

Brain Injury

March 2019

# HOPE

supporting the  
brain injury  
community

MAGAZINE

OUR FOUR-YEAR ANNIVERSARY ISSUE

March is...

**Brain Injury  
Awareness Month**

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# Welcome

Publisher's Introduction

## HOPE MAGAZINE

*Serving the Brain  
Injury Community*

**March 2019**

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### **Welcome to the March 2019 issue of HOPE Magazine**

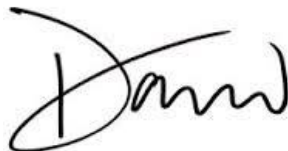
As most people within the brain injury community know, March is *Brain Injury Awareness Month*, a month dedicated to advocacy and spreading awareness about brain injury of all kinds.

Together as a global family, it is a great time to reflect on the ground we have already covered, and to look to the future toward a world that better understands and embraces those living with brain injury.

In the eight years since my own brain injury, so much has changed, but there is still so much to be done. Advances in diagnosis and treatment continue, as does public awareness.

Each of us is presented with teaching moments every day. I challenge you to move forward using these moments to help advocate for those who need it most.

Peace,



David A. Grant  
*Publisher*

# Contents

What's Inside

March 2019

- 
- 2 Publisher's Introduction**
  - 4 Seasons of Change**
  - 7 Embrace the Life You Have**
  - 11 Coming Out of My ABI**
  - 16 Five Success Strategies**
  - 21 I Have a Disability - I'm Not Disabled**
  - 24 Supporting Each Other**
  - 27 The Importance of Sleep After Brain Injury**
  - 31 News & Views**

*"Encourage, lift and strengthen one another. For the positive energy spread to one will be felt by us all. For we are connected, one and all."*

-Deborah Day



# Seasons of Change

By Norma Myers

As I sit on my porch listening to the faint sound of fireworks in the background, memories take me back to what Independence Day looked like when my family of four was *intact*. I remember carefree family get-togethers celebrating our country's independence, enjoying family picnics, and standing in awe as my heart captured our sons' mesmerized faces reacting to the splendor of a firework display.

But since the auto accident six years ago that took Aaron's life and left Steven with a severe traumatic brain injury, holidays have been filled with both pain and celebration. Pain from grieving the loss of our first-born son coupled with celebrating the miraculous life of Steven. Aaron and Steven were not only brothers, they were best friends, our only children.

After the accident, we knew nothing would be the same, but we were not prepared for how strongly our emotions would swing during holidays and changes of seasons. For our family, each season encompasses more than a change in weather. Arriving with spring and summer is the plethora of holidays and celebrations. The same celebrations that we used to look forward to with sweet anticipation now require us to be mindful of how our hearts will react. No matter the holiday or special occasion, each offers a bittersweet effect. Each year, as the busyness of

“But since the auto accident six years ago that took Aaron's life and left Steven with a severe traumatic brain injury, holidays have been filled with both pain and celebration.”

summer subsides, we find ourselves releasing the breath that we weren't aware we were holding. Saying goodbye to summer is saying hello to fall, which was Aaron's favorite season.

Fall has also become Steven's favorite season. Like Aaron, Steven embraces the gift of spending time in nature, where he feels the closest to his brother. Followed by the beautiful fall season, it doesn't take long before we hear the dreaded moaning and groaning that arrives with the first bite of winter. The sting of winter for us is not equated to the temperature; it's the harsh reality of celebrating another season and Christmas without Aaron. What takes the bite off is not layers of clothing, it is slowing down and focusing on the birth of our Savior, the one that provides the healing to our wounded hearts and reminds us that when the calendar page turns once again to a new year without the earthly presence of Aaron, we are not alone.

I don't share our feelings to gain sympathy. I share them to give others a glimpse of what life is like for those that live with grief and invisible disease. We never want to be excluded from celebrating special occasions, but at the same time, we do not want our pain to be a dark cloud on your special occasion. There are times when no matter how much we physically want to be included in celebrations, we must listen to our bodies and do what's best for our family, this could mean celebrating with you in spirit, but nonetheless, we are with you. It's these times that we desperately ask for patience and understanding.

*Back to Independence Day.* This year, when I think of Independence Day, I am reminded of how the accident totally stripped Steven's independence away. As parents we watched Steven grow through each stage of life, from infancy to adulthood ***all over again***, and trust me, that experience was not for the faint of heart!

**I don't share our feelings to gain sympathy. I share them to give others a glimpse of what life is like for those that live with grief and invisible disease.**

The second time around was so grueling at times. I didn't know if we would make it, but, together as a family, we did! Steven has fought long and hard, physically, emotionally, and financially to be able to experience another "first" this fall as he has spread his proud wings and flown to his own bungalow.

I know in my head that Steven is ready, but my heart needs a bit more convincing. Ten minutes away for this Mom might as well be ten hours. I find comfort in knowing Aaron will take over my role of providing a watchful and protective eye.

"I know in my head that Steven is ready, but my heart needs a bit more convincing."

My husband and I are already attempting to prepare our minds, but mostly our hearts, for this new season: empty nesters! Our feelings are like most emotions since the accident, two-sided. We're happy for Steven, and we are so proud of his accomplishments, but I feel anxiety kicking into high gear, and he hasn't even moved yet! I'm sure there is an empty nest anxiety support group (like I need one more support group).

Seriously, I'm so thankful that Steven is patient with me. He understands that my anxious feelings go hand in hand with experiencing trauma, and these feelings are escalated due to double trauma. Right along with bumps in the road that will come along with this new chapter, we will do what we have done each step of the way—cheer Steven on, stay strong as a family, and take one step at a time as we depend on our faith and each other.



## 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.*



# Embrace the Life You Have

By Debra Gorman

An old friend from my many years of living in upstate New York shared with me a blog post recently that really resonated and caused me to think. At the beginning was this quote by John Piper, a well-known author and theologian:

***“Occasionally weep deeply over the life you hoped would be. Grieve the losses. Then wash your face. Trust God. And embrace the life you have.” ~John Piper***

This is the first time I remember being given permission to weep over my losses. It also implies that the grieving never ends. Five sentences only, but they are a balm to my sore heart. No one gets out of this life alive, so it seems reasonable that if we live long enough, we will suffer many losses, whether health, loved ones, disappointments, you name it. Pain is pain, no matter its origin.

“The only way I know to find peace in the midst of suffering is to discover purpose in it.”

The only way I know to find peace in the midst of suffering is to discover purpose in it. Although I would never choose brain injury, it is my life now. I believe that because my life has so completely changed and I didn't die that day, August 20, 2011, the day my brain bled, there is a reason I am still here. Many of my deficits are invisible, but some are obvious and have humbled me greatly—I thought I was humble enough. I find I have a natural platform from which to speak and empathize

with fellow sufferers. I can be trusted because I don't speak from theory only. I am a reliable source; I have experience.

