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Brain Injury Journey - Hope, Help, Healing helps persons with brain injury, families, and providers successfully navigate challenges and live a full and satisfying life. We offer empowering personal stories, interviews with experts, and clinical updates and research findings. Above all, we provide a community to enhance hope and foster healing after brain trauma or disease.

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From the Editor
by Barbara Stahura, CJF

Chicken Soup for the Soul: Recovering from Traumatic Brain Injuries (http://tinyurl.com/m2nssoon) has been released, and I’m proud to say that stories from a number of our writers here at Brain Injury Journey have been included. Of course I knew that all of our writers—people living with brain injury, family members, or providers—were terrific writers. But their poignant, heartfelt accounts in this new book touched me deeply and made me even prouder to be working with them. Their stories offer hope and inspiration to the thousands of people who will read this book. Although brain injury greatly changed their lives, they are determined to live the best lives they can, often by being of service to others in the brain injury community.

So congratulations go to David Grant, Rosemary Rawlins, Mike Strand, and Carolyn Roy-Bornstein (also one of the book’s editors). I have a feeling that they all shared a common experience while writing about such a painful, confusing subject. Carolyn expressed that experience very well in one of her stories: “…the writing was actually therapeutic after all. It gave me the opportunity to exert some control over a completely senseless situation…I could not change the outcome [her son’s traumatic brain injury at the hands of a careless driver], but I could try to make something positive out of it, by sharing the experience with others, by giving readers a more nuanced understanding of brain injury…”

Which is exactly our goal at Brain Injury Journey Magazine.

Letter from Lash & Associates
by Marilyn Lash, MSW

Hope is the theme of this issue—and it is the universal message of families and survivors of brain injuries. You’ve heard those sayings, like “light at the end of the tunnel…darkest before dawn…hope springs eternal.” While we hear these phrases so often they may seem trite, it’s easy to overlook how essential hope is when faced with the crisis of injury.

Very simply, hope is the wish or desire that something will get better. What that “thing” is differs for each individual. Hope is both universal and highly personal. It has no timetable, delivery date, measurement, or price tag. While it may be dampened or threatened by external factors such as medical tests, finances, or resources, hope is an internal force that comes from an individual’s core beliefs and desires. Hope is literally and figuratively the “candle that lights the darkness.”

The statement that I have most often heard is, “Let me hold on to hope. It’s what gets me through each day.” It’s a reminder that without hope, the present and future can be bleak. Those of us who work in clinical or professional roles must always be aware that respect for the hopes of families, survivors, and caregivers is essential. It is too easy to dismiss hope as “denial” or “unrealistic.” Too often we hear accounts by individuals who were told they would never (fill in the blank). By acknowledging and respecting the importance of hope at every stage of the brain injury journey, we recognize the power of the human spirit.

I raise my glass in a toast to HOPE!
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The Dignity of Risk:  
A Family Perspective with Pia Pearce

by Rosemary Rawlins

In the summer of 2013, Hugh and I sat together on our sofa and watched a documentary called The Crash Reel about snowboarding Olympic hopeful Kevin Pearce, who suffered a traumatic brain injury (TBI) in 2009 while training for the Vancouver Olympics. Kevin was at the top of his game when he almost died after crashing face first on the icy half pipe while practicing a difficult maneuver. By the end of the film, we both sat in amazement, at Kevin, his family, and how much their feelings matched our own.

“Look what I put you through,” Hugh said. “This is the closest I’ve come to really understanding what you and the girls have been through.” Hugh related to Kevin and his desire to return to snowboarding while I identified with Pia, Kevin’s mother. I recently had the chance to talk with her about Kevin’s injury and how she balanced her maternal instinct to protect her son with his desire to snowboard again.

“I realized the better he got, the more capable he became.”

Pia and her husband, Simon, have four sons; Kevin is the youngest. They are a close family who banded together after the accident and experienced a groundswell of support.

Back on the Snowboard

Three months post-injury, Kevin watched the Olympics on television and said he wanted to return to snowboarding. In the film, he says, “Snowboarding is my true love.” He’s determined to get back to it, even while his whole family is struggling emotionally and trying to convince him to reconsider. In one scene, the family is seated around their large table discussing Kevin’s desire to snowboard. Kevin’s brother David says, “I just don’t want you to die.” You can see this heart-rending statement settle right on Kevin’s heart in the silent heaviness that follows.

I asked Pia about those intimate family dinners. “Those dinners often gave us the ability to talk at a deeper level,” she said. “Kevin’s brother Adam told me, ‘You know, Mom, we need to be extra good with our communication about this because we will disagree on things,’ and he was right. We did not shy away from difficult discussions.”

My husband, Hugh, was injured in a car vs. bike accident, and he wanted to return to cycling after his brain injury. The thought of it made me sick, but Hugh insisted that it was the only way he’d feel like himself again. I wanted rules: no riding alone, no more racing. I laughed when Pia said, “Rules never worked in my house with four boys. If I said ‘you can’t,’ that would certainly guarantee that they would! Families can create conflict if they take it all on by themselves. Instead, I enlisted the help of doctors.” Pia said that Kevin’s doctors helped by explaining the risks to Kevin.

She also talked about how difficult this was due to Kevin’s lack of insight and self-awareness. Brain injury can affect a person’s ability to see his or her own limitations, and it affects impulsivity. These two things...
combined can lead to poor judgment and risky behavior.

Pia’s strategy was to have Kevin come to his own decisions armed with as much information as possible. Instead of rules, she chose guidance, and hoped that Kevin would make good decisions.

IMPORTANT INFLUENCES

His family and time would help Kevin realize how risky returning to snowboarding could be. “Kevin’s accident affected every member of his family deeply, yet Kevin had no concept of what everybody else was going through for a long while,” said Pia.

It took over a year for Kevin to really understand how detrimental a second brain injury could be. His brother David, who has Down syndrome, was able to relate to Kevin in a way no one else could by sharing his feelings about dealing with limitations in his own life.

Kevin was fortunate to keep his friendships going, too. When friends understand exactly what is happening with brain injury, they usually help out. “Kevin’s friends understood that drinking, smoking, and staying out too late were not good for Kevin, and they were supportive,” Pia said. “Many times it’s up to families to help friends be good friends by explaining why these precautions are in place.”

COPING

Pia appears a calm, serene person in the film, but there’s one scene where she clearly looks devastated as Kevin insists he wants to snowboard. “How did you cope with your fear?” I asked her.

“I try to be a calm person and do exactly what I preach—eat a healthy diet, exercise, get outside, take care of others, and take care of myself. And I keep perspective. I have so much to be grateful for.” Pia rides a bike for cardio, weight trains, and loves Pilates. She also acknowledges that she has a huge extended family and network of friends, which helps immensely.

THE DIGNITY OF RISK

Pia and I both agreed that while sports can be dangerous, life is dangerous, too. You can sustain a brain injury doing ordinary things. There has to be a balance. “Kevin has to have a life that feels like a life worth living,” she said.

“Dignity of Risk” means respecting every individual’s right to self-determination. Balancing this concept with solid information and reasoning is the approach the Pearce family followed. Pia believes in erring on the side of caution rather than risk, but she acknowledges that Kevin is an adult and has the right to make his own decisions.

Kevin returned to the mountain on his snowboard with his brothers and friends for the first time in Colorado, two years after his injury. Pia remained at the bottom of the hill and admits to crying, alone. “I wanted him to have that time with his friends. It was all about Kevin.” While he still loves to snowboard, he no longer competes.

GOING FORWARD

Kevin has made remarkable strides, and his documentary is touching millions. Pia is proud of the way he is helping others, and it has become a family affair. “We’ve always supported Special Olympics and now we all support the TBI community, too.”

The Crash Reel clearly demonstrates that brain injury is a family injury, and Pia will tell you, it ultimately speaks to the resilience of the human brain. When I asked her, “What do you want people to take away from the film?” she answered, “So many things, but I guess the most important thing is that anything is possible.”

Rosemary Rawlins is the author of Learning by Accident: A Caregiver’s True Story of Fear, Family, and Hope. She is a regular blogger for BrainLine.org and speaks nationally on caregiving topics. Learn more at http://www.rosemaryrawlins.com
A BRAIN WITHOUT OXYGEN: HYPOXIC-ANOXIC INJURY

by Janet Cromer, RN, MA, LMHC

Traumatic brain injury (TBI) has received increased attention in the media, military, medicine, schools, and sports. This has resulted in more awareness, research funding, and treatment approaches. However, there is another category of acquired brain injury that affects thousands of adults and children annually, yet generates much less attention and specialized treatment. That is hypoxic-anoxic brain injury (HAI). This occurs when the brain does not receive enough oxygen and vital functions are impacted.

