Feature Story:

PREVENTING AND HEALING COMPASSION FATIGUE
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Nathan D. Zasler, MD
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Mission Statement
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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**LETTER FROM LASH & ASSOCIATES**

by Marilyn Lash, MSW

Launching a magazine is a tremendous undertaking. As in life, it’s never as easy as you think and it usually takes longer than expected, but it’s clearly been worth it. The comments that we’ve heard from families, individuals, clinicians and educators have been so positive and confirmed our belief that *Brain Injury Journey* addresses a need to support and inform everyone in the brain injury community as they travel this journey together.

I want to especially thank our authors. It’s easy to focus on content; it’s a lot harder to write and engage readers with the grace, sensitivity, awareness and insights that they bring from their personal and professional perspectives. As Editor-in-Chief, Barbara Stahura, has done a masterful job in managing everything from detailed timelines, to correcting grammar, to negotiating revisions. She makes my job easy.

Finally, I want to encourage readers to keep spreading the news about *Brain Injury Journey*. Use those tweets and social media to let others know that it is available. Our distribution channels are expanding rapidly worldwide.

**LETTER TO THE EDITOR**

I just read your article, Brain Injury and Grief: Fact or Fiction? in the premiere issue of *Brain Injury Journey: Hope, Help, Healing*. I picked a copy up in Dr. Nathan Zasler’s office this past week in Richmond, VA, when we took our 29 year old daughter for an assessment. In January of 2011, Katie fell down our front steps (8) and landed on her head. She suffered a severe brain injury, followed several days later by three strokes and anoxia. She was in the hospital for 6 months, rehab for 7 months and has been home for over a year. She is a spastic quadriplegic, has very little means of communication, and her vision is greatly affected. We are on a very long journey.

This is the first thing I have read about grief that describes my feelings so well. My feelings are so complex! And the picture that is in the article is so appropriate. It’s beautiful but dark, hopeful but sad, lonely but, because of my faith in God, I know the person is not alone. I realize that I’m not crazy. If it weren’t for our faith, I don’t know where we would be. Thank you, and I look forward to reading your book, “Extraordinary Mourning: Help for a Broken Heart.”

Blessings,

Cathy Ralcewicz, Richmond, Virginia

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**FROM THE EDITOR-IN-CHIEF**

by Barbara Stahura, CJF

I’ve heard it said that “when you’ve seen one brain injury, you’ve seen one brain injury.” So true! Each brain injury is as individual as the people who sustain one.

Yet a common element among people with brain injury (and their family members) is the need to adjust to and ultimately accept the changes the injury has caused—if they still want to live a life as good as they can make it. Sadly, some people wrongly believe that acceptance means giving up.

Instead, accepting what has happened means you acknowledge your situation is now different than it used to be. Without acceptance, you drain your energy by fighting against something that cannot be changed. This leaves you with little or no energy to continue making progress in your recovery.

I recently had the privilege of hearing Al Foxx speak about living with brain injury. Now in his 50s, he sustained a severe brain injury at age 18. After a month-long coma, he could not speak clearly (he sounded like a barking seal, he says), walk, or even hold his head upright. The left side of his body was paralyzed. His parents were told their son “would never be the same.” In the following years, as he has written, “I saw myself as pathetic, someone to be pitied, not someone who deserved respect or admiration.”

But today, he is a motivational and keynote speaker. He has been a stand-up comedian, often using life with brain injury as material, and won awards for his performances. Known as Attitude Man, he is founder and president of the Winners Don’t Quit Association. Al credits his success to finally accepting his situation, some 20 years after his accident—years he is sorry he wasted in fighting against his new reality—and moving forward from there. Only then could he rebuild his life and learn to care about someone other than himself. Before acceptance, he says, “I was still breathing, but I was not really alive.”

Not everyone with a brain injury will find the same success as Al Foxx. But sincere acceptance of change and loss will help you find your own success in your own way. In *Brain Injury Journey*, we offer a variety of methods to help you do just that—all provided by members of the brain injury community.
Family Chaos or Cohesion?

by Rosemary Rawlins

We grow up in our families knowing where we fit in, and functional or dysfunctional, we come to know what to expect from day to day. Family routines, schedules, rituals, and traditions reinforce our sense of security and belonging. Shared values, love, and trust bind us. So it follows that when something unexpected and devastating happens to one family member, each member of the family is profoundly affected.

Finding a new family rhythm after one member has sustained a brain injury can be challenging at best or chaotic at worst, because brain injury causes immediate and drastic changes for all family members.

Crisis can bring out the best or worst in us. Naturally, family members go through a period of shock and denial, and often want their old life back. Emotions run rampant. In a perfect world, every family member would cope flawlessly with this sudden life change, but this rarely happens. Fear, anger, and tension usually build up over time. Getting through each day with the heavy weight of worry and uncertainty creates exhaustion in every way a person can be exhausted.

If the injured family member usually provided a major portion of income for the family, the strain may be even more severe. Disrupted finances will put pressure on all family members, compounding emotional strains.

