BRAIN INJURY

HOPE

Magazine

Summer 2021

support
education
inspiration

Welcome to Our Sweet Summer Issue

A Summer of Hope

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Welcome

Publisher's Introduction

HOPE MAGAZINE

Serving the Brain Injury Community

Summer 2021

Publisher
David A. Grant

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Nicole Bingaman
Patrick Brigham
Darron Eastwell
Donna Figurski
Sarah Kilch Gaffney
Rosalie Johnson
Dawne McKay
Norma Myers
Rosemary Rawlins
Rob Staffen
Barbara Stahura

Welcome to the Summer 2021 issue of HOPE Magazine!

Summer is here in full swing, and people are increasingly out and about again. From backyard barbecues to days spent at a local beach or lake, with summer comes outdoor fun.

With summer also comes our seasonal "Best Of Hope" special issue. We've poured through the HOPE Magazine archives to bring you some of our favorite articles of all time.

In this special issue, you'll find a mix of legacy articles as well as new stories to read. All speak of life after brain injury as it really is, so often two steps forward and a few steps back. Honest and real, our writers share about their experiences as they navigate the waters of life after brain injury.

To all of our contributing writers, we again thank you. Without you, there would be no HOPE Magazine.

Be safe this summer,

David A. Grant
Publisher

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What Lies Within

By Rosemary Rawlins

The brain controls everything, so when a brain is injured, it feels as if everything's out of control, and there's nothing we humans love more than being in control.

I don't know what it's like to want to say one word and have another word come out of my mouth, or to try to walk, only to find my feet all tripped up, but I've witnessed the man I love most struggling to perform simple tasks, and I've felt out of control myself because I could not help him.

> "Many years have gone by now, and I've learned a good deal about resilience."

In the early days of caring for Hugh after his severe TBI, I'd feel a bit annoyed when people would say things like, "Take it one day at a time." I'd sometimes whisper in my mind, "How about YOU take it one day at a time, I'll go back to my old life, thank you!" Not nice thoughts, I know, but true. I wanted control. I wanted a problem I could fix.

Many years have gone by now, and I've learned a good deal about resilience. In a resilience study, Dr. Emilie Godwin reports that resilient individuals and families know how to "normalize crisis." The phrase sounds like an oxymoron to me. Normal and crisis don't belong together, like the words "awfully good" or "painfully lucky." But when I realized what she meant by this, it all made sense. Normalizing crisis simply means that people see their problems as something manageable, something they can handle. When we don't normalize crisis, we remain in crisis mode (one definition of crisis is "dangerous or worrying time") and we're stuck in a frame of mind that keeps us from moving forward. In short, we see our problems as hopeless.

Over the course of my entire experience as a caregiver I've learned this vital lesson: All of our problems have solutions. They are among us and within us.

We find solutions to our problems and even our crisis-like problems when we reach out to others, when we accept help, when we listen and follow sound advice. These are the solutions we find among us. When some problems prove too difficult to overcome, when they feel insurmountable and there seems to be no help available at all, the solution lies within us. We dig deep to find the fortitude, acceptance, and grace to move forward day by day until we eventually emerge from the fog as we draw strength from our personal faith and our human need to seek meaning from adversity.

"We find solutions to our problems and even our crisis-like problems when we reach out to others, when we accept help, when we listen and follow sound advice."

Sometimes, the only answers to our problems lie within us. These answers may be hard to find, but they are worth seeking because they bring us peace. The first step is knowing they are there, inside us, waiting to be found.

Meet Rosemary Rawlins

Rosemary Rawlins is the author of Learning by Accident: A Caregiver's True Story of Fear, Family, and Hope, an inspirational memoir about learning and growing through adversity.

When Rosemary's husband suffered a severe traumatic brain injury after a car hit him on his bike, she struggled for two years to bring him back home and back to himself, and when he was finally better, she fell apart. Rosemary has had many years of experience as a full-time caregiver for loved ones with brain injury, dementia, and COPD, and has a keen understanding of caregiver stress.

She is also Editor of BrainLine blogs and a national speaker on caregiving topics.

Making the Grade

By Nicole Bingaman

Close to a year and a half after my son's traumatic brain injury, we began working with a Neurological-psychologist. We found a terrific doctor, who seemed to grasp not only the medical side of brain injury, but also the emotional impact specifically relating to Taylor.

Following a few sessions of becoming acquainted with Dr. Randy, cognitive testing was recommended. This would allow us to gain a better understanding of where Taylor's thinking processes were. A baseline could be established offering insight into a different aspect of the injury than that which was glaringly obvious.

I was still a fairly new student in the classroom of TBI, and was once again, not fully prepared for the lesson I was about to learn. Hours of testing took place and a few weeks later, we were called in to discuss the results. The fact that Taylor could undergo and complete the test process itself was an accomplishment, but sometimes even positive milestones feel painful.

> "I was still a fairly new student in the classroom of TBI, and was once again, not fully prepared for the lesson I was about to learn."

Up until this time in parenting I had been fortunate to have three sons who were healthy in mind and body. They had each successfully navigated their high school education, sports and extra-curricular activities.

They were part of the National Honor Society, All-Star Sports Teams and took part in community service. Taylor even graduated first in his class at the technical school where he learned the skill of being an HVAC specialist.

As I sat with Dr. Randy that day listening to the results, I felt like the world was about to suck me in to another unexplored layer of sadness and shock. I could hear my heart beating, as my intuition warned me that something bad was about to happen. My body and mind prepared for the blow.

The doctor explained that Taylor was functioning at the level of someone who was around nine years old. He discussed the challenges in thought processing, understanding, word recognition, insight and an exhaustive list of things that represented more of what the injury had stripped away. I don't know what I came in expecting the results to convey, but it certainly was not that. I felt as if I was being punched in the gut. Ever aware that brain injury changes everything.

The strangest occurrence happened to me in those moments. I swallowed my tears, I took the deep breaths I had become accustomed to taking, I inwardly scolded myself for coming to the appointment alone and I heard again the silent scream that had become my friend in this classroom. That scream defined the emotion I could not let out, the parts of me that no one would ever see.

