

SEPTEMBER 2015

# TBI HOPE & INSPIRATION

Magazine

The background of the entire page is a photograph of numerous pumpkins in various sizes and shades of orange, some with green stems. Scattered throughout the scene are several autumn leaves in shades of red, orange, and yellow. The lighting is soft, highlighting the textures of the pumpkins and leaves.

**LIVING IN A  
WAR ZONE**

**CREATING  
SUCCESS  
IN OUR LIVES**

**10 THINGS  
I'VE LEARNED**  
*From my TBI*

**I AM A MIRACLE!**



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TBI Hope &  
Inspiration  
MAGAZINE

*Serving All Impacted by  
Traumatic Brain Injury*

**September 2015**

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**Publisher**

David A. Grant

**Editor**

Sarah Grant

**Contributing Writers**

Nancy Bauser

Amiee Duffy

Grant Evans

Ron Gains

Nattie Griffith

Katherine Kimes

Jeff Sebell

**Resident Cartoonist**

Patrick Brigham

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# Welcome

Fall is in full swing here in New Hampshire. Local farms have brightly colored orange pumpkins on display, apple picking season is here and there is a hint of a chill in the morning air. In another couple of weeks, our local forests and woodlands will be ablaze with the type of vibrant color that makes even the locals grab for their cameras.

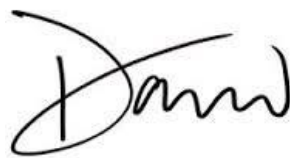
Later this fall, the calendar will tick by with another anniversary of my own traumatic brain injury. This year will mark five years since my life - and those of everyone close to me - was forever changed.

And what a five years it's been!

As time continues to pass, "who" I was in my past life continues to be more elusive. Remarkably, it seems less important to look back these days. Rather, my focus is on the present and on the future. My life has been enriched in so many ways over the last few years. Amazing people now define the landscape of my life - most of whom I would never have met had it not been for that fated day back in 2010.

I am pleased to present to you another issue of TBI Hope and Inspiration Magazine. Like past issues, you will read stories of survival and rebuilding life anew.

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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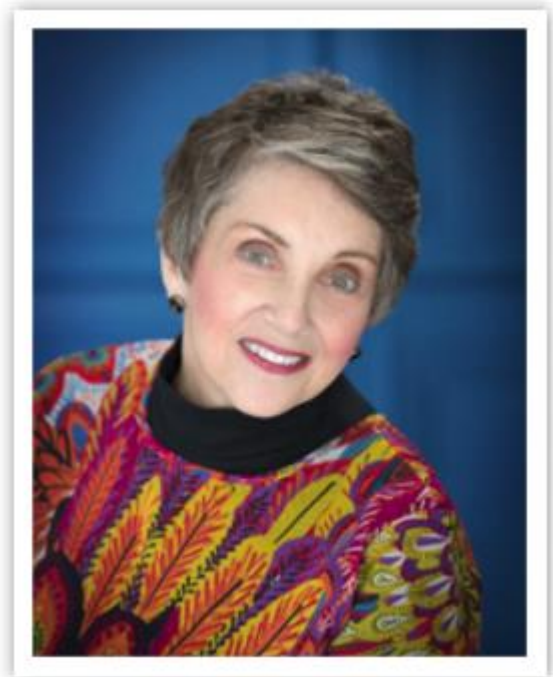
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# Living in a War Zone

By Nancy Bauser

After a trauma, an illness or an addiction, life becomes an uphill battle in all situations. Whether it's dealing with doctors, drug companies, mental health and rehabilitation professionals, or any other support staff, living as an independent, self-sufficient human being is simply no longer possible. There are countless adjustments, accommodations and modifications that need to be made to ensure the possibility that a quality life will be realized.



Now, let's bust some myths about living with challenges: First, true independence is simply no longer a possibility. Total dependence on anything is undesirable. A mixture of both independence or self-sufficiency, and dependence or getting assistance when needed becomes your new normal. Being interdependent with the environment becomes a new success strategy. Not over-using available support shows strength as you make progress and achieve new goals.

It's important to remember that behavior after tragedy is often fleeting and needing reminders of directions is not unusual or a cause for concern. Having memory problems is simply your new way of being. This document is for all those who've lost something and wonder if they will ever regain a life worth living.

It is also for people who haven't experienced a life altering calamity and want to know what that feels like. After existence as you had known it has ended, you must fight your way back! I make that statement because it's simply the absolute truth – for everybody! Regardless of the injury, disability, illness or addiction, that's just the way it is.

Since sustaining a severe closed head/brain stem injury in 1971, I've had more than my share of medical & psychological problems. I'm as healthy as I can be for a brain injured person. I address my difficulties as they arise. I see lots of specialists & I undergo medical procedures all the time. I have problems with my balance, my memory, and the organization of my days. I have to write down

everything that I want to do and remember. I keep two calendars. One is in my kitchen near the telephone and the other I carry with me wherever I go. My cell phone isn't a smart one, because I know that I wouldn't remember how to use it. I take public transportation because I've lost my driving privileges due to excessive speed and poor decision making.

