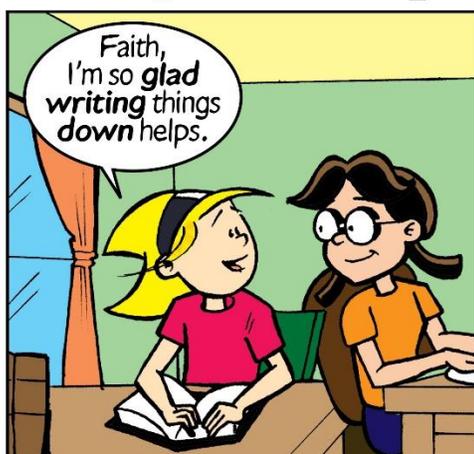
Meet Lori Harrison



Lori 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.

Living With Hope

By Patrick Brigham



Graduation Day!

By Diane Lisowski



“Hey, our last trip!” I exclaimed, as our car navigated over the hills and back roads of western Wisconsin. Dennis, Jonathan, Michelle and I were making our way to the University of Wisconsin-Stout for something I’d been hoping for the past two years – Jonathan’s graduation day, and thus, the end to the boatload of turmoil riveting my insides since his brain injury nearly two years earlier.

Our son and daughter-in-law, Nathan and Jessica, followed in their car. I’d driven myself to the university area so many times it was automatic. Turn right after the Amish farm. Turn left at the Chippewa River Bridge. And watch out for the sharp corner by the gray two-story farm house.

The sun was shining in the car windows on that sub-zero December morning. Strips of snow that the plow had neglected to remove were packed down and frozen, rock-hard on the asphalt. It was too cold to melt and so they stuck there, shining brightly in the winter

“

**Oh God, you
deserve to walk
down that aisle.
You've worked so
hard to graduate.**

”

sun and reflecting into my sunglasses. The brisk winter wind blew wafts of powdery, loose snow from the open field clear across the centerline of the highway.

As we arrived at the campus athletic complex, Jonathan pointed out the parking lot and I swerved into the first empty spot. Proud parents and their graduates were already scooting from their cars toward the two sets of double doors from all directions and we joined the ranks. I was happy that Jonathan had decided to participate in the day's event. Back in October, he had complained about my appeal to him that he should attend the graduation ceremony.

"But the cap and gown cost \$42.00. That's a rip-off!" he spouted.

Jonathan could be so frugal sometimes.

"I don't care. I'll buy it." Goosebumps erupted out of both of my arms as the thought of Jonathan in a cap and gown electrified me. I stood my ground. "You're walking down that aisle." I smiled as if I were joking, but I meant it. In my mind, he had to walk the walk. He had earned it. Maybe not with the best of grades, but with the most perseverance I'd ever seen. "Oh God, you deserve to walk down that aisle. You've worked so hard to graduate – you *need* to take that walk. Please, please, please ..." I begged.

Making our way through the freezing air in the bustling university parking lot, I pulled the collar of my wool coat up around my ears and held it tightly under my chin to keep the blast of winter wind from penetrating beneath it.

The six of us shuffled inside as quickly as possible, becoming one large mass of people all congregating in the lobby. I was anxious to cross graduation off the list of things I needed to witness in order to prove to myself that Jonathan had recovered. I needed to see some tangible evidence of all the hard work I'd done to help make it happen for him.

Jonathan stopped, as a bewildered look spread across his face.

“Now where do I go?”

I pulled out the folded up graduation instruction sheet from my bag.



“IT Management is supposed to line up by W245. That must be on the 2nd floor – in the west wing.” I scanned the lobby for some direction. “Over there,” I pointed to the stairs. “Dennis, you guys wait right here for me while I help Jonathan figure out where he’s supposed to go.”

“I knew that he wouldn’t have found room W245 by himself.”

I led the search as Jonathan and I scooted through a maze of hallways until we finally found room W245. I pointed to the sign above the door that directed those in his major to line up right there.

“Here it is. We’ll meet you back in the lobby after the ceremony,” I said as I headed back down the stairs to find the rest of my family.

“Okay,” he said, still seemingly unsure about what to do.

Jonathan’s confusion quickly doused my graduation delight. I knew that he wouldn’t have found room W245 by himself. How many other grads needed their moms to help them figure out where to be? How much longer would I have to give him step-by-step directions? When would my role in his recovery be over? The reality of his brain injury had once again surfaced. There was no guarantee that he’d ever be able to find his way anywhere in the world. And if so, Dennis and I would have to take care of him for the rest of our lives, which would leave no time for either of us.