More of my son was gone that I realized. Then I saw something flash in front of my memory that has bothered me since that day. I saw the bumper sticker that said, "Proud Parent of An Honor Roll Student." The hurt and anger inside of me wondered what our bumper sticker would say, "My once strong, bright 22 year old is now functioning at the level of a nine year old." I was ashamed of my thoughts.

Questions like "Why did this happen to Taylor?" ran through my head, and the truth is they still do. But please understand this…I wish with all of my being that brain injury never happened to anyone…ever…again.

"My once strong, bright 22 year old is now functioning at the level of a nine year old."

Since that time, Taylor has been retested. For round two's results, my husband and other sons came along. We sat together for the news. The test can only take place every two years, so they were spaced out for about that length of time. I came in to that meeting with fairly high hopes. Dr. Randy did not dive right in this time. Instead, he talked to each of us about what Taylor's injury meant in fairly concrete terms. We then discussed some ways that it affected our family and relationships. We were all uncomfortable in this room, with this psychologist, wondering how we ever got here. It has been said "the tension was so thick you could cut it with a knife," but what was thick that day, was pain.

On that day I learned a tremendous lesson. I learned that people are much more than their grades, their academic accomplishments or what club they belong to. Intellectually I knew that before, but now I knew it in my heart. There are beautiful souls, who are functioning at a level far less than their peers, who are more than exceptional and deserve recognition. Before then you may have heard me talk about GPA's, and various achievements, but that has become a part of life that I have let go. Those things matter, but they do not define a person.

Underneath all of the ink blots, timed sequences, and recognition of simple objects such as comb or toothbrush, was my son's mind. Taylor worked with his beautiful, broken brain, which was trudging through some thick mud to come back even the tiniest bit. And although the results were less than we had hoped, they were something to be proud of. In our society we are often impressed by the letters behind someone's name, PhD, MD, MA, and so on. The letters behind Taylor's name will always be, TBI survivor, and for that I will always be grateful.

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 brain injury 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 "Love Wins."

Overcoming Barriers

By Sarah Kilch Gaffney

I was fourteen or fifteen years old when I got my first concussion and nineteen when I received my last, amassing approximately eight in the intervening years. This occurred before we knew much about the cumulative nature of head injuries and before we paid much attention to them, and the last one was where they all caught up with me.

In my final college soccer game, I collided with a player from the opposing team. The details are fuzzy, but ultimately her knee connected directly under my chin.

I was stunned and it took a few minutes to get me off the field. Sitting on the sideline, I took off my goalkeeper gloves and, realizing I had forgotten my mouth guard that day, palpated my jaw, grateful that my teeth were still intact.

> "When I brought up my continued symptoms, the athletic director told me that I did not need an evaluation and I certainly did not have a concussion."

My tongue swelled, and the student athletic trainer crushed up something so that I could swallow it. The next day, I was exhausted and in pain. My parents, both former EMTs, wanted me to be evaluated. When I brought up my continued symptoms, the athletic director told me that I did not need an evaluation and I certainly did not have a concussion because "he saw concussions every day in football."

When I finally saw a doctor over a week later, I was told I had classic concussion symptoms. After weeks of sleeping nearly twenty hours a day, taking incompletes in all of my classes that term, and months of headaches and medications, I eventually recovered. I stopped playing soccer and swore off activities that might easily result in another knock to the head.

The following summer, I decided to serve as an AmeriCorps volunteer on a backcountry trail crew in the Maine wilderness. There, on a mountain on the Appalachian Trail, I met Steve, a tall, lanky fellow from northern Vermont. Less than two years later, on a bright October day, Steve and I were married on that same mountain.

Shortly after our third wedding anniversary, Steve and I arrived back at our car after a weekend hike, and he couldn't speak. First there was silence, then gibberish, then real words but in no logical order, then it was as if nothing at all had happened. He was completely back to himself and assured me he was fine.

The following day, Steve was diagnosed with a massive brain tumor. He was 27 years old.

Steve was a champion of patience and humor, attributes that had served him well in his work teaching others how to build trails, and he held onto his good nature and easy-going attitude as we faced an uncertain future.

He joked, laughed, and smiled his way through two awake brain surgeries, radiation, multiple chemotherapies, and proton beam radiation.

I can't count the number of times we walked down the halls of his cancer center hand in hand with me in tears and him telling me it was going to be okay.

When he awoke from the first brain surgery with cognitive and speech challenges, Steve dove head first into speech therapy, earning himself an *"Overcoming Barriers"* award from our local hospital.

When the radiation therapy left him permanently disabled, he maintained his positive outlook. When he became homebound during the last few months of his life, he was still able to smile – a fact for which I will always be extremely grateful and in absolute awe of.

Shortly after his diagnosis, Steve's oncologist had revealed to us that his tumor would eventually be terminal, and we tried our best to live our life while carrying that knowledge. Along the way, our daughter was born, and Steve loved her with absolutely everything he had.

Steve's doctors never talked about brain injuries. Though, of course, that is what he was experiencing, over and over again. His oncologist was concerned with the efficacy of chemotherapy, his neurosurgeon with the delicate balance of cutting too much versus too little, his neurologist with controlling his seizures. And, so, no one talked about brain injuries, or what to expect, or where to seek help, support, or information. We didn't even talk to a social worker until the week before Steve started hospice.

Until the last couple weeks of his life, Steve had little pain. His fatigue, however, was immense and unrelenting. Everything made him tired and each new treatment increased the weight of that burden, building over the years.

As treatments failed and his tumor progressed, Steve slowly lost cognitive and physical function. Eventually, he could no longer walk, no longer leave the house, and then no longer leave the hospital bed that we had squeezed into our bedroom.

Steve died at home two months shy of his 32nd birthday, four and a half years after his diagnosis. I found myself reeling, widowed with a toddler, and with no idea what to do or how to make my way through life now that Steve was no longer by my side.

When Steve became disabled, I had started working towards nursing school. We had both continued to work in the conservation field after we met, but I felt that I now needed a different career to support our family. I fought hard to follow through with that decision, juggling Steve's treatments and care with raising our daughter, work, school, and managing a house.

> **“As treatments failed and his tumor progressed, Steve slowly lost cognitive and physical function. Eventually, he could no longer walk, no longer leave the house.”**

I left nursing school to take care of Steve during the last months of his life, and returned after he died, but despite my 4.0 GPA and outward success, I was miserable and it became clear that it was no longer where I needed to be. At the time, it seemed hard to believe that there would ever be another right path, but I desperately needed a change and a break.