Author Robert Kiyosaki wrote, *"Inside every problem lies an opportunity."*

The real problem may be our perspective, how we view our situation. How can we see our plight as a gift to be shared? We may hold a particular insight that few people have. We can come alongside someone else who may benefit from our unique point of view.

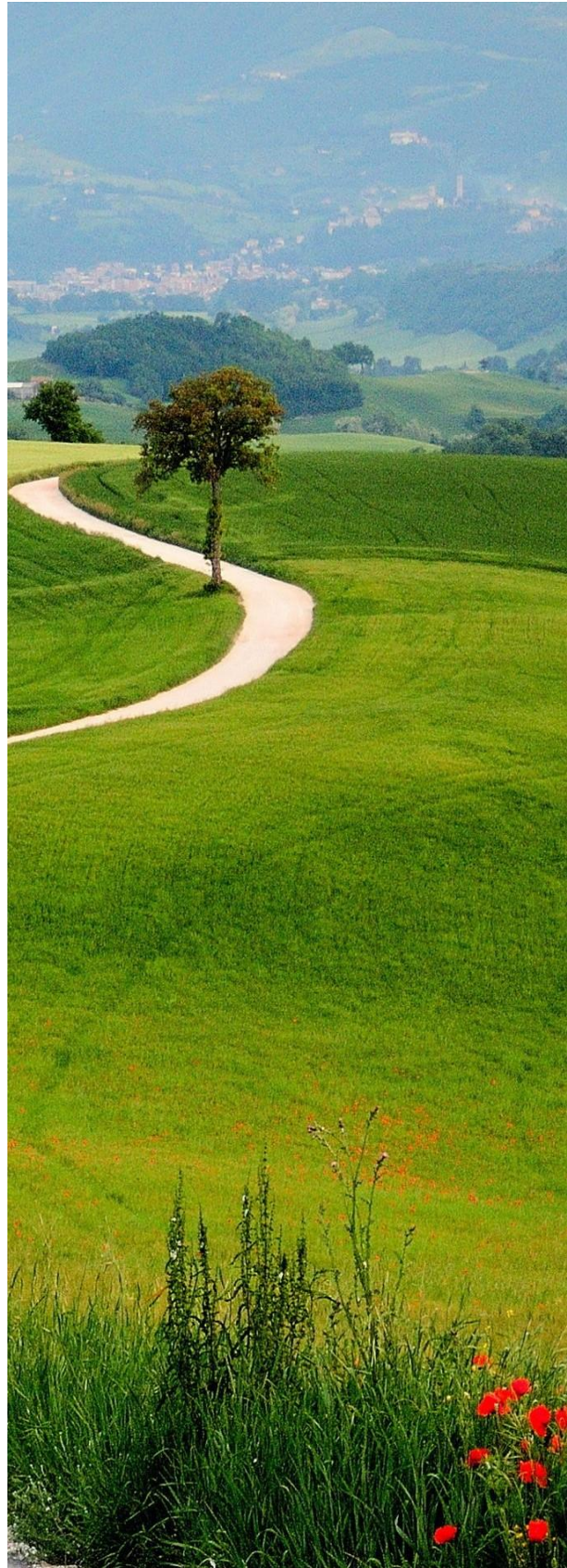
Due to my disability I have been unable to continue my nursing career. This has allowed me to pursue other interests such as writing. I also trained my Golden-doodle to be a therapy dog. She brought smiles to the faces of residents and staff alike at the neighborhood assisted living and memory care facility where we visited weekly.

Sasha has since gone to doggy heaven but for three years we visited there the joy was palpable as the residents' patted and stroked her, a mutual love fest.

I continue to believe that life is a gift. But to appreciate its value, it must be shared. We all have something to give. It may be something as simple as providing a listening ear, no small thing. I find I view disabled persons differently than before I became one. I feel compassion and a comfort around a population I had little in common with before. I'm sure they feel some isolation, as I do at times.

Piper says that after grieving deeply, "wash your face." To me that is suggesting that our pain does not have the power to crush us. We may revisit our grief regularly, but after a time we must clean up, go out and face our world, putting one foot in front of the other, always being ready to grant the gift of understanding, helping to shoulder the weight of adversity.

When grief returns, as it likely will, it can serve as a reminder that life may be very difficult at times, but





many others also experience deep hurt. It keeps us in the empathy zone. Sometimes one's greatest contribution is to come alongside another with the assurance they are not alone. I can see my disability as a gift, albeit one I didn't eagerly stretch out my hand to receive. I trust that God knows the best way to mature me and use me to accomplish the purposes for which I was created. I don't like it; I had other plans for myself, but I'll do the best I can to not waste my circumstances.

It would hardly be fair to not consider clinical depression, a depression lasting more than two weeks and you cannot reason yourself out of it. True depression is a biochemical condition. It is a real illness and help is available. With proper treatment, most people with depression will overcome it. Sometimes it is not possible to simply be positive or talk oneself out of uncomfortable feelings. Medical help is required.

In most cases, however, it is up to the individual to choose how to react to a given situation. As John Piper says, and I am paraphrasing:

Grieve and then appreciate the life you have.

## Meet Debra Gorman

*Debra Gorman was fifty-six years old when she experienced her brain injuries. The first was a cavernous angioma, causing her brain to bleed, and four months later, a subdural hematoma. She later learned that she also had suffered a stroke during one of those events.*

*She finds a creative outlet in writing. She is able to use a keyboard, tapping keys with her non-dominant forefinger and thumb. She enjoys writing for her children and grandchildren and has written articles that have been published for hospice. Currently, she writes for her blog, entitled Graceful Journey. [debralynn48.wordpress.com](http://debralynn48.wordpress.com).*



## Join our Facebook Family

What do over 25,000 people from over 40 countries and five continents all have in common? They are all members of our vibrant Facebook family at [f/TBIHopeandInspiration](https://www.facebook.com/TBIHopeandInspiration)