AUDREY’S STORY

Audrey was in her office when she felt a crushing pain across her chest. Before she could call for help, she lost consciousness and dropped to the floor. Audrey’s startled colleague, Warren, couldn’t feel her pulse, so he called 911 and started cardiopulmonary resuscitation (CPR). Moments later Audrey was rushed into the emergency department as the paramedic called, “Cardiac arrest, down ten minutes, no response.” Doctors and nurses swung into the controlled chaos of CPR, yelling, “Everybody off!” as the defibrillator restored Audrey’s heart to a feeble rhythm. Twenty-five minutes after her heart stopped, Audrey came back to life.

The cardiologist gathered Audrey’s crying family and said, “Audrey had a severe heart attack (myocardial infarction). Her heart stopped, and her brain did not get enough oxygen for a long time. Our plan is to treat Audrey with therapeutic hypothermia. We’ll cool her body down for several hours because that seems to improve survival and neurologic outcomes after cardiac arrest.” The next priority was to find the cause of the heart attack, followed by treatment to repair her heart.

Audrey’s family knew that brain cells start to die in just minutes without oxygen. What challenges would Audrey face when she awakened from the coma? Then they met with a solemn-faced neurologist. “I’m afraid that Audrey has a hypoxic-ischemic brain injury,” he said. “That’s a type of injury that happens when the body can’t provide enough oxygen-rich blood to reach the brain, circulate, and perfuse critical areas. We see this when patients have heart attacks, strokes, or cardiac arrhythmias. Eventually Audrey will require brain injury rehabilitation to regain skills and functioning.”

To diagnose the extent of the damage, Audrey underwent MRI, CT scan, EEG (electroencephalogram), and an evoked potentials test to measure her response to stimuli.

WHAT IS HYPOXIC-ANOXIC BRAIN INJURY?

Audrey’s family started reading about hypoxic-anoxic injury and attending a support group. They learned that the brain consumes about one-fifth of the body’s oxygen supply. The brain needs energy to send electrochemical impulses between cells and to maintain the ability of neurons to receive and respond to signals. It only takes a few minutes of oxygen deprivation before cells start to die, and a cascade of problems results. One problem is the disruption of neurotransmitters, which regulate many cognitive, physiological, and emotional processes. Another problem is that inflammation, the release of toxic chemicals, and disruption of metabolism also cause damage.

HAI can be caused by many disease processes and injuries and is divided into types based on the specific mechanisms causing the injuries. Audrey sustained the most common type, which is hypoxic-ischemic brain injury (H-I BI). Other causes include respiratory arrest, anesthesia and obstetric accidents, cardiovascular disease, chest trauma, near-drowning, and airway obstruction. Carbon monoxide poisoning, certain poisons, and severe hemorrhage can contribute to HAI.

Audrey’s husband asked, “How is HAI different than traumatic brain injury?” TBI tends to cause more localized damage in the area where the person was struck or absorbed the force of a blast injury. In contrast, HAI tends to cause more diffuse injury in many areas. This can make it difficult for adjacent brain areas to compensate for the injured area.

Mel Glenn, MD, Director of Outpatient and Community Rehabilitation at Spaulding Rehabilitation
Hospital, explains that the presentation can vary, but some of the most vulnerable areas affected are those with the most tenuous blood supply or the highest metabolism. These include the basal ganglia (causing movement disorders, cognitive impairment), the hippocampus (causing deficiency in the ability to lay down new memories), the occipital cortex (causing cortical blindness), and the cerebellum (causing incoordination and intention tremor). The cerebral cortex can be diffusely affected, resulting in cognitive and motor impairments.

**AUDREY’S JOURNEY**

In a few weeks, Audrey was transferred to a brain injury rehabilitation unit. The initial evaluation showed that she had trouble walking. Uncoordinated arm movements made it hard to dress herself. She couldn’t remember her past or today’s events. Her family was shocked when the speech-language pathologist said that Audrey could not read, or write her name.

The neuropsychology evaluation concluded that Audrey had the most common HAI cognitive impairments. Her deficits included impaired attention, slowed processing speed, memory impairment, and problems planning and carrying through on tasks. She also had problems remembering and understanding words (anomia). Her family noticed personality changes, agitation, and depression, which improved with behavioral strategies and medications.

Over months of rehabilitation, Audrey regained some essential skills. She read and wrote at a third grade level. She learned new strategies by doing procedural and self-care activities over and over. She enjoyed walking in the park and singing Broadway show tunes. Her family built on her strengths, while grieving the losses and helping Audrey build a new identity.

Innovative research is being done to understand the complex mechanisms underlying HAI and to target treatment and rehabilitation to the specific needs of HAI patients and families. We all need to advocate for national surveillance, more funding for research, and comprehensive treatment programs.

**TIPS FOR CAREGIVERS**

- Ask about the cause, type, and severity of your family member’s brain injury. Specific information might help with prioritizing treatments.
- Request an evaluation by a neuropsychologist and a rehabilitation specialist as soon as possible. Explore all options for meaningful rehabilitation.
- Adaptation, or recovery, often takes a long time. Build a support network for the survivor and family early. Bring in new sources of hope, education, advocacy, and healing often.
- Seek physical, cognitive, and vocational rehabilitation from a variety of providers. Try TBI services, as well as local and state disability programs.

**HOW MANY PEOPLE HAVE HAI?**

No one really knows. While TBI registries track how many people are diagnosed with TBI annually and their care, there is no similar program for HAI. Because HAI is usually the consequence of a medical illness or accident, it is not viewed as a separate injury. This means that HAI may not be coded in insurance and public health surveillance as a distinctive diagnosis.

David Arciniegas, MD, Senior Scientist and Medical Director for Brain Injury Research at TIRR Memorial Hermann, estimates that up to 85,000 people survive cardiac arrest with a significant brain injury each year. That’s just the beginning of estimating the impact of HAI from many causes.

**RESOURCES**


NINDS Cerebral Hypoxia information [http://tinyurl.com/9vw7](http://tinyurl.com/9vw7)

NeuroRehabilitation. Vol 26, Number 1, 2010.

Therapeutic hypothermia [http://tinyurl.com/7yde7](http://tinyurl.com/7yde7)

*Janet Cromer, RN, MA, LMHC is a psychiatric RN and author of Professor Cromer Learns to Read: A Couple’s New Life after Brain Injury. She is a national speaker on stress resilience. [www.janetcromer.com](http://www.janetcromer.com)*

The brain needs energy to transmit electrochemical impulses between cells, and to maintain the ability of neurons to receive and respond to these signals. It only takes a few minutes of oxygen deprivation before cells start to die.
Acceptance is not defeat. It is where you begin

By Janelle Breese Biagioni

Motivational speaker Tom Krause said, “When life knocks you down, you have two choices—stay down or get up.” That is easier said than done, especially when something catastrophic happens and causes significant life changes. You can’t say, “It’s done and get on with it.” Life, tragedy, and healing don’t work that way.

A brain injury isn’t something a person intended to happen or planned for. When the injury occurs, it is without choice or negotiation. Once it has happened, there is no turning back. As we know, a brain injury brings about significant changes for not only the person but also for the family. The person living with the brain injury is often not the same, and he or she and the family have to adjust to personality changes, a shift in family roles and responsibilities, and lifestyle changes.

Many clients I work with—and certainly this was our family’s experience as well—are told to “accept” what has happened and get on with life. Again, this is easier said than done. The person giving the advice is implying that by coming to terms with what has happened, one can move on. The people receiving the advice on the other side, however, see acceptance as defeat. For them, acceptance brings resignation. “I have to accept where I am at… nothing will change… I will not get better… I can’t get to where I was pre-injury….” Many clients and families I work with feel that by accepting the situation they are resigning themselves to a life they did not ask for and don’t want. And that feels hopeless.

Acceptance is not defeat. Acceptance is yes, examining life as it is today, in the moment, but it is also where you begin to make a plan and implement change. Acceptance is empowerment. Defeat, on the other hand, is where one is blocked from achieving an aim or goal. It is resignation, and it disempowers people. Acceptance brings relief because it acknowledges where you are and helps you to determine what you have control over and what you don’t have control over. It does require examining every area of your life (such as relationships, personal growth, finances, lifestyle, etc.), which demands honesty as to the state of these areas. But once you have awareness of where things really are, then you can decide where you want to go.