“I keep two calendars. One is in my kitchen near the telephone and the other I carry with me wherever I go.”

I don't work because I'm never sure which days will be good ones and I'll be able to do what I want, the way I want, and which days are ones that I shouldn't have left the house. Oh well - that's my life in a nutshell. It's not pretty, but I make it work for me!

With any wound, it takes time to recover. Things never seem to get back to just the way they were. Typically, this is when depression rears its ugly head. When the realization that you just can't do things the way you used to becomes a reality, then a choice has to be made by you, the survivor. Do you give up and stop trying or do you fight the long battle back? It's your choice. No one can decide for you, not your significant other or your parent, employer, doctor or commanding officer. They can help you on your journey back to health and well-being, but they can't do what needs to be done. Only you can! So, what do you do?

I'll tell you what I do. I accept what is, because I have to. I don't have the luxury of having multiple choices. Then, I find the good in my situation and I forgive all those who I think may have hurt me. My attitude is that I will not let my circumstances control me. I will make adjustments in how I live, so that I can have the life that I want. It's really that simple!

### **More about Nancy Bauser**

Nancy Bauser is a disability life coach and the owner of Trauma Recovery Expert LLC. Over forty-three years ago – in 1971, Nancy sustained a severe closed head/brain stem injury while attending undergraduate school. A longtime resident of Bloomfield Hills, MI, Nancy maintains an active profile in the community and supports organizations that benefit healthcare recipients. In her spare time, Nancy's interests include writing, exercising, long distance walking and being with friends and family. You can read more of Nancy's work here: [www.survivoracceptance.com](http://www.survivoracceptance.com).



# I'm Still Here!

By Ron Gains

My name is Ron Gains, I am currently 51 years old and, irrespective of what you'll read further down, I am the happiest and most content I've ever been.

Back in October of 2013 I was in my 33rd year in the Motor Trade. I was Service Manager at a BMW Dealership and I'd reached the point in my career where I planned to stay until retirement. After which, I would move to our retreat on the North Yorkshire coast.

In 2013, I had been married for the second time to my lover and best friend of last 15 years, my

son was an adult, and to be honest, life was pretty damn good!

Then "WOW" – completely out of the blue my life was turned upside down.

I'd had a headache for two weeks and Jayne (my Wife) forced me to go to the Docs. It was a Thursday and little could be done because the symptoms didn't appear to ring any bells, and it was decided I should have my eyes tested. We were up in Scarborough that weekend and after a routine vision test, the local Optician decided my current prescription was massively incorrect and new specs were needed and ordered. I went back to work on Monday, still with a nagging headache, to await my new glasses.

On Tuesday morning I left my office to go look for a vehicle around the rear of the building. I walked past one of the valeting team and bid him a good morning, then "BANG" I collapsed. I have no recollection of this, and I was discovered seconds later in a bad state and the emergency rescue services were called.

I was scanned at the local hospital and the results dictated I was immediately transferred to the Neuro Team at the Hallamshire Hospital in Sheffield. Jayne was told that the findings of the Angiogram showed that it was likely I was not going to survive. I'd had a sub-arachnoid hemorrhage of a dissecting PICA



aneurysm and due to its size and location, the practiced coiling/clipping method was impossible.

Bring in Mr. Umang J Patel, the genius Neurosurgeon and my life saver! He took a look at my scan, rubbed his hands and talked at length to Jayne about performing a bypass operation that had only ever been completed 6 times before in the whole of the UK - 4 of those by himself.

The risks were great and the likelihood of me coming out of the 18 hour operation at all were slight, and a massive stroke afterwards was almost to be expected.

Before any brain surgery could be attempted however, there were some things to take care of. Due to a sudden loss of blood pressure when the hemorrhage occurred, I'd suffered a ruptured small intestine and an emergency operation left me with an ileostomy pouch for some 10 months. I really did push the boundaries further because after the stomach operation I suffered a massive internal bleed.



When that was sorted I suffered a blood clot which also tried to finish me off and today, I still have a “trap” inserted in my vein to prevent clots travelling up into my heart/lungs. I've also got a permanent VP shunt fitted in my head because, to add insult to injury, I suffered badly with hydrocephalus after the surgery and require this to maintain correct pressures in my head forever.

When the day of the brain surgery finally arrived, and 15 hours into the 18 hour operation, Mr. Patel rang Jayne in the middle of the night - 3 hours earlier than expected. He calmly told her he'd performed the major part of the operation and then broken for his tea. He said he was going back in to finish the surgery - but all had gone well!