The news isn’t all bad

While we may not be able to control our circumstances, we can try to control our own reactions and behavior, and this is where we truly have influence over whether our family falls into chaos or becomes more cohesive.

There are ways of interacting that can help families through this time of upheaval just as there are ways of interacting that cause more disruption and pain. Here are a few insights garnered from my own experience, and believe me, I have exhibited all of these behaviors multiple times.

What does not help

• Criticism does not help: Think about how you feel when someone starts a sentence in any of these ways:
  “You definitely should have…”
  “I can’t believe you didn’t…”
  “Why on earth would you…”

• Being pushy or controlling does not help: As in the phrase: “You need to…” which instantly makes me want to do the opposite of what is being requested. “You need to stop being a pain!” or “You need to clean your room!”

• Yelling does not help: If you must yell and scream, do it alone. I used to scream to let out my frustrations when I was alone in the house or car, or I’d blast the car radio and sing (scream) along.

• Blame and defensiveness do not help, especially when discussing treatments with family members. In fact, defensiveness usually escalates the situation because it often leads to back and forth defensiveness, like this:
  “You think I need to check everything with you?”
  “Doesn’t my opinion count for anything?”
  “Oh, so now it’s my fault that you feel left out!”
  “You never include me. You just do what you want…”

This conversation can go on forever without accomplishing anything.

• Resisting change does not help: Try not to say, “That’s not my job.” When one family member is critically injured, role changes are inevitable, so try to make peace with it and be helpful.

And what does help

• Respect helps: When family members respect each other’s feelings, allow them to be expressed, and when family members share their hopes and fears together, family bonds usually strengthen.

• Requesting help directly and politely helps: “I could really use your help. Would you please do the dishes while I ….”

• Checking yourself helps: Don’t let a bad day get worse by blowing up at someone who doesn’t deserve it. Head it off by saying, “I’m overtired today, so if I sound angry, please realize it’s not you, and call me out, okay?”
• Diffusing arguments helps: If you find your own anger escalating because someone is picking a fight, take a deep breath, and try to listen to the other person as best you can to diffuse the argument by showing that you understand what the other person is saying. Using the example above, you could respond, “I value your opinion, but the doctor said she needed a decision on the spot.”

• Admitting when you make a mistake helps: Brain injury creates a steep learning curve for most people. Expect to make mistakes, but own up to them when you do.

“I should not have criticized you. That was wrong.”

“I thought I was right, but I made things worse. I’m sorry.”

One final thing that helped my own family remain close is this: we often laughed until we cried, or cried until we laughed—together. Looking back now, eleven years later, we are all thankful that we each made a huge effort to get along during some very tough times. It has made our lives during smoother times all the sweeter.

Rosemary Rawlins is the author of Learning by Accident, a memoir. You can learn more about Rosemary at www.rosemaryrawlins.com

Silent Screams
By: Melissa Fernandez (grade 9)

Invisible injuries screaming for attention, but heard only at a whisper if acknowledged at all.

The headlights burn; a red screen blurs vision, leaving imprints in the mind.

Silence grows deafening, while questions rapidly develop with no emerging answers.

Plastic overwhelms the senses, steady beeps fade in and out, white walls brightly blind reality.

Told that impact was sudden and sharp, a guardian angel must have been close by, feeling foggy is normal, no worries.

“Healing well,” is planted upon everyone’s lips; outside is the picture of strength and health, inside is weak and faulted.

Cracks, breaks, and lines shape deep, hidden drawings in the brain, inserting new-found lapses in memory.

Flashes of the past; anxiety rises and nerves tense; always remembering.

The web of lines outstretches and grows, entrapping its victims to speed up the inevitable.

Pain welcomes depression, laughter seeps through earlier emotions, fear kindly greets the unknown.

Whispers are finally listened to, help is finally reached, but damage is already done.

My name is Melissa Fernandez, and I attend Middle Creek High School where creative writing is my favorite class. My uncle, David Lilyquist, is a brain injury survivor and I am very proud to call him my uncle. I wrote my poem because I want to spread awareness about brain injuries and how they are more common than one would think.

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“What makes NCC unique is that our services are provided in the individual’s home or community environment and are functionality based.”
Susan couldn’t figure out why she felt so exhausted and down on herself. She had been caring for her husband, Mike, for four years. He was the only survivor of a multiple-car accident. Although the couple felt blessed that Mike lived, they struggled with the effects of his brain injury, chronic back pain, and headaches. Mike had also been diagnosed with post-traumatic stress disorder (PTSD) from the accident. Cognitive problems and PTSD made it hard for Mike to hold on to a job, so Susan worked part-time in a busy insurance office. She juggled helping Mike learn basic skills, caring for their five-year old son, Jason, and paying the family’s bills.

When Susan first became Mike’s caregiver, she worked hard to understand his brain injury and to empathize with his emotions of grief, fear, anxiety, and anger. She was very aware of the pain he suffered, and the long road to recovery. Susan moved beyond empathy to compassion when her understanding fueled her commitment to relieve Mike’s suffering and help him recover in every way possible.