Clarity requires honesty

By examining life, whether you are the person living with the brain injury or a family member, you gain clarity and perspective on the situation. This, however, requires you to be honest with what you contributed or didn’t contribute to the circumstances. For example, if you determine that you need to lose weight, you must be honest about the amounts and types of food you eat, when you eat, and how often you eat. These are things that you can control. If you are built with a large frame and everyone in your family has a large frame, then you cannot control that. You can’t shrink your bones to a petite frame, but you can still strive to be a healthy weight. Gaining clarity and perspective can be achieved through:

- Journaling – Write about the situation including how it used to be, how it is now, and how you want it to be.
- Feedback – Ask others for feedback on the situation and perhaps your behavior. This requires you to be prepared to receive some honest opinions.
- Try on another view – Tell the story out loud (or write about it) from another point of view. Try the point of view from someone else in the family. Or take on the point of view of you in the future. This is fun because you talk (actually make up) how you achieved what you did and gain tremendous insight on how to make something change or happen.
Once you have clarity, assess what you can control and change what you cannot. For the things you can change, make a plan, break down the steps you need to take, and start taking action—every day. For the things you cannot change or control, either change your perspective about it or let it go. Often, the things we need to let go of include unrealistic goals or dreams, unhealthy relationships, and emotions that keep us stuck. This often requires forgiveness.

**THE HEART WORK OF FORGIVENESS**

 Forgiveness is not about letting the person responsible for a situation or action off the hook for what he or she did. Forgiveness is about no longer allowing yourself to be the vessel carrying the poison. It is about turning your attention elsewhere and not allowing negative thoughts and feelings to take up head or heart space in your life any longer.

This work certainly brings up many emotions and feelings. It’s important to pace yourself so that you don’t jump into an “ocean of emotion.” This means that you set the tone for doing the work (such as quiet, uninterrupted time) and self-care (like someone to debrief with, taking a nap or a walk, enjoying a soothing soak in the tub).

I don’t want to imply this is easy and straightforward. It isn’t. This is heart work and it’s hard. It is not uncommon for people to feel discouraged or angry that they have to do the work. When you feel discouraged, you need to give yourself a pep talk by acknowledging that discouragement is a way of keeping you stuck where you are. It’s trying to pull you into defeat, and it is a negative energy. Anger is a common, normal response in loss; it’s what you do with the anger that is important. If anger comes up for you in the work, then acknowledge it and find a way to safely express and release it. If you don’t, it too will hold you in a negative place.

**ASKING FOR HELP**

An important part of coming to acceptance is asking for help. This is not weak, nor does it mean you are doing any of this wrong. There are things only you can do, but having to decipher, sort through it all, and develop a plan are not necessarily things you need to do on your own. The other reason to ask for help is that the people helping you are not immersed in your pain. This gives them a different perspective, and therefore they can help you to flesh out ideas of where you want to go and how and what you need to get there.

Acceptance is important because it brings freedom and empowers you to move forward. In accepting your situation, you are taking personal responsibility for your life and regaining control. When you have control and feel empowered, you open the door of endless possibility to welcome new and meaningful activities and relationships in your life. The more you have of these two elements in life, the more joyful you will feel. The more joyful you feel, the more of these opportunities you will attract. It begins a cycle of positivity and creates a healthy wholeness in life—and nobody deserves it more than you!

**Janelle Breese, RPC, is an author, speaker, and counselor with expertise in grief, loss, life transitions, and brain injury. She resides with her family in Victoria, BC. She is the author of A Change of Mind: One Family’s Journey through Brain Injury and the upcoming book, Life Losses: Healing for a Broken Heart. Visit her website at www.janellebb.com and follow her on Facebook at www.Facebook.com/JanelleBreeseBiagioni. She can be contacted at Janelle@janellebb.com**

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Two people sustain similar brain injuries. One person flies through rehab. He continually moves forward—working hard, asking for the next exercise and the next step—so much so the rehab clinicians have to rein him in on occasion. It’s inspiring to see. Meanwhile, his counterpart has a terrible time. Empathy notwithstanding, she needs extensive support to get the day started, let alone participate in rehab on a consistent basis. There are just as many steps backwards as there are forward. We see this often in rehab: people repeatedly struggle for the lack of—and, conversely, thrive because of—hope.

WHAT’S HOPE GOT TO DO WITH IT?

Hope is more than just wishing, it’s more than a presidential campaign platform, and it’s more than the metaphorical lift one gets from Emily Dickinson’s poetic description of hope, “the thing with feathers.” When you peel away the layers, you see how hope is defined in the scientific literature and why it’s crucial.

Hope has three parts. The first is goals. Goals are the dreams and aspirations that we imagine and desire. Goals range from learning how to make an omelette to learning how to walk again. The second component is what’s called the “will power.” It’s the motivational component in hopeful thinking. It’s the belief you have in your ability to reach a goal. Some examples of “will power thinking” are “I can do this” and “I am not going to be stopped.” The third component is called “way power.” This is the cognitive component. It’s that skill whereby you develop step-by-step instructions, paths, or workable routes to your goals. An important part of way power is having flexibility and preparedness for roadblocks and detours. With wishing you get hope, but with hope you get wishing with a goal, and you add the ways to achieve that goal, plus the effort to close the loop to take you from here to there.

We know the importance of hope, but can it be taught or enhanced? Yes! The repertoire of hope interventions is rapidly growing. People with brain injuries and professionals alike can learn to develop a hopeful mindset and reap the benefits of hope-fostering strategies.

THREE STRATEGIES TO FOSTER HOPE

Hopeful stories surround and inspire us. They paint a picture we can all resonate with and draw strength from. There are many user-friendly technologies at our disposal. From smartphones and tablets to blogs and social media, we can both consume and produce hopeful stories on a daily basis. Practicing reading and watching as well as producing and writing hopeful stories have been shown to increase what is deemed a hopeful mindset.

Brainworks’ “Finding the Silver Lining” technique is a simple yet powerful strategy. It’s not about minimizing the trauma, loss, or challenge, but rather moving forward from it. Finding one genuinely positive component of a difficult situation strengthens a hopeful mindset.

Here are two examples of this strategy in practice to illustrate its usefulness:

• Learning to use a smartphone as a memory aid? Find the silver lining: the tech skills you are learning will rival the modern teenager.

• Changing your vocation? Find the silver lining: you are learning new skills and you will learn much about yourself, particularly your resilience. Realizing you have resilience is a powerful component of a hopeful mindset—an ally for years to come.

One of the most important aspects of hope is to look forward, to the future, towards the goals you want to achieve with the skills you are mastering to achieve those goals.
you up for thriving as you work toward a more hopeful future.

Brainworks’ “Don’t Look Back - You’re Not Going That Way” is an effective strategy that with practice can curb those negative thoughts and help you to turn towards the future, towards the goals you are working on now. An example of the exercise: Notice yourself thinking about the past or talking about the past in a negative way; when you do, intervene with the script, “Don’t look back, you’re not going that way.” Put away the negative thoughts and replace them with a hopeful script: “You are looking forward; forward progress only.”

A practical and specific example might look like this: “I used to play ice hockey. I hate that I can’t play anymore.” When it gets turned around it can sound like this: “I can still enjoy watching hockey. Now I get to have fun with a little golf and I am learning some woodworking. I look forward to making a table with my own hands.” There is a crucial difference between dwelling on the past, learning from it, and ultimately moving forward with lessons learned. Practicing viewing rehab and life in general through a future-oriented and hopeful lens has been shown to be crucial towards developing that hopeful mindset.

**Hope is real, a choice, and can be learned**

When you choose hope, the ripples start from within and spread in every direction. From the heart to the home, from the classroom to the boardroom, hope matters. Rehab gets transformed from something you survive to something you thrive in. Hope won’t give you feathers nor will it make you fly, but it does make reaching for the stars a reality. As Christopher Reeve said, “When you choose hope, anything is possible.”

References can be found at [http://www.brainworksrehab.com/hopetherapy/hopetherapy-references/](http://www.brainworksrehab.com/hopetherapy/hopetherapy-references/)

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**My Reality**

By Matthew J. Brown

Hands grow cold
Skin prickles
As I feel the first bit of adrenaline
Starting to take hold

A thin sheet of sweat
Begins to veil my face
Breath quickening
  Short
  Ragged
  Staccato

It is happening
Fight or flight
Full bore
Nothing to stop it now
My body reacting

A car backfiring
Has my mind struggling
Teetering on the edge of panic
Wrestling with reality

All rational thought
Is thrown out
Once the panic sets in
Knowing the real answer
Knowing the truth

There is no threat
No gunman
But this is my life now
A guarded life
A life with PTSD

Lance Corporal Matthew J Brown USMC RET is an aspiring military author who has overcome many of the struggles of living daily life with PTSD and a traumatic brain injury and now has made it his life goal to help others through these same struggles with his writing.
A DREAM OF DRIVING

by Barbara Stahura

Teenager Chris Cochran loved to drive. For years before he got his license, he imagined himself behind the wheel, skillful, free, independent. When his parents, Terry and Monica Cochran, delivered the news that they would not buy him a car, he immediately began saving. He bought his first car, a Honda CRX, on his sixteenth birthday, license in hand. He couldn’t actually drive a stick shift yet—but with lessons from his dad, he became proficient in a day.