I was unconscious for a long, long time after the initial collapse, and then away with the fairies for weeks before the surgery was carried out so my memory during the months I spent in hospital is very sketchy. For some reason however, I do remember Jayne coming to see me after the operation with pipes and tubes still connected, monitors beeping and 24 hour staff glued to my bed, I winked,

which told her “I’m still here and I’m going to be OK”.

Now some 22 months later I still need to “pinch myself” to convince me I’m still here. I defied all medical expectation and to be called Mr. Patel’s “miracle” by the Neuro Team is very humbling. His skill, along with my will to live, and Jayne telling me I wasn’t allowed to die saved me.

I’m a million miles away from where I was before. I stagger about like I’m drunk and can’t walk without my stick as I’ve got lifelong problems with pressures in one of the ventricles of my brain. I’m tired most of the time, get headaches almost every day, my short term memory is non-existent and I realistically cannot manage without Jayne guiding my life in the right direction but I’M STILL HERE!

“I’m a million miles away from where I was before.”

I love every second of every day and I am determined to make our life the best I possibly can. I’ve been given a second chance and I’ll tell you now I’m going to make our time left on this wonderful planet the best I can. Positivity has been massive in my success story and that, along with the love and support of friends and family, mainly my Jayne of course, is the reason I’m still here. There are occasionally times I just sit and sob and I’m sure in the future there always will be but I’ll keep fighting all the way.

I like to think that my story and my positivity has already helped others and I will willingly continue to share it. Hopefully I can continue to help others get through some pretty rough times too. Thanks for reading my little story.

### **More About Ron**

Ron exceeded all medical expectations and survived a massive Sub Arachnoid Brain Hemorrhage. Ron and his wife live and work together having bought a village Post Office with a general store attached. “Retirement from Management in the Motor Trade initially was hard but now me and my ‘rock’ Jayne work side by side and life really is pretty fantastic,” says Ron.



# Ten Things I've Learned from my TBI

By Amiee Duffy



1. Have Patience - I need continuous reminders to have patience with myself. Healing is a process. Learning is a process. Growth is a process. Often our healing, learning, and growth don't happen as quickly as we'd like. This can be especially true when recovering from an TBI because the recovery is not linear. Be Patient - it will come.

2. Have Patience With Others - Remember that the people who see you often are healing and adjusting too. If you are/were the primary caregiver, or have a spouse or live-in partner, this can feel like "abandonment" to them even though they rationally know that is not the case. Try to educate others about your TBI and post-concussive syndrome. Often the comments made and their lack of patience is just because they are uninformed.

As for "strangers" who make inappropriate comments or are generally rude or impatient in their treatment of you, the same thing goes. This one has gotten tough for me sometimes. I have wanted to have a recording on my phone or a badge that I can clip on to explain why I may be having a difficult time. Sometimes I tell them, other times I don't. It certainly is a good reminder for me to have patience with those I come across who have difficulties.

3. I Am Not What I Can Accomplish, Produce, or Do. - I am valuable and of worth just because I am. So if I am unable to do a lot on a certain day, recognize it, accept it, and be especially thankful on days that I can do more.

4. Stop Fighting! - Stop fighting change. Stop fighting the process. Stop fighting the diagnosis.

Accept. When you accept these things that is often where the healing, learning, and growth occur. And when you "can't", see number one! Don't feel guilty for being angry or mourning your losses. You are human. Human beings get angry,

sad, and frustrated. That is NORMAL. Just try not to treat others poorly and if it happens often, you need some new coping strategies!

5. Change is Good. Uncertainty is Good. - This one is especially tough for me. I like to be in control and to control my environment as much as possible. That is not happening with TBI at any stage! In illness and a change in life circumstances, there are things we may not be able to do any longer, either temporarily or permanently. But there are things we learn to appreciate more or talents or gifts we discover as a result of that illness or change in circumstances.



Embrace uncertainty, there may be a miracle right around the corner!

6. Don't Rush! - Let's face it, you are probably driving yourself crazy with how slowly you physically move. The brain fog forces you to slow down whether you like it or not. My coping strategy is to try to enjoy it. Make more eye contact. Hug a little longer. Notice things in nature. Enjoy the sun on your face. Take deep breaths. As I am getting better, I find I savor things a bit more than I did prior to my TBI. Rushing and pushing yourself only brings on more fatigue and a crash, so make the best of your inability to do things as quickly and relax.

7. Accept Help - I've never been good at this one either. I'm much more comfortable with being the "helper". I like my independence. I certainly don't like to have to admit I can't do something that previously I did without any thought and minimal effort. If you feel the same way, remember this: most people offer help because they care for you. They feel better because they are able to do something kind. Let them. You will be able to return the favor someday. Perhaps not in the same way, but in your own way. Even if all you can do is listen and have empathy when they are having a difficult time, which is returning a kindness. Think of how much someone listening to your experience has meant to you. If you have difficulty not being able to "pay them back", work on your listening skills. It makes everyone feel better.