As time went on, Susan witnessed Mike’s frequent flashbacks to the car accident, and listened to his angry outbursts about the driver who caused the accident. She started having vivid nightmares about the crash scene. When she awoke with her heart pounding she thought, “Wow, it’s almost like I was in the accident.” Susan’s deep empathy had blurred the boundaries between Mike’s experience and her own. She developed what is called a secondary traumatic stress response.

Sometimes Susan and Jason were the targets of Mike’s anger. Her stress level mounted as she tried to protect her son from his father’s unpredictable behavior. Susan barely noticed that she’d become burned out. Her compassion ran dry, and she felt numb to everything except her love for Jason.

When Susan went to her support group the following month she said, “I feel like my last nerve is fraying. I wake up with a headache after being on alert all night. I screamed at Jason when he broke his toy. Mike is not even close to being the guy I married, yet he pesters me for sex all the time. He never even says ‘thanks’ for everything I do; not that what I do seems to help his progress anymore. I can’t concentrate at work, so the boss yelled about the five mistakes I made in a report. I feel so alone that I wonder if God even cares. Maybe I should take up drinking to forget it all.”

The group facilitator said, “Susan, have you ever heard of compassion fatigue? It sounds like you might have a classic case. You are smart to recognize how much you’ve changed. Fortunately, there are many ways we can help you get better.”

What is compassion fatigue?

Compassion fatigue is a form of complete exhaustion that results from the prolonged stress of caring for a very sick or traumatized person. Compassion fatigue depletes our physical, emotional, and spiritual reserves, so interventions must replenish those dimensions. It even interferes with how the body and mind function. Living with this extreme stress is dangerous because it can contribute to medical illness, mood disturbances, behavior changes, and substance abuse. Compassion fatigue builds up slowly as the stress response stays in overdrive for weeks, or even months.

Some caregivers are more vulnerable to compassion fatigue because they have personal or role-related risk factors. One important risk is a personal history of trauma, abuse, violence, war, or severe illness. Witnessing another’s suffering can stir up memories or flashbacks of your own worst experiences, even if you moved on from them years earlier. Other personal risk factors include...

- Being a “triple duty caregiver” who bears responsibility for parenting children, keeping the family afloat financially, and providing rehabilitation and support for a person with a brain injury.
- Not prioritizing self-compassion and resilience skills.
- Not getting enough help even though feeling isolated, depressed, or burned out.

Any caregiver can attest that there are risks inherent in the caregiving role. These risks include…

- Caring for a person with personality changes, behavior issues, substance abuse, mental illness, PTSD, or inability to keep himself safe.
- Threats to personal safety from verbal or physical threats or actions.
Responsibility for complex or painful medical treatments beyond one’s training.

Frustration with a person who can’t, or won’t, participate in treatment.

Compassion fatigue signals

The symptoms that Susan experienced were caused by living in a prolonged state of hyperarousal, coupled with a secondary traumatic stress response. Physical signals include hypervigilance, poor sleep, nightmares, appetite changes, muscle tension, headaches, stomach problems, or high blood pressure.

Emotional signals include losing your sense of humor, sarcastic comments, and anger. Feeling like your efforts are never enough can lead to guilt or withdrawal. Mood swings, depression, hopelessness, helplessness, or numbness should be reported to a mental health professional. If you feel like harming yourself or the person you care for, please get emergency help right away.

Susan had some of the cognitive signals such as trouble with attention, concentration, problem solving, and memory. She was bombarded with negative thoughts that kept her from thinking constructively about the family’s situation. Her brain was on overload.

Behavioral signals include avoiding or being mean to the person you care for, and displacing anger. Secret behaviors offer the temptation of short-term relief, but lead to other problems. Be alert to drinking, smoking, eating, gambling, or shopping excessively. Over-using prescribed medications for pain, anxiety, or sleep is always dangerous.

Spiritual signals include feeling unable to find solace or meaning in faith. You might feel punished, angry at, or abandoned by God.

Cultivating resilience

Susan felt relieved to learn that she wasn’t crazy or a bad caregiver. Compassion fatigue is a response to an extreme situation, not a sign of failure. Prevention is the best approach. However, the same skills and strategies can both prevent and heal compassion fatigue and traumatic stress.

Susan realized that she deserved and required more time for self-care. She worked with a counselor to shift some of the kindness and love she gave to others to self-compassion. She sought treatment for depression and secondary stress, and shared her spiritual confusion with her minister.

Susan scheduled a meeting with her husband’s treatment team. She advocated for more training and help at home. She requested a behavior specialist to work on Mike’s outbursts. Susan set boundaries with Mike around communicating more respectfully and finding healthier outlets for his anger. She chose which areas she wanted to focus her energy on, and then called a meeting of everyone they knew and successfully appealed for help with a long list of specific tasks.

Part of the imbalance Susan felt was from not having fun anymore. So, she signed up for a Zumba class to dance out her tension with friends. She practiced meditation daily to shift from the stress response to a more relaxed, focused state. She and Jason laughed as they built a bird house and planted a garden. Within a few months, Susan started to feel more resilient, energized, and purposeful.