But an accident in a frigid Michigan winter put an abrupt halt to Chris’s driving and many other aspects of his life. He slid on black ice while driving his beloved Honda and sustained a severe traumatic brain injury at age 17. He had five surgeries while in a ten-day coma. After later being released from the hospital, he spent five months in in-patient rehab. With full left-side hemiplegia (one-sided paralysis), he came home on Memorial Day 1997, where his parents had installed a hospital bed for him. Intensive outpatient rehab came next, and he has continued to improve over the last 17 years with various kinds of therapy.

Living with his parents, Chris still has challenges with speech and walking, and he will soon graduate from the University of Phoenix. His parents have always done whatever they could to support his improvement, with the ultimate goal of Chris living as independently as possible. “One thread we heard through all these years,” says Terry, “was the medical model of looking at deficits and fixing them. But we look at Chris’s strengths and use them as a platform for the next step.”

THE NEXT STEP

In 2013, the next step was driving. Chris had undergone a driver rehabilitation evaluation in 2005. While Chris believed he had done well, “the evaluator said it was the scariest check ride she had ever done,” says Terry. In late summer of 2013, Chris had 18 sessions in the driving simulator at the University of Virginia. This test showed that he could control a simulated vehicle, but he needed to be evaluated on the road, in a safe environment.

After being turned down by driving schools around the country, Terry contacted Willow Springs Raceway in Rosamond, California. Willow Springs personnel recommended he contact Rick Seaman, one of the country’s top stunt drivers, who runs his driving school there. Rick was eager to help, with 40 years’ experience teaching Hollywood stunt drivers, security professionals, and, he says, “500 problematic teen drivers.” But he wanted to do more. As a Vietnam veteran who had sustained a brain injury there, and with “a few dozen minor concussions” in his stunt work, Rick thought Chris’s driving clinic could be a springboard to a larger program.

He is a board member of the National Veterans Foundation (http://www.nvf.org), of which his friend Shad Meshad is founder and president. Among other activities, the NVF counsels and assists veterans with brain injury and PTSD. Shad, a therapist who also sustained a brain injury in Vietnam, was enthusiastic about the possibilities of a driving program for veterans of recent wars who are unable to drive because of brain injury. “I’ve seen so many miracles in my life with vets,” he says, “and I know how Rick teaches. It’s doable.” Shad agreed to attend the driving clinic, in case a therapist was needed.

They added another element to the project: telling Chris’s story on film as a documentary, which would publicize it and help raise funds. Producer Julie Michaels has volunteered over the years to work with injured veterans, and she eagerly joined the team. Chris approved the making of the film not because it would focus on him but because “it would be helping others,” he says.

With the film crew, several of Rick’s top stunt drivers, and photographer Denise Duff on hand to take still photos, the project got underway this past December in the high desert of Southern California. Everyone who gathered at Willow Springs for the project donated their time.
THREE DAYS OF PRACTICE

The frigid weather at the raceway could not cool the team’s enthusiasm. Rick chose a track with a broad tarmac and several miles of straightaways and loops covering rolling hills and flats. He began the training with easy maneuvers such as driving straight ahead and then stopping at a marked location. Next came practicing turns, followed by more aggressive starts and harder braking. Despite the 17 year gap since he had last driven a car, Chris quickly proved able to handle the basic maneuvers.

Tired at the end of the first day, Chris let the car, already beat up from stunt practice, roll into a wall with a crunch. Disappointed in himself, he was nevertheless happy with his progress. He had done well, all things considered, yet Rick was concerned that Chris had trouble returning to the starting place, remembering routines, and paying attention to stop triggers. However, he noticed that Chris did better when they moved on to a course that was more challenging—that is, fun.

Over two more days, Rick continued to lead Chris through increasingly difficult tasks, including driving with other cars, driven by the stuntmen, on the course. When Chris seemed unable to handle some basic tasks, Rick reminded him that they would be included in a driving test. Taking the message to heart, Chris improved.

He also found a surprising way to make up for his slight crash of the first day. On day two, Rick instructed him to stop on the tarmac about 20 feet from a wall, in front of which Terry stood. But Chris kept slowly moving forward, seemingly ignoring Rick’s instructions of “Let’s stop now. Let’s not hit the wall. Let’s not hit Dad!”

Terry fled from the path of the car. But just as Rick was about to hit the car’s kill switch, Chris grinned and stopped smoothly, only three feet from the wall. “He was going to ignore my alarm and show me and Dad that he could do it without crashing,” says Rick. “That was huge!”

At the end of the third and last day of the driving clinic, Rick presented Chris with a treat: learning how to perform 180-degree spins, powering up from the starting place and fishtailing around a barrel. With just a few minutes of instruction, Chris was driving the 180s “just like the Hollywood pros,” Rick says. To honor his accomplishments in the driving clinic, the crew presented him with a cap sporting the words “Stuntmen’s Association of Motion Pictures.”

ON THE ROAD AGAIN?

Chris and Terry returned home to wait out the winter. Then in May, Chris got his learner’s permit, and this summer he is working on his driving with an occupational therapist. He may work at the raceway with Rick and crew again or with the driving simulator. Whatever happens, Chris’s desire to drive today remains as strong as it was all those years ago. When asked how he would feel driving once again, he says, “It would bring me so much joy. Insurmountable joy.”

Barbara Stahura, certified journal facilitator, is co-author, along with Susan B. Schuster, MA, CCC-SLP, of After Brain Injury: Telling Your Story, the first journaling book for people with brain injury. Editor of Brain Injury Journey, she presents journaling workshops around the country to people with brain injury, family caregivers, and others, and is a member of the faculty of the Therapeutic Writing Institute and the Lash & Associates speakers bureau. She lives in Indiana with her husband, Ken Willingham, a survivor of TBI. http://www.barbarastahura.com
**Veteran Voices**

**The Ripple Effect of Hope**

by Julia Warton

Many family caregivers struggle under the immense weight of caregiving in isolation. They do not know that any number of good support groups can help them not only cope but learn how to thrive. Hope is a major ingredient of the best of these groups, including those designed for family caregivers of wounded warriors.

Marshele Carter Waddell, founder and president of Hope for the Home Front, began telling her story in 2002 about how her home was profoundly affected by war. “I look back now and see that the bittersweet blessing of writing with honesty and transparency about our family’s journey through the nightmare of combat stress has been God’s hand leading me toward a deeper healing than I could have imagined,” she said. “I have made up my mind not to let combat trauma define my family or my nation. I will not let this journey be the end of my joy.”

While visiting the Vietnam Veterans War Memorial in Washington, D.C., Marshele gained a new perspective. “My reflection was superimposed over and behind and between hundreds of names,” she said. “My life touched theirs and theirs mine from one end of The Wall to the other. Their lives were part of my reflection and therefore a part of me. My daughter and I stood there, the spouse and daughter of a combat veteran, reflected by, swallowed by and sent by The Wall, to give voice to the countless casualties of war that still live.”

For many women who are battling the daily stress of being a caregiver to a wounded warrior, it takes courage to take the risk and attend a support group or a retreat. There are organizations all over the country hosting such events and providing information and support. By sharing the experiences of women who have done this, we hope that others will step forward to make this connection.

Here are a few of those voices.

**Wives of Warriors**

Mari, whose husband suffers with post-traumatic stress disorder (PTSD), traumatic brain injury (TBI), and physical wounds, said, “When I first heard Marshele tell her story, I was truly stunned. I thought we were the only ones struggling with the chaos that is life after war. I felt a huge sense of relief, sadness, and hope all at the same time. It was the first lifeline I had been thrown. Spending a morning listening to another’s story energized me to start fighting for my personal wellness, home, and marriage. It is because of Marshele and so many other women I have connected with since, that I stand firm in knowing that I am not alone and there is always hope.”

Another wife who prefers to share anonymously said, “My husband sustained a head injury and though we understand it, I still can’t say we are ‘used to it.’ The challenges of daily life impact our entire family. I really felt isolated, but being a part of a support group and a bigger story has helped me. I am also benefitting by ‘giving back’ as I support other women by reminding them that microscopic progress is still progress.”