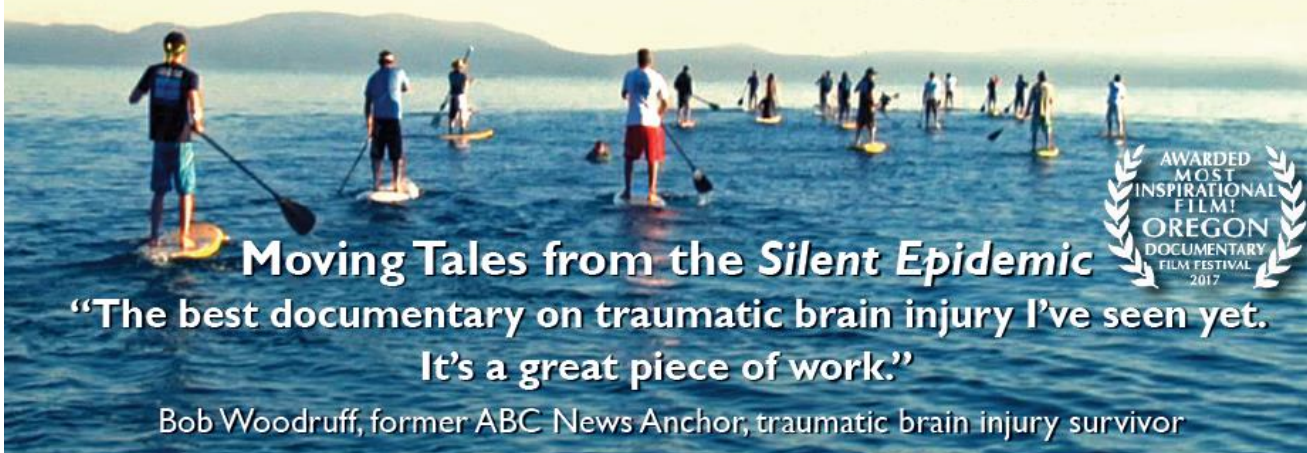
Announcing the national PBS broadcast  
and DVD/Blu-ray release of

# Going the Distance

## Journeys of Recovery



*Produced and directed by David L. Brown*



**Moving Tales from the *Silent Epidemic***

**“The best documentary on traumatic brain injury I’ve seen yet.  
It’s a great piece of work.”**

Bob Woodruff, former ABC News Anchor, traumatic brain injury survivor

**Going the Distance: Journeys of Recovery** is an hour-long character-driven documentary in which four survivors take us inside the experience of traumatic brain injury (TBI) to reveal their personal stories of devastation, heroism and hope. Produced and directed by three-time Emmy Award-winner, David L. Brown, **Going the Distance** focuses an intimate lens on the daunting, inspiring journeys of the survivors as well as the people who love and care for them.

**“Going the Distance: Journeys of Recovery** is insightful, thought-provoking and beautifully crafted. I am especially impressed by the hope, compassion and inspiration captured and conveyed throughout the film. It will clearly be an extremely welcome and valuable media resource for the TBI community.”

—Susan Connors, President/ CEO, Brain Injury Association of America

Special rates on DVDs and Blu-rays for TBI survivors and TBI organizations.

Streaming to be available by December 20, 2018.



[www.goingthedistance.info](http://www.goingthedistance.info)



# Coming Out of my ABI

By Nimali Pathirana

Before my diagnosis of ADEM (Acute Disseminated Encephalomyelitis), I was on top of the game. I was somewhat of an overachiever some would say. I was in Year 11 studying Physics, Chemistry, Maths extension, Advanced English, Physical Education and Italian. I was a healthy, active teenager. My hobbies included touch football, netball, music and gymnastics. I also enjoyed having a wide network of friends.

In early 2005, I was infected with the common flu virus. Following the flu, I was somewhat dizzy and went to see the General Practitioner a few times, but they diagnosed it as postural hypotension since I was doing a lot of sports. There was nothing to be concerned about. This continued for some time and my left side began getting a bit weaker. For the next three months, I experienced gradual physical deterioration with symptoms including weakness, fatigue, bilateral upper limb tremors and my handwriting was going downwards.

These were so subtle and every time I would go to the General Practitioner or physio, I performed everything fine. One week prior to my admission to the hospital my symptoms got really bad, and I remember it happened overnight. On admission to hospital in mid-2005, I came up with some symptoms such as a left hemiparesis, right involuntary movements, left facial palsy, bilateral ptosis, swallowing difficulties and limited verbal communication. I also had episodes of postural hypotension, confusion and urinary urgency. I was in hospital for seven weeks.

During that time, I didn't realize that I had undergone a personality change. It wasn't until I was thrust back in to school that I realized that I was a different person.

My parents discussed with the teachers what had happened to me prior to my discharge from hospital. The school then sat down my whole year and explained to them what had happened and what it meant to have a brain injury, and to help me when they could.

All my friends from my original year group had gone into Year 12 before me. I couldn't go to the Year 12 formal that all my original year group went to. That was so hard for me. I wasn't included; I felt very left out and alone. I had this brain injury, I was a totally different person, but no one understood it. Not even I understood it.

I lost some friends, and some stuck by me. I noticed over time that I wasn't the same. People around me were not behaving the same towards me. They didn't realize that what I had been through was a huge traumatic experience. Since the brain injury I always felt left out.

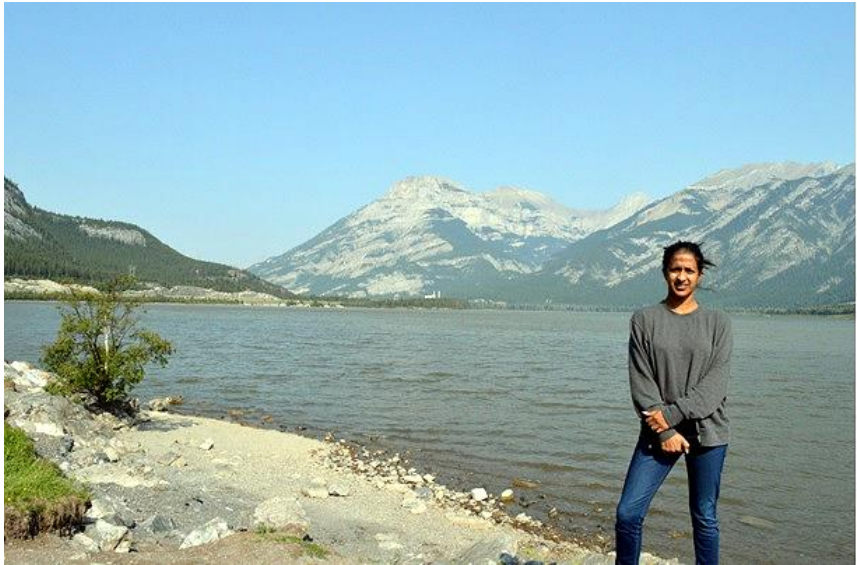
Some of my relationships and friendships changed. Hanging out with my normal group of people didn't feel right anymore. I wasn't able to enjoy it like I used to. I just couldn't process things in the same way. In my head, I thought I was the same person I used to be, but when I came out of hospital, I was more open with limited ability to control my feelings.

I hated my body. It wouldn't do what I wanted it to do. It wasn't obedient. I had involuntary jerky movements in my left arm. I lost the ability to self-care, write, type, cook for some time. Still now, there are some minor issues with my left arm movement, but it may not be that obvious. I used to get tired easily and need frequent breaks. I still can't concentrate for long periods. Working with sharp objects, electricity or heat became a safety issue.

“I noticed over time that I wasn't the same. People around me were not behaving the same towards me.”

