

November 2016

TBI HOPE

Advocacy & Education
MAGAZINE

supporting the
brain injury
community

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BOLD NEW
Look!

Letting Go

An Unexpected Miracle

RIPTIDE!

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TBI HOPE MAGAZINE

*Serving All Impacted by
Brain Injury*

**November
2016**

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Welcome

Welcome to the November 2016 issue of TBI HOPE Magazine!

Later this week, those of us living in the United States will celebrate the Thanksgiving Holiday. Long known as a time to spend with family, friends and those we love, it can also be a time for stress for those within the brain injury community.

Brain injury comes with a high cost. Strained relationships, pressure on those we love, and financial challenges define life for many of us as we struggle to navigate this new life after brain injury.

But a meaningful life can indeed be built again. It takes time, more often measured in years. It takes work – more than most will ever know. It takes patience and it takes love.

November is National Gratitude Month. Sometimes it helps to take a moment to look for the things you are grateful for. Those who stuck by us? Thank goodness for them. Health care practitioners who really understand the complexities of brain injury? You are cherished.

But it's relationships with others who share our fate, fellow survivors and family members alike. These can be the shining light on the new pathway we walk.

It is my heartfelt wish that you find others to walk with, who understand your struggles – and who love you unconditionally and without reservation.

Happy Thanksgiving!



David A. Grant
Publisher

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"I have a lot to be thankful for. I am healthy, happy and I am loved."

~Reba McEntire





Riptide

by Barbara Stahura

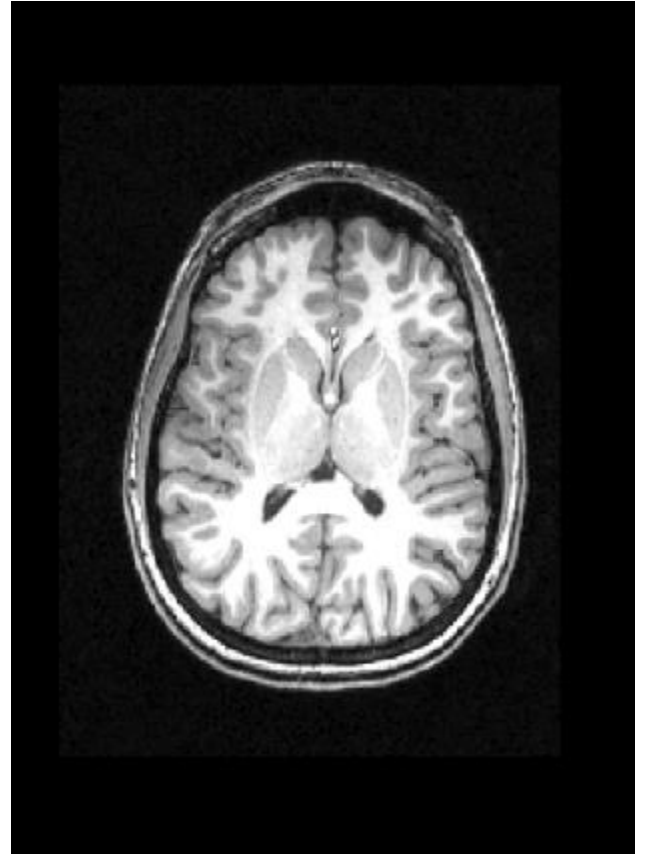
In my favorite photo of us, we're astride Ken's BMW motorcycle in our Tucson driveway. Ken is laughing at the camera as I, sitting behind him with arms clasped around his waist, kiss his ear. We wore none of our usual protective equipment—full-face helmets, boots, jackets, gloves - because we had jumped on the bike strictly for the photo. Months later, in December of 2003, Ken was wearing all his gear when he took his other motorcycle, a Ducati sport bike, to run some errands. But when a white sedan turned suddenly in front of him, there was nothing he or his equipment could do to prevent what happened next. Ken hit the passenger side near the back wheel; helmet striking steel, face smashing into helmet, brain slamming into skull. He crashed to the asphalt. The sedan disappeared.

An injury to the brain is unlike any other. Along with physical functions, the brain controls awareness, personality, temperament, and cognitive processes like memory - all those things that commingle to form a "self." And while that self does not necessarily reside in the brain, the brain is the part of us that animates it. So a traumatic brain injury can kidnap the dear self of someone you love, dragging him far from shore as a riptide does a swimmer, sometimes beyond rescue, even though in reality he is holding your hand or smiling at you across the dinner table.

The day of the accident, exactly nine months after our wedding, Ken left around noon and had planned be home in a couple of hours. Instead, I found myself at the University of Arizona Medical Center's ICU around 7 p.m., staggered by the sight of my husband. There was a ventilator tube in his mouth; a cervical collar around his neck; a stitched cut above

his left eyebrow; left eye purple and swollen shut, right eye nearly so; nostrils filled with crusted blood; broken right hand captured in a sling; left hand tethered to the bed rail. Naked under a single sheet and his face streaked with dirt, Ken moaned and tossed in delirium.

A CT scan showed two minimal contusions on Ken's brain. The neurologists told me worse injuries invisible to imaging machines were likely. The brain floats within the skull, and if the head's momentum stops suddenly, as Ken's did when it came to an instant halt against the car, the brain rebounds within its bony home in a motion called *coup contrecoup*. Neurons are sheared off: Millions of connections in that tiny, internal universe can, like exploding stars, blink out of existence in an instant.



The fact that Ken had suffered a traumatic brain injury (TBI) became apparent when he could talk again, four or five days after the collision. Much of his speech consisted of parroting words in a sing-song voice. After developing aspiration pneumonia, he tried to cough but couldn't cough deeply enough for relief. Smiling at him and stroking his forehead, I said "Bummer." He sang back, "Bummer, bummer, bummer," much as a toddler would.

Next, he began repeating nonsense phrases. The first was, "Happiness is, happiness is," in a gentle rhythm. I added, "Happiness is a warm puppy," which he chanted for a while and gradually transformed to "Happiness is a warm country."

But as Ken began to speak in complete sentences, I grew more alarmed.