**Mom and Grandmother of a Warrior**

“Ten minutes into the first seminar I felt like I had come home to friends I never knew I had,” said a mom who recently attended a support group retreat. “I craved knowledge about PTSD, TBI, and addiction—all conditions my Marine son returned home with after two tours in

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Afghanistan. I did not realize that my drive for information was being fueled by grief. The retreat gave me an outlet for my tears in a safe environment where people who also grieve for their combat veteran understood me; however, I was not left in despair. This was an unpretentious group of ladies, all battling different, yet similar, situations with regard to their serviceman and the physical, mental, emotional, and spiritual war wounds. I was there as the mom of a wounded warrior, and my mom was there as a grandma. Together we shared the hope that is built on faith and love. I returned home equipped with resources, connections, and I feel inspired to help other women understand, not only the importance of their role in helping their combat-veteran and families heal from the traumas of war, but also their role in perpetuating hope—if we don’t retreat.”

WOUNDED WARRIOR

Hope extends to the warrior, as well. Fernando said, “When I was initially diagnosed with Post Traumatic Stress, it drained the life out of my wife. But I saw a spark in her eyes that had been missing for a long time after she attended a support group retreat. She learned so much and was able to share those educational points with me that not only aided in finding resources for my treatment, but it really opened up my eyes to my wife’s needs. Through the retreats and support groups, my wife has learned to take care of herself, which allows her to be stronger for our family.”

DAUGHTER OF A WARRIOR

Finally, I would like to give voice to the daughters (or children) of wounded warriors. My father served in WW II and like most warriors, he did not talk much about what had happened to him, but there is no question that it was a very harrowing experience. When I was 11, my parents divorced and my father received custody of the minor children. He was in and out of the VA hospital for treatment regularly until he died, so I and my five brothers had to assume responsibilities far beyond our age. I became a caregiver, housekeeper, mother, tutor, cook, and laundress. Resilience is a word I learned to embrace before I could even spell it, and I believe this is true for so many of the children whose parent served and sacrificed in war. My involvement with many families across the country through support groups and retreats has become an opportunity to continue my personal healing journey as well.

OUR STORY

My story, your story, our story… “We’re part of a much larger story, and its theme is hope!” Our vision is to see an army of overcomers—wives, mothers, sisters, grandmothers, and daughters—rise up and bring purpose, strength, and beauty from the ashes of war to hope for the home front.

Julia Warton is Executive Director of Hope for the Home Front (www.hopeforthehomefront.com) a 501(c)3 non-profit organization dedicated to reaching and restoring women connected to combat veterans. She is the daughter of a WW II combat veteran (deceased), the daughter-in-law of a combat veteran who served in Korea and Vietnam (deceased), and the wife of Lt. Col. (USAF Ret) George (Kip) Warton II. They have three sons, two grandchildren, and reside in Colorado Springs.
Brain injury takes so much from an individual that it can be difficult to even consider giving away legal control, or worse, having control forcibly signed away by a judge. But relinquishing some (or all) legal control may be the best option for people who no longer have the ability to make sound decisions, or who need a little extra help to keep their lives running smoothly.

There are many legal actions that can help people with brain injury and their families. The most common are Power of Attorney, Trusts, and Guardianship. Each accomplishes a very specific purpose, but they all have limitations and complications. Over the next few issues, we’ll talk about all these legal protections. This month, we start with a discussion of Power of Attorney.

**POWER OF ATTORNEY**

The simplest of all the legal control documents is called Power of Attorney. It allows you to grant someone the power and authority to act on your behalf in specified financial, legal, or health-related matters. Alternatively, you can give Power of Attorney for all your legal and financial matters.

What makes the Power of Attorney so simple is that courts do not become involved. In fact, in most states you can get sample Statutory Power of Attorney documents online and fill them out for your specific needs (http://www.formsmax.com/power-of-attorney-form.html). It allows you to specify exactly which rights you are allowing another person to sign for—banking transactions, real estate transactions, tax matters, Social Security, and many more.

You can also specify exactly how long the Power of Attorney should last. For example, if you anticipate needing two months to heal from surgery, you can sign a Power of Attorney for exactly those two months.

The only critical requirement for a Power of Attorney is that you must be mentally competent to make this legal decision—a Power of Attorney granted by someone who could be considered incompetent can be challenged in court. For people who cannot make their own decisions, family members can seek to establish a guardianship, which is much harder to attain, has financial checks, and must be administered through the courts. (We’ll discuss the topic of Guardianships in more detail in a future issue of Brain Injury Journey.)

**THE PROCESS OF GETTING A POWER OF ATTORNEY**

The requirements for a legally binding Power of Attorney vary from state to state, so be sure to look up what is needed in your state before proceeding. In general, the process looks like this:

1. Agent. Find a trustworthy person to be your agent (or, as they are legally known, your “attorney-in-fact”). This will be the person who represents you in whatever legal way you designate, so it should be someone who has your best interests at heart.

2. Document. Download a sample Power of Attorney document from the Internet and specify the authority you wish to give to your agent. If your needs aren’t covered by a simple form—if the need is complex, or with a lot of different caveats—or if your state doesn’t allow template forms, then ask an attorney to draft a Power of Attorney specific to your situation.

3. Notary. You and your agent should sign the document in the presence of a notary public, who will sign and seal the document to add an extra layer of validation. While not every state requires a notary, many institutions—especially banks and hospitals—will be more likely to view a Power of Attorney document as valid if it has been legally witnessed. A notary public can usually be found at an attorney’s office, your local city hall, or bank. Alternatively, look at the Notary Locator online on the website for the American Society of Notaries (www.asnnotary.org).
4. Dispersal. A copy of the Power of Attorney should be given to your agent, and also to every institution that will be dealing with your agent, such as all of your doctors, the local hospital, your bank, and your lawyer’s office.

Legal Link columnist Carol Svec went through the process of attaining a Power of Attorney to benefit her sister Ann, who has brain injury from a tumor and the extensive surgery required to remove it. As is so common with the memory loss from brain injury, Ann was having trouble in a number of areas of her life, including keeping track of her medical needs and paying bills on time. With a Power of Attorney, Carol was able to get copies of all of Ann’s medical records, talk to Ann’s doctors about her treatment, and follow Ann’s banking transactions. Because Carol and Ann lived in different states, they had an attorney draw up the Power of Attorney papers. Once both Carol and Ann had them signed and notarized, copies were sent to Ann’s doctors and bank. With that tool in place, it took only a short time before the records turmoil was straightened out. Although the Power of Attorney remains in place, it hasn’t been used in years—Ann is managing everything on her own.

**FINAL THOUGHTS**

A Power of Attorney is a great solution for people who are mentally capable but still want or need help managing their lives. With a Power of Attorney, you can still sign legal documents for yourself, but your agent also can sign for you. It’s a totally customizable tool: You get just the help you need, when you need it. In fact, you can assign multiple agents, or different agents for different purposes. And because Power of Attorney is voluntary, you have the ability to revoke it at any time. It’s the most flexible solution for people who are still able to participate in their own lives but also know they need help.

*Thomas Henson Jr. is a partner and Head of the Complex Litigation Group at HensonFuerst Attorneys, based in Raleigh and Rocky Mount, North Carolina. He serves on the board of directors of the Brain Injury Association of North Carolina (BIANC), and was appointed by the Governor to a four-year term on the North Carolina Traumatic Brain Injury Advisory Council.*

*Carol Svec is the creative director at HensonFuerst Attorneys, and an award-winning health and wellness writer. Her publications include The Inflammation Cure, The Body Shape Solution to Weight Loss and Wellness, and Joy Bauer’s Food Cures, which became a #1 New York Times bestseller.*
Brain Basics:
The Temporal Lobes
by April Groff, Ph.D.

The temporal lobes are the sensory processing center of your brain. All the information that you take in through your eyes or ears is input to the temporal lobe. There it is processed and organized, and then output to other parts of your brain. The temporal lobes are responsible for your hearing, your ability to make sense of what you see and hear, your ability to understand and speak, and your ability to recall your memories.

The temporal lobes are located on each side of your brain, above your ear and behind your temples. The right and left temporal sides each play a different role in processing information. For example, the left side controls your verbal memory and processes speech sounds. The right side controls memory for non-verbal information and processing music.

The effects of an injury to the temporal lobes depends on the type of injury and its location, as well as the person’s level of ability and functioning before the injury. Generally speaking, it can disrupt the following areas.

Making Sense of What Is Seen and Heard

“It feels like I am going 30 miles an hour in 75 mile an hour world.” When the temporal lobe is injured, it can affect how you process vision and sound. People with damage there may complain that others are talking too quickly. They often appear to have a hearing problem. Damage to this area of the brain makes it hard to discriminate between sounds when they are presented quickly. It can also affect the ability to recognize the correct order of sounds as they come in, making it hard for the person to “keep up.” All this can be very frustrating and causes people to tune things out. This then makes it even more difficult for people to follow and understand verbal instructions, lectures, or even everyday conversations. Even the ability to name things or put thoughts into words can be affected.