I didn't take much of a break, but I did find the change that I needed. A little over a year after Steve's death and just over a month after I left nursing school, I accepted a position as the Program Coordinator for the Brain Injury Association of America's Maine Chapter. It's a dream job, and I still sometimes pinch myself to make sure it's real.

Now, I get to spend my days increasing awareness about brain injury, helping survivors and families get the resources and support that they need, and being an important voice for those with brain injury in Maine. I get to provide the support that didn't exist when Steve was sick, and I get to make sure survivors and families aren't without somewhere to turn when they have questions or need help. I cannot think of a better way to honor Steve's memory and I am grateful for the opportunity every day.

Meet Sarah Kilch Gaffney

Sarah Kilch Gaffney is a writer, maker, and brain injury advocate living in Maine. She writes about grief, motherhood, exploring the natural world, brain injury, women's health, and many things in between. She is a member of the Maine Writers and Publishers Alliance (with a profile on MWPA's Find Maine Writers site) and a volunteer reader for Hippocampus. You can find her writing at www.sarahkilchgaffney.com.

Because I Can!

By Rosalie Johnson

When I go to Florida in my motorhome, it's a fresh start. Each day is planned and planned again, well in advance, using the strategies I learned while recovering from a Traumatic Brain Injury.

On the road, I can only move forward. I can still remember my other life: work, volunteer, play, maintain a home and still have plenty of time to spend with my husband Randy, family, and friends.

> "Like most survivors, I remember when that world crashed – December 8, 2001."

Like most survivors, I remember when that world crashed – December 8, 2001. In my new reality, I feel as if I am a child's toy top spinning so fast that the centrifugal force is randomly spewing away my thoughts and plans to be productive. Some days the top slows down, and on others, it rotates so quickly that it is all I can do just to hang on and ride.

Travel gives me back control. With my itinerary plan and the larders stocked, Randy tries to start the trip with me. We head south in the late winter. Each day we drive 250-300 miles easing into a routine and trying to miss any snowstorm in the forecast. Arriving at an RV campground, we level the motorhome, extend the slides, and connect the water and sewer.

Next, I walk the "Road Warrior" – my old Yorkie, Lilly. Then there is dinner to prepare, clean up, and finally sleep. The next morning the routine is reversed. Any items we used must be stowed, as they become projectiles while traveling. At some airport along the route, I usually have to drop Randy off to fly home, so he can return to work. You should see some of the looks we get when driving our motorhome through the departure area of an airport! Being a pilot, he will be able to meet me at future destinations down the road.

I spend a week here or two weeks there, eventually making it all the way to Key West. Every day is planned, such as stopping for gas or groceries along the way, because once the RV is parked and set up, I can't just drive to any store. I get around on my bicycle for planned adventures. I am very fortunate to have family and friends join me along the way. I love the company for exploring new areas but there is one stipulation: they have to be ready to bicycle or walk everywhere. Just ask my friend, Anne, about her "Vacation Boot Camp!" I have baskets and coolers to attach to our bicycles, along with a cart to carry groceries, laundry, or beach chairs.

When traveling alone, I am rarely lonely. Walking Lilly, I meet many other dogs. Each evening finds most campers at the waterfront to marvel at the beauty of the sunset. More bonds form. The people I encounter are from all over the world, and all share the same bond: "Wanderlust." In meeting so many interesting folks, the number of Traumatic Brain Injury and Stroke survivors is astounding.

With one particular couple, the wife suffered a stroke some years ago. Each evening her husband bundles her up and helps her into their golf cart, then drives to the waterfront to watch the sunset. Due to the severity of her aphasia, she is only able to speak three words. She will take each person's hand, place it on her heart, look deeply into their eyes and say "I love you, I LOVE YOU!" Is there any better way to share a sunset?

Along the way, I'm invited to join other RV'ers for potluck dinners, Yoga, airplane rides, museum tours, and much, much more. The people I have the pleasure to meet share so much of their lives with me. They are like little gifts. Each day I learn something new: the name of a flower or tree, or the mating habits of dolphins or alligators.

When learning that I am a Traumatic Brain Injury survivor, many other travelers will ask me how I can drive the RV and do all of the set up mostly alone. I respond, "Because I can!"

Meet Rosalie Johnson

Before her Traumatic Brain Injury, Rosalie Johnson was a Registered Nurse and loved volunteering for various non-profit organizations. She was able to travel, and live and work throughout the country with her husband, Randy and their ever-changing family of dogs.

These days Rosalie can be found running the Seacoast Brain Injury Support Group and volunteering at Krempels Center in Portsmouth, New Hampshire. She is a seven-year Board Member for the Brain Injury Association of New Hampshire, author of "Meet the Artist" article printed quarterly in HEADWAY Newsletter published by BIANH.

I Stumbled, but Did Not Fall

By Donna Figurski

Recently, as I got out of my car, I stumbled on the curb. Somehow in the darkness, I did not see it. Though the event took less than a second, one thought ran through my head. It was not, "Oh, no! I am going to break a bone or scrape my knee." It was not, "What a klutz! I'll ruin my clothes." And it was not about how embarrassed I would be. All of those possibilities probably would have been my first thoughts before brain injury entered my life in 2005 when my husband had a traumatic brain injury.

Now my mind is only a thought away from brain injury. So, as I tripped and stumbled, but did not fall, I thought, "Please don't let me hit my head." I didn't care how silly I looked or about my clothes being ripped or about getting any broken bones (they would heal). I was concerned about getting a brain injury.

"I worried about how a brain injury could change my life forever."