"I have to rewire your circuitry so I can manage you better," he told me in all delusional sincerity. He claimed his staid, seventy-seven-year-old parents were members of a steel drum band; no, wait, a plastic drum band. He insisted he had to get up and care for his patients (he's a software engineer) and that Scott, his chiropractor, repaired his motorcycles. One night, when he couldn't even sit up without help, he somehow clambered over the bed rail, wandered down the hall, and fell, hitting his head.

Fortunately, he incurred no further injury. The nurse who called me said he kept repeating, "I have to find the motion. My wife and I have to find the motion." He didn't know where he was or what was happening. Even worse, he didn't know that he didn't know - a very bad sign.

After this incident, Ken was placed in a Vail bed, a mesh-sided, enclosed bed that zips from the outside. Much better than putting him in restraints, the nurse told me.



Ken's short-term memory also had been damaged. He recognized everyone who came to visit but for weeks could not recall that anyone but me ever had. His speech therapist hung signs in his room as memory aids: "I was in a motorcycle vs. car accident on December 29," and "My wife's name is Barbara." She also started a memory book for him, to which I added photos of our wedding, his kids, our house, and our cat, along with affirmations proclaiming good health and normal life.

During the first few weeks, even though Ken carried on long - if sometimes weird and oddly chatty - conversations, he never really engaged with anyone. He spoke animatedly, but his gaze was distant, unconnected. Although physically in the room, he was not present; he existed in some inward place, unable to transcend the damage to his frontal lobes.

His rehab team warned me that impulse control is often a casualty of TBI, and Ken was no exception. Still weak and in danger of falling, he moved too quickly for safety. He gobbled his food. I became a nag, perhaps too protective but terrified of another injury. I reminded him again and again to slow down, be careful. Stubbornly, he refused, brushing away my concern like a pesky fly. Once, I cried in frustration, fearful that he would choke on huge forkfuls of dinner. He simply looked past me with distant eyes and continued bolting his food.

A month after the accident, Ken developed a pulmonary embolism and was transferred from rehab to an acute care hospital. One morning, he called me from there. “I don’t know where I am,” he whispered. “I think I’ve been kidnapped by foreign nationals.” I stood in our kitchen, phone to my ear, stunned. Just yesterday, he had sounded so normal again. Where was the man who had looked so intensely into my eyes as he said, “I do”? Smart, articulate, an enthusiastic reader, an excellent computer programmer and woodworker, the real Ken had disappeared, replaced by someone who looked just like him but was missing essential ingredients. Should I have applied for his Social Security disability, as his case manager had advised? Would I forever be his caregiver, exhausted, frightened, and missing him?

“I don’t know where I am,” he whispered. “I think I’ve been kidnapped by foreign nationals.”

I wanted more than anything to look inside Ken’s brain, to see what the scanning machines could not, to find his lost self among the blasted neurons and bring him home. I researched TBI on the Internet, read books about it, and found many chilling and many encouraging stories about survivors. I pestered Ken’s doctors and therapists with questions. Would Ken’s brain heal? How much? When? But of course, no one could provide the answers. There was nothing to do but move through the days.

When a reason for hope appeared, I clung to it - the first time Ken hugged me, remembered our phone number and called me at home, recalled a visit from neighbors the night before. And when hope lagged, I read reminders I’d hung around our house: “Relentlessly Optimistic.”

Two days before his homecoming, my husband made an omelet - perfect and golden - just as he used to make for us every Sunday. All by himself. It was part of his occupational therapy. I took photos, the last one showing Ken standing in the rehab kitchen, proudly displaying his creation. We ate it for lunch. Later that day, he couldn’t remember the word “omelet.”

Nine months post-accident, Ken still fights headaches and fatigue, and fears he’ll always be wobbly on his feet. His memory is better, although the right word often eludes him, but he still wrestles with once-easy tasks, thanks to damaged cognitive functions. He has sold his two remaining motorcycles, returned to work, and vows he won’t abandon himself or

me by giving up. Nearly released from the riptide, my husband, resolute and a little scared, struggles to free himself for good. When we vacationed along the Pacific Ocean, we walked the beach every day. I watched Ken cheering the surfers cresting their waves, and I silently cheered him, praying his determination would be enough to return him all the way to shore.

••

More than a decade after the accident, Ken has recovered remarkably well. He was able to return to shore, thanks to his great determination and many other factors, for which we are deeply grateful. We are involved in our local brain-injury community and do what we can to raise public awareness of the growing silent epidemic of traumatic brain injury.

This essay originally appeared in the Jan.-Feb. 2005 issue of Science & Spirit magazine.

Meet Barbara Stahura


Barbara is a Certified Journal Facilitator and has guided people in harnessing the power of therapeutic journaling for healing and well-being since 2007. She facilitates local journaling groups for people with brain injury and for family caregivers at HealthSouth Deaconess in Evansville, Ind., journaling for wellness and well-being classes for Ivy Tech Community College.

She also presents or has presented journaling events for state Brain Injury Associations/Alliances. Co-author of the acclaimed [After Brain Injury: Telling Your Story](#), the first journaling book for people with brain injury, she lives in Indiana with her husband, a survivor of brain injury. www.barbarastahura.com.



Letting Go

by Nicole Bingaman



I opened the door, exited the yoga studio and quickly glanced around. The street was barren and I was safe. The sob I had been holding back erupted and it felt good to release the emotion I'd been suppressing. I spoke, "I miss you" into the air, mostly to the son whose body remains, but whose person has shifted so much, he's often unrecognizable. Maybe part of him was out there in the autumn sky.

It's October and people are discussing the holidays. In class someone mentioned Thanksgiving and a lady who worked in our former pediatrician's office was in attendance. The word Thanksgiving combined with seeing someone connected to my past started a ball of grief rolling in my mind. Throughout the night's practice my thoughts drifted.

I saw my three little boys, and myself, many years ago. An old movie played in my head, and I could not shut it off. I thought of how adorable Taylor was, and how he forever took charge as the big brother, wearing being the eldest like some magical cloak. I remembered how curious all of my boys were, with the whole world ahead of them.

