

OCTOBER 2015

TBI HOPE & INSPIRATION

Magazine

One Small Step for Man

One Giant Leap for TBI Survivors

A New Way

to Look at TBI Moments

A Caregiver's Journey

Recovery is...
a Marathon



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TBI Hope &
Inspiration
MAGAZINE

*Serving All Impacted by
Traumatic Brain Injury*

October 2015

Publisher

David A. Grant

Editor

Sarah Grant

Contributing Writers

Amiee Duffy

Linda Greear

Norma Myers

Micki Scherwinski

Jeff Sebell

Jennifer White

Resident Cartoonist

Patrick Brigham

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Welcome

As fall rounds the bend here in New England, we find ourselves approaching another Thanksgiving. What a great time to reflect upon things to be grateful for.


Life has become more challenging for those of us affected by traumatic brain injury, but even in the midst of seemingly overwhelming challenges, gratitude can indeed be found.

Many of us find ourselves surround by friends we would not have met had it been for the hand of fate. I've shared many times in the past that the last few years have brought some of the most amazing people into our lives.

Just under the radar screen of the life I left behind are some of the most amazing people that I never knew existed. My wife Sarah and I have lives that are enriched because of them.

Sometimes you need to dig deep, but a reason to be grateful can always be found.

Once again, to our regular readers, welcome back! To anyone new to our publication, a warm welcome. You are among friends.



David A. Grant
Publisher

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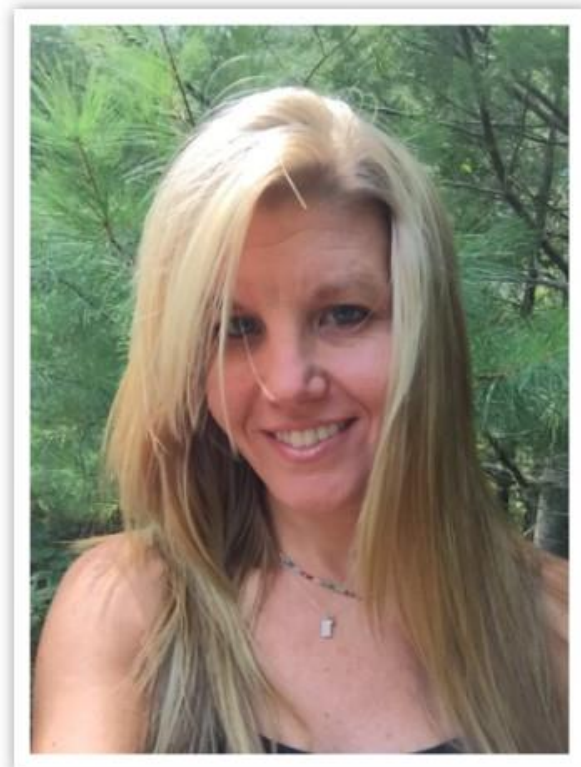
Only 17 at the time of her traumatic brain injury, this survivor shares about the slow process of rebuilding a life after traumatic brain injury.

A New Way to Look at TBI Moments

By Amiee Duffy

Instead of getting angry or frustrated with myself when I have my "TBI" moments, I'm trying to use them as a reminder to be kinder to myself. Having them usually means I have not been practicing my new rules of living:

1. Self-Care is more important than a clean house!
2. Get into Nature at least 10-15 minutes every day. If you can't go out in nature, bring it inside with flowers, rocks, feathers, shells, or autumn leaves.
3. Attempt to Meditate or do some sort of spiritual practice. Some meditation apps I use are: Headspace, Mindshift, Happier, or Take a Break. Zen Space allows you to create a Zen Garden.
4. Be creative at least two times a week - paint, write, cook, dance, garden, take photos, or make music. TBI survivor Ruby Taylor used her creativity to design an app called Smope (smiles + hope). It combines your photos with inspirational quotes.
5. Do something nice for someone else. Even if you just close your eyes and send them good vibes, it gets the focus off of you.
6. Take a nap!
7. Write in a gratitude journal.
8. Make sure to have a few "take out" restaurants on speed dial or have some previously prepared meals in the freezer. Don't feel guilty about not being up to cooking!