The loss of control was extremely difficult to come to terms with. My personality and behavior changed. When I was in the presence of unfamiliar people, I lost all inhibition and reserve. I engaged in riskier behaviors and put myself in uncomfortable situations which I am still ashamed of. I lost the ability to discern between appropriate and inappropriate behavior. My family had to work hard to protect me and support me to develop and to learn to manage the symptoms, which were physical, cognitive and emotional.

Through the fourteen years since the brain injury, I have had to re-learn how to regulate my emotions, and how to properly discern risks and safe people. I continue to work hard to develop my endurance and my focus. However, I am glad to say that they are all in the past now. I am on my pathway to full recovery. I understand that there are still some issues and concerns I need to address but I positively think that I will be able to overcome them and achieve my goals to be an independent and successful lady.



I am determined to get my life back and have a normal family life. I am blessed with a number of support service personals including physiotherapy, therapeutic massage, acupuncture, sport physio, meditation, councilors and academic learning support. With their support and my family's guidance, I have come a long way since my injury.

I have many friends. However, even now, my only close friends are really from High School. I do have a wonderful group of friends at work as well as at my service providers now.

Looking back over the past fourteen years, I have come so far. I have an amazing quality of life now, which I could never have imagined when I was first diagnosed. I gained an Associate Degree in Business and International Tourism and am currently studying for a Diploma of Clinical Coding, so I can work as a medical coder. I have a great job at my local hospital.

I have travelled in many countries both in northern and southern hemispheres with my family. I just celebrated New Year's Eve with my family. I do have mixed feelings though. While I love my family and am so grateful for their support and presence in my life, I feel isolated and a world away from my peers who all seem to be getting married and with children.

If I could go back and talk to my sixteen-year-old self, freshly diagnosed with ADEM, I would tell her to be strong and keep going. Don't give up. There are no instant fixes even though I know you

want one so badly. It won't be this hard forever. You will become a stronger, better person through this. Although it feels like everything is out of your reach, you will gain the skills to live a great life in time.

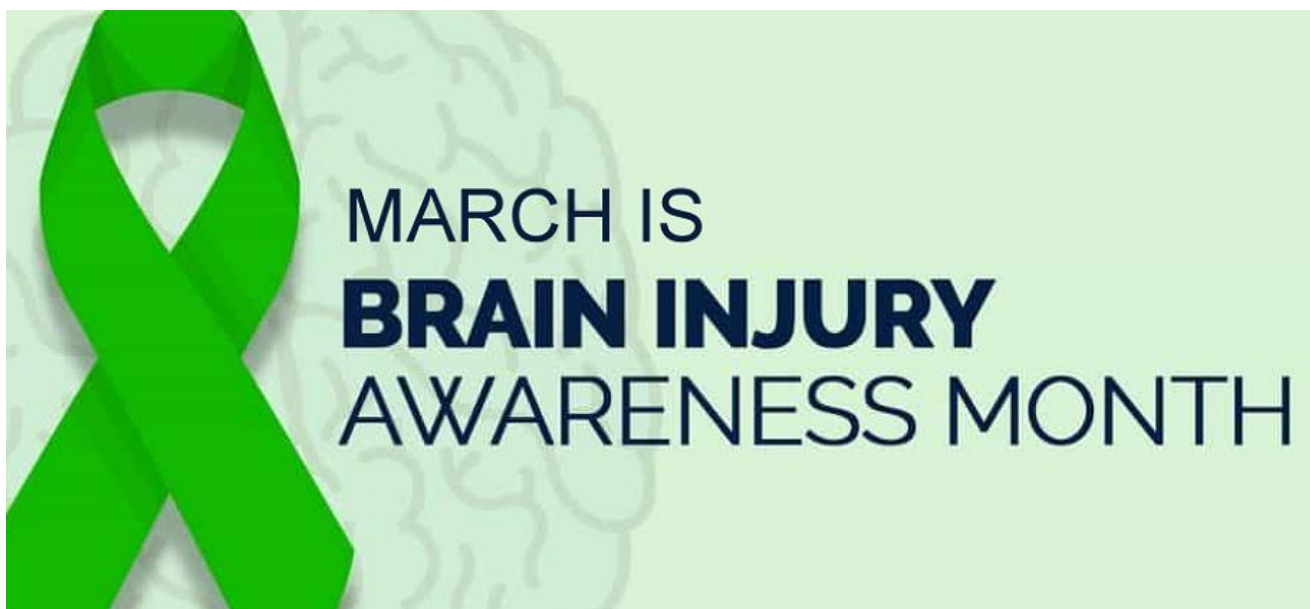
Be positive and mindful!

## Meet Nimali Pathirana

*Nimali writes...*

*“I was born in Ohio, USA in 1988. I came to Australia with my family when I was three years. Since then, I have been living at a beautiful coastal town in northern NSW. I had a very active childhood doing a variety of sport activities, music, gymnastic and studies. I was diagnosed with ADEM when I was doing my HSC in 2005. I had to spend several weeks in the hospital.*

*I recovered from the injury, but it slowed down my studies and adjustment back to my normal day to day life. However, I got into university and completed my degree in business and international tourism, and I am currently doing a clinical coding course. While doing the course, I have also been working at a local hospital on a part time basis. One day, I hope to work as a clinical coder and am looking forward to a successful family life.”*



# What's needed to decrease stroke deaths?

## RISK FACTORS FOR STROKE

Knowing and managing your risks for stroke are key.



**HIGH BLOOD PRESSURE**  
a leading cause of  
**STROKE**



**TOBACCO USE**



**DIABETES**



**HIGH CHOLESTEROL**



**OBESITY & PHYSICAL INACTIVITY**

## Recognize the signs of stroke **F.A.S.T.**



### FACE

Ask the person to **smile**. Does one side droop?



### ARMS

Ask the person to **raise both arms**. Does one arm drift downwards?



### SPEECH

Ask the person to **repeat a simple sentence**. Are the words slurred?



### TIME

If the person shows any of these symptoms, call **911** immediately.

**Learning the signs of a stroke can HELP SAVE LIVES**

SOURCE: Adapted from the Cincinnati Pre-hospital Stroke Scale, University of Cincinnati, 1997.