My mind drifted from the yoga mat to looking at caterpillars on milkweed, waking up to witness a meteor shower and summer sailing. I didn't know it then, but I felt it, the best years of my life with three blonde-headed, blue-eyed wonders, which made every day a gift.

My sons and I were always close. My husband was present and a great father, but I stayed at home for many years, while Keith worked a demanding job. The boys and I made crafts, cooked brownies and watched baby birdies fly from their nest for the first time. It was through the eyes of my children, that I learned about life, love, and how hard parenting really is. But I worked hard at it, and I felt as if all of the love I had inside was poured into my tiny people.



We read “Where the Wild Things Are” countless times, played games and sat inside on rainy days watching movies for hours. Many nights before bed we would read stories about what it meant to be kind, good, just and fair. And I prayed for them...every single night.

As they drifted off I would whisper prayers or sing them to sleep, rattling off the list of those who also adored them while gently rubbing their little heads. I would sing, “Mommy loves you, daddy loves you, Nina loves you, go to sleepy town. Grammy loves you, Pawpaw loves you, Jesus loves you. Go to sleepy town.”

I prayed about their friendships, I prayed for their teachers, I prayed for the girls they would come to love and hopefully marry. I prayed that life would make them strong where I had been weak, and that they would always and forever see the infinite light of their own being.

As they grew up, the things that we enjoyed together shifted and trust me, the adolescent years were far from perfect, but I knew they could have been much harder. In it all, my love for my sons continued to grow beyond my scope of understanding. There was something about a trio of boys that fit me, and I felt blessed as they blossomed into young men.

Taylor was twenty-one years old when he fell. And although he had fantastic friends, a great career and was one of the most handsome guys I had ever seen, he was not at an ideal place. He was at a “What am I going to do with my life?” place, and it was difficult.

The moment he fell, his entire life came crashing down and later I would learn that our lives would crash too, just in different ways.

A few days before the fall Taylor sent me a long message that I will forever cherish. Our relationship was stressed and we were both hurting. Taylor had been pulling back from his brothers, his dad and I, and others in his family. He seemed to be connected to his friends, but in truth I don't know.

In the message he thanked me for being his mom and recognized that our relationship was important. In maturing, he was discovering that I was not perfect, but my love for him would be a constant. I have the message saved, but I haven't read it in over two years. It feels too painful now to see that part of him in black and white, and to know that things weren't perfect causes a lump in my throat that won't go away.

I'd imagined life evolving for my sons in a very different way than it has, and I am still adjusting to what was supposed to be, versus reality.

Taylor was supposed to get married and eventually have children. He wanted more of a simple life and still defines himself as a country boy. He can't understand why there has been such a drastic shift in his personhood and wonders who he now is.

“My other sons still have the whole world ahead of them. But I understand that they may feel tethered to us, and to Taylor.”

My other sons still have the whole world ahead of them. But I understand that they may feel tethered to us, and to Taylor. What does his future mean for them? Will they be expected to pick up Taylor's care when we are no longer here? And how do they, in their twenties, sort through the kind of ambiguous loss that they feel, when I, in my forties, don't even know how to process it?

Taylor's injury sits on all of us, like a heavy weight involving endless emotions that either whisper or scream in our heads all of the time.

I practice yoga to get on the mat, and to let it go, but this night I couldn't. In final savasana I feel myself filling up with sadness. Grief fills my lungs, my heart, and my being from my head to my toes. I am full of tears. I literally have to hold my sobs back, like I am holding my breath.

I put away my bolster and blanket. I roll up my mat, and get my sandals on, and walk into the night air.

I opened the door, exited the yoga studio and quickly glanced around. The street was barren and I was safe. The sob I had been holding back erupted and it felt good to release the emotion I'd been suppressing.

Meet Nicole Bingaman

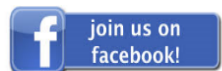
Nicole has worked in the human service field for over twenty years. Since Taylor's injury Nicole has become an advocate and spokesperson within the TBI community.

Nicole's book "[Falling Away From You](#)" was published and released in 2015. Nicole continues to share Taylor's journey on Facebook. Nicole firmly believes in the mantra that "Love Wins."



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An Unexpected Miracle

by David A. Grant

I was finally able to do something that I've not been able to for several years, and I was able to do it with new hope.

On the top shelf of my office closet sits a cardboard box. Inside that box are some of the most treasured memories of my life. Long before the age of the digital camera, I was a chronic and habitual picture taker. Inside the cardboard box? A couple of decade's worth of life pictures.

Why not touch these precious memories for years? A seemingly simple question, with quite a complicated answer. It boils down to pain. In the years since my traumatic brain injury, some of my friends faded away.

If you have a life affected by a TBI, you know exactly what I mean. In fact, I see you nodding right now. But the biggest shocker was the exit strategy that my sons used. Over the years, three of my four sons simply walked away. No explanation, no conversation. Nothing.

One day we were speaking and the next they were gone. Phone calls unanswered, emails unreturned, texts ignored. I lived in bewilderment for several years. Did I say something offensive early on, when my emotional and verbal filter was shattered? Were my sons unable to understand and accept who their new dad was?

Over the years, this amounted to the biggest source of pain in my new post-TBI life. I cried rivers and rivers of tears, missing my own children with a soul-level anguish that can't be described.

When I thought I was done crying, I cried some more. Those close to me, those I trust; those who love me unconditionally – they told me that the best I could do was to be open “when” my sons came back into my life. I carried myself with dignity and honor; my head held high for years. Ready. Waiting. Hopeful.

Earlier this year, everything changed. In my story, I wish to offer hope to those who need it most. As I was about to board a plane in Manchester, NH, my phone rang, and one of my son's names showed up on the caller ID. When I answered the call—dead silence. It rang again. And then again.

I texted him: *I missed a couple of calls from you. Might just be a butt dial, so Hi.*

I expected nothing back.

Dad, I need to talk to you.

NOW BOARDING ZONE TWO

I texted him back and told him I was getting on a plane and that I'd call him during the layover in Minneapolis. As it happened, our flights were delayed as flights so often are these days, leaving us with mere minutes to run from one end of the airport to the other, huffing and puffing all the way.

We found our gate with only a couple of minutes to spare. I called my son. He answered.