9. Have some positive Ted Talks or podcasts at the ready for when you need some inspiration or just a distraction. Currently I am listening to Brene Brown and Tony Robbins on Ted Talks and The RobCast. Magic Lessons, Good Life Project and the Hidden Brain are my current favorite podcasts.

10. HUG a loved one, a friend, pet or pillow. Cry or yell if you need to and remember that this too shall pass.

We are not going to ever be exactly like we were "before." Even those of us with a TBI have to recognize that some things will never be the same. I still have rough days where I am just trying to get through to the next hour. They are not fun or filled with rainbows and sunshine.

However, I am realizing that the more I let go of attempting to return to the way I was, and instead work on being a more positive and creative person, the more I am able to be at peace. I am yielding to what is. Hopefully in time I will be able to embrace it!

Meet Amiee M. Duffy, M.Ed

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

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One Small Step for Man, One Giant Leap for TBI Survivors

By Jeff Sebell

A glorious Sunday in September, September 27 to be exact, was marked by thousands of small steps and rolls, made by hundreds of TBI survivors.

The occasion was the first annual Walk and Roll for Brain Injury, put on by the Brain Injury Association of Massachusetts, on a track around a football field in Framingham, Massachusetts, a stone's throw from where the National Head Injury Foundation began.

For that lap or two or three, we were all in motion as one; united by the common language of Brain Injury. In fact, I would go so far as to say that it didn't matter how we actually made our way around that track; as we sang and walked that first lap, we were all floating on air.

There was an energy and a spirit that levitated us, almost as if we were hovercraft, gliding seamlessly around that 1/4 mile track. For those moments together, not one of us was disabled. We were all doing the best we could with the tools we had, yelling, "This is who we are," being proud of what we could do; as individuals and together, as a group.

In a way we were going back to our roots, back to the beginning, as Marilyn Spivack eloquently reminded us. She brought with her the same good-hearted spirit, energy and determination she brought when she founded the NHIF, and made Brain Injury a national issue.

Being there with all my people - all the survivors - was moving and empowering, and struck by the spirit, I reminisced on how things had been, way back when. Back then, 35 years ago, I was the only one the NHIF had to call for peer support.

The newly opened office was small but busy. Marilyn reminded me I was the first visitor in that first office.

Look at where we are now

As much as we feel the need now to educate other people about TBI, at least Brain Injury is in our current vocabulary. Thirty five years ago we called it Head Injury, and it was a new frontier in medicine that not many people were aware of.

Walking around this track with all these brave survivors also brought me back to my own journey around a track, forty years ago.

Back then, when I was in the rehabilitation hospital, they would let me go home on weekends so I could spend the time with my family and get some understanding of what the transition to home would be like. Although I was in a wheelchair in the hospital, they would send me home with a cane so I could learn how to walk.

“Although I was in a wheelchair in the hospital, they would send me home with a cane so I could learn how to walk.”

Learning to walk was challenging, and I was discouraged at the stop/start, uneven movement of my attempts. I came up with a theory: if I moved as though I was running, I would have some fluidity to what I was doing. That meant being in motion, pumping my arms and constantly moving forward. My thought was that being fluid would allow my instincts to take over and stop me from thinking and analyzing every little thing I tried to do. Following my instincts would allow my natural balance to take over and take me where I wanted to go: I was sure of it.

My eight year old brother and my father and I went to the high school track, where I ceremoniously threw down my cane and, with my head down and my arms chugging, I began my lap. I felt as though I was running at breakneck speed, but in reality I was only taking baby steps. I did finish, and only fell once.

The pieces that made the walk so special this year was that the lap was done not only with all my fellow survivors and their supporters/caregivers, but also with my now eighty-five year old father, my brother, and my daughter.