Damage to the right temporal lobe interferes with how you process non-speech sounds and visual input. An injury here affects your ability to detect differences in loudness, quality, and pitch of sounds, making it difficult to process music for example. It may be hard to recognize faces or to make sense of visual signs. For example, “I saw the stop sign, but didn’t stop because it didn’t mean anything to me.”

Tuning In and Tuning Out

Today, information overwhelms our senses continuously. We can only process so much sensory information at once. The brain is constantly making decisions about which inputs to focus on in any given moment. Acting like a switchboard, the temporal lobes are responsible for plugging us in to the most important sights and sounds in any given situation.

Selective attention is the brain’s ability to tune out what isn’t relevant and to hone in on what is crucial. Imagine the simple task of crossing a busy intersection. Moving cars, people, signs, and buildings fill the visual landscape. Sounds of traffic, people talking, and phones ringing fill the air. The temporal lobes sort out this incoming data and alert the brain to hone in on the traffic signal or to the sound of a car horn to guide your behavior. For a person with damage to the temporal lobe, the brain may not pay attention to the most important sounds or sights. The person may act based on the wrong signals. For example, “I crossed the road because I saw a friend on the other side. I didn’t notice the light or hear the car coming.”

Organizing by Context or Categories

Although it is often unconscious, you rely on contexts and categories for learning, memory, and guiding your behavior. For example, if you need to get apples, broccoli,
bananas, and corn at the grocery store, you are likely to mentally sort these items into “fruits” and “vegetables.” At the store, when you think of what you need to buy, thinking “fruits” prompts you to recall apples and bananas. Thinking “vegetables” prompts you to remember broccoli and corn. Damage to the left temporal lobe makes it difficult to put items into categories, which can get in the way of learning and remembering.

We can only process so much sensory information at once. The brain is constantly making decisions about which inputs to focus on in any given moment.

Conclusion

An injury to your temporal lobes does not directly affect sight and hearing, but it does affect how well your brain can process what you see and hear. As the functions of these lobes demonstrate, the brain plays a crucial role in how we experience the world through our senses.

April Groff, Ph.D. is a licensed clinical psychologist specializing in neuropsychology. She currently is the clinical director at Learning Services in North Carolina, where she oversees post-acute residential rehabilitation and supported living program for individuals with acquired brain injury. Her previous roles include director of the Polytrauma Transitional Rehabilitation Program and staff psychologist within the Polytrauma Rehabilitation Center at the VA Palo Alto Healthcare System. She has extensive experience working with active duty service members, veterans, and civilians with brain injury and their family members.

Memory

Deep within the temporal lobe is a sub-structure called the limbic system. It has a crucial role in how you create memories. It is responsible for the “fight or flight” response and assigns emotion to experience. It’s what signals you to automatically jump out of the way of a speeding car. Emotions act as a context or category for learning and guiding behavior. This is why you tend to remember really good times and really bad times but don’t have as vivid memories for mediocre experiences.

The limbic system sends signals to the other parts of the temporal lobe about what sensory information is critical in any given moment. That information, along with categories and contexts, helps you build, create, and recall memories. People with damage to the left side have more difficulty learning and remembering verbal information, regardless of whether it is presented visually, in writing, or orally. People with damage to the right temporal lobe may have difficulty learning and remembering non-verbal information such as faces, patterns, or melodies.

Personality and Behavior

Personality and behavior can also be affected by a severe injury to the limbic area of the temporal lobes. This type of injury can disrupt the emotion signals that get attached to experiences. People with this type of injury may appear to others as over-reactive, attaching strong emotions to trivial day-to-day experiences. Other common behavior changes after this type of injury include paranoia, preoccupation with religion, aggressive outbursts, and disturbance of sexual behavior.
VISION THERAPY AFTER BRAIN INJURY

by Dr. Danna Haba, FCVD

Even at age 39, Todd’s vision was near-perfect, but when a skiing accident left him with a brain injury he discovered that vision is more than 20/20. It’s also the ability to gather information with our eyes and to process the information we see. The injury damaged his brain’s visual processing system, causing Post-Trauma Vision Syndrome (PTVS). Todd was no longer able to interpret the world appropriately and could not remember what he saw. He also now saw the world at a shift of five inches from reality. This meant he did not know where he physically fit in his surroundings. His world now tipped slightly to one side, so all his movements skewed five inches away from what they should have been. He compensated visually by adopting postures such as leaning to one side, but this created more stressors for him, including damage and fatigue to the eye muscles, balance disorders, double vision, and a variety of motor and cognitive deficits.

VISION THERAPY

Fortunately, vision therapy, or VT, helped Todd address these vision issues. VT is a prescribed program of treatment by an optometrist to improve visual skills and processing. Through carefully designed exercises and the use of various lenses, prisms, filters, patches, and other tools, Todd learned to use his visual abilities in new, more efficient ways. His other therapists incorporated VT into his overall rehabilitation, which produced quicker results in physical and occupational therapy treatments.

YOKED PRISM GLASSES

Todd had the most immediate results with eyeglasses fitted with prism lenses; his were called yoke prisms. These special lenses altered his perception of space by working to shift where an image seemed to be located. This forced Todd to make a visual adjustment to cope with the distortion.

With his world no longer askew, his posture improved dramatically. Once again, he could walk down a hall and sit upright rather than tipping to one side. His optometrist also added tinted filters to Todd’s yoke prisms to help reduce his light sensitivity and create the feeling that things were not moving.

EYE EXERCISES

Todd’s optometrist, who is an expert in eye issues after brain injury, also prescribed eye exercises, which helped Todd’s other senses work more comfortably. One exercise improved his visual tracking, so then he could more easily find the foods he wanted when walking down the aisles in the grocery store. He also practiced eye teaming, which improved his depth perception so he could once again feel safe when navigating curbs, stairs, and escalators. While Todd’s PTVS did not cause him to reverse letters while he read, his optometrist explained that, if this had been the case, it would have been important for Todd to do another set of exercises so he could retain his good spelling ability.

Since he had difficulty with his visual memory, or the ability to create a picture in his head, Todd had difficulty with visual thinking, which directly affected his cognitive skills. For this, he worked with a speech-language therapist on improving his cognition. As his ability to process information improved, so did his ability to reach his goals in therapy.

Vision therapy plays an important role in the overall rehabilitation process for a person with brain injury and PTVS. When vision problems are not diagnosed and treated, rehabilitation can take longer and be impaired.

Vision therapy plays an important role in the overall rehabilitation process for a person with brain injury and PTVS. When vision problems are not diagnosed and treated, rehabilitation can take longer and be impaired. Vision therapy offers a practical and effective way to help improve the flow and processing of information between the eyes and brain, which can impact a person’s ability to perform activities of daily living and to improve quality of life.

Dr. Danna Haba is a consultant for the Visual Rehabilitation Program at Special Tree Rehabilitation System, a Michigan-based rehabilitation provider specializing in brain injury and spinal cord injury.
CLINICAL CORNER

HEALING WITH YOUR EYES CLOSED

by Jennifer Papa Llado, MS, CCC-SLP

The mind-body connection, which includes meditation, is becoming a hot topic in medicine. While some consider it to be “woo-woo,” there are over 1,000 publications on the benefits of meditation. As a speech-language pathologist, I’ve found ways to integrate meditation into rehabilitation, but this means more than simply training clients to meditate. As neuroscientist and stroke survivor Jill Bolte Taylor suggested, practitioners are responsible for the energy we bring to our clients. So meditation is also a fundamental practice for healthcare providers to access the optimal state for providing high quality care and healing to those we serve.

WHAT IS MEDITATION?

The goal of meditation is to calm the mind. To do this, we must, first, become aware of the incessant stream of thinking that creates most stress and anxiety. We all have a little voice in our heads disguised as repetitive thoughts and mental stories. Our little voice says things like “I shouldn’t have eaten that chocolate cake” or “I am too tired to do therapy today” or “When is this going to be over, so I can feel better.” No matter how convincing it may be, we are not the little voice in our head repeating the same 70,000 thoughts each day. We are, however, the simple awareness that knows the voice exists.

As we become more familiar with our patterns of thinking through practicing meditation, we can begin to break our identification with the little voice. Holocaust survivor Viktor Frankl said, “Between a stimulus and response, there is a space. In this space is our power to choose our response; and in our response lies our growth and freedom.” Meditation provides us with access to the space between our thoughts. Getting into this space is the foundation for stress reduction and high performance.