My life changed forever. “Dad, my daughter was born three weeks ago,” he said. “I am a father, and you are a new grandfather. We need to put the past behind us and move forward.”

I burst into tears, very much like the tears that stream down my face as I write this. “Oh, and I'm engaged, too,” he continued.



NOW BOARDING ZONE TWO

Oh no, not again!

I let him know that I had another plane to catch. We texted back and forth while the plane taxied on the runway. He texted me a picture of my new granddaughter. And another. And another.

My new granddaughter had just entered my life in the most unexpected of ways. I sat in the window seat, numb for the next flight, my head reeling. A date was set. Sarah and I would visit my son, his fiancé and our new granddaughter when we returned from our trip.

“I had my son back in my life and a new granddaughter – both at the same time.”

I had my son back in my life and a new granddaughter – both at the same time. We spoke on the phone the next day. And the next. We started by taking small steps forward—rebuilding our relationship on new ground.

I found myself finally able to pull down the picture box and go through memories of times when my kids were small—when they were all part of my life. I texted my son baby pictures, elementary school pictures, Disney vacation pictures.

Dad, this is awesome!

You think?

I still have one son who has yet to come back. He was married last year. I saw a picture from his wedding on the internet. That’s about as close as I got.

Today I live with a renewed hope. I am careful not to set my sights too high – lest the fall to reality becomes painful. But I have hope. And my granddaughter? Sarah and I were invited to my son’s home after we returned home from our trip. He lives a short fifteen-minute ride from our own home. He opened the door, welcomed us in, and gave me a big hug.

The next two hours went by in a heartbeat as we slowly began the process of catching up, our new granddaughter in my arms for most of the visit. For a week or more, I was just

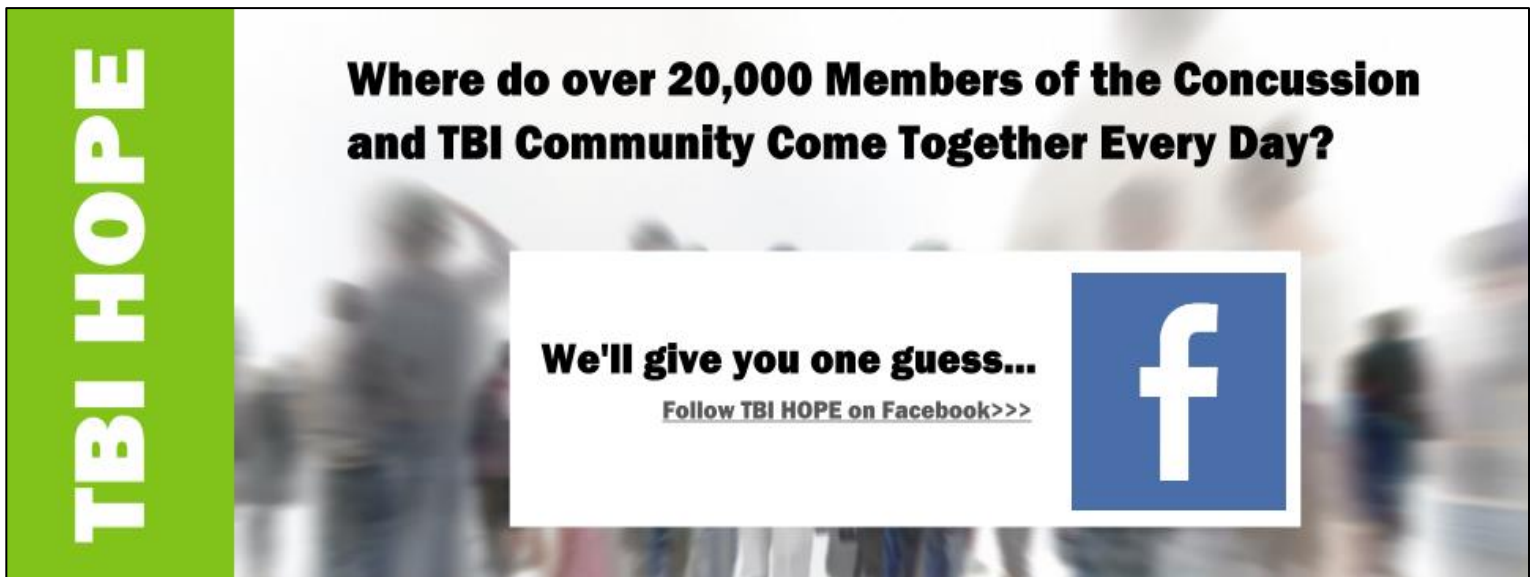
numb. Happy, elated, grateful, but numb all the same. Even now, nine months later, I still find myself not believing it all.

We now talk or text several times a week. I am using all the restraint I have to not call him several times a day. What a cherished problem to have. The David that is today is the only David that my granddaughter will ever know. There will be no “before and after.”

Sarah and I now stop by our local Babies R’ Us store pretty regularly. And to think, for almost the first month of her life, I didn’t even know that she existed. Simply amazing.

Meet David A. Grant


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



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Brain Tips: Inspirational and Motivational Calendar

by Cheryle Sullivan, MD

Over the years, we have met so many inspiring souls – souls who have taken their own deeply personal experiences and have used them to help others, to help lift humanity higher. We would like to congratulate Dr. Cheryle Sullivan on her successful publication of this new resource for all affected by brain injury. Cheryle, thank you for all you do for so many!

Cheryle writes...

“My mom was the inspiration for [*Brain Tips: Inspirational and Motivational Calendar*](#). At age 61 she fell on stairs in her home despite being active and healthy, dying of a traumatic brain injury (TBI). After her death I opened a perpetual calendar she'd previously given me. It contained daily inspirational quotes, something she and I both collected. On my January birthday, I found her note next to the day's quotation saying, “If we are not together today, know we love you.” That was special! A month or so later she had written next to a quote “This fits you so well.” I paged through the calendar, finding notes here and there as quotes inspired her. It was an amazing gift that I used for years until the pages began to fall out. They are saved in a plastic bag with hopes of finding a way to resurrect the calendar.