Now it’s your turn to compose a compassion resilience plan with gifts for your body, mind, and spirit.

Janet Cromer, RN, MA, LMHC, is a psychiatric RN and the author of Professor Cromer Learns to Read: A Couple’s New Life after Brain Injury. Janet speaks nationally on family and professional caregiver issues including stress resilience, traumatic stress, compassion renewal, seasons of caregiving, and creativity and healing. See more at www.janetcromer.com
Life is a constant learning process after brain injury. That’s true for both the survivor and caregiver or care partner. Whether you are a new caregiver or a seasoned pro, there are five foundation skills that can enhance your health and resilience:

- Embrace self-compassion.
- Counterbalance the stress response.
- Live mindfully.
- Construct sustaining connections.
- Express your creativity.

Self-compassion is the gateway skill because it empowers us to prioritize self-care. Carlos cares for his wife who has a brain tumor. He showers Maria with compassion and kindness while encouraging her to talk and feed herself. He criticizes himself harshly for not being able to take away her sorrow or pain. He imagines a caregiving judge holding up a low score card, like the mean judges on the TV dancing shows he watches.

So, how can a caregiver shift from neglect to self-compassion? Kristen Neff, Ph. D, in her book *Self-Compassion: Stop Beating Yourself Up and Leave Insecurity Behind*, describes self-compassion as having three components:

- Kindness
- Recognition of our common humanity
- Mindfulness

Kindness means that we actively soothe and empathize with ourselves, much as we would with a friend who is going through a rough time. One of the most healing changes to make is to replace your inner critic with an inner mentor to guide you on your journey.

You can visualize an inner mentor by remembering a trusted friend, colleague, or family member in whom you could confide. Imagine that person’s presence and voice as he or she listens and responds to you with compassion and wisdom. Carlos visualized his Uncle Alfred smiling warmly as he said, “Ah, Carlos. You show Maria so much love. You’re a top-scoring husband! Relax and enjoy your time together.”

Self-compassion heightens self-respect. One way this might manifest is in setting healthy boundaries. Have a conversation with the person you care for about how you plan to show each other respect through your communication and behavior.

Another core component of self-compassion is our shared humanity. This means you take pride in all that you contribute to the person you care for and others. You take responsibility for what you can, but also forgive your mistakes. It’s a relief to realize that we are only human, with the talents and limitations that implies!

**Reverse the stress response**

The second foundation skill is to counterbalance the stress response. The stress response evolved as a brilliant survival mechanism meant to give you the power to fight off a threat or run for your life. This response starts automatically, whether the perceived threat is physical or emotional, real or imagined. The chemical and hormonal activation that the body and mind undergo is meant to subside within a few hours after the danger ends. Contrast a few hours with the weeks or months of unremitting stress that some caregivers experience. That may be one reason caregivers have higher rates of chronic illness than non-caregivers.

First, learn to identify your personal stress triggers and signals. What sets you off? How do your body and mind react? Margaret said, “When I have to argue with my husband to take his blood pressure pills, my whole back knots up and I want to scream at him.” Her husband always likes dessert, so Margaret decided to quietly offer him the pills before serving the cake.

Awareness empowers you to intervene early. Think of ways to prevent or minimize how often your trigger happens.

Learning ways to elicit a more relaxed state of being pays off in health dividends. Proven techniques include meditation, mindfulness, yoga, tai chi, time in nature, and repetitive exercise such as swimming laps. Margaret joined a yoga class to relax her back and ease her mind.

The hypervigilance that results from caring for another person round the clock is particularly dangerous. Margaret hired an aide to help out two nights a week so she could rest.

Schedule daily respite breaks, and do whatever it takes to get away regularly.
Take the mystery out of mindfulness

The third foundation skill is to live mindfully. Does this mean that you have to withdraw from the world and meditate for hours a day? Not at all! Mindfulness means being in the present moment as fully as possible without judging or exaggerating your feelings or experiences. It means being aware of both the good and the difficult, and open to new approaches.

There are many forms of mindfulness meditation, and you can find classes, books, and CDs to guide your practice. Sitting quietly and focusing on the flow of your breath is an effective way to start.

Early in the morning, set a positive intention for your day. Build in “peak moments” of small sensory or emotional pleasures and give them your full attention. Carlos bit into a ripe peach and savored the fragrance and juice. Throughout the day, do a body scan to release tension and attend to a hidden emotion. At the end of the day, list three things that you did well. (For a beautiful body scan technique from Kristin Neff, see http://www.self-compassion.org/guided-self-compassion-meditations.mp3.html)

Construct connections

The fourth foundation skill is to build sustaining connections. Avoid the isolation that can trap caregivers and contribute to stress and compassion fatigue.

Think about what you need from friends and helpers at this juncture, and what you can contribute to a relationship. Be honest. Then train people in how to help you. Do you want someone to listen while you vent, or help problem solve? Margaret asked a young neighbor to look up information on the Internet for her. Cultivate relationships with people who share your experiences, as well as those with a different perspective who can help you grow. Call on a professional counselor to heal trauma, explore intense emotions, or learn adjustment skills.