We re-enacted that lap made forty years ago.

Lagging behind at first, my daughter and I watched and smiled as my father made his way around the track, walking fluidly and with purpose, just as all those survivors were doing. I got choked up several times, as I sensed the power and determination of all the survivors, and also thought back to my own family and how far we had all come.

Brain Injury is no longer an unknown issue. On many levels it may still be a mystery, but it is something we are all facing head on, some of us because we have to, and others because it is the right thing to do.

We still face many challenges as we work to educate and live our lives, but look where we are now: instead of traveling on a dirt road, all rutted and bumpy, the road has been paved and we are all on our way working to live a fulfilled life.

About Jeff Sebell

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

Living With Hope

By Patrick Brigham



A Caregivers Journey

By Lydia Greear

On June 29, 2013, at 11:58 pm in Lexington, Kentucky, a speeding vehicle hit my son while he was walking in a crosswalk. He suffered life threatening injuries including a Traumatic Brain Injury. He was rushed within minutes to the local University Medical Center for urgent care. Our son was 37 years old rooming with a friend near the scene of the accident. He was with another friend who witnessed the entire accident.



My husband and I were on a trip to France. We had two more weeks of travel and site seeing. We had been out all day with friends in Paris and our cell phones had no battery power. We arrived at our hotel and put the phones on the charger. Once the charge was renewed to the phones there were text messages, voice messages, and Facebook messages from our two children in the US and others trying to contact us. “Call home, it’s urgent,” was the theme of every message.

We called them around 11 PM Paris time to learn of the tragic accident. In shock we sat for what seemed hours not knowing what to think or do. Sometime after 1AM local time we contacted the airline to see what options we had to get home as soon as possible.

The airline accommodated us easily and the next day we travelled from the nearest international airport to Lexington, where we rushed to the hospital to see our son. The doctors had taken him to surgery to relieve pressure on the brain and we waited to hear the news. Hours passed and with no information from the medical staff we had to leave to get a hotel room. We left contact information for them to call immediately.

Early the next morning we had still not received any news about our son. We called the hospital and they said he was still in recovery. We rushed to the

hospital and found that he had been moved from the original Urgent Care room. After some confusion we were able to finally find our son. A chaplain came to us and was there to prepare us for what we would see.

Our son was lying in a highly elevated hospital bed with tubes and drains all around him. Several bottles of fluids were above his head. He had a combination of dried blood and blacktop caked in his head. He had an extremely large stitched area from the front part of his head to the back. We were told this was where the neurosurgeon stitched up the injury. He had fresh bandages around the drain tube on the right side of his head.

We waited and prayed. We asked questions. We were still stunned and had no way to know what had happened that night. Our son had no belongings because everything was taken to the “drying” room at the local police station. The young man with our son had recovered a piece of a black guitar he was carrying when the accident occurred.

For 19 days we waited for him to give signs of life and awake from his coma. His first gesture was to squeeze the hand of the doctor and lift his thumbs. His eyes opened and we were not sure what he was seeing. He had a broken leg and his nose had several fractures.

“For 19 days we waited for him to give signs of life and awake from his coma.”

For the next two years he would slowly recover from this TBI. Doctors first told us that this experience takes 18-24 months to know what normal looks like. After 29 months we still don’t know what normal looks like.

Today, our son can walk and talk. He perseverates (repetition of confused words or phrases) vocally and also in behavior. He has a frontal lobe brain injury. We felt it was best to place him in a Community NeuroRestorative facility where he has received Occupational Therapy, Speech Language Pathology, Behavioral Counseling, and Life Skills Therapies. The challenges are as present today as they were in the first days while he was comatose. We walk in the dark daily on what is best for him.

We accomplished the government medical coverage and even were fortunate to have an “Acquired Brain Injury Waiver” to compensate all other expenses related to his rehabilitation. These waivers are lengthy in process and I was able to acquire the waiver in one week. I press forward with hope.