"Let's just sit over there," I said as I pointed to the bleachers at the far end of the gymnasium, facing center-stage.

Dennis, Michelle and I climbed ten rows up, and Nathan and Jessica found seats in front of us.

The audience rose as the university band began to play “Pomp and Circumstance” and the graduates began filing in from the doors to the right of the stage.

“There he is!” Michelle hopped off her seat and pointed to the grads parading around the corner until they were almost in front of us. She was right.



Jonathan walked in perfect cadence with the others, putting one foot in front of another. My lower lip started to quiver. I blinked hard to try and push the tears back in. Two years ago he couldn't even open his eyes, let alone walk. I hadn't been sure that he would ever walk again.

One tear slid out of my eye, then another – there was no stopping them.

As my son rounded the corner to take his seat, I wiped my eyes with my fingers, trying not to smudge my mascara.

Chancellor Sorenson spoke. And then, all of the parents in the audience – who had been waiting for years – finally heard their sons' or daughters' names called. One by one, the grads made their way to the stage to receive their diplomas.

“Jonathan Peter Lisowski,” the chancellor's voice echoed from the microphone.

He walked up the steps and across the stage.

Jonathan grasped the chancellor's hand and then his diploma. And then my son smiled. The same smile which popped out the same dimple he'd flashed at me when he was a baby. A smile in spite of brain injury. A smile in spite of the odds.

I smiled along with him. Salty tears and all.

Meet Diane Lisowski



Diane Lisowski has been writing “snippets of life” about motherhood for her family and friends to enjoy since 1999. After her son's near-fatal car accident in 2004, Diane quickly realized that it was up to her to help her son further rehabilitate and regain his life skills after his formal therapy had ended. Diane currently lives with her daughter in west central Wisconsin, where she has been on the administrative support staff at the local high school for twenty-eight years. She intends to publish a book about her son's rehabilitation in the future.

“You cannot swim for new horizons until you have courage to lose sight of the shore.” — William Faulkner

My Hope and Inspiration

By Brian D. Sweeney

It was a beautiful summer day and we could both hear the golf carts coming up around the corner on the tree filled course heading right towards us. Every time there was a break, Steve and I would talk about everything from what life was like pre TBI compared to what life is like now and how much we both appreciated our recoveries to date.

Although no recovery is identical, Steve and I would both share stories of the “First year” of recovery.

In the Military, veterans who suffered severe injuries, be it loss of limbs, TBI, loss of sight... unfortunately, the list goes on, refer to the day they were hurt as “Alive Day”. I just look at it as the day the engine may have stopped running and required a “re-start.” Of course, once it was re-started all of the original features may not operate as they once did, or in some cases not operate at all. Either way our “Re-start day” is always the first of a long, and impossible to predict, recovery. A recovery that may not break speed records, but it is a recovery that never ends.

As the last cart of the day pulled away from our table and we began to prepare to make our way back, Steve asked me, “If you ever get the chance to put your story in front of a bigger audience would you let them know I am still in here?” I just looked at Steve’s face and nodded “Definitely”.



When I wrote “*Every 21 Seconds*” in 2009, a TBI occurred every 21 seconds in the USA, thus the catchy title. I remember saying my goal was for that statistic to one day change to every 21 minutes, then every 21 hours. It did change in those eight years, unfortunately now it is every fifteen seconds that one American man, woman or child suffers a TBI. That’s two million a year. I really believed that if we made a film that had a great story line but at the same time opened so many millions of eyes to what is going on here, we would make a difference.



When I wrote *Every 21 Seconds* in 2009, a TBI occurred every 21 seconds in the USA, thus the catchy title.

What if ten thousand kids decided to wear a helmet when bike riding, how many TBIs may be avoided? What if ten percent of those who do not wear a seat belt put one on because of what we created. Maybe we could add some seconds to the statistic that states every fifteen seconds someone in the USA suffers a TBI. I admit my dream was for my book to be converted to a movie, not about “Me” about “Us”. “Us”, being those

who have suffered a TBI and entered the strange world of piecing their life together one day at a time, needed a voice. My dream needed to happen and nobody chases your dreams better than you do. However I tend to believe the dream of providing TBI survivors a “Voice” is a dream shared by millions.

It’s about an extremely strange world, the world of having your brain, the one part of your body that controls every single thing you do, what you think, how you think, what you feel, your emotions, your abilities and so on, taken over by something you never even considered happening. Your brain is who you are, it’s what you use to perform every single function.