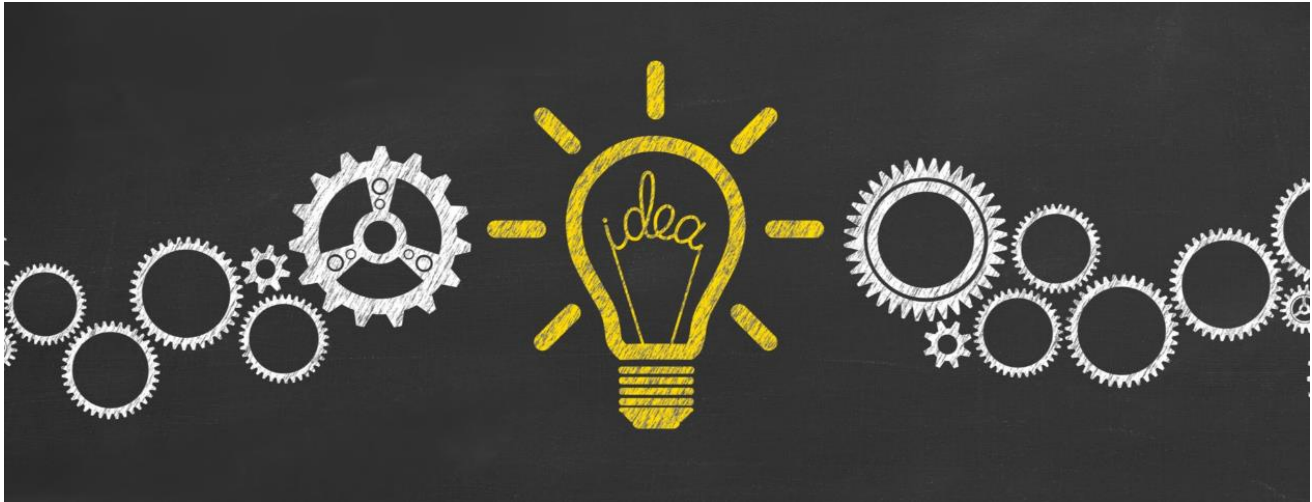
## Stroke Systems of Care

<b>Community</b>	<b>Pre-Hospital</b>	<b>Hospital</b>	<b>Post-Hospital</b>
<b>Detection</b>	<b>Delivery</b>	<b>Decision</b>	<b>Discharge Coordination</b>
Everyone knows the signs of stroke and the need to call <b>911</b> immediately.	Fast emergency medical services (EMS) transport to the hospital with pre-hospital notification that they are on the way.	Identify stroke, quickly decide on and provide appropriate treatment.	Patient rehabilitates, recovers, and returns home.

SOURCES: Paul Coverdell National Acute Stroke Program, CDC; Guidelines for the Early Management of Adults with Ischemic Stroke, Circulation, May 22, 2007.



The **STROKE SYSTEMS OF CARE** depends on coordinated partnerships among health systems and professionals, smooth transitions from one care setting to the next, data-driven quality improvement programs that provide the best care to every patient every time, consistent hospital discharge processes with all of the patient's healthcare professionals, and continued actions that improve patient care and save lives.



# Five Success Strategies

By Nancy Bauser

Have you ever thought about how you would feel if you woke up one day and could not remember why you were wherever you were? I'm not talking about waking up after abusing a substance or forgetting where you slept. Those of us who are brain injured all get betrayed by our memories. Today, I'm speaking of a state of being that is far more frightening.

Suddenly, you find that you are unable to do what you remember you could do. Your life terrifies you, you trust no one and you can't recall needing the assistance that you now require.

How do you continue? What do you have to do differently now and in the future? Is doing all that you can worth the struggle? Why should you listen to me? What's in it for you?

“For nearly five decades, I have worked hard at recovering.”

Over forty-eight years ago, I was a passenger in a small sports car that crashed into a large vehicle and I sustained a severe closed head injury. The accident happened when I was in undergraduate school at the University of Michigan.

For nearly five decades, I have worked hard at recovering. From being a patient on life-support, in the neurosurgery intensive care unit at University Hospital in Ann Arbor, to the Rehabilitation Institute in Detroit Michigan, I have continued to crawl out from some horrendous circumstances, one step at a time.



Immediately after my trauma, I had to relearn how to walk, talk, think, and take care of my most basic needs. If I considered the magnitude of what I had to accomplish, I would have given up, but fortunately I didn't think that way. I chose to concentrate on things that I could accomplish immediately. I built one success upon another. To this day, I have continued to gently push myself forward.

Upon returning to college, I began to learn how to reintegrate into the mainstream. After an injury, an illness or an addiction, life becomes an uphill battle in all situations. Whether it's dealing with doctors, drug companies, medical professionals or any other support staff, living as a self-sufficient person is simply no longer possible. Adjustments, accommodations and modifications must be made to be certain that a quality life will be realized.

Absolute independence is no longer possible and total dependence on anything is undesirable. A mixture of both, self-sufficiency or getting assistance when it is needed, becomes the new normal. When brain injury is the disease, learning how to live is the cure.

**Upon returning to college, I began to learn how to reintegrate into the mainstream. After an injury, an illness or an addiction, life becomes an uphill battle in all situations.**

### **Strategies for Living with TBI - Simple not Easy**

Being interdependent with the environment must be the goal for the coping strategies that I use. I choose who I want to be and how much I value who I am. My feelings about myself are a combination of my self-concept and my level of self-esteem. My self-concept is defined as, "*Who I believe I am*" and my self-esteem is rooted in how firm my belief is.

Only after acknowledging and then admitting that I have difficulties, can plans for future achievements have any changes for long-standing success. Continuously and constantly learning old and new information and acquiring skills needs to be a priority. Though it takes me longer than others, I refuse to give up, no matter how long it takes to reach my goals.

Though like my old self, some things were very different. Suddenly, I had limitations which required goals founded in my new reality. I was only able to accept a little at a time.

Immediately after my trauma, denial dominated my life. Repeated failure eroded this denial. Improvement was not possible until I experienced fully what I had lost. When I was done grieving for each lost ability, I became ready to accept that loss and carry-on with my recovery.

Since awareness precedes taking effective action to solve problems, I needed to pay attention to what I could not do.

Awareness comes before acting to solve problems. The degree of difficulty encountered depends on what needs to be fixed. When I'm seriously committed to change, then capitalizing on strengths and managing weaknesses, becomes the most direct route to accomplishing goals.

*Here are five success strategies that I use...*

*Do One Thing at a Time.* My primary difficulty is my ability to organize and prepare for action. My first success strategy is to simply do one thing at a time and do what is most necessary first. It's in my best interests to finish whatever task I start, before I move-on to a new project. In other words, I've learned to prioritize.

*Get Adequate Rest.* My next difficulty concerns my energy and stamina. My second success strategy is to get adequate rest and try to achieve as constant a state of tranquility as possible. If I want to remain persistent, I try to schedule activities when I'm at my best and for me, that's in the daylight hours.

I need to be vigilant about how I eat, sleep, exercise and take my medications. My doctors, who are all specialists, have prescribed many drugs for me. I have learned to use medication organizers to help me remember when to take which pills. I use three one-week organizers. Then, every two weeks, I refill two of them, while using one. This makes taking an excessive quantity of drugs very simple.

*Just Do It.* My third success strategy is to just do it! If I want to live as well as I can to not have seizures, be free from pain, and able to sleep through the night, I follow my doctor's instructions.