8. Learn Humility! - Ugh! You actually CAN'T do it all. You actually cannot speak, figure out how to make the doctor appointment, drive yourself, balance your checkbook and take care of your children. ASK FOR HELP. Explain that you can't do it today, or you don't understand what to do or where to begin. Tell the person on the other end of the phone to slow down or repeat. Tell the doctor or

the nurse you need help. Ask someone to hold your hand when you are afraid. There is no shame in asking for help with basic tasks you "should" be able to do. There is no "should" right now. You can't. I know it is frustrating, but remember that 99% of people are happy to help. See numbers 1, 2, 3, 4, 5, 6, AND 7!

9. Enjoy the Good Days - When you have a day when you have energy, the tendency will be to try to cram in all the things on your "to do" list. It is a good feeling as well as necessary to do laundry and get shopping and cleaning done. However, don't forget to balance your good days out with time with a friend, a walk on the beach, or anything else that only serves the purpose of enjoyment.

10. Take Time to Tell Others How Much You Appreciate Them!

### **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.

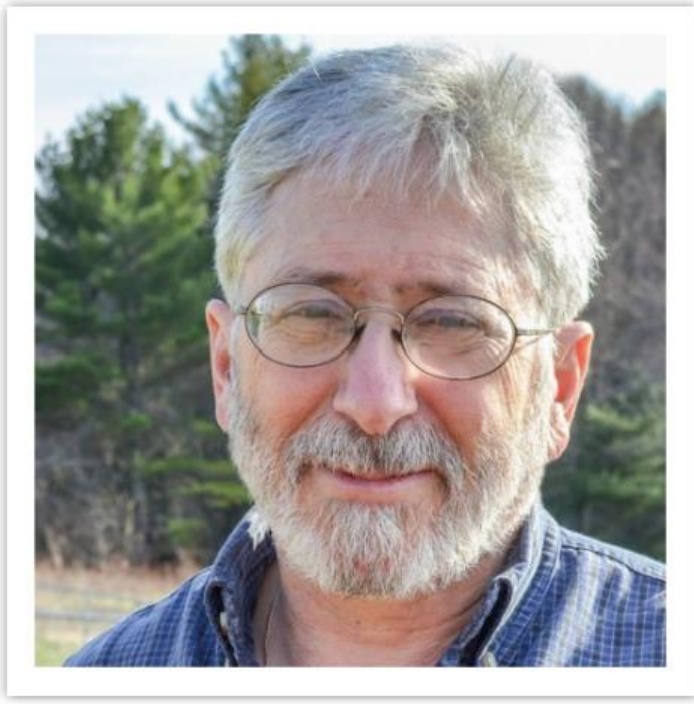
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# Creating Success in our Lives

By Jeff Sebell

Life changes when you experience a brain injury: those of us who have experienced a TBI know this better than anyone else. Life becomes a crazy, mixed up jumble, where everything has changed...except for one thing.

That one thing that doesn't seem to change is our expectations: our expectations about what we should be

able to do, as well as how we should be able to function as human beings.

A Brain injury is sudden and cataclysmic. After experiencing a TBI, we are forced to go through a learning period where we attempt to come to grips with the changes that have occurred. That takes time. There are so many changes that it literally takes years for us to understand exactly what our capabilities are. Not until we understand our capabilities, can we adjust our expectations.

Learning about ourselves and adjusting our expectations is crucial to creating success.

Many of us feel that changing our expectations is the same as throwing in the towel and giving up. Of course, no one wants to surrender, and we need to realize that changing our expectations is not the same as giving up. Rather, we are adapting to our new circumstances. We are learning what it takes to thrive in a new world.

Much of our self-worth and happiness is based on how we, as human beings, relate to and fulfill those expectations. When our capabilities change due to TBI and our expectations do not adjust, we are setting ourselves up for repeated failure. Basically, we are stuck in an old reality, and we constantly beat ourselves up and get down on ourselves for not being able to do something we have always been able to do.

Some of the most debilitating effects of brain injury are these negative feelings that we develop about ourselves, and how these feelings and thoughts affect



what we do. However, how we feel about ourselves is driven by our expectations, and thus, is something we can control.

Yes, while we may not be in complete control of our capabilities, we are in control of our expectations.

The equation is simple: In order to feel more successful I would need more successes, and in order to have more successes I'd have to change my expectations of what success is for me. I need to adjust so I am not beating myself up so much.

### *Starting Anew*

We spend years getting to know ourselves and creating expectations of ourselves. These expectations come naturally when we see how we function in situations, and we take pride in being able to perform and fulfill our expectations.

The knowledge we have gained over the years is thrown away in a split second by brain injury, and rebuilding that knowledge base is difficult. No one wants to chuck aside all their life experiences, as well as all the work they have invested in themselves -the work that has created the expectations they have - and start anew.