I have personally spent every two weeks since his entry into the NeuroRestorative facility traveling from my home in Florida to Kentucky. He doesn't remember me being there. He knows that I come to see him but has no concept of how often or for how long.



His psychiatrist told us early on that there is no proof he will heal faster if he is at home without therapies or in a facility. The behaviors he exhibits (agitation, frustration, inappropriate yelling and aggression) are still prevalent. His behavior therapist works diligently to help him be more aware of his actions and body language. It is difficult for him to understand why he is in a facility. He has no compassion

or acceptance of so many people working with him every day. Yet, he has never missed a day of therapy in two years.

We do not know what the future holds. I have kept regular records of every aspect of our son's care and my visits with him. He has two children by his ex-wife. All of his friends have moved on with their lives. In the beginning people were near to us and wanted to stay informed about what was going on with our son. Now we rarely hear from them. His siblings, his children, and his friends don't visit him at all. My husband and I continue to walk this journey on our own.

Meet Lydia Greear

Lydia Greear lives in Florida with her husband of 40 years, Asa. They have three children together, and six grandchildren. She earned a bachelor's degree in sociology from the University of Kentucky. She is a licensed fitness instructor and certified personal trainer, and is also an active member of the Anastasia Baptist Church in St. Augustine. Lydia enjoys traveling, and has spent 14 years living in Paris, France, Benin and Côte d'Ivoire.



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Wait... What Do I Believe?

By Jennifer White

Immediately after I realized that I had survived a massive brain injury that kills most people, I was thankful and prayerful.

This was a natural reaction from someone who spent her youth in church all day on Sunday's, nights at weekly prayer meetings, Thursday's at church lock-ins, at least one year presiding as State President of the Baptist High School Student Union, and a summer traveling internationally with a religious singing group.

Although as a result of natural attrition while in college, I started attending church less often and started wondering what I actually believed in. I never stopped believing in a higher power, but I started questioning my true beliefs.

Then my world was rocked by a massive stroke...an acquired brain injury as my rehab facility called it. Honestly it was difficult for me to rejoice in the fact that I lived in spite of my physician's predictions.

I could not understand how I could work my fingers to the bones and become an executive at a company dedicated to raising money for health and service organizations, only to be struck down from a brain injury that literally forced me into early retirement in my early 30's.

Simply, I had my whole life ahead of me. Then, 24 hours later I was forced to learn how to walk again...how to talk again...how to eat again. I had already gone through this learning process as a child. How could a powerful entity that I dedicated my entire life to for so many years allow this to happen to me?



I was in pain and hurt as if a friend had slapped me across the face. Then I read a book about how bad things happen to good people and I felt a little better. Honestly, it has taken quite some time to accept the fact that my surgeon recommended that I not have children.

“Honestly, it has taken quite some time to accept the fact that my surgeon recommended that I not have children.”

I mean really...is it fair that my husband has to suffer because I had the stroke? The answer is no, but it is what it is and I still believe that there is a guiding light in my life that led me here.

So I will deal with the loss of old friends that I had prior to the stroke because we have little in common relative to raising children and I will deal with the inability to acquire new friends because of our incompatibility regarding child rearing. It is because I will not define the quality of my life based on my ability to raise children.

After feeling sorry for myself for quite a while and feeling guilty that I had lived when others had died, I decided that even though I didn't have the answers I would continue to believe in something greater than myself. My faith has gotten me through a lot of hard times and I believe it helped me survive this brain injury when all I wanted to do was sleep.



The truth is I have always believed in a higher power...when my mother died of cancer...when my father died of cancer and throughout my life when there were times that seemed unbearable. Sometimes I think I was kind of dense, but it is who I am. Dense and all.

I realized after the stroke that I did not have to have answers to every question. It is okay not to know the answers. It was simply hard for me to accept what I had learned all my life, (believing in something greater than yourself and more powerful than you are) is having a blind faith.

Believing in something that you can't necessarily touch physically is very powerful and gives you strength when you need it most.