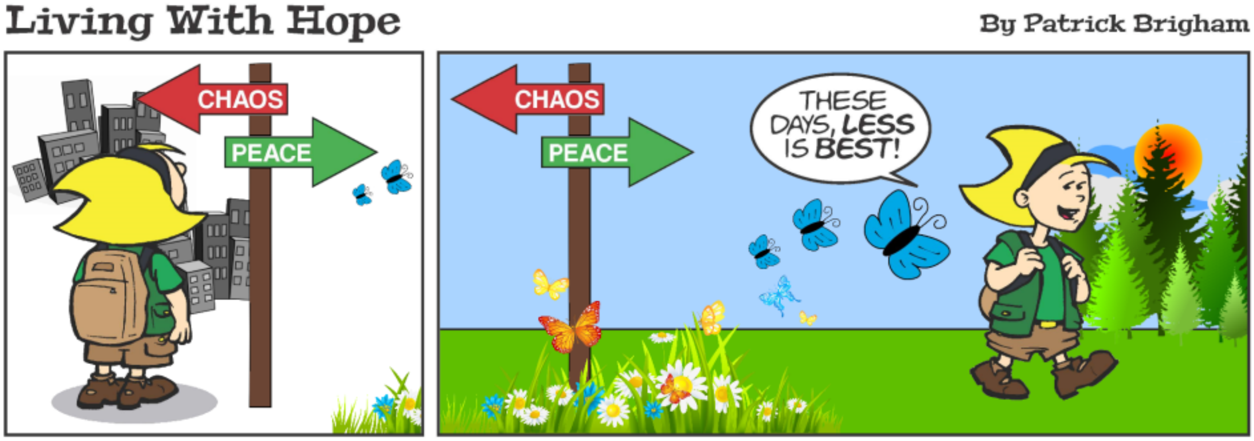
I worried about how a brain injury could change my life forever. I worried that if I were hurt, I could not sufficiently care for my husband, who needs my daily attention. Yes, those thoughts raced through my head in that fleeting second.

It only takes a second for a brain injury to occur. Most brain injuries occur because of an accident. Though we may be aware of the possibility of accidents, we cannot avoid all of them. Fortunately, my accident was avoided – just barely. I can only hope that my potential accidents will be few and far apart in the future. I hope yours will be too.

Meet Donna Figurski

Donna Figurski, whose life revolves around traumatic brain injury (TBI), is a wife, mother, granny, teacher, playwright, actor, director, picture-book reviewer, radio host, speaker, photographer, and writer.

As a brain injury advocate, Donna has published articles in many brain-injury-related magazines on the web; has written chapters included in two books; writes a blog called "Surviving Traumatic Brain Injury"; is host of her international radio show, "Another Fork in the Road," online on the Brain Injury Radio Network, and is a speaker concerned with survivors of brain injury and their caregivers.



"You are braver than you believe, and stronger than you seem, and smarter than you think." -A.A. Milne

The Day I Broke my Brain

By Darron Eastwell

I have always loved mountain biking. There is something indescribably wonderful about being out on the trails. Fully immersed in nature you never know what you are going to see, and what you'll experience. Every ride is a completely unique experience.

In late May of 2015, I planned on a day of mountain bike riding at Tewantin National Park. Located on the Sunshine Coast in Queensland, Australia, Tewantin is a mountain biker's dream. The terrain is varied, with some very aggressive climbs.

It was a perfect day for riding. But, unfortunately, fate had other plans for me that day.

> "Little did I know that my life, and the lives of those who love me, would be drastically changed forever."

My GPS speedometer indicated that I had been riding for a couple of hours. As I have no memories from that day, I can only rely on the data. My pace was slow and easy as I rode. The hills were steep and I was enjoying my ride. The speedometer data show an abrupt jump in my speed up to almost 60km per hour (almost 40 MPH). It was clear that I had entered into a steep downhill descent.

This was to be the last cycling descent of my past life.

The day that started so sunny and full of bright promise ended abruptly when I crashed my mountain bike and sustained a traumatic brain injury.

Little did I know that my life, and the lives of those who love me, would be drastically changed forever.

The type of brain injury that I sustained is called Diffuse Axonal Injury. I spent the next seven days in a medically induced coma. My injuries included a fractured skull, a wedge fracture to my T7 vertebrae, and a fracture to my neck.

Post Traumatic Amnesia affected my memory to the point of having no memory of that fateful day, with the memory of my mountain biking accident forever erased from my brain. I cannot tell you where it happened, how it happened, the pain I was in, the ambulance ride to ICU or being admitted to three different hospitals over the two months that followed.

About the only memory I have been able to retain was of being discharged from the hospital. I had met the recovery expectations of the medical staff, so I was allowed to leave to continue my rehab and recovery on an outpatient basis.

I was advised by my occupational therapist that to help assist with improving my memory, speech and fine motor skills, I should start to write a daily journal of what happened, and what I had done or was supposed to have done during the day. To this day, I can’t remember when I started writing my journal however, very slowly the words started coming out. I did the best I could to put them down on paper.

My handwriting was adversely affected by my brain injury. Before my injury, I had very neat handwriting and could write very quickly and legibly.

After my injury, my writing was the complete opposite. It was messy with numerous spelling mistakes. Just like my new speech challenges, it was not flowing easily or naturally. Using a computer brought no relief as I had forgotten how to use it and was suddenly unfamiliar with the keyboard.

I persisted with my new chicken-scratch handwriting, trying my best to remember and write down my thoughts. I don’t know how long I had been writing my journal, though I think it was approximately twelve months before I could sense some improvement with my writing, language, speech, and concentration. My memory and neuro-fatigue were still the biggest challenges I faced. It was at that point that I read several books about TBI survival and recovery.

Prior to my injury, I had never heard or read about TBI. I said to myself, “Darron you need to write a book about your own TBI story as it will help you, but more importantly, it could help other TBI survivors and their families that are going through what you have gone through.”

This is when my book, The Day I Broke My Brain, started on paper.

I re-read my journal notes as often as I could because I couldn't always remember what I had written. Diligently, I would pen chapter suggestions and topics to write about. It took me almost a year of writing. Writing a book was entirely new to me as I had never set out to do anything like it before. Like so much of life after brain injury, it was unchartered territory for me.

At this point in time, my story was entirely handwritten. I knew that to get the book project started, I needed to be able to email what I had written. My next step was to type up my scribbled handwritten notes so that I would have a readable format. I set myself up to type a few pages on a daily basis. I set myself a goal to have it completed within a month's time.

The typing was very much a form of rehab and mental stimulation at the same time. Though the overall process was very rewarding, after a couple of long days of typing I suffered from bad neuro-fatigue. It knocked me out for days, I was so mentally exhausted. This happened several times as I worked my way through the typing out of my book. I took the required breaks to help myself recover, and then I would start again. I was determined to finish.