Our pride is involved. Our ego too. We find it difficult to give up what we knew about ourselves, but, the reality is we have changed, and we are asking our expectations, based on what we have learned about ourselves, to change. It is important to understand that creating a culture of success has less to do with what we do and more to do with our expectations.

We are facing some period of time where we are getting to know our new “selves”. It’s not always easy to adjust our expectations. We have to go through a lot of trials and failures in order to learn about ourselves. And you have to put your ego aside so that you can accept your new expectations.

If we don't adapt and learn we will be trapped in a cycle of failure. We want to

build a culture of success, where we understand our capabilities and we build our expectations around what is possible.

Finding a way to be successful in life after TBI is so very important. It can also be scary. Anything that involves risk and change can be scary. In fact, we may even be more comfortable keeping our old expectations, knowing we will continue to fail, rather than to take risks and try to be successful.

Changing your expectations doesn't mean giving up dreams and aspirations, but it may mean changing them or re-examining them in order to either make them come true, make some semblance of them come true, or make something else happen.

The goal here is not to beat ourselves up all the time, either for things we can't do that we think we should be able to, or for ways that other people act towards us. The ultimate goal should be to feel successful and productive, and we can start by making a very personal choice to change the expectations we measure success against so they are realistic and attainable.

## 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](http://www.TBISurvivor.com)

## Living With Hope

By Patrick Brigham







# I Am a Miracle

By Natalie Griffith

My life forever changed Christmas night of 2009. My mind body and soul were different. I dropped my four girls off with their dad when we were done having Christmas brunch with my parents, said my good-byes, gave them kisses and left. I went to a birthday party for someone I worked with, 45 minutes north.

I had a blast! I laughed and drank alcohol then decided around 10:30 pm to go home.

I gave hugs to the people at the party, said my good-byes and they asked, “Are you okay to drive home?” “Totally,” I said and assured them I was fine and left. Heading north on the 57 freeway, I was confused and lost so I called a close friend for directions.

He could tell I was drunk and told me to pull over and he would pick me up. I didn’t listen and while arguing with him, I rolled down an embankment onto the 60 freeway just below the freeway I was just on! I hit alternator sand barrels which stopped my car; I hit no one else but was trapped in my car unconscious. While knocked out, in a coma, I spoke to the Spirit of God; I felt incredible peace and love. He said He is going to take care of me, not to worry, just rest in Him. Sadly, people passed my crashed vehicle on the side of the road without stopping to check to see if I was okay; close to 11 pm, about 20 minutes after the accident happened, someone stopped to try and help me out. When he couldn’t, he called 911.

The paramedics came within minutes and had to use the Jaws of Life to cut the car open and get me out. Not knowing where to take me, UCI or UCLA either by ambulance or helicopter, they decided to take me to UCI by ambulance. I wasn’t breathing well and broken in several places including the shattering of my face and right arm; I was assessed in the ambulance, my breathing was short. I was considered Ring Jane Doe when taken to UCI because I was wearing a wedding ring but still needed to be identified. Jesus was with me every moment.

After UCI assessed me, they concluded I suffered a traumatic brain injury (TBI). My friend, whom I was speaking with when the accident happened, called my apartment and several hospitals to see if he could find me because our talk was cut off when the accident occurred. Once he called UCI, they told him a woman was brought in but they did not know who I was, so he had to go to the hospital to verify I was the person on my driver's license; this was the evening after Christmas.



He called my sister to let her know I was in an accident and in the hospital. She then called my parents and they came to the hospital to see what state I was in. I was given a 38% chance of living. The first three days were most crucial for my survival; I had two surgeries. The first surgery was to fix my head and my face. I had six plates and some metal screws put into my face and my jaw was wired shut. The second surgery was to work on my very broken right arm; a long plate was put in place of the shattered bone.

Through all of this, I nestled in the Lord's presence while in my coma; He kept telling me He loved me; He is taking care of me; He has big things in store; trust and rely on Him and never, never give up!

I was in a coma for 2 ½ weeks, and then my eyes began to slowly open. Once somewhat awake, UCI transferred me to a rehab hospital in Brea named Kindred Hospital. I had to relearn EVERYTHING like how to walk and talk again, how to eat food, even how to use the bathroom! I was a quick learner; my spirit wanted me to improve.

I was discharged from Kindred on St. Patrick's Day, March 17, 2010. I was unclear about so much, but I listened and trusted the people helping me, plus the Spirit of God was with me encouraging me. I moved in with my mom and dad because I was separated from my husband, he did not want me to live with him and the kids. But I received many visits from my four girls. My mom picked them up or their dad dropped them off; they needed to see their mom they almost lost and I needed to be around them to help my memories come back.