One of the advantages of trusting supporters is that we are less likely to keep dangerous secrets. Brain injury caregivers can witness, or be the target of, verbal outbursts, substance abuse, or physical aggression. Sometimes we hide these problems out of fear or shame, but the first priority must be to keep everyone in the family safe. A volatile person or situation is a signal that an emergency assessment and plan of action are needed. When Carlos confided that Maria scratched his face, his doctor arranged a medical check-up for Maria as the first step.

Express yourself

Expressing your creativity in as many ways as possible is the fifth foundation skill. You might write a journal or blog, draw a graphic novel, or tell your story to raise awareness. Creativity invites you to claim ownership of your narrative, integrate emotions, and gain a new perspective.

Getting absorbed in a hobby or fun activity is a proven stress buster! Carlos noticed that when he strummed his guitar and sang, he felt at peace instead of worrying.

Whether you paint a landscape, cook up a pot of chili, or build a bookcase, you’re in control of the process and the outcome. You have something to show for your time, and you get better at that skill. For these reasons, creative pursuits have the potential to counterbalance some of the uncertainty and lack of control caregivers feel in helping a person live fully after a brain injury.

Janet Cromer, RN, MA, LMHC is a psychiatric RN and the author of Professor Cromer Learns to Read: A Couple’s New Life after Brain Injury. Janet speaks nationally on family and professional caregiver issues including stress resilience, traumatic stress, compassion renewal, seasons of caregiving, and creativity and healing.

See more at www.janetcromer.com

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Splattered Pie and a Reality Check

by Christine Durham, PhD

Then: Tears of shame

I found myself standing in the middle of the mall with pie dripping from my hands, covering the front of my coat. To my bewilderment, my daughter, Ann, who’d brought me on this shopping trip, ran away. I didn’t blame her. I’d run away from me too, if I could! I was so ashamed! I didn’t know what to do so I kept on trying to eat the pie. I’d been apprehensive about this outing to the shops, several months after I’d left the hospital after my car accident, but I hadn’t realized I’d be so totally confused and lost.

I just wanted to go home—but I didn’t know how to get home, I didn’t know where I lived, and actually I didn’t even know my own name. Tears ran down my cheeks. I started to sob uncontrollably; I was a sodden, soggy mess. Suddenly through my tears I recognized my daughter coming toward me with a fist full of paper napkins. She wiped my face, hands, and clothes, and led me to the car.

Once we got home Ann put me to bed, where I fell into an exhausted sleep. When I awoke I could hear her clattering in the kitchen making dinner. The other children were home from school and university, and dusk was falling. I cursed and berated myself. “Fancy making such a spectacle of yourself in public! You stupid bumbling idiot! Talk about pathetic—and into the bargain here you are feeling sorry for yourself all because of spilt pie—you know there’s no point in crying over spilt milk or spilt pie! In the world children are dying of starvation, and here you are crying over pie!”

Slowly I came to realize it was not the pie, but what the pie stood for, that was breaking my heart. The “old” pre-brain injury me—mother of four, teacher of hundreds, wiper upper extraordinaire—would have known what to do in a flash. The “new” brain-injured me couldn’t work out what to do most of the time!

This pie episode shone a spotlight on how different I was, and further damaged my fragile self esteem. I felt unlovely, unlovable, and it was unlikely I’d ever feel any different. My husband and family must be just pretending that they loved me. I’d lost confidence in myself, I thought I was a bad person, I could no longer solve the simplest problem. I felt completely hopeless and helpless. A bleak, uncertain future stretched out in front of me. I believed I was doomed.

Now: Tears of delight

It’s now over two decades since the pie episode. Just the other day I found myself standing in front of a large audience with tears coursing down my cheeks. But this time it was in happiness. I was so pleased with their reaction to my presentation where I’d told stories to help them understand what it’s like to struggle with brain injury.

I look back on this long, long journey of discovery. I ponder the journeys of the hundreds of people with brain injury I’ve spoken to, and the participants in my PhD study, and realize that we have all learned so much. We’ve learnt that we are not alone, that other people have similar experiences that leave them feeling low.

Brain injury is like a wizard that can turn optimists into pessimists, confident people insecure, hopeful people hopeless, and with vanished self-esteem. We can blame and berate ourselves (and be our own worst enemy), when we need to be kind to ourselves (and talk to ourselves like our own best friend).

My journey has progressed from the faltering first steps of finding ways to help myself get dressed and so on, to helping my kids by unpacking the dishwasher and setting the table (even if these were challenging tasks). Learning about brain injury was crucial. There wasn’t much information around twenty-odd years ago, so I wrote down my difficulties and worked on them, and worked things out. I found out information and wrote a book about brain injury, Doing Up Buttons, which Penguin Books published. As I struggled with all the challenges, I realized I hadn’t gone mad. It was my brain injury that tripped me up. The experts couldn’t make me better; I had to find ways to help myself. No matter how hopeless things seemed, I had to have hope—to keep on trying.