We all know how good it feels to be in the zone. We call it “the zone” because we are not thinking about anything. We are simply focused on the task at hand. Getting beyond the thinking mind is the only way to access the zone state. By practicing meditation, we train our brains to be in this state on a more regular basis.

THE BRAIN AFTER MEDITATION

The new research is consistently demonstrating that meditation literally changes your brain. Meditators experience:

- decreased activity in the amygdala (the location for the “flight or fight” instinct)
- increased grey-matter in the hippocampus (our center for memory and learning)
- increased blood flow in the brain
- increased gyrification (the folds in the brain which occur during brain growth)
- increased activity in the temporo-parietal junction (the center for compassion and empathy)

Meditation has also been shown to slow down and even reverse age-related deterioration in the brain.

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Benefits of Meditation

As a speech-language pathologist, I was particularly interested to learn that meditation improves cognitive performance in the following areas:

- memory
- attention
- visuospatial skills
- verbal fluency
- executive functions
- creativity

In my practice, I have also used meditation for individuals with mild to moderate aphasia to reduce communication frustration and enhance the use of word finding strategies.

As our brain changes and our thinking improves, our bodies also reap the benefits of meditation. Studies have shown meditation also:

- decreased stress
- decreased anxiety
- decreased depression
- decreased cortisol levels (the stress hormone)
- decreased pain
- increased quality of life

**Meditation = Decreased Stress = Improved Cognition**

The truth is that stress and cognition are entangled. Stress actually decreases and even damages the hippocampus (our center for learning and memory). In fact, stress-prone individuals are 40% more likely to develop a mild cognitive impairment. Increased vulnerability to stress is correlated with a higher risk of developing dementia and a more rapid cognitive decline. The hormones of stress, such as cortisol, actually push the genetic buttons for disease. I would challenge anyone to find an easier or less expensive way to improve the health and wellbeing of our brains.

**Integrating Meditation into Therapy, Recovery, and Life**

Whether you are a caregiver, provider, or person with brain injury, meditation can improve your game. A meditation practice does not have to be lengthy or intense. Begin with a short 5-10 minute meditation to get yourself accustomed to the practice. Meditating any time of day can be beneficial. If you are looking for heightened creative power, meditate first thing in the morning when your brain is still lingering in alpha brain waves. I also suggest meditation music or a guided meditation recording; headphones are best when using music. There are various guided meditations available for free on the Internet.

Beginning meditators may notice the mind jumping wildly from one thought to the next. It is important not to judge yourself. Your little voice will want to say, “I can’t stop thinking” or “My brain won’t shut off.” Instead, think of each thought like a cloud and simply wait for it to pass. Eventually, the clouds will become less and less as you train you brain and body to stay in the present moment.

Below is one of the meditation exercises from the Meditation FlashBook by Bright Side Therapy, LLC. The FlashBook provides printable instructions on a USB drive for 20 different meditations, which can be used by people with brain injury, caregivers, or practitioners themselves.

**FEELING “I”**

**Time:** 5 Minutes

**Background:**

“I” is the most misused word in the English language. It is often used to reinforce identification with emotion. As an example, you might say, “I am stressed.” The irony is that using this language creates more stress. This exercise will help you to understand that the greater part of who we are is ENERGY.

**Intention:**

To connect the WORD “I” to the FEELING of who we are.

This interrupts the thought process that creates ongoing stress.

**Instructions:**

Turn your palms up, close your eyes, and FEEL your hands. If you are having trouble doing this, ask yourself…

“How can you know your hands are there without looking at them?”

“Can you FEEL them?”

Once they can FEEL their energy, alternate repeating the following…

“I am this feeling. This feeling is me.”
I hope this meditation exercise will begin to open the door to this subtle awareness: The truth of who we really are is greater than our minds and our bodies. With this knowing, the possibilities for your life are endless. Enjoy!

Jennifer Papa Llado, MS, MS, CCC-SLP is a speech-language pathologist and Area Rehab Director for Athena Health Care. Jennifer is the founder of Bright Side Therapy, LLC, (http://brightsidetherapy.com), which produces innovative rehab products for SLPs working with the adult population. She is also a consultant for Key Insight Coaching, training healthcare professionals on the importance of emotional intelligence and consciousness. Contact Jennifer at jen@brightsidetherapy.com.

The Dark
by Molly Dorhauer

Watching life in a slideshow,
Unable to keep up.
Sitting by the wayside,
Sinking into thought.
Remembering my childhood,
The good times then the bad.
The crash it took to wake me up,
Left me mangled in shreds.
Moving on to different dreams,
People come and go.
Walking softly in the past,
My feet can’t seem to move.
Feeling the wreck that is my life,
knowing I couldn’t choose
Forgetting what destiny once was
and letting my spirit lose.
Whispering softly to myself,
Clenched fists and broken heart
Feeling others watching me
Tearing me apart
Pushing through to feel myself
Dropping to the ground
A mind confused and face of tears
Noises that echo in my ears
A pause to be overwhelmed
Memories gone in a short time,
stress from “fine” to “I break.”
I swallow fear to carry on,
Not wanting to look back
Taking only a meager step forward
Shaking with regrets
So for the moment I cannot go
Pain is just too real
Wishing I could just stop time,
Forget what it’s like to feel.
Consuming me are memories,
Screaming to the heart.
Sacrificing the present,
To sit here in the dark.

Molly is a 25 year old TBI survivor who has found life after her injury possible in writing, music, and the love of her family.
Glucose drives the brain, and more activity in the brain requires more glucose. When demands on the injured brain require more glucose than is readily available, as in a too-quick return to school, the student faces greater potential for concussion symptoms to worsen (Giza & Hovda, 2001). It’s important to limit schoolwork, television, video games, and other screen time to allow adequate glucose absorption for healing. Low-key social interactions that do not cause symptoms are allowed and can help the student maintain contact with friends and help keep depression at bay (Masters, et al, 2012). Return to school should be gradual rather all at once in order to avoid worsening symptoms.

THREE PLANS FOR SCHOOLS

Schools should have in place three plans to care for the occurrence of a concussion:

1. All parents, teachers, and athletes should be educated about the signs and symptoms of concussion. Student-athletes should have an annual baseline assessment of brain function.

2. Schools should follow return-to-play (RTP) guidelines as outlined in their state’s laws about athletes returning to full participation in sports following a concussion. RTP should be gradual.

3. Parents and faculty should know about the school’s return-to-learn (RTL) plan of accommodations. For instance, concussed students may need additional rest time, a seat away from bright light, a more subdued room for eating lunch, and more time for tests and assignments. The plan needs one or two key people to activate and monitor the plan for returning students; typically, the

RETURN TO SCHOOL

A concussion is a medical diagnosis, as is clearance from this injury. After a student receives a medical clearance, schools are best suited to make the necessary adjustments in his or her cognitive return. School-employed professionals such as nurses, psychologists, and school athletic trainers can actively collaborate to complement and improve upon existing student services in the best interest of the recovering student.
school nurse and psychologist are most skilled in this area (Hossler, et. al. 2014). RTL should be a gradual process, with students allowed to move ahead only after accomplishing a step successfully and with no adverse affects.

**SUMMARY**

An early, accurate, multi-disciplined, and broad philosophy of dealing with a student’s concussion will make a difference in cognitive, social, emotional, and behavioral success. Constant and frequent adult intervention will provide a smooth return to school activities and reduce the occurrence of symptoms by ensuring properly paced and spaced return to learn steps.


Masters CL, Gioia GA, Leddy JJ, Grady MF, Pediatric Annals, September, 2012

Phil Hossler is a certified athletic trainer at a large high school in New Jersey. He is the author of five books and thirty-eight professional articles on athletic healthcare topics. He is a member of several halls of fame as an athletic trainer.

### Return-to-Learn Plan

<table>
<thead>
<tr>
<th>Stage</th>
<th>Activity</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Activity</td>
<td>Complete cognitive rest: no school, no homework, no reading, no texting, no video games, no computer work</td>
<td>Recovery</td>
</tr>
<tr>
<td>Gradual reintroduction of cognitive activity</td>
<td>Relax previous restriction on activities in 5-15 minute increases</td>
<td>Gradual increase in sub-symptomatic threshold cognitive activities</td>
</tr>
<tr>
<td>Homework at home School work at school</td>
<td>Homework in longer increments 20-30 minutes at a time</td>
<td>Increase cognitive before stamina by repetition of short periods of self-paced cognitive activity</td>
</tr>
<tr>
<td>School re-entry</td>
<td>Part day of school after tolerating 1-2 cumulative hours of homework at home</td>
<td>Re-entry with accommodations to permit controlled sub-system threshold increase in cognitive load</td>
</tr>
<tr>
<td>Gradual reintegration into school</td>
<td>Increase to full day of school</td>
<td>Accommodations decrease as cognitive stamina improves</td>
</tr>
<tr>
<td>Resumption of full cognitive workload</td>
<td>Introduce testing, catch up with essential work</td>
<td>Full return to school; Return to Play protocol</td>
</tr>
</tbody>
</table>

My dad was diagnosed with Parkinson’s disease some years ago, and as his PD became more pronounced, I could see his world begin to shrink. Not only was the physical nature of his PD challenging, but Dad began to feel social challenges as people backed away from him when he would venture out. So for him, what we call “social capital” began to shrink.