After coming home with my parents, my mom drove me to Winways, a place to relearn for people with brain injuries. I received many therapies five days a week for two months. Due to the problems with my perception and not knowing much, it was recommended that I go to Coastline Community College, a program that focused on different strategies following an acquired brain injury. It also was recommended I continue hand therapy so I could bend and move my fingers, and that I continue outpatient speech therapy so I wouldn't slur my words or often repeat myself.

I began Coastline College June 21, 2010 (my 32nd birthday). Although I wasn't completely together in my mind, my spirit and my soul wanted improvement and I wanted what was lost! I went to the 'brain-school' four days a week, four hours a day, for two years. OCTA took me every day until I got my license reinstated 2 months before finishing Coastline College in 2012. Jesus was with me every step of the way! And just like He told me in my coma, He was and is taking care of me, do not worry! I honestly do not get through my days without His help and guidance; He saved me for a purpose! I AM A MIRACLE!

### Meet Natalie Griffith

Natalie was brought back to life, given a second chance at life on Christmas Day. She has been working on relearning how to be a mom and interact with her children. Say's Natalie, "I love to make things pretty, BEAUTIFUL, so I have started a cleaning organizing straightening job, bathrooms & kitchens are my specialty. Never, never, never give up!"

**HELP KEEP ATHLETES SAFE *from* CONCUSSIONS**  
**AND OTHER SERIOUS BRAIN INJURIES**

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Remind your athletes to tell coaching staff right away if they think they have a concussion or that a teammate has a concussion.
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Keep the Heads Up Action Plan at all games and practices.

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# My Experience with Brain Injury

By Grant Evans

I open my eyes and I have no idea where I am. Am I dreaming? My Aunt and Uncle are standing over me. I reach out and grip my Uncle's hand as tightly as I can. I can't let go. Looking down, my brand new jersey is ripped open. Soccer boots on my feet, socks,

shin guards still on. Wires are stuck all over my chest and there is a tube in my nose. I can hear machines beeping behind me. Slowly it dawns on me something must have happened. I am in a Hospital bed. "You had an accident at soccer," my Aunt says.

That's the most I can remember of waking up that day, March 18<sup>th</sup>, 2013. I have no memory of what occurred several hours prior, but now I know that it has changed my life forever. It was the first game of the season for my soccer club, Kangaroo Point Rovers, and I was the Goalkeeper. My team had trained hard in pre-season and was confident of mounting a challenge for the grand finale. What follows is an account of the events, as told to me by others who witnessed them. In the third minute of the game, the ball fell between an opponent and I, both sprinting at full pace to try and get to it first. I dived at his feet to try and get my hands onto the ball, and just beat him to it.

As his momentum carried on, he tried to hurdle over me but his knee struck the left side of my head, just above the temple. My head snapped backwards. Players from both teams looked on, not knowing what to do as I went into a seizure. My limbs jerked, my eyes rolled back and I foamed at the mouth. Fortunately, a team mate that day was an off duty ambulance paramedic and immediately knew what to do and gave me immediate care. I often wonder what might have been had he not been there. Completely unconscious I was rushed to the Princess Alexandra Hospital by ambulance.

I spent a few days recovering and being monitored at the PA. The Neurologists had performed a quick CT scan whilst I was unconscious. The scan revealed a

minor bleed on the surface of my brain as a result of the collision. Thankfully, I was assured this was nothing to worry about and would make a full recovery. Feeling quite relieved, all I could think about was getting back onto the soccer field as soon as possible. Being out of action didn't feel like an option at this point in my life, also professionally I was really starting to gather pace and didn't want to take time off work either.

Prior to that day in March 2013, I had worked from home as a freelance draftsman and my business was really taking off. Having grown a bit weary after 13 years of employment with various engineering consultancies in the UK and Australia, I had decided to go solo and set up on my own. Relationships were being forged with clients and they were returning regularly with new projects for me to work on.



Working hard and playing hard, I was one of the boys, with plenty of big drinking sessions to enjoy with my soccer mates and I was always right in the middle.

When I was discharged from hospital, it quickly became apparent to me that I didn't feel quite right, though it was hard to put my finger on it. Physically I seemed fine, and on the outside I looked normal. I was incredibly tired all of the time. Exhausted and vague. People would talk to me and I couldn't fully understand what they were saying. It was as though they were talking in a foreign language at times. Communication became a problem – I could not articulate how I felt or what I needed. The words felt as though they were on the tip of my tongue but would not come out.

Most of those around me quickly became frustrated. What is wrong with you? Why can't you tell us what is wrong? You need to snap out of it! These were regular anecdotes from a variety of people in my life. It wasn't their fault for saying these things and they wanted to help, they just didn't understand it and were very worried. Those valuable relationships with clients I had worked hard to foster ceased to exist as I became completely incompetent at my job, and my bank account dwindled. The old Grant seemed to be disappearing fast– and people were regularly telling me so, which added to a growing sense of shame and guilt. Having no idea at the time what all of this meant, I couldn't seem to get things together. Becoming increasingly isolated, I became very thin and rarely left my bedroom. I would later find out the extent of damage to my Brain

was far greater than first known.