*Treat Others the Way You Want to be Treated.* After my injury, I found relationships difficult to maintain. I had become demanding, selfish and rather unpleasant to be with. My fourth success strategy is to treat others the way I want to be treated. This applies to everyone, from doctors and health care workers, to anyone who provides me with assistance with anything, at any time, in any location.

*Use Calendars or Note Pads.* Finding solutions to my memory difficulties continues to be an ongoing problem. I put something somewhere, and nearly immediately forget where I put it. I miss appointments or things that I know I want to do. My fifth success strategy is to use calendars or note pads to remind me of my commitments.



Along with those tools, I post reminder messages in places where I know I will see them. That could be on the back of my front door, on my refrigerator or kitchen table. To refrain from misplacing objects, I must put things in the same place, even when it's inconvenient to do so. That's the only remedy I've found for this problem.

When I familiarize myself with the difficulties that might occur, my distress seems to be reduced, as well as my fear and anxiety about life with all my problems. When I no longer need to be afraid of what might happen, I'm better able to prepare for the options or success strategies, that I need to use. Life has taught me that if I want to make changes, I must have goals. Those goals must be realistic and attainable. I recognize my difficulties in the here and now.

When bringing about genuine change, a sustained effort must be made. It takes determination, effort and time to modify behavior. While it's important to set reasonable expectations and respect the reality of every situation, I must never lose sight of what I eventually hope to achieve. Living has taught me that I was not singled out for the terrible misfortunes that I've experienced. That insight alone does not reduce the suffering that comes from struggling with the facts of my life.

Today, I work as a Trauma Recovery Expert/Disability Life Coach. The actions that deplete my energy are ones that I just don't do. I lead an interdependent life and I'm comfortable asking for assistance when I need it.

Successful people not only have goals, but they have goals that are meaningful for them. They know where they want to go, and they enjoy the journey. When someone is moving toward realizing goals that they have identified, difficulties become solvable problems, not insurmountable obstacles.

**“Successful people not only have goals, but they have goals that are meaningful for them.”**

With any wound, it takes time to recover. Behavior after tragedy is like being on a roller-coaster. Having memory and balance problems is just part of your new way of being. When the realization smacks you, that you just can't do things the way you used to, then a choice must be made. Do you give up and stop trying or do you fight the long battle back to living as well as you can? In nearly fifty years of recovering from a severe brain stem injury, I've learned that I needed to accept what I absolutely could not do, before I would allow myself to learn the skills necessary, to do what I want.

Then, I must realize that every day and every task is different. Just because I'm able to do something on one day, at a particular time, doesn't mean that I will be able to perform in a similar fashion, on another day or at another time.

Recovery is a continuous process. What each person can do, when they begin the journey is where they start. How they make progress is up to each person. Since taking sole care of myself has become one of my problems and needing assistance to live comfortably is my new normal, healthy interdependence must become my new goal. I must combine my independent spirit with my needs for care.

Change is never comfortable. Most people resist change because the tendency to want life's circumstances to remain the same and familiar is strong. However, the only constant in life is change. When life's circumstances shift, welcoming change as an opportunity to learn and grow is a positive means for dealing with that which is uncertain. I will continue to learn, and to grow, for as long as I am alive.

And today, I am okay with that.

## Meet Nancy Bauser

*Nancy Bauser survived a head-on collision in which she sustained a severe brain-stem injury while she was a senior at the University of Michigan in 1971. After rehabilitating and recovering for only nine months, she chose to return to school, complete her undergraduate education, and decided to continue her education. She received a Bachelor of Science degree from the University of Michigan in 1973 and a master's degree in Social Work from the University of Wisconsin-Madison in 1976. After graduation she achieved admission to the Academy of Certified Social Workers. Nancy is still learning and growing, still working for those who she feels need her help.*





# I Have a Disability – I am Not Disabled

By Teah Beglau

I was an outgoing, athletic, popular sixteen-year-old and on August 8, 2000 I crashed, sending my vehicle 388 feet off the road. Seven days later I awoke, not knowing what happened, where I was, how I got to this horrible state and why I was in excruciating pain. (I not only suffered a TBI, my legs were severely burned.) Due to the TBI it was as though I had returned to the mental state of a young child. I laid in the hospital for 64 days while I slowly regained the strength of both my burned legs and injured brain.

I missed the first quarter of my junior year of high school due to the hospital stay, and although others in my life wanted me to take another year I refused, telling them I was part of the class of 2002 and was going to graduate on time. People were telling me I could not do it which made me work harder. My personal saying, which I still live by is, “don't tell me I'm not capable of doing something, unless you want me to succeed. All your words will do is push me harder to prove you wrong.”

“I laid in the hospital for 64 days while I slowly regained the strength of both my burned legs and injured brain.”

While in the hospital I had great support from my home community. They raised over \$2,000 for my family, sent cards and called me numerous times, showing their love. When I first returned home great happiness from them was shown towards me. However, when I began to re-socialize I was not yet at the mental state of a sixteen year old and the “Teah” my friends remembered was not only gone, she was never coming back.

The last two years of high school were the hardest years of my life. As implied, I was not the same person my friends had remembered and due to our young age they were not able to accept the new “me.” The only friendships I had were my mother and my father. No matter the pain caused, to this day I hold no grudges towards past friends. It was not their fault. At that age the outcome of a TBI is not understandable and they expected me to return as the person they all remembered. Although my friendships were lost causing depression at times, with the help of my parents and my will to succeed I stayed strong, made up the entire quarter of work and graduated on time with a 3.75 GPA.

After high school I attended Eastern Oregon University which, as all TBI survivors understand, was more difficult due to my TBI. Although nothing was directly said to me, there were hints of “she's not going to be able to make it.” But just as in high school, my will to succeed, my optimism and strength helped me earn a Bachelor of Science degree.



One of the greatest things my parents pushed upon me was that, although my brain was injured my mind was in great shape and in no way hurt. There is a difference between a physical brain and a psychological mind. When it comes to physical and psychological states people need to know that one of the worst lies told to a child is “sticks and stones can break your bones, but words will never hurt you.”

Although the physical pain I suffered due to the burns was extremely intense and I had to regain the ability to walk, my legs are now completely repaired, and working great. The emotional pain I suffered was unexplainably more intense than the physical pain. I tell people, in no exaggeration, if I had the choice, I'd take ten times the physical pain all over again in replacement of the TBI. Although I have learned to overcome the emotional pain it is still inside me and will never completely leave. I have changed the saying to “although sticks and stones can break your bones, words can break your heart; your bones will heal, however your heart might continue hurting for the rest of your life.” As we all know, those are much truer words.

I was reminded that I do have a disability (epilepsy and severe short-term memory problems), however, I am not disabled. Just as the comparison of a brain and a mind, there is a difference between “disability” and “disabled.” All people have disabilities of some kind, ranging from something as small as having difficulty reading to being unable to walk. They might slow a person down, but it does not mean the person is disabled. Those of us who are able to live a full life after a TBI show a large amount of strength in overcoming our disabilities.