Although I always felt very guilty for questioning anything religious, I learned throughout my life that much of my strength comes from questioning things that I do not understand. I realize that it is okay to question things. Questions bring answers, and I believe they make us stronger. I was raised in a fire and brimstone church where I felt guilty for questioning my religion. I feel guilty no longer. The God I believe in is fine with my questions!

Meet Jennifer White

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

New on VoiceAmerica™ Radio...

The Sky's the Limit, hosted by TBI Survivor Karen Leavitt!



The Sky's the Limit is a motivating, inspirational program which is based on my journey from medical professional to patient, highlighting people from all walks of life and various stages of overcoming adversity! Please join me every week.

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Double Trauma

By Norma Myers

It's been almost three years since the knock on our door completely changed our lives forever. My husband ran downstairs first, and I heard a voice saying, "There's been a fatal accident. Your oldest son didn't survive, and his brother is in very critical condition with a severe head injury. He isn't expected to live." All I could say was, "You have the wrong house."

I waited for the police officers to leave. They didn't. When I begged to go to our oldest son, Aaron (he was 26 when he died), I remember my husband saying to me, "Norma, there is nothing we can do for Aaron, but Steven needs us. This is what Aaron would want." At the time, his truthful words made me angry, but those words ended up being a defining moment for me. Shock took over my body coupled with a determined "I will do anything I can to keep my only son alive" mentality! I spent every allowed waking moment by Steven's side, begging my 22-year-old to live.

I somehow managed to shift gears as needed to be Steven's cheerleader while making lists to ensure that Aaron's life celebration was everything he deserved. When forced to leave Steven's room, I would start checking off my "Aaron" list. There was an obituary to be written, perfect songs to be chosen, pictures to sort. Aaron's hunting trophies, including a 300-pound bear, needed to be delivered to the church. There was no time for sleep.

I felt guilty when we had to leave the hospital to go to the funeral home and was plagued with more guilt because I couldn't focus on the painful task of picking out a casket for Aaron — I was afraid Steven would die while we were at the funeral home. If humanly possible, more guilt consumed my worn-out body as I attended our son's visitation and life celebration, silently praying that Steven

would live until I could get back to him. So when asked how I coped with Steven fighting for his life while trying to accept the fact that we lost our first-born son, I give credit to God for creating our bodies in such a way that allows us to operate even while in shock.

I somehow managed to compartmentalize my emotions. While Aaron was on my mind every minute, I was consumed with dread: I have to get Steven through this, he can't die, we have to get him to the best rehab, and we have to make whatever sacrifices necessary to give him the best possible chance of recovery. To be honest, it was easier to focus on Steven's recovery than to focus on the reality that Aaron died.



I found out the hard way that when faced with trauma of this magnitude, your body has many protective layers; and as the layers are slowly peeled back, you find out exactly what resiliency is. As the third-year anniversary of this horrible accident approaches, I'm living with delayed grief. I've learned first-hand what PTSD is. As our surviving son becomes more independent with each passing day, I'm left with attempting to figure out what's next for me. I have learned many lessons through counseling; one of the most valuable is accepting the reality that you can't put a time limit on grief. This is especially true when dealing with a double trauma and delayed grief.

For today, I will focus on being thankful for the years that Aaron so richly blessed our lives and cherishing each day with our miracle son Steven. While we don't know where this journey is ultimately leading us, we will continue to persevere, being thankful to God that we have each other, our family, friends, and our community!

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Meet Norma Myers

Norma and her husband Carlan spend much of their time supporting their son Steven as he continues on his road to recovery. Norma is an advocate for those recovering from traumatic brain injury. Her written work has been featured on Brainline.org, a multi-media website that serves the brain injury community. Her family continues to heal.

Recovery is a Marathon

By Micki Scherwinski



I never imagined my life being any different than it was the day I woke up on July 7th 2011. My life was full. I had many friends, I was always busy. There never seemed to be enough hours in the day to do all the fun and crazy things a typical 17 would do... I would spend every day with one friend or another. We made plans at the spur of the moment and never seemed to slow down.