Returning to the Brain Injury Rehabilitation Unit (BIRU) at the PA Hospital, I discussed my symptoms with the Specialists and was given further testing. Detailed MRI scans revealed what the original quick CT scan had not picked up. I had suffered what is known as a Diffuse Axonal Injury. At the moment the opposing player's knee had collided with my head, the impact caused my Brain to bounce around within my skull. This caused dozens of minor bleeds and areas of damage where the soft brain tissue made contact with bony ridges on the inside surface of my skull.

The results of Diffuse Axonal can be catastrophic. The outcome is quite often coma with most patients never regaining full consciousness – yet I had been incredibly lucky. The prognosis was very uncertain - people with even a minor brain injury can still have ongoing significant cognitive problems after 6 to 12 months and patients with more serious injuries can be relatively back to themselves just a few months down the line. One thing is for sure, with any injury of this type the road to recovery is uncertain.

“The results of Diffuse Axonal can be catastrophic.”

No two brain injuries are the same. For me, a long period of rehabilitation as an outpatient followed. Every week I would attend the BIRU to try and re-train my brain to overcome and adapt to the injuries it had received. The Occupational Therapists showed me a book with pages of different faces and asked me to memorize a dozen or so of them. Ten minutes later when asked which faces I had previously seen I could not recall most of them. As a test, they asked me to go down to the hospital café and order a coffee, buy a newspaper and then return to the BIRU.

Roughly 30 minutes later the staff found me wandering around the hospital confused – I had no memory of the instructions I had been given just minutes previously. These are a couple of examples but there were countless more. This period of my life brought various emotions, fear, anger, resentment, guilt, shame. Most of all, confusion. Considering myself a fairly competent person, I found it all terrifying.

Thankfully, following a relatively successful period in rehabilitation, things slowly began to improve for me. Today I am two and a half years down the track

from my brain injury. I feel like I am getting better every day but still have moments where I have to slow things down. My recovery is still ongoing. Without the support of my Aunt and Uncle, I wouldn't have come through it, they really were fantastic and picked me up during some tough times. I will be forever indebted to them. Many of the friends and drinking pals I had accumulated before my accident are now long gone - but the good mates have remained through thick and thin.

I decided to give up alcohol to aid my recovery, as it's toxic for the brain, especially a damaged brain. This was very difficult and took some getting used to. For 15 years the booze had been my primary source of fun but had also taken me to some dark places and I knew I had been using it too much to cope with the stresses in my life. Having not touched a drop for 30 months now, I don't miss it at all - especially the hangovers!

I can say with all honesty that my brain injury is the best thing that has ever happened to me - and I wouldn't change it. Coming to terms with it has helped me become a better person and I have met and befriended some amazing people as a result, people I would never have crossed paths with had it not been for my accident. Participating in voluntary group work with others at the STEPS group is something I have found very rewarding.

On Monday mornings, I give my own time to assist with leading the STEPS skills program, a Queensland Health initiative which delivers support to people in the community who have suffered an ABI (acquired brain injury). Usually these car crash, stroke, fall, and other accident victims are discharged from hospital once the physical wounds have healed. Often little is known regarding the full extent of the damage that has been caused to the brain and the person's psychological wellbeing. STEPS offers group work sessions to help them share their experiences with others and learn how to adapt and look after themselves following such life changing injuries. Having been through it all myself, I can offer advice, empathy and understanding. It has helped my recovery, and especially my mental health, immensely.

I am a big advocate of discussing mental health, especially in men. Coming from a working class English town, you are conditioned to keep your feelings bottled up. You work hard and play hard, and keep your problems to yourself. You get on with it. That's just the way it is. Having had my own battles with depression, both before and after my brain injury, I'm not ashamed to admit I have sought treatment and counselling. I found this the hardest thing to admit to myself and



especially others that I needed help. I just wish more men would do it if they are struggling – suicide is the biggest killer of men between the ages of 20 and 49, not Cancer or lifestyle related diseases. Men are expected to be men, and always be strong. I'm not saying women don't suffer, of course they do, but men are more inclined to keep things bottled up and not talk about it whereas women are more likely to. Men can often see it as detrimental to their masculinity. I think the stigma surrounding mental health is slowly improving, especially with high profile public figures, especially sports stars going public with their own struggles. Sadly, I feel there is still a long way to go before mental health issues are more out in the open and widely accepted.