“Fifteen years after my TBI, when I was only thirty-one, I was diagnosed with germ-cell cancer.”

Fifteen years after my TBI, when I was only thirty-one, I was diagnosed with germ-cell cancer. All people in my life asked how I was able to make it through the cancer with such a positive attitude. My doctors were amazed at how fast I came back from the physical weakness that chemotherapy causes. I always told them how cancer is a walk in the park in comparison with a TBI. I am cured of cancer, however the recovery of my TBI is never ending.

It's been extremely hard, but I am now a much stronger woman who will continue to grow. The glass is always half full in my life. The struggles I have gone through were and still are at times very difficult, however they have turned me into a wonderful person whom I am proud to be, always remembering that although it could be better, it could also be a heck of a lot worse! We've all heard that what doesn't kill you definitely makes you stronger. I am living proof.

## Meet Teah Beglau

*Teah writes...*

*“My name is Teah Beglau and am from the tiny town of Wallowa, OR. I graduated from Eastern Oregon University in 2007 with a Bachelor of Science degree in Liberal Studies (Sociology and Gerontology), as well as a third minor in Gender Studies. As of now, I live in Walla Walla, WA engaged to Corey Davis and loving life to the fullest.*

*My parents are Charles and Nancy Beglau and I have two brothers, Kieran and Tanner. I'm an energetic and fun person who has always been the one that socializes with everybody, no matter what the situation is. I always try to turn something negative into something positive. in other words, I love life!”*





# Supporting Each Other

By Mary Langdon

In 2013, I was involved in a car accident. I sustained eight herniated discs in my neck and back, and a mild traumatic brain injury. All of this happened in a split second. But that isn't all the damage my brain has sustained through a life of living like a normal person.

My first brain injury happened when I was fourteen years old. I was horseback riding with friends, and I was thrown off the horse head first into a telephone pole and was knocked unconscious for several hours. My friends called my mother who told them to bring me home. She was a nurse and she thought she could look after me instead of taking me to a hospital. Back then the medical community did not understand the extent of damage such a trauma could cause.

“We ultimately realized that I had sustained multiple concussions during my life.”

Now almost fifty years after a lot of testing for more recent injuries, doctors asked me if I remembered any other time in my life that I may have sustained a head injury. We ultimately realized that I had sustained multiple concussions during my life.

Sometimes we don't realize that we're not thinking or reacting normally. Brain injuries don't give us high fevers or broken bones. Unless there are people around us who notice things we don't see or understand, symptoms can go unreported for a long time. I now know that I have lost my short-term memory, partial hearing, and have Aphasia, but recognizing the losses are not instant or easy.



One afternoon shortly after my 2013 car accident, I was sitting in my living room and realized that I could hear a noise. I just sat there trying to figure out what the noise was until finally, I realized that it was the doorbell. I didn't get up to answer the door, because I didn't remember that was what I should do. By the time I got up and answered the door, nobody was there. I sat back down and just kept thinking that I was in real trouble. What was happening to me?

I began to find some answers to that question when I visited the seventh doctor that I had seen since my car accident. Fortunately, this new doctor started me down the path to better health. He was a kinesiologist chiropractor who was going to medical school and studying neurology. He recognized the possibility that I might have a brain injury and sent me to an imaging center for an MRI. The test came back positive, so he referred me to a neurologist who ultimately sent me to the University of California-Irvine for additional testing.

While the testing continued, I did a lot of reading and research online. There I found a new doctor. He was a physician, psychiatrist, professor and author who operates several clinics which apply "brain imaging science" to help people with emotional, behavioral, cognitive, and learning challenges. I felt that I had finally found someone who I could relate to and who would really understand everything I had been going through.

Diet has greatly improved my health, but I still had pain from back problems, and I found it difficult or impossible to walk even a hundred feet. Doctors wanted to fuse my neck and back at seven different locations. I simply couldn't convince myself to do the surgery, so I focused on alternative remedies.

During this time, I was eating better and focusing on eliminating sugars from my diet because sugar causes inflammation and inflammation causes pain. Eventually, my pain subsided, and I was truly regaining my quality of life back. I was back to walking and working out in the pool. The depression, anxiety and PTSD which accompanies ill health was no longer a large part of my daily life.

"I felt that I had finally found someone who I could relate to and who would really understand everything I had been going through."

I did research for and joined a brain injury support group. When it was disbanded in the spring of 2018, I stepped forward and offered to take over the group. I searched for a new location to hold meetings and approached NeuroRestorative, a provider of post-acute rehabilitation services for people of all ages with brain injuries and other neurological challenges. The Director of Nursing was enthusiastically supportive and offered our group a new home.

I hope my life's journey has given you some insight into being brave and becoming your own advocate regarding your health and wellbeing. I believe that doctors are a wonderful resource and, in many cases, lead you to a much better and healthier life. However, science is also about eating smart and providing healthy foods to assist your body in helping itself.

## Meet Mary Langdon

*Mary Langdon is the Founder of Wealth for Natural Health (W4NH) and partners with NeuroRestorative Nevada. W4NH focuses on people with traumatic brain injuries (TBI). She holds twice-monthly support group meetings for survivors, caregivers, families, and friends. Mary is constantly working to bring more awareness and education about TBI to the community. Mary discovered a lack of community awareness and education regarding TBI and that led her to founding W4NH and to hosting support group meetings.*



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# The Importance of Sleep After Brain Injury

By David A. Grant

It's time to put a label on one of my biggest fears as a brain injury survivor: Backsliding.

In the eight years since my traumatic brain injury, my recovery has continued unabated. It has not been a true linear recovery as there have been both ups and downs over the years. At the end of every year, I look back and ask myself if I am better than I was a year prior. For eight consecutive years, the answer has been a resounding yes!

Time has shown a couple of years to be significant growth years. In year four, I began to read again. Though I had never really lost the ability to read, what I did lose was the ability to retain what I had read. I would read a page and promptly forget what I had read. Though it was a retention problem, the net result was that I was unable to read anything longer than a short news story. Thankfully, that is now behind me.

“Though I had never really lost the ability to read, what I did lose was the ability to retain what I had read.”

It was during my seventh year that I returned to work on a full-time basis – something I had been told would be virtually impossible. Did I ever tell you that I like to defy the odds? In 2016, I jumped into working again, and never looked back.

Interestingly, it was also during the seventh year that I began sleeping more regularly. It took me a while to play connect-the-dots from my improved sleep pattern to the lessening of many of my brain injury symptoms.

Over the years, I've met countless fellow survivors. Most, like me, see year-over-year gains. A few seemed to have plateaued and stayed at a certain point – better than they were, but their forward progress seemed to stall. But there are other survivors I have met who, after a period of ongoing recovery, started to backslide, losing hard-fought gains. Challenges that they had already put behind them came back with a vengeance.