After my own 2002 TBI, my sixth concussion, I was left with residual cognitive challenges. As a family physician, medical office clinical manager, pilot and daughter of a mom who taught me how to be organized, I found I was using tools and strategies to

make my life run smoother that many others did not use. Doing volunteer presentations on how to use these cognitive tools to better function after brain injury for a state brain injury agency led to the idea to put together a calendar with daily inspirational quotes and brain tips.

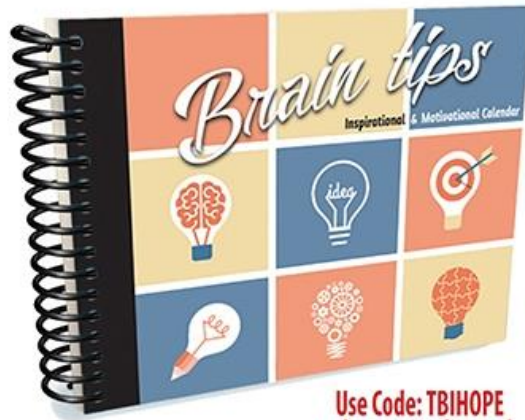
I see several ways those with cognitive challenges, no matter the cause, can use this calendar. Besides providing daily inspirational messages and brain tips, the calendar can encourage daily journaling. According to Dr. James W. Pennebaker, a social psychologist at the University of Texas at Austin, "When people are given the opportunity to write about emotional upheavals, they often experienced improved health. They go to the doctor less. They have changes in immune function."

It also can be a gift to those with cognitive challenges or even their family or caregivers. Family or friends can write encouraging messages throughout the calendar. Besides the daily inspirational quotes, personalized messages can help encourage someone dealing with challenges then and in the future when they are revisited. The pages allow space to write about how a tip may be useful, to note or plan how they can be included in a typical day and can self-motivate the user." [More Information>>>](#)

Meet Cheryle Sullivan

Cheryle received her medical degree from Michigan State University and completed a Family Practice Residency at Saginaw Cooperative Hospitals in 1986. She worked as a solo family physician in Michigan then as a family physician-clinic administrator for a large non-profit HMO in Colorado.

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The Brain Tips Calendar - for TBI survivors and caregivers, has room to make notations and the inspirational quotes will push you to live life to the fullest. A great gift any time of year!

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Checking in with Yourself

by Jeff Sebell

After we experience a TBI we feel as though we've been dropped off on a deserted island with no supplies and no support system.

We have no choice but to become self-reliant.

It's important to remember that we are responsible for our own well-being, both physically and mentally. We are the last line of defense. In other words: it's up to us because no one can do the work for us.

To be up for this challenge, we need to think about something that may not be so obvious, and that is: we need to try to develop an awareness of ourselves.

One habit I've developed to help keep me positive and moving forward in my life is to check in with myself to see how I'm doing. I try and look at where I am in my life in order to gain some perspective. In other words, I not only examine where I am and what's going on for me, but I look at it in relation to where I've been and how far I've come. I always try to be positive.

It's so important to take stock of ourselves once in a while because it's easy to get stuck and do things as if we are on remote control. We get stuck doing the same thing over and over again without even realizing it.

Moment to Moment

At any one moment, multiple things are going on in my life. I'm being bombarded with stimuli from the world that surrounds me, and I'm also slammed with emotions that are the residual effects of events from the past. Between the stuff that's happening around me coupled with the thoughts and emotions I have, things can get pretty confusing and overwhelming.

Somehow, I need to take a step back in order to be objective so I can have some understanding of *how I am really doing*, versus *how I think I am doing*.

Reality Comes a Callin'

I learned to do this three or four years after my TBI when I moved to Boston from Breckenridge, Colorado to be closer to my family. I lived in a tiny, cockroach infested room in Cambridge, Massachusetts, right outside of Harvard Square. The change from the mountains to the city was shocking. I went from living at 9600 feet with a view out my window of the Ten Mile mountain range, to looking into someone else's apartment 3 feet across an alley.

Even though I lived smack dab in a busy city, I was completely alone and rudderless. One afternoon I was walking down the sidewalk when I started to think that it didn't matter if I lived or died. Life was just too confusing and difficult.

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Then I started to think about the things I needed to live and persevere for: mostly, my family who were so close to me, but also for myself, because I didn't want to let myself down by losing this battle.

I didn't want to be remembered as a man who faded away or had given up because I thought my life was out of control and not worth living. Thinking of these things snapped me out of it, and from that experience I developed the habit of checking in with myself by asking myself a simple question: "If I died at this moment, would I be happy with the way I lived my life?"

I wanted to do my best to live with no regrets.

It's not About Achievement

This is the way, every so often, I would put a stick in the ground and measure my progress. The things I would check-in on weren't necessarily material things or have to do with money. My check-in was about the way I was living my life. The legacy I would leave. How my family and friends would think of me after I was gone.

It was about me, the human being.

I am not going to sit here and tell you I was suicidal, that day on the sidewalk in Cambridge, because I really wasn't. However, I will tell you it was an important moment for me, in that it helped me put things in perspective and develop a way of looking at my life post-brain injury.

“Some of us wonder why we are still here on earth.”

Some of us wonder why we are still here on earth. At times it seems as though a cruel joke is being played on us, and they can make sense of what has happened. Many people think things happen to them for reason. My feeling about that is only very slightly different.

I believe that *things happen to us for no reason at all*. That doesn't mean there isn't one, though.

Each individual is in charge of creating a reason for whatever happened to them. That is our way of making our life mean something. If you are lucky

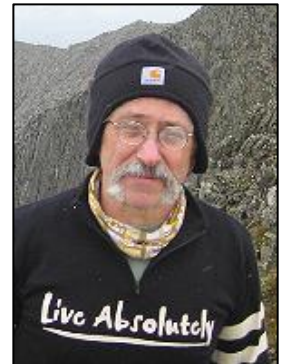


enough to find a reason, you can then live a life that has meaning, and that is the greatest gift you can have.

Checking in with yourself as often as possible may help you discover things about yourself, keep you on the straight and narrow road to success, and put you on the path to discovering the meaning behind your life.