A full month later, I completed typing the first draft of my upcoming book. The Day I Broke My Brain was born!

I was feeling really proud of myself, given what I had already been through. While writing my book, I was still recovering from my brain injury and all the TBI difficulties it brings to me on a daily basis. Writing my book is one of the most satisfying things that I ever have done in my life.

I still can't believe it really. I am actually going to have a book about my own TBI story. This is so exciting. The main purpose of writing my TBI story is to provide help to other TBI survivors and their families. My hope is that my new book may provide them with hope, motivation, and inspiration to keep positive and push themselves during their own recovery process. Readers may try something I did during my own recovery that assisted me, as it could help with their own recovery.

I have a framed quote in my lounge room. It was something I looked at regularly and read on a weekly basis.

It reads as follows…

"Sometimes the best thing you can do is not think, not wonder, not imagine, just breathe and have faith that everything will work out for the best."

I have used this statement as a kind of mantra to help me to live in the moment and not look too far ahead during my recovery. I still do it to this day. I believe that everything in life happens for a reason. I often say to myself that I survived my TBI so that my experience can help others.

At the time of this writing, I am almost two years out from my accident, an accident that gave me life membership as a brain injury survivor. My recovery is still improving and today I love my life. I hope to never forget that I am one of the lucky ones.

Meet Darron Eastwell

Darron Eastwell is a brain injury survivor from Queensland, Australia. The survivor of a 2015 mountain biking accident, Darron has emerged with a strong desire to serve those within the brain injury community.

His first title, “The Day I Broke My Brain,” was released on Amazon in June of 2017. Darron and his wife Bianca share their love for their two children and have embraced their new life together.

Journaling a New Story

By Barbara Stahura

When a brain injury happens, the familiar story of a life can be altered in ways not possible with any other kind of injury or illness. So much you knew about yourself—the wealth of information you depended upon to lead your life—can blur or disappear, leaving you stranded and struggling in an unknown place.

> “You can feel as though you’ve been kidnapped to an alien planet where nothing is familiar.”

Along with cognitive and emotional challenges, you may face challenges with your physical abilities. You can feel as though you’ve been kidnapped to an alien planet where nothing is familiar, and you are lost in dangerous territory.

Family caregivers can feel equally bewildered, as well as terrified. I certainly did when my husband sustained a serious traumatic brain injury more than a decade ago. But my journal offered a safe sanctuary where I could pour out my deepest thoughts and feelings without judgment or criticism.

Writing somehow made them more manageable. Despite being diagnosed with secondary traumatic stress, journaling allowed me to hold on and cope with the overpowering uncertainty, fear, and anxiety.

As I’ve found during eight years of guiding journaling groups for people with brain injury and family caregivers, telling your story through journaling can enhance the healing process. “Healing” here does not mean restoring your injured brain to its former functioning or your life to the way it used to be.

Instead, it means finding healthy ways to become aware of, accept, and acknowledge what has happened so that you can move forward into your new post-injury story. Journaling, for even five or ten minutes at a time on a regular basis, can help release you from yearning for the past and open positive doors to your envisioned future.

How to Journal

There are no rules in journaling, except perhaps to date all your entries. So don't worry about correct spelling, grammar, or punctuation. You need not be a "good" writer. Simply write in whatever way is comfortable for you. You can write on paper or use a keyboard. If a brain injury prohibits you from doing either, you can speak your entries into a recording device, use speech-recognition software, or find a trusted confidante who will scribe your words without judgment or changes.

Keeping your journal private allows you to write honestly. But if you occasionally write an entry that you never want anyone to read, you can tear it out and destroy it. The benefit of journaling comes in the writing, not in preserving what you write.

To begin, you can simply pick up your pen or put your hands on the keyboard. But it's helpful to create a structure for yourself by starting with a prompt (for example: Today I feel… or, The most important thing I can do now…) You can experiment with various techniques such as Dialogue or Unsent Letter, or even setting a time limit.

If you're writing about a traumatic experience, don't simply begin writing with no structure in place. Even something as simple as a five-minute limit can help you avoid writing yourself off an emotional cliff with no way back to safety. Stop writing if you feel yourself getting unusually upset. And over time, try to keep a balance between positive and negative so that you don't end up endlessly ruminating on the darker aspects of your life.

> **"Even something as simple as a five-minute limit can help you avoid writing yourself off an emotional cliff with no way back to safety."**

After a brain injury, you might not be able to write much or for very long. Do whatever you can, and please don't judge yourself harshly. As your condition improves, you will be able to write more. If you're a caregiver, you might have difficulty finding time for self-care, but know that you can journal in only five or ten minutes at a time. A small journal will fit in a purse or pocket, and you can write wherever you are.

As you continue journaling, you will have written memories of your healing and of how far you have come since brain injury altered your life. And there, in those words on the page, you—whether survivor or caregiver—have created the foundation on which to build the new story that will carry you into the future.

Meet Barbara Stahura

Barbara Stahura, Certified Journal Facilitator, 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.

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. To learn more, please visit www.barbarastahura.com

"The only time you fail is when you fall down and stay down."

-Stephen Richards

Suddenly Changed

By Dawne McKay

One week prior to my accident, I was on vacation in Florida with my boyfriend, and I was suddenly jolted awake in the middle of the night with a terrible feeling that something awful had happened to someone close to me. It was a feeling that I had never experienced before and I thought I was going to get a call that someone had passed unexpectedly. I carried this feeling with me for days and I just couldn't seem to shake this unsettling anxious feeling, no matter how hard I tried. Exactly one week later, I was involved in a horrific car accident.

I was on my way to work and had stopped to make a left-hand turn. I was rear-ended by an SUV clocked at 80 mph, and I was pushed into the path of a transport truck. My life as I knew it suddenly changed in a matter of seconds. I was transported to a local hospital, but my injuries were so severe that they had to transport me to a trauma hospital. When I arrived in the trauma unit, I remember being greeted by the Chaplain as I was truly lucky to be alive. I suffered a moderate head injury with laceration, five broken ribs, fractured vertebrae, fractured finger and a horrific seatbelt wound on my thigh.

> “I suffered a moderate head injury with laceration, five broken ribs, fractured vertebrae, fractured finger and a horrific seatbelt wound on my thigh.”