With a lot of planning and preparation and the love of my family and friends, I have slowly learned to push myself outside my comfort zone. Nature, the seasons, feeding the birds, finding things I love to do—walking in the bush, writing, going out, doing “normal” things—have also helped dry my tears of shame.

If the brain injury wizard has put a spell on you, break that spell by learning about brain injury, thinking about how you cope and finding new ways to cope, and never ever
An educator by training, Christine Durham suffered extensive injuries including brain injury in a horrific car accident two decades ago. Author of Doing Up Buttons (Penguin Books, where she brought to life her experience—from being unable to walk, talk, see, or think properly to how she regained her life—found her feet, her thoughts, and her confidence) and Chasing Ideas (Finch Publishing), Christine speaks to a wide variety of audiences. Christine’s 2012 PhD identified ways people with brain injury can help themselves to feel and fare better. She received the BrainLink 2012 “Woman of Achievement Award.” She lives in Australia.

Then: I got terribly upset!
Now: I think about it!

MY REALITY CHECK

When I feel upset, anxious, stressed, worried, angry, guilty, frustrated, embarrassed, insecure, jealous, etc.

When I behave in an undesirable way, act impulsively, slam the door, yell, say nasty things, tell fibs, and isolate myself…

I ask myself:

- What positive steps can I take to resolve this situation?
- Are my emotions helping or hurting me?
- Are my emotions hurting my family (they don’t deserve to be upset!).
- What am I telling myself? Am I seeing the “truth” or is my thinking distorted? Am I filtering – only seeing what I want to see, using black and white thinking (things are either very bad or very good)?
- What are the facts?
- Am I exaggerating or distorting things? Do I think things should be “fair” as I see it? Am I blaming others when it is not their fault?
- Are there other explanations to this situation?
- What’s the worst thing that can happen?
- Am I “awfulizing” this situation? Am I catastrophizing this situation (seeing small things as catastrophes)?
- Am I taking this all too seriously?
- Am I taking this too personally?
- Am I unrealistically demanding success in everything I do (with brain injury it can be impossible to succeed in everything!).
- Am I unrealistically seeking approval? Control? Fairness? My way?
- Do I think I am always right?
- How can I think more realistically? What are my options?

Christine Durham ©2013

Then: I thought I was hopeless!
Now: It’s not the end of the world!

I measure my worry against the trauma-catastrophe scale, then try to react in the appropriate way.

0. …….2……4……. 6……. 8…….. 10……

A. I write down the event/happening that is upsetting me.

B. Then I read the following and ask myself: “How long will this event or situation upset me?” as I put my finger on the “Measure It” Scale.

10 = This will still upset me (and my family) and affect my (our) life in 5 years. (Death of a family member, life threatening illness/accident of family member) – I tell myself, “It’s ok to cry and be very, very, very upset.”

8 = This will still upset me (and my family) and affect my (our) life in 3 years (house burn down, bad car accident) – I tell myself, “It’s ok to cry and be very, very, very upset.”

6 = This will still upset me (and my family) and affect my life in 1 year (Spouse loses job, house is robbed) – I tell myself, “It’s ok to cry and be upset.”

4 = This will still upset me (and my family) and affect my life in 6 months (dog dies, best friend goes to live overseas) – I tell myself, “It’s ok to cry.”

2 = This will still upset me and affect my life in one month (then other things will happen and I will feel OK and get used to things being different) – I tell myself, “It’s ok to feel sad at times.”

0 = This will still upset me and affect my life for a day (then other things will happen and I will forget about it) – I tell myself, “You need to find a way to cope with this—talk to someone about it. Remember that people aren’t mind readers. You may feel disappointed or frustrated, but it’s not the “end of the world.”

Christine Durham ©2013
When we are younger, so much of life is centered around the process of learning. We learn to speak. We take those cumbersome first steps as we become toddlers. Fast forward a few years as we learn life skills, like reading and writing, that enable us to become a productive part of society.

Once a specific skill is learned, most people move on through life. But a brain injury is a veritable game-changer. Like an eraser on a super-sized pencil, a brain injury can virtually erase so much of what we took for granted.

This I can share from a personal perspective, for it was on November 11, 2010, that a brain injury “erased” much of my life when a teenage driver broadsided me while I was out on my daily 30-mile cycle ride.

In two ticks of a clock, my life was forever changed. But I didn’t yet know the full extent of it.

Symptoms slow to emerge

While many folks who have sustained a brain injury know immediately that “something was different,” such was not the case for me. Symptoms of my brain injury started to surface slowly over the first couple of months after my accident.

In the second month after my injury, my ability to speak was abruptly compromised. For someone who communicates for a living, this was a devastating blow. Unending vertigo struck with equal force, making the simple act of walking an unexpected challenge. As memory issues surfaced, my ability to remember the day of the week, or even the current month, began to evaporate.

Like a giant eraser cutting a swath through the middle of my life, my injury was removing, sometimes quickly, sometimes slowly, the skills I needed for daily life.