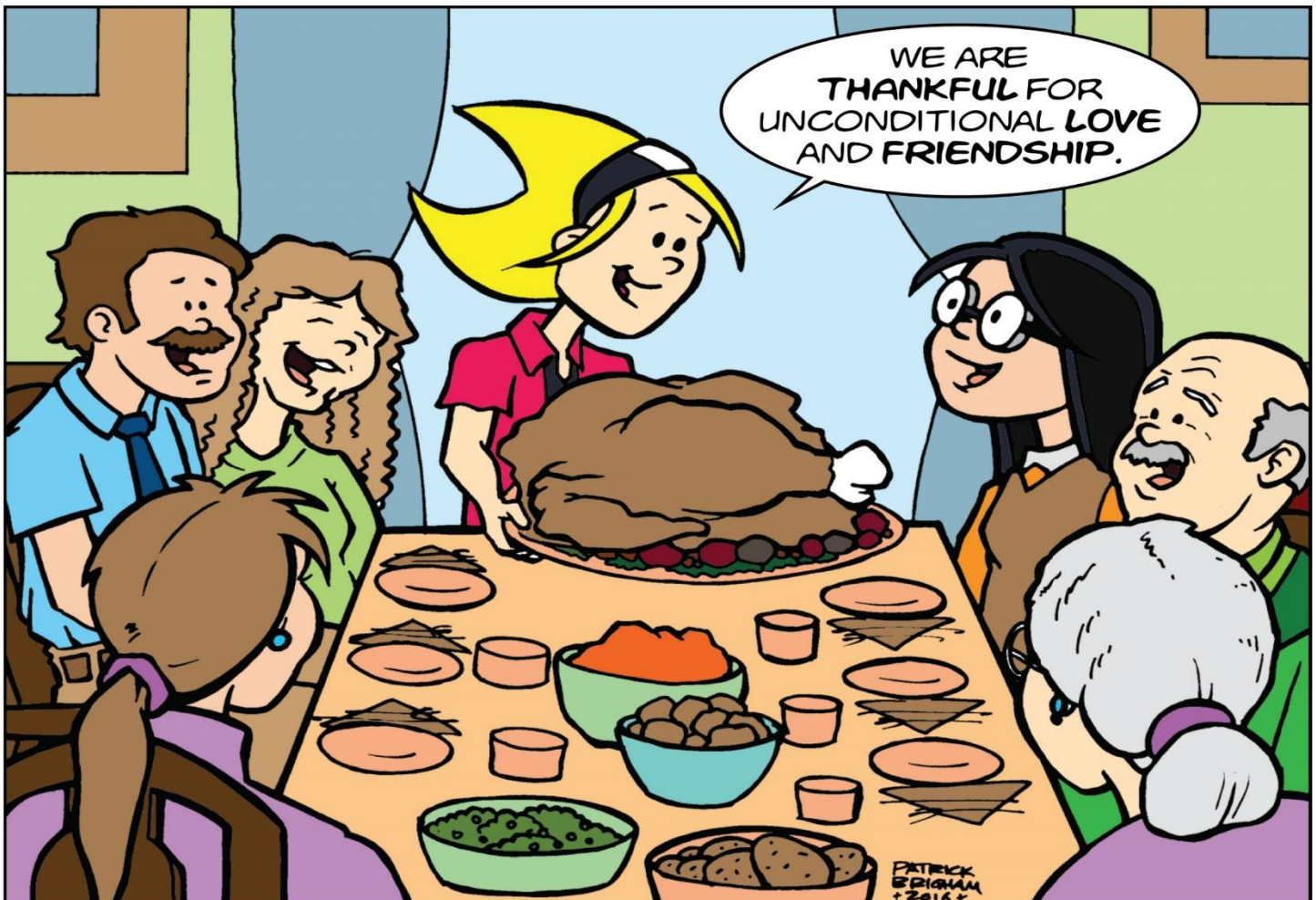
Meet Jeff Sebell

Jeff is a nationally published author, speaker and blogger - writing about Traumatic Brain Injury and the impacts of his own TBI which he suffered in 1975 while attending Bowdoin College. His book "[Learning to Live with Yourself after Brain Injury](#)," was released in August of 2014 by Lash Publishing. Jeff is a regular monthly contributor to TBI HOPE Magazine.



Living With Hope

By Patrick Brigham





Distractions and Diversions

by Norma Myers

Recently, while going through my nightly routine, I was startled by the reflection in the mirror. Yes, it was my reflection, but not the carefree southern girl I used to recognize. I immediately started laughing and crying simultaneously. I laughed because my own reflection startled me, and cried because I didn't recognize myself. Sadly, my image could not be blamed on a mid-life crisis or hormones or failing to use anti-aging products. Any of these reasons would be a welcome culprit compared to the true robber of my identity. Up until the night of the auto accident that caused the death of our son Aaron and left son Steven with a TBI, both my husband and I held professional titles. Most importantly, we were honored to hold the most prestigious title of being Mom and Dad to Aaron and Steven.

A knock on our door with news of a car crash not only stripped me of my titles and identity, but it also left me with a broken heart. One-half of my heart left this earth with Aaron as he drew his last breath. Even while beating frantically out of rhythm, the other half kept beating with a purpose to lend strength to our son Steven as he lay in the ICU fighting for his next breath.

Four years later, as some of the dismal fog lifts, I can see that out of fear of letting anyone down, there have been many times that I had proudly adorned the "I'm fine" mask. The mask is not healthy, and it can mislead family and friends into thinking that I'm the same person they knew before August 13, 2012. The truth is, there is no way to be the same

Mom, wife, daughter, sister, aunt, friend or anything, after every fiber of your being has suffered radical rewiring.

My mask is tattered and torn; it's long overdue for retirement. In retrospect, it was an unrealistic expectation I placed upon myself that I needed to be the same Norma I always was for the people in my life. I wanted to be the same. No mother willingly signs up to trade her normal life for a life of caregiving, TBI, advocacy for her son's needs, and being that Mom that no one knows what to say to because she lost her first born son.