I only spent three days in the trauma unit, as they decided to discharge me even though I couldn't walk. I think back to that morning and I was actually excited to be leaving the hospital and couldn't wait to have a shower, wash my hair, and put my pajamas on. I didn't realize that I would be absolutely terrified to get into another vehicle, how bad the pain would be once the morphine had worn off, and suddenly I realized that I could not walk, and I was in excruciating pain. Daily nursing, physiotherapists, occupational therapists, PSW's and numerous medical follow up appointments had now become my new way of life. Not to mention financial strain, flashbacks, sleepless nights, constant pain, the "what if's" and anxiety. I had a job that I loved and my social life and friendships as I once knew them came to a screeching halt. Friends who I thought would be there for me weren't, and I suddenly found myself realizing who my real friends were. (This is apparently quite common, as I talk to people in similar situations.)

> **“As I had never been in a motor vehicle accident quite like this, it was a HUGE learning curve and recovery for me.”**

As I had never been in a motor vehicle accident quite like this, it was a HUGE learning curve and recovery for me. My accident happened in 2012 and I still continue to attend outpatient rehabilitation. I am still trying my best to cope with the chronic pain, sleepless nights and flashbacks.

Today and every day, I try my best to be as positive as I can, and I recently decided to create a Facebook support group for Motor Vehicle Accident Victims. I took it upon myself to not only build the support I was seeking, but to spread it out to others who were in similar situations.

The group has over 500 members, and a lot of them are either recovering from their accident or just starting to go through the process.

Knowing you are not alone is the main thing and bringing people together and finding support in one another is very therapeutic. I find that once motor vehicle accident victims are discharged from the hospital, they really don't have anywhere to reach out to other victims. The group is strictly to provide members with emotional support while they recover physically, financially and legally. No medical advice, legal advice or solicitation is allowed in the group.

Meet Dawne McKay

Dawne started her career as a legal secretary and for the last 15 years has worked in the healthcare industry. In 2012, she was a survivor of a life changing automobile accident. She is the creator of an online Motor Vehicle Accident Support Group that went live in April of 2016. This is a closed group on Facebook designed to bring victims together to share their story, share information, resources and emotional support. Dawne’s advocacy work continues.

Colter’s Story

By Mandi Seipel

Colter Pollock is an amazing, energetic, brave seven-year-old boy who suffered a Traumatic Brain Injury after a tragic fall from his second story bedroom window. On July 7, 2014, after a weekend of camping, the evening was supposed to be spent winding down but became our worst nightmare.

Five-year-old Colter was in a timeout in his bedroom after having poor behavior at the dinner table. At that time, his eight-year-old sister Jayden, and two-year-old brother Jaxon were playing in the backyard while I was cleaning up after supper. The sliding glass door was open, a slight breeze coming through and I could hear and see Jayden and Jaxon using their imaginations, playing away. Just as I was about to walk upstairs to talk to Colter about his manners at dinner time, the unimaginable happened.

“I ran outside to see Colter lifeless and blue, lying on his back on the concrete patio.”

I heard a loud crash that sounded like an egg cracking. Immediately, I ran outside to see Colter lifeless and blue, lying on his back on the concrete patio. Lying next to Colter was the window screen. Frantically, I urged my daughter to run and get help while I retrieved my phone and called 911. I was in such panic that I almost forgot my password to unlock my phone and even contemplated what number to dial. When the responder answered, I yelled my address and repeated it twice. At about this time, Jayden came running back saying our neighbors were not home.

While on the phone with 911, my hands were shaking so badly that I couldn’t find the pulse on Colter’s wrist. What I did know is that he was turning blue and was not moving. Just as I was hearing the sirens, Jayden returned with our neighbor Ryan Ostrander, who happens to be an EMT. He calmly and quickly performed CPR on Colter and affirmed that he did have a faint pulse. Some days, it feels like it just happened yesterday… raw but almost dream-like.

Later at the ER, we learned that Colter had traumatic damage to his skull. His brain was swelling, there was a bleed and he also had fixed dilated pupils. However, I had no idea what a brain injury entailed. We would find out that Colter suffered a Severe Traumatic Brain Injury, along with a secondary diagnosis of left frontal temporal lobe contusion with a small subarachnoid hemorrhage.

After being life-flighted in a helicopter to Swedish Medical Center in Englewood, Colorado, I was told by his neurosurgeon Dr. Kimball, that Colter was a very sick boy and the chances of his survival were slim. He explained that Colter would need a left frontotemporoparietal hemicraniectomy for subdural hematoma evacuation to relieve the swelling in his brain.

The only glimpse of hope he gave me was when he said he had performed a craniotomy over 100 times and that he had not lost anyone yet. Signing consent papers stating that one of the outcomes could be death left me both hopeless and ill.

Over the next 4 months, Colter's journey became a list of unknowns. Miraculously, he did not break or damage anything else. However, the questions were never ending: Will he survive? When will he open his eyes? When will I hear his voice? Will he have his memory? Would he walk? How would he be cognitively?

Colter spent three weeks at Swedish Medical Center then was transferred to the rehab unit of Children's Hospital in Colorado.

It was at Children's Hospital where Colter began learning all of life's simple, basic skills. We basically witnessed all of his life milestones for the second time.

During many moments, it felt like he would never be "normal" again. But, what I did not know then is that not only is TBI an invisible, uneducated injury, but that he would never 100% recover.

Colter is purely God's miracle. While Colter was in an induced coma, Dr. Kimball said that Colter's life will be a marathon. In the past two and a half years I often come back to the word, "marathon."

Colter has defied the odds in his journey thus far. This marathon has not been an easy race. We have hit a lot of bumps along the way and are still learning how we can pace him on his journey. One of the hardest parts of his injury is that he looks and appears to be normal, and it is easy for his behaviors to be misinterpreted. Hard days are hard, but we are blessed and very proud of his achievements.

Today, Colter is a determined seven-year-old, first-grade boy who loves sports, is great at math and reading, and plans to grow up working with animals. Although Colter is defeating the odds, it's important to note that his journey of healing has not been an easy one. He has challenges and struggles that include his eyesight, sensitivity to light, perseveration, impulsiveness, safety awareness, headaches, and fatigue.