Then in a split second, my life took a drastic turn in the opposite direction. The unthinkable happened: I lost control of my car, it rolled over 3 times, and I was ejected from the vehicle. As I lay unconscious on the highway my life was about to take a drastic turn. The impact of my brain injury was going to change everything and affect everyone in my circle.

I spent weeks in the hospital and months in rehab, not knowing what the outcome would be. I sustained a very serious head injury and minimal physical injuries. My physical injuries healed within a few weeks, but my head injury was much more severe and required months of healing.

Four years later, I am still healing. My short term memory loss is the hardest to deal with. My parents are always telling me it's ok to forget some things but at age 21 I don't want to have the same forgetfulness as my aging parents have!

I am very physically active, I am a runner and avid exerciser. I fully believe that physical exercise has a huge impact on healing my TBI. I should have been getting ready for my senior year and preparing for my college future, as my friends were. Instead I was focusing on relearning how to talk, walk, eat, and taking care of my daily needs.

My friends went on to finish high school and I was focusing on re-gaining all I'd learned throughout my grade school years. I did receive my diploma and was able to graduate with my class, but they were moved on to college and I went

back to high school. I tried to reconnect with my high school friends but they were ready to move on, while I was left behind.

I am currently enrolled in a college course and I continue to work hard at whatever I am doing. I have made some friends (other TBI survivors) and have some adult friends, but it's not the same as it was in high-school.

I miss not being able to jump in my car and just take off with my friends. Most things in life are a challenge and I have to work harder at achieving my goals. The one thing that has changed for the better is my love of running and exercise. It makes me feel good! I love the results I get from a good work-out or a long run. I have finished two half marathons, many 5k's and 10k's, and a Ragnar Relay where I ended in Chicago.

I have been working with Tanya from Independence First for the past couple of months. She has been helping me with projects that I need some assistance on. She would have me set certain goals and would help me to achieve those goals. I have learned to always set goals for myself and I feel so proud when I accomplish them. I encourage anybody to set goals like that for themselves!

Meet Micki Scherwinski

Micki currently resides in West Bend, Wisconsin. When she's not out running marathons, Micki Scherwinski is a college student at the University of Wisconsin.



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Traumatic Brain Injury Survivors Prayer

The Prayer

God,

I come before You as one whose injury
Cannot be seen by your other children.

While others see me, they know not that
My wounds are invisible.

I come before you as a
Traumatic brain injury survivor.

You alone know the depth of my pain,
Of my despair, of my confusion, of my aloneness,
And of my overwhelming loss of self.

Humbly, I ask of You...

When exhaustion strikes, please
Grant me the strength I need to continue.

When others leave my life, help me to
Remember that You are always there with me.

When unsteadiness causes me to stumble,
Please take my hand and lead me safely forward.

When my memory so often fails me,
Help me to never forget what is really important.

God, so many of your children walk daily with
Challenges that dwarf my own.

By understanding this, I can see my own
Life in a better perspective.

Help me for today to accept my fate in this life
Knowing that if I trust in you,
All will be well.

Amen.

The Story

In November of 2010, my life changed forever
when I was struck by a teenage driver. I
survived the devastating accident and have
lived ever since as a Traumatic Brain Injury
Survivor.

Out cycling one day a couple of years after my
accident, this Prayer came to me unasked for. I
was going through a tough time in my recovery
and the words that unfolded in my mind
brought me comfort and a degree of hope.

In the years since, thousands have found
comfort in this Brain Injury Survivors Prayer.

This Prayer is now available in a professional
printed format for **only \$9.99**. At 11"x17", it is
quite suitable for framing.

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Holiday Story Call-Out!

TBI Hope and Inspiration Magazine is looking for stories about how survivors deal with the complexities of the holiday season. Submit your story to mystory@tbihopeandinspiration.com.



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