The fear of letting others down is self-inflicted. I became so obsessed with ensuring that Steven's every need was met that I not only lost sight of myself, I lost sight of the fact that others need me now. They need me to say, "I'm not okay!" They need me to show up vs. playing the "I'm too busy" caregiver card, when the truth is: yes, I am busy, but at times the avoidance game is more appealing than finding the strength to talk about my reality while everyone else is moving on with their lives. I know that my family, friends, and community will accept me for better or for worse; but I can't always accept myself!

If I were to attempt to describe all the ways double trauma has changed me, I would run out of blog space, so I will focus on one instrumental way my perception has changed. My husband has lovingly adorned me with the title of being a "Noticer." Yes, even noticing and stopping to take a picture of a random, broken, upside down, but still standing headstone adorning none other than my last name. We stumbled on it, and it hit hard. Ironic, I know! For some, this incident is too morbid to mention, but to me, all I could

think was how many times I felt like this headstone inside. Broken over not seeing plans and dreams for me, my husband, and my sons come true. Upside down from the roller coaster ride of double grief; earthly separation from Aaron coupled with ambiguous loss. Still standing, but not steady. The headstone left me thinking about that old jingle: Weebles Wobble, but they don't fall down. That's the Myers family!

“Do not miss someone so much that you miss the people in front of you.”

Recently, someone shared these bold words with me: “Do not miss those you have because of those you miss. Do not miss someone so much that you miss the people in front of you.”

Upon receipt, the words penetrated my heart in an unpleasant way. I felt angry, angry because without intentionally doing so I know I have missed and been missed. Raw tears are streaming as I type and feel those true but painful words.

The heartache I feel from the earthly separation of Aaron is unbearable, but I know that he would not want me to miss our faithful family and friends that remain right in front of us. It doesn't take away from how much I miss him; nothing could do that, but if I allow

myself not to miss those in front of me I will gain a reservoir of strength to tap in to when my own is depleted.

Trust me when I say my genuine desire is to not only physically show up, but emotionally, genuinely and vulnerably show up—even when I don't feel like it! I'm thankful for those in my life that have not given up on me, even at times when I have given up on myself.

It's both frightening and freeing to be mask free. This journey is not for the faint of heart. TBI sucks for the survivor and the family. The loss of a child is not



natural; it is unacceptable. I have learned many life lessons along our journey; some I prefer to embrace, and others I prefer to ignore.

Above all, at this pivotal moment, I'm thankful for the healthy lessons that at first I ignored, but now I embrace. It's imperative to let go of unrealistic, self-inflicted expectations, and it is okay not to be okay. It's not a sign of weakness to admit this, in all actuality, I realize it's a sign of bravery to say, "Please be patient with me. I need you. I can't do this alone."

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.



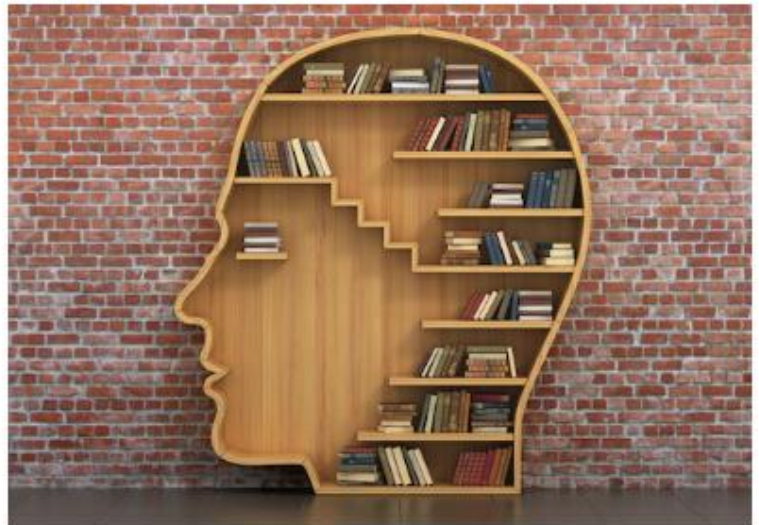
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One Day at a Time

by Drew Palavage



Hi all. It's been about a year and a half since my injury and about eight months since my first submission to this publication (see February, 2016 edition). Well, I've made it through the summer and am now laid up following a foot surgery.

For those who don't know, I suffered a DAI (TBI) and brachial plexus injury in a snowboarding accident in March of 2015. I was in the hospital for 2-3 weeks and in inpatient rehab for 4-5 months. I was very wobbly when I tried to walk and stand, very weak on the right side, had speech deficits, and had double vision. I needed a wheelchair, commode, and shower chair for ADLs. Before the accident, I worked in a neuro-ICU, personally maintained my home and yard, and competed internationally in outrigger and dragon boat canoes.

Well, the summer has come and gone. In the spring, I did have strabismus surgery on my eyes and now wear prism glasses to correct the double vision. I also got and put together an adult 3-wheeled bike. Then, like most "ordinary" summers, we spent it at the Jersey shore. My daughter got a counselor job at the camp she went to for many years. I spent my time trying to get stronger and act as normal as possible. Many of the neighbors were really glad to see me, for they knew of the accident and they hadn't seen me at all the previous year.

I spent the first week or so getting the yard in order. This included going to the lawn supply store and getting some plants. I spent much of my time transplanting them to larger pots. I also cleaned up the yard as best I could and climbed under the house to turn the water back on. My wife was a nervous wreck!

I made it a point to get out and ride my bike (3-wheeler) at least once each day. The first few times my wife went with me to make sure everything was okay. In the mornings we would ride up to, and on, the boardwalk when bikes were allowed. I didn't see that many 3-wheelers.

When I would see one, we would casually nod to each other, like folks on motorcycles do. At times it would be very crowded and I'd have to weave in between bikes and pedestrians. The total length of the boardwalk was about two miles and it was about a mile to the boardwalk. I did the whole thing a few times! Once my wife felt comfortable and I got brave, I rode up and down the bridge I used to train on.



The toll collectors must have been saying “who’s this nut on a 3-wheeler!” I must admit I was the only trike to be found on the bridge! I also rode my bike to the beach, the store, and all around town. The neighbors would say: “oh, there he goes again.”