These are not closed chapters, but ones that are real to the effects of a Traumatic Brain Injury. We continue to not only advocate for window fall prevention but also raise awareness about brain injuries and preventable accidents. It is our hope that we can prevent these types of accidents from happening to other children and families.

Meet Mandi Seipel

Mandi Seipel has been an educator for nine years, and most recently is a Title Reading Interventionist Teacher in which she helps kids improve reading skills.

Mandi continues her own journey with PTSD, while also learning more ways to help the whole family discover healthier nutrition and lifestyle choices. Mandi's determination will continue to raise awareness on both TBI and preventable accidents. She hopes to eventually be able to share her story and experiences to help others with their recovery.

> **"A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles."**
>
> ***~Christopher Reeve***

Two Life-Sustaining Questions

By Norma Myers

All parents are faced with the same common questions while raising their children. We were no different. *Will we be good parents? Will our boys be healthy? How will they do in school? What professions will they choose? Will they meet their soulmates and make us grandparents?* These are normal, casual, and expected questions until your worst nightmare becomes a reality. For us, the nightmare was a fatal car accident that took our firstborn son and left our only surviving son with a severe Traumatic Brain Injury (TBI) and a life without his brother, his best friend.

> "In the blink of an eye for our sons, and with an unwelcome knock on our door for my husband and me, our family changed in a way that we could not even begin to comprehend."

When we answered a knock on our door in the early hours of the morning expecting to see our sons, we were instead looking into the bleak faces of police officers as questions immediately started formulating. Because of the protective layer of shock that consumed my body, I couldn't audibly ask the searing questions that I so desperately needed to be answered: *What caused the accident? Did my boys suffer? How long did they wait for help*? The agonizing questions kept swirling in my head, spinning like a washing machine stuck on the spin cycle.

The once casual questions of early parenthood turned into heart-wrenching screams, assaulting my heart like a machine gun stuck in an automatic mode. Unfortunately, some of my questions were answered without being voiced: *Aaron wouldn't get to experience the magical moment of saying, "I do!" He was robbed of the joys of fatherhood. No more hunting trips with his buddies. No more quality time with his brother. Family beach vacations for the four of us are now memories from the past*.

In the blink of an eye for our sons, and with an unwelcome knock on our door for my husband and me, our family changed in a way that we could not even begin to comprehend. While we didn't physically change addresses, it felt as if we had morphed into a new life full of unknowns. The chapter of our life as an intact family of four was removed from our parental handbook; in return, hospital staff offered a manual about TBI, and the funeral home handed us a brochure addressing grieving the loss of a child. These resources were meant to be a comfort, but all I wanted to do was find a shredder and do to those resources exactly what the accident did to me, tear them into a million pieces, with no chance of being put back together in the same way again.

The merry-go-round of questions left me feeling queasy from the never-ending thoughts of what's next. The questions changed with each season of recovery coupled with each season of grief; *will Steven survive and what will recovery look like? How will I plan a life celebration for Aaron? How do I go about securing resources for Steven's rehabilitation and recovery? How does a family recover from such a catastrophic loss? When will we grieve? Will our marriage survive the greatest test of our thirty-two years together? Will our family, friends, and community continue to be there for us?*

As we watched our surviving son fight his way back to us, the recovery road wasn't easy. There were insurance battles. There were tears when therapists gave up too easily. And then there was our favorite: reminding healthcare providers that Steven could answer their questions himself, and on top of that, they didn't have to yell—his TBI didn't cause deafness. If I sound a bit sarcastic, it's because TBI has forced us to encounter the worst of the worst coupled with the best of the best. There are defeats that lead to tears and celebrations that are never taken for granted.

TBI alone causes a unique kind of grief, but when it collides with devastation from the death of your other child, it causes guilt for smiling. Laughter is followed by tears, not the kind of welcomed tears from a belly laugh, but tears from the remnants of a broken heart and ultimately experiencing a sense of sadness every single day, even when feeling happy. It's a complex journey.

I remember the early days following the accident. Amid the chaos, and despite the unknowns, my husband and I joined hands and hearts asking God to give us the physical and emotional strength to make whatever sacrifices necessary to ensure that we were by Steven's side providing security and support, all while doing everything humanly possible to keep Aaron's memory alive.

As we approach five years since the knock on our door, we are thankful that Steven doesn't let his TBI define him. We proudly watch as he sets, pursues, and achieves goals. TBI is an invisible disability; it can be very lonely if people are unwilling to get out of their comfort zone, become educated, and just show up. We are thankful for those that see beyond Steven's TBI and have the privilege of being exposed to his positive outlook on life. He possesses a *never-give-up* attitude and an infectious smile that reminds me of his brother.

Each day my heart experiences a tidal wave of emotions that threaten to sweep me off my feet. By the grace of God, I stay grounded, always asking myself two life-sustaining questions:

What would Aaron want me to do? What does Steven need?

I choose to believe that Steven needs and deserves the same mom he and his brother have always known, a mom who offers unconditional love, puts family first, forgives freely and never gives up. I know this is what Aaron would want.

Life goes on with traumatic brain injuries, with the loss of loved ones, with broken hearts, and unanswered questions. I am committed to remaining by Steven's side as he continues healing both physically and emotionally, and I will speak Aaron's name daily to keep his memory alive. I will continue to travel this path that was paved for me with grace and faith, trusting in strength that comes from God who so graciously restores my depleted strength daily.

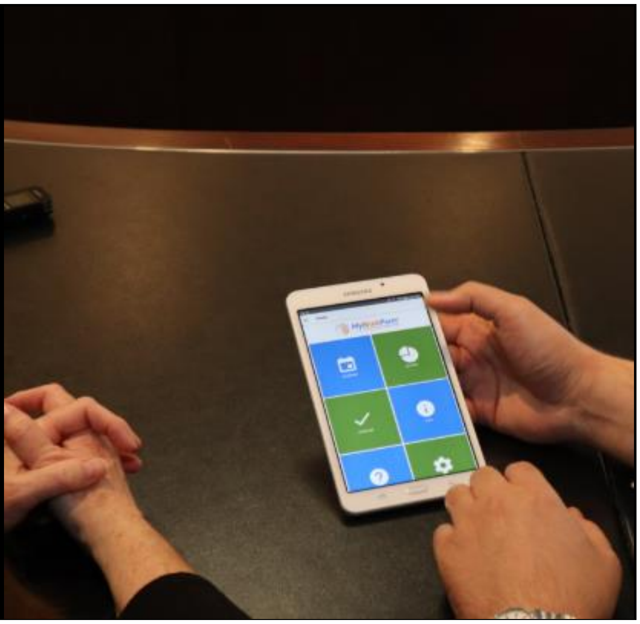
Meet Norma Myers

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.