The notion of friendship is a critical one to all of us, yet friendship is often thought to be such a simple concept that it hardly merits any deep study or discussion. We know that friendships are important, but rarely do we ever think we have to work at the concept. However, friendships are critical, especially for people who have experienced a disability, and there is much for us to consider.

Sociologists use the term “social capital” to describe friendship. To the academics, the term “capital” is one that relates to resources that can advance or promote a profit. They speak of “physical capital,” which refers to things like land or machinery. “Economic capital” might refer to goods or to services that drive an economy. “Human capital” is often thought to be the people needed to do the work to create the goods or services.

However, in the eyes of the academic, “social capital” suggests the connectedness among and between people. Convincing research now shows that the more social capital people have in their lives, the better their lives become. In fact, today we know that the more social capital people have in their lives, the healthier they are, the happier they are and—listen to this—the longer they live. That’s right. Social capital, or friendship, is linked to the three highest quality-of-life indicators known to humankind!

**REAL IMPLICATIONS**

This is powerful stuff and has real implications for all of us. We know too that social isolation (the opposite of social capital) is one of the biggest challenges that people with disabilities, including some brain injuries, have and that families fear. This has been continually verified in our experience and in the literature. In my own life, I watched my dad’s social isolation grow as his Parkinson’s disease progressed.

You don’t have to dig too deep to understand the reality of social isolation, or limited social capital, for people with significant disabilities. We hear over and over again, and see in vivid ways, that people with disabilities have fewer friends and social opportunities than people without disabilities. In *Social Capital: The Key to Macro Change* (2014) ([http://alcondeluci.com/social-capital-the-key-to-macro-change](http://alcondeluci.com/social-capital-the-key-to-macro-change)) we report on a recent Community Engagement Survey conducted by the Interdependence Network ([http://www.buildingsocialcapital.org](http://www.buildingsocialcapital.org)) showing that people with significant disabilities have nearly two-thirds less—yes, 66% less—social capital than their able-bodied peers!

This is powerful and penetrating finding. And it begs for some basic answers and actions.

Like most vexing questions, the answers are simple yet complex, and the direction should be clear: All people are better when they have more social capital, and people with disabilities have less social capital. So how can we help all people, with and without disabilities, develop more social capital?

**A FOUR-STEP STRATEGY**

As a family, we began to develop some strategies to slow or remove this isolation for Dad. First, we stayed focused on the things he liked to do or had an affinity or deep interest in. Second, we searched for places where Dad shared similar interests with others and used these as a start point for making new friends. Third, we made
sure that one of us could physically support Dad so we did not have to ask or expect potential friends to play these support roles. Rather, we wanted people to see Dad for his interest in the same thing they enjoyed. Fourth, as we looked to initiate Dad in these new venues, we searched for a gatekeeper, someone who could help pave the way for his involvement with the new group.

These four steps, which I summarized later in my book Together is Better (2008), have been used since by families and support professionals as they work to help people with disabilities develop, maintain, or sustain these important relationships in our lives.

So, let’s get to work. Regardless of where you find yourself in the scheme of things, you can help in this effort. All of us play a variety of roles in our community. To this extent you are a potential “gatekeeper” in building social capital. Think about this the next time you are engaged in community and do your part to help build social capital.

Al Condeluci, CEO of Community Living and Support Services (CLASS), teaches at the University of Pittsburgh, and writes, speaks, and consults on issues related to culture, community, and social capital. For more on social capital see, www.alcondeluci.com or follow @acondeluci on Twitter.
ARE WE ASKING TOO MUCH OF FAMILIES?

By Marilyn Lash, MSW

I admit it—I got hooked on Rosemary Rawlins’ book Learning by Accident and read it in three days. I even snuck downstairs at 3 a.m. one morning to pick it back up. Her very personal account of her husband Hugh’s brain injury is unlike any other book I have read. What is so very special is how she brings the reader into her home as a wife and mother who is thrust into the world of caregiving. Unfortunately, her experience is not unique. What is unique is how she chronicles her husband’s journey from the brink of death through the long grind of surgeries, therapies, and complications into an uncertain future for their marriage, their children, his employment, and their family. This gives the reader an appreciation of how long and complex this journey is and how pivotal the caregiver is during every step along the way.

WHAT ABOUT THE CAREGIVER?

Rosemary is no saint. She does what so many family caregivers do as she neglects her own needs and health until the mounting signs of stress finally force her to recognize that she needs help as well. The real value of this book is the insights you will gain of the less often told story about brain injury—that of the caregiver. Rosemary reveals her emotional trauma that was the inevitable partner to her husband’s neurological injury. She unflinchingly shares her fears, doubts, and anxieties as she travels the rocky road from grief to gratitude for his survival. But living is more than surviving.

While providers have intensive treatment protocols for brain injury treatment and rehabilitation, much less attention is given to the secondary traumatic stress known as compassion fatigue that is found among so many family caregivers. They are quickly exhausted physically, emotionally, and spiritually. While insurers, physicians, and therapists have guidelines and regulations to allocate the number of days or visits that will be approved and provided to the person who has been injured, the timetable for caregivers is unending. As an example, Carolyn Rocchio in Florida is now 81 and has been caring for her son Tim 24/7 for 31 years. She started the caregiving journey at age 50, and while many providers and experts have come and gone, Tim still lives with her at home.

With so much attention and resources focused on the person who has been injured, family caregivers often become collateral damage. Carolyn and Rosemary’s stories are not unique. With the wounded warriors returning from Iraq and Afghanistan, there are many more caregivers joining this journey. A recent report by the RAND Corporation finds there are 5.5 million military caregivers in the U.S. with nearly 20% caring for someone who served since the terrorist attacks of 9/11. This is a younger population of caregivers who are simultaneously juggling young families, budding careers, and recent marriages. Just as in the civilian community, these military caregivers are typically under-recognized and underserved. Where are the supports and resources for them?

THE FUTURE IS STILL UNKNOWN

Regardless of the medical advances that have been made, we still cannot predict what the course or timetable for recovery will be after the brain has been injured. We can not even define or predict what “recovery” will be or mean. This uncertainty that hangs over families is like the brooding storm cloud that never clears. Sure there are promising gains, but there are also recurrent setbacks; the horizon is never clear of storms that may roll in any moment. The optimistic well wishes for recovery that initially surround so many families and survivors starkly contrast with the anxiety and stress of caregivers as they grapple with the unknown quality of life for the future.
HOW MUCH?

We place enormous expectations on families as they transform from spouse, son, daughter, parent, or sibling to becoming a caregiver. It’s important that we ask the question, How much is too much?

When I worked as a social worker in a rehabilitation hospital long ago in the late ’70s, patients with severe traumatic brain injuries routinely received three to six months of intensive inpatient treatment. This gave families considerable time to benefit from the support, guidance, and training by a team of brain injury specialists. In today’s era of managed care and cost containment, rehabilitation is delivered at warp speed. Lengths of stay are now counted in days or weeks, not months. That’s assuming that rehabilitation is even an option; many more individuals are discharged directly home from the hospital.

As Rosemary’s story attests, families are still reeling in shock from the initial trauma when rapid discharge dates are set. Families suddenly find themselves being instructed in managing not only physical care, medications, and therapies but a complex set of social, cognitive, and behavioral changes. The person coming home is truly not the same person. This book will give health care professionals new appreciation of how much we ask of families and, I hope, lead them to question how we can better prepare families with the knowledge, skills, and support to navigate this long journey of brain injury.

Learning by Accident is a very personal look at the Rawlins family story, but it also has a universal message for caregivers, professionals, families, and survivors and I highly recommend it.

Marilyn Lash, MSW With over 35 years of experience working with persons with disabilities and their families in medical, rehabilitation, educational, and vocational settings, she is a speaker and author of many articles and books on the emotional trauma of brain injury. As founder and president of Lash and Associates Publishing/Training, she believes that practical and user-friendly information is essential for families, survivors, providers, and professionals.
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