Every time I think about someone whose recovery was not what was hoped for and how they must struggle to achieve a feeling of belonging, I believe this must happen. Every time a TBI survivor is fired, or not hired, I believe this must happen. It’s not about what we can’t do, it’s about what we can do. If you ask or give us a try you may find there is so much we are capable of. We think, differently in some cases, but we do think. We actually try harder than others who may not have gone through what we go through.

On December 23rd, 2014 I received a text message from a number I did not recognize. It just said, “Are you interested in moving your book to a movie, if so please call”. I figured maybe Santa suffered a TBI and was giving out gifts on the wrong day. The message came from an actor named Shannon Brown who also owns *Two9 Productions*.

“

We actually try harder than others who may not have gone through what we go through.

”

After meeting with Shannon he began to share my passion, and understood why this was important to me, and it became important to him. I told him I just want the millions of TBI survivors to finally have a voice.

Shannon and I continued to meet regarding this, and we created a Facebook site called “*Every 21 Seconds*”, as well as a website www.every21seconds.com. We filmed a documentary that can be seen on the site. The documentary included TBI survivors.

This would be a film with an accurate portrayal of what the first year of recovery was like. The first year can be most often described as confusing, frustrating, unrewarding, exhausting, scary, unknowing, devastating, slow, sad, mysterious and emotionally draining to name a few feelings.

There were also over 300,000 Iraq/Afghanistan U.S. war veterans who suffered TBIs while protecting our freedom. They needed a voice. We needed something more for this piece and one day he showed up.

Jon Jans was a Marine Corporal who served in the war in Iraq. If someone asked you to draw your version of what a Marine looked like, it would be Jon. Jon and I talked for hours and the more we spoke, the more I realized how much he struggled with. His TBI and PTSD were obvious and Jon



never denied the affect both have on him. But his concern was more of “What about the other veterans?” Jon and I had something in common. My concern was always “What about the other TBI survivors?” and Jon’s was his concern for other disabled veterans. Jon agreed to fuse his story with mine, TBI bingo!

One day in the summer of 2016, Shannon sent me a text that read, “Check your Facebook”, so I did and there was a post by Shannon letting everyone know that the script entitled “*Every 21 Seconds*” was nominated for best original screenplay!

I had this idea that seemed to make our goal of making this film so easy: if less than half of those who suffered a TBI last year sent us one dollar or ten dimes or one hundred pennies, we could get this done easily. We TBI survivors are one determined group, we don’t quit. Nobody but us knows what we are capable of. Nobody. We continue to prove those who believe they have the answers, wrong, and we will continue to persevere.

I have always said, I don’t care whose story we tell, we have to tell the story of what two million Americans go through every year. TBIs are not hereditary, you never see them coming, but they keep coming. As Neurologist Dr. James Young said, “This story has to be told” and that is our goal. Not the story of Jon and me, but the story of the other millions of TBI survivors.

You may want to help us show what TBI survivors experience and how we prevail. If so, please go to www.every21seconds.com. Help us make sure everyone knows Steve is still in there and has so much to contribute. I promised him I would. Our efforts are intended to provide hope and inspiration to the millions who deserve it.

Meet Brian D. Sweeney



Brian D. Sweeney grew up on the south side of Chicago and currently resides in the south suburbs of Chicago with his wife and four children.

Over the years he has worked with TBI survivors and their families. Brian has been an advocate for those with traumatic brain injuries for years. He has spoken at universities, corporations, hospitals, high schools, brain injury seminars and rehabilitation facilities.

Brian has appeared on ESPN where he did a TBI special with former Chicago Bear Tom Waddle. He has worked with those who have suffered TBIs and always saw possibilities where others see limitations.

His goal has always been to open the doors of the all too often misunderstood world of life with a traumatic brain injury.

We hope that you've enjoyed this issue of TBI HOPE Magazine and that our new stylized layout was even easier to read.

Our February issue is already under development and will be filled to the brim with stories of hope, inspiration and perseverance. We'll be featuring the story of an NFL wife who saw firsthand the effects of multiple concussions. Watch for the story of a member of the Royal Canadian Mounted Police. This Mountie has quite a story to share.



As we move forward in 2017, we are looking for Premier Sponsors for upcoming issues. Premier Sponsors get cover-level exposure, a full-page ad as well as an organizational write-up within our publication. If you, or your organization, are interested in sponsoring an upcoming issue of TBI HOPE Magazine, I'd love to hear from you. Please feel free to email me personally at david@tbihopeandinspiration.com.

Peace,

A handwritten signature in black ink, appearing to read "David". The signature is stylized and cursive.