The MyBrainPacer App - A Real Game Changer

By Rob Staffen



It’s proven to be a game changer for me and my family. It’s called MyBrainPacer, an innovative new app from St. Joseph’s Health Care, London, Ontario, Canada. It was launched mid-February of this year.

As we know, when a person experiences a concussion or brain injury, it can be difficult to return to their normal routine. If they push themselves too hard, they can make their symptoms worse. But if they don’t do enough, it can delay their recovery. Becky Moran, an occupational therapist at the Parkwood Institute (St. Joseph’s Hospital-London, ON) Acquired Brain Injury Program, developed a system to help her patients by assigning points to day-to-day tasks (e.g., grocery shopping, driving, reading and exercise) based on difficulty, energy required, and symptoms triggered.

As we know, when a person experiences a concussion or brain injury, it can be difficult to return to their normal routine.

By working toward personal quotas, patients can understand their limitations and gain control of their recovery. Individual users are given a total number of points per day that will keep their symptoms in the “safe range” and are encouraged to increase their points as their recovery progresses.

With the generous support of community donors like the Cowan Family (Insurance) Foundation and other community supporters through St. Joseph's Health Care Foundation, the points system has evolved into the MyBrainPacer app (Concussion recovery points planner). Moving from paper to an app allows patients to self-monitor their recovery on the go. Developing the app required strong partnerships and a dedicated project team of St. Joseph’s researchers, therapists, IT experts, patients and donors.

The concept, based on St. Joseph's Pacing and Planning Program, has helped hundreds of St. Joseph's rehabilitation patients achieve their recovery goals.

Seriously Injured in 2012

It's been almost 9 years since I was in an accident that would change my life forever; cycling down a mountain near Palm Springs, California in October 2012 when suddenly my road bike malfunctioned, catapulting me head-first into the rock-strewn desert landscape. The impact to his skull resulted in a severe traumatic brain injury.

A concussion is a brain injury caused by a hit to the head or body that forces the brain to move back and forth inside the skull. Known as an invisible injury, a concussion can affect a person's physical, mental, behavioral and/or emotional health. While 80 percent of people recover from a concussion, 20 percent have persistent symptoms that can develop or worsen over time. Too often after a concussion people either stop activity all together, delaying recovery or push themselves doing too much too quickly -- intensifying their concussion symptoms.

Helping Patients Live Full Lives

On a personal note, I credit the lessons learned as a patient at The Parkwood Institute with helping me get my life back on track. "Without the team at The Parkwood Institute, I'm pretty sure I wouldn't be where I am today." "The tools they provided helped me balance my life, so I can stay active but keep my symptoms under control by resting when I need to.

"With their guidance, I was able to return to work and resume my passion for road biking. In 2018 friends of mine including my son Matt climbed the Mountains of the Tour de France including the two famous Mountains, Alpe d'Huez and Mont Ventoux. I'm not totally recovered, but I can do the things I love -- I just have to know my limits, which is perfectly okay."

The MyBrainPacer has been almost fully funded by the Brain and Mind Matters (BAMM) Community Fund (their family charity) https://stmarysgolf.com/pages/brain-mind-matters, the Stratford Perth Community Foundation (SPCF), the Cowan Foundation, and Siskinds Law Firm in London, ON.

A toolkit of resources

MyBrainPacer™ is part of a toolkit of resources St. Joseph's ABI team has created to help concussion patients self-manage their condition and the app is FREE!. The resources also include a series of Concussion Care videos, an audio playlist of mindfulness exercises, and tools to aid recovery for common concussion symptoms like visual disturbances, noise sensitivity and balance issues.

The Concussion Care video series is the brainchild of former patient Jill Wright. She suffered a concussion after hitting her head on a granite countertop and her persistent symptoms affected every aspect of her life. Wright found it difficult to find timely access to resources and support in the community to help her manage. She wanted to use her personal experience, combined with her professional background in creating educational resources and philanthropic connections through the London Community Foundation's Making A Difference family fund, to improve concussion care for others. The videos include tips and tricks from the health care team from St. Joseph's ABI Program and testimonials of lived experience from patients.

MyBrainPacer, meanwhile, is available to the public to use for free. It will also be marketed to physicians and care providers as a resource for their patients. In turn, users will be invited to participate anonymously in ongoing research so that St. Joseph's can continue to test, revise and optimize the app.

All of the tools, including the app, are posted to St Joseph's Parkwood Institute public website: https://www.sjhc.london.on.ca/regional-acquired-brain-injury-outpatient-program/information-patients

Meet Rob Staffen

Four years ago, Rob Staffen fell off his bike at the Joshua Tree National Park in California at high speed and suffered a traumatic brain injury. Since that time the family has been working hard to support Rob and also to help break down the barriers and stigma associated with these types of illnesses. Back in 2013 the family established the Brain & Mind Matters (BAMM) Community Fund at the Stratford Perth Community Foundation (SPCF) to provide a lasting funding resource for outpatient care focused on local brain injury and mental health programs and projects.

News & Views

By David & Sarah Grant

The last month or so has felt like one long exhale as life begins to look a lot like it did before the pandemic took hold fifteen months ago. Schools and retail stores are opening up, social gatherings are resuming, and on the surface, life is starting to look normal again.

While that me be the case for a lot of what defines normal, there is an unseen challenge that many will face moving forward – mental and emotional struggles that have been exacerbated by the societal trauma that we've all lived with since early 2020.

Even for the healthiest of us, it's not possible to live through times like these and not be affected in some way. Recovery from the pandemic will most likely be defined in years, and not days or even months.

As we continue to move forward, we encourage you to keep a close eye on those you love. Very much like brain injury, while things may appear to be okay on the surface, looks can indeed be deceiving.

If you, or someone you love, needs help, we encourage you to not try to go it alone.

Allow yourself time to heal.

-David & Sarah