If the story ended there, this would be a tragic tale indeed. But such was not the case. Long before my injury, I was known to be quite tenacious. Sometimes even called “stubborn.” Looking back with the benefit of hindsight, it was my stubbornness that saved my life.

Being stubborn helped

I simply was not going to let my brain injury beat me. We only get one shot at this life. If my fate was to live with a brain injury, I was going to make the most of it. From my strong-willed standpoint, there were no other options.

Slowly, over the months that followed, I did my best to understand what my specific new deficiencies were. It was only after I identified and understood them that I could start to develop compensatory strategies to again live my life.

A few of my symptoms self-resolved over time. Gradually, at what felt like a snail’s pace, I watched vertigo drift further into the background of my life. As I was also diagnosed with Post-Traumatic Stress Disorder, symptoms well beyond my brain injury haunted me as well. It was well over two years after my accident that my persistent PTSD nightmares started to abate.

But many of my newfound challenges simply would not go away. The passage of time proved to not always be my friend.

For example, when it became clear that my ability to be certain of the day of the week was not coming back, and that my recall of the current month was not getting better, it became time to look at an alternative method for enhancing my compromised ability to recall.

This took the form of a multifunction wrist watch with the day, date, month, and year within arm’s reach. Though this may sound like a natural solution to my chronological challenges, brain injury sometimes hides such simple solutions from me.

“It can’t be as easy as just wearing a different watch,” my mind shouted when my wife, Sarah, suggested this solution.

But to this day, when I have the need to quickly pull the day of the week out of my hat, I no longer rely on my brain. My instinctive reaction now is to look at my watch. I did not
relearn how to pull this information from a damaged brain, but found a new way to achieve the same result, thanks to Sarah.

My compromised ability to speak was more challenging to resolve. In fact, I had to learn a new way to talk. Long gone was my ability to speak fluidly without much forethought. I began the tedious process of “pre-thinking” every word before I spoke it aloud.

For months, the speed of my speech was painfully slow. But like an athlete in training, my speed picked up. Today, years after my brain injury, I still use this adaptive strategy. Longer conversations wear me down like never before. But there is a huge sense of satisfaction when a conversation closes—and no one present can detect my speech challenges!

New solutions rebuild life

About a year into my life as a brain injury survivor, a neuropsychologist made what I now know to be a life-changing suggestion: “Move as much mental processing out of your brain as possible.” He went on to share that this would free up my remaining internal resources for the tasks of day-to-day living. Suffice to say, he was correct.

From moving my ability to tell time to the outside of my brain, to using a web-based calendar to schedule the day-to-day events that defined my life, over many months I slowly migrated into a new way of living.

Yes, that eraser wiped away so much of my life. At first, I thought this to be a bad thing. But now I see it for what it was. By cleaning the slate, I was able to begin much of my life anew.

I read a while ago that brain injury is the last thing you think about, until it’s the only thing you think about. While this is true, I have found that a life, one very much worth living, can be rebuilt.

Developing a new way to live my life has become close to second nature to me. While it does not take away the fact that much of my life is more challenging than it’s ever been, it does leave me open to trying new solutions to unexpected brain injury-related challenges—suggestions that now have a proven track record of improving the quality of my life.

David A. Grant is a writer based in New Hampshire and the author of Metamorphosis, Surviving Brain Injury. A survivor of a harrowing cycling accident in 2010, David openly shares his experience, strength, and hope as a person with a brain injury. Recently recognized by the Brain Injury Association of America, David’s book offers real-world insight into life as a brain injury survivor. For more information, please visit www.metamorphosisbook.com

Attention / Concentration

The ability to pay attention and concentrate can affect everything from managing a household to succeeding in school or performing a job. Attention is the ability to focus on something. It may be a conversation, a movie, a sound, or an activity. How long the person holds this attention is called concentration. Something might get your attention, but may not keep your concentration if it doesn’t interest you or is too hard to follow.

Do you...

☐ Find it hard to stay focused on a task?
☐ Have trouble focusing on more than one task?
☐ Become easily distracted?
☐ Leave tasks unfinished?
☐ Find it hard to follow conversations?
☐ Have problems following instructions or directions?

Tips on compensatory strategies...

✓ Focus on one task at a time.
✓ Break tasks down into steps. Allot a short period of time for each step.
✓ Clear home and work areas of unnecessary distractions.
✓ Perform tasks in a quiet area.
✓ Use timers, alarms, and checklists to mark completion of tasks.
✓ Remind the survivor when the conversation goes off the topic.
✓ Ask for instructions or directions to be repeated.
✓ Eat a balanced diet and get proper rest.
✓ Discuss medications that help with attention with a physician specializing in brain injury rehabilitation.