I returned to playing soccer roughly 12 months ago, which was difficult at first but I am somewhere near back to my best again. Perhaps my reflexes are a little slower, but maybe that's just age creeping up on me! In a recent game I fractured a cheekbone, on the receiving end of an opponent's stray elbow, which shook me up a little. I have been warned by doctors that another significant head injury could be disastrous. Being fully aware of the risks, I have to be very careful, but it's a physical game and strong challenges are part of it. People often ask if I am crazy for going back onto the field but my answer is always the same, I just love the game and I'm not thinking about retiring from the game anytime soon!

## **Meet Grant Evans**

Grant was born in a town called Barrow-in-Furness, which is located just south of the lake-district in North West England. Grant spent the majority of his life in Barrow-in-Furness, apart from 7 years as a child in Sydney, and the last 5 years of his life in Brisbane, Australia. He enjoys living in Brisbane because it has such a relaxed vibe and has made some amazing friends there – friends for life!



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# Effective Service Coordination for Students with Acquired Brain Injury

By Dr. Katherine Kimes



Changes in a student's physical well-being, cognition, emotional and psychosocial behaviors after a traumatic (TBI) or acquired brain injury (ABI) can stigmatize the child in school. Therefore, it is important to address all these areas within the education system through effective service coordination. The key to successful in-school service coordination is to help provide an enriching learning environment.

## **The foundation that fosters effective service coordination**

Three essential factors need to be working in conjunction to establish the foundation for the successful coordination of in-school services and supports. It is important that these factors work together in order for service coordination to be effective and sustainable. The building blocks of this foundation include:

- Broad-based participation and support of school administrators, community leaders, youths and families.
- Collaborative communication between constituents (to include inter-agency communication). This includes having a personal advocate, who is knowledgeable in the area of brain injury on the team, in order to educate all staff about the specific needs of the individual student.
- Appropriate training, support, and technical assistance of school staff.

Together these three components help build and strengthen a comprehensive and effective system of services.

## **The three components and why they are essential for coordinating services**

Specific aspects of each of the above mentioned three components: broad-based participation and administrative support, collaborative communication, and appropriate training, support, and technical assistance are discussed below. Specifically highlighted are those elements that need to be established prior to building a supportive environment for service coordination to effectively grow within school systems.



### **1. Broad-based and administrative support**

The key is to instill broad-based support and administrative support. It is essential to have key leaders that are motivated to encourage system change and to have the school administrator's buy-in of the change process and his/her continued support. On-going support is vital to the success of the process. Broad-based support is a key change agent because all parties involved need to help support and sustain its effectiveness.

If it is not on the administrator's agenda, typically the issue will be ignored. Therefore, it is important to make administrators aware of the problems that exist in implementing effective services and supports to students with brain injury.

### **2. Collaborative communication**

Another key component that helps to ensure service coordination is successful focuses on the importance of collaborative communication between constituents, all parties involved in the process of providing and coordinating services. This highlights the importance of the frequency of contact and the collaboration among those professionals and school staff. It is also important to ensure that the student (when appropriate) and the parents are included in the planning. An advocate, who is knowledgeable about the needs and educational planning for the student with a brain injury, is vital and should be on the IEP team.

A key to promoting effective service coordination is the interdependency of the existing infrastructure, i.e., those services that are already in place, and the

communication that takes place within that infrastructure. Communication is essential to help ensure service coordination is effective and sustained. The goal is to build an enriching learning environment and to accommodate for the student's ongoing and ever changing needs.

### **3. Appropriate training, support, and technical assistance**

The third component includes having school professionals educated on the implications of brain injury on students' lives. It is important to have those professionals who provide support on a daily basis be aware of the unique needs of these students. School professionals need to be properly trained to understand their roles and responsibilities to fully understand the importance of the IEP team structure and those services guaranteed to the student under the law.

A tiered system of training and a system of technical support and assistance are two resources that can help professionals understand and recognize how their responsibilities and roles can positively influence the success of service coordination. It is important to have a foundation of professionals that have been adequately trained to implement appropriate services and supports to students with acquired brain injury.

While it is important to understand the factors that build the foundation for successful service coordination, it is also important to understand those factors that can inhibit service coordination. These factors include, but are not restricted to: a limited time-frame to develop services, establishing interpersonal trust among constituents, negative or conflicting attitudes, breaking old and establishing new habits, mobility and turnover, lack of funding, geographic location, the breakdown of communication among constituents, inadequate training, and specific roles not being clarified within the system of services.

#### **Meet Dr. Katherine Kimes**

Dr. Katherine Kimes has a Master's Degree in Literary and Technical Writing from DePaul University. She also has a Master's degree in Transition Special Education with an emphasis in acquired brain injury and a Doctorate in Special Education also with a concentration in acquired brain injury, both degrees confirmed by the George Washington University. She has worked as a CSPPPD Service Coordinator and is a Certified Brain Injury Specialist. Please visit her website, [www.ABI-EdServices.com](http://www.ABI-EdServices.com), for more information.



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