The other thing I longed for was to get back out on the water. I used to paddle my 1-person outrigger for miles off shore. I used to be able to swim like a fish. Now I would sink like a rock. I bought a good PFD (life vest) from a place that used to know me as “the guy with the outrigger.” I researched kayaks that I could paddle or pedal through magazines and online. I eventually bought a kayak that could be paddled or pedaled, from a local store. The stipulation before the purchase was that it must be very stable. That is to say not tippy!

We loaded it on to the roof racks (no easy feat with one good arm) and headed to a good launching point on the bay. I assured my wife that I would stay close to shore. I did stay

close until I felt completely comfortable with the craft, THEN I ventured out farther. It felt GREAT to be on the water again!

I also grilled dinner about every other night, went to the beach on my bike and then walked (hobbled) in the sand to a good sitting point. When we went to the store (we had to replace the TV which went on the fritz and buy new porch furniture), I found that holding onto and pushing a shopping cart made this doable. I also continued to work out every other day, doing the erg (rowing machine), weights, and the TRX. I also walked/hobbled around a LONG block with my wife and my trusty walking stick.

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Overall, it was and is an okay summer and early fall. I have “mostly” met, or partially met my goals. You see, cognitively I seem to be “all there”. I don’t get headaches, seizures, or suffer any short term memory loss. My deficits seem to be all physical. I have balance problems, suffer right-sided weakness (particularly my right arm), have double vision (corrected after surgery and glasses), and am still a bit dysarthric (speech problems). Compounding it all, I’ve just had foot surgery on a couple of toes that were painful/wouldn’t bend. Hopefully walking will be a bit easier after they heal.

I still get “down” at times, particularly in the mornings. I would encourage everyone

going through this to seek out people via support groups, the Internet, etc. who have already been through this! Their input and support has been a god-send. You realize you’re not alone!

I also realize that people are basically good and want to be helpful. I’ve made it a point to be polite and respectful, whether it be to my wife, the medical personnel who draw my blood, or a complete stranger who holds the door, for example. They didn’t have anything to do with my accident. They’re just trying to help out, but also allow me to try whenever possible. A couple of other things that have also helped me: keeping busy, and having a loving pet (besides my family of course). I usually lie in bed at night and think of what I

want to accomplish the next day. This usually gives me incentive to get up and ready the next day.

My dog “Kia” (short for Kialoa, the paddle I used to use) and me, are best pals! He loves me unconditionally (as does my family, I think). He just simply likes spending time, like walking in the yard, with me. My wife drives him and me to the woods where I used to walk him. This way I get walking practice and he gets to run!

My goals/desires for this year mostly revolve around getting stronger for my daughter. She will be going to college next year. I would love to visit schools with her and I want to be able to carry at least one of her bags when she does finally leave the nest. Even though it’s probably a ways off, I want to be able to walk her down the aisle one day! I don’t want her to have to support her dad. After all, she and my wife are my reasons to push on!

Oh well, back to the couch to elevate my foot. Once healed, I’ll return to PT, OT, and Speech therapy. I’m sure there will be yard work to do before the winter too. Again, just like before, I approach this journey one day at a time.

Meet Drew Palavage

Drew takes pride in being a good husband and father. He was/is also a fierce competitor and works hard every day. Right now he enjoys working out and maintaining his home. His passion for outdoor activities continues to drive him in his personal recovery.



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WITH A FRIEND OR COLLEAGUE

TBI HOPE Back Page

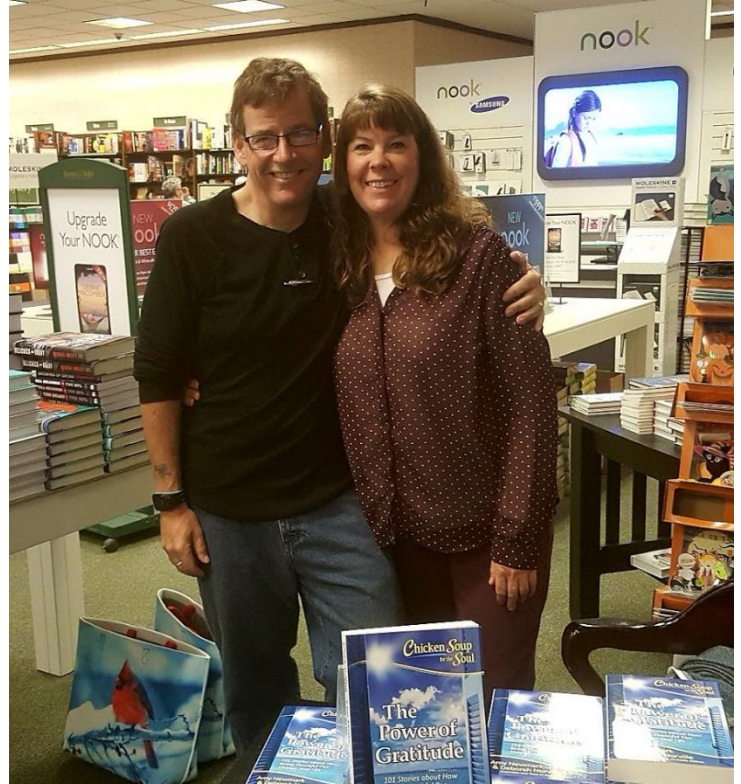
At the time of this writing, we are only a few days away from the Thanksgiving holiday. And like I often do, I use this as an opportunity to look back, to reflect on the path our family has walked, and to look forward to a future that is a bit less uncertain than it was a few years ago.

Brain injury reshapes and redefines so much of life. Jobs change – or go away. Many old friends fade into the background of our lives – only to be replaced by new souls we that have met in our journey. And families are reshaped in ways unimaginable.

For many years, I steadfastly defined family as those we share DNA with, or are bound to my marriage. I no longer hold this view. Brain injury has reshaped our own family in a way that is unexpected, at times heartbreaking – and at times wondrous. Shared before, brain injury sure does complicate things!

It is our hope that this Holiday Season, you are able to spend time with people that you love – and who love you for who you are. We wish you happiness, strength, resilience and health.

From our family to yours, Happy Thanksgiving!



David