And therein is the crux of my fear. Would I be one of those who saw life get better, only to slip back beneath the waters, unable to keep myself afloat any longer?

Over the last couple of months, I began to fear that this was happening to me. Things got very difficult again – and stayed that way.

Let's get specific, shall we?

My ability to process information began to slip. I was having trouble following conversations, unable to process words as quickly as people were speaking. My tinnitus, never-ending since the day I was struck by a car, started ramping up again to unbearable levels. My PTSD nightmares that had slowed down to only a couple of bad nights a month suddenly became three-to-four bad nights a week. Vertigo started to make a grand comeback, and I said to Sarah on many occasions, "This feels like my first year all over again."

I was struggling like a TBI newcomer. Frankly, it sucked. It still does.

Last month, I attended a holiday party for my local brain injury support group. At one point during the evening, another survivor shared with me that lack of sleep exacerbated brain injury symptoms. And in two ticks of a clock, the lightbulb went on over my head.

My recent uptick in symptoms was not a backslide in my brain injury recovery. Not even close. Over the last few months, I have been walking through the most stressful part of my life as my mom continues to decline after she had a stroke in September. Within a week, she went from a fully independent eighty-two-year-old woman to being institutionalized and needing 24-hour care. The stress has pushed my PTSD off the charts and left me sleep-deprived for months.

The reality is that my current challenges are the result of sleep debt and not the result of a backslide in my brain injury recovery. Though my challenges and accompanying stress remain, and the nightmares continue, I have experienced overwhelming relief.

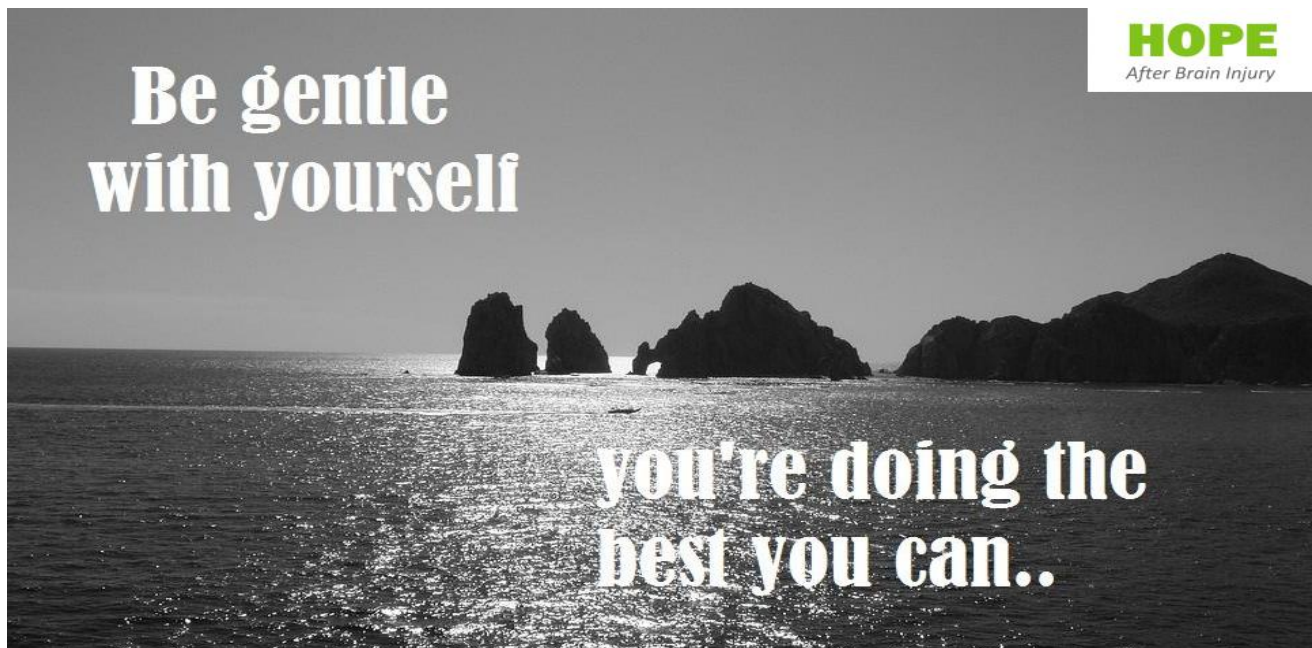
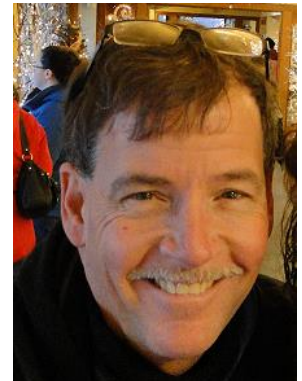


My past experience has shown that once my sleep cycles get back to somewhat normal, I will again see relief from this most recent flare-up of brain injury symptoms. Knowing that I have come out the other side of this before offers me hope that I will again.

This chapter of our lives remains very difficult. And with the stress comes sleep debt brought about by PTSD. But at some point, there will be an end to this chapter. As I was taught early in my recovery, I need to live one-day-at-a-time. Today I'll take care of what's in front of me. The future will take care of itself. It always has.

## Meet David A. Grant

*David A. Grant is a traumatic brain injury survivor from Salem, NH. In addition to publishing HOPE Magazine, David is also a staff writer for Brainline.org as well as a contributing writer to Chicken Soup for the Soul, Surviving Traumatic Brain Injuries. David is a board member of the Brain Injury Association of New Hampshire. When he's not working, David can be found cycling the back roads of southern New Hampshire.*





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Brain Injury Awareness Month is now in full swing. While anyone within the professional or social circles of the brain injury community is aware of this, once you step beyond the brain injury sphere, very few people know about our month-long opportunity to educate and advocate on behalf of those affected by brain injury.

We challenge you to look at it through a different prism, from the outside in.

Have you seen any reference to Brain Injury Awareness Month in your local paper? Not very likely. Has Brain Injury Awareness Month been mentioned on the local or regional news? If it has, we've not seen it.

How about any mainstream news outlets or news apps? You see where we are going with this. Step outside of the brain injury community, and it's still not a topic you'll see or read about.

Here is our challenge. As we move through this year, you have the ability to advocate and serve the brain injury community in a way you might not have thought about. We challenge you to look for teaching moments in your day-to-day life and use those moments to educate others about brain injury. It may take a five-minute investment of your time once a month, or even once a week.



But here's the take-away: enough small conversations over time can add up to a loud voice, one that says to the world-at-large that we are here, and that we are part of an unasked-for community that numbers in millions.

Change comes slowly over time. We challenge you to be part of that change.

*~David & Sarah*