Excerpted from Lash & Associates Tip Card called Cognition: Compensatory Strategies after Brain Injury (CCST). Tip cards on all sorts of brain injuries, concussion, PTSD (and more) are available by calling 919-556-0300 or online at www.lapublishing.com/brain-injury-ptsd-adult/
THE ONION EFFECT:
UNDERSTANDING THE TEARS
AND LAYERS
OF LOSS

by Janelle Breese Biagioni, RPC

As an individual travels the journey of grief, the magnitude and impact of loss is revealed in layers. Much like peeling an onion, the deeper the cut, the more tears shed. Why? Loss is incredibly painful, life-changing, chaotic, and strikes without choice.

Traditional teachings state that loss results from death, divorce, and other life transitions. Today’s expanded list includes Alzheimer’s, chronic illness, and catastrophic injuries such as spinal cord and brain injury. A medical model, which is to assess, diagnose, and treat, was the typical approach to help the bereaved. It didn’t work. The pain and suffering resulting from loss is not time-specific, orderly, or predictable. Much more fitting is the Companioning Model, which is to be present for the person and walk alongside them for however long they need to explore and give expression to their feelings.

Historically there was little else to offer those suffering from loss. Erroneously, society believed that keeping a stiff upper lip or not talking or dwelling on what happened were the proper ways to cope. The truth was, the outside world didn’t know how to help people work through the devastation they struggled with. Thankfully, in 1969, Dr. Elisabeth Kübler-Ross wrote On Death and Dying. This ground-breaking book was like taking water to the parched. Until then, social workers and others in the helping profession were not equipped to facilitate the conversation about loss. Kübler-Ross opened the doors for that dialogue.

Having said that, her model, known as the Five Stages of Grief (Denial, Anger, Bargaining, Depression, and Acceptance), was interpreted as a list of emotions to be experienced in a specific order. Before her death, Kübler-Ross declared the model was not meant to be a list of absolutes but rather a list of potential responses.

Dr. Alan Wolfelt, of the Centre for Loss & Life Transitions, offers a much more expansive range of responses which include shock, numbness, disbelief, disorganization, confusion, anxiety, panic, fear, physiological changes, explosive emotion, sadness, and more. He teaches that ultimately the person works towards reconciliation and healing.

Don’t sidestep the journey of grief

As the layers of loss are revealed, it is not unusual for the person to resist and/or suppress feelings. That’s okay for a while—it’s actually healthy to take a bit of a break from the sorrow. But when the pushing aside becomes an outright dismissal of the pain, then additional problems may set in. You cannot sidestep grief. There is no way to get to the other side of it except to go through it. Unresolved grief will take any opportunity to rear its ugly head.

I like to use the analogy of a yard flush with bright yellow dandelions. You can mow the grass and cut every head off. But before the lawn mower is tucked away, you witness the lemon-colored petals of another head pop up from the ground. Why? Because you only skinned the surface with a blade—you didn’t get the root.

The work of grieving is the same. Unless you get to the root of how you feel and work through those feelings, grief will pop up again and again in your life. Much like the snowball effect, it will get bigger and bigger. Remember: the only wrong way to grieve is to not grieve.

As people grieve, their loss morphs into a multi-dimensional journey which requires an unknown length of time to reconcile. The reason is that loss isn’t an event, it’s a process. It is not time specific. As time passes, people discover how what has happened impacts them personally and in their daily life, thus revealing the layers. This applies to loss through death, divorce, and separation, as well as developmental losses (such as empty nest or retirement), loss of external objects (such as a house fire), and a loss of self.

The latter—a loss of self—resonates the most for people with a brain injury. They are no longer the same person, and they no longer function in the same way as they had before being injured. This is painful and causes suffering.

Brain injury means loss for the whole family

The entire family experiences loss through their loved one’s brain injury. How can it be that the family suffers a loss when the person is alive and home with them? Isn’t it only the person who is living with physical and/or cognitive deficits who suffers? No, because often the roles and responsibilities shift in the family.

For example, after my husband was injured he could
not return to work. Given there was little community support in place 23 years ago, his care and supervision fell onto me. This meant that I could not work, as taking care of him was a full-time job. He was a police officer so we continued to receive his pay until he died. But I was self-employed, and if I wasn’t working there was no extra money coming in. This resulted in lifestyle changes for us.

My children suffered as well. Not only was their father unable to engage with them as he had prior to being injured, I was also not functioning as the mother that I had been either. They were still fed and clothed and went to school, but I had no time for extras like reading, playing games, or just spending time with them. Everything went into getting their dad through the day. Our children, as other children do, assumed responsibilities that were not theirs. They became equal caregiver with me, often having to help out with their dad instead of being outside playing with their friends.

It’s not fair, but it is the reality that many families live with. Each of us experienced a layer of loss and had to work through that.

S.H.A.R.E.

Individuals and families living with loss have special needs. When loss is escalated by the impact of brain injury, these needs are significant, and people need help. The S.H.A.R.E. list provides ways to help:

**Supports** – people need short-term and long term supports from a variety of people.

**Hope** – an effect of loss is hopelessness. They want to know happiness will return in their life; however, they have little capacity to hear it. Gentle reassurance is important.

**Acknowledge** – help the person to express and acknowledge what it is they have lost. Don’t persuade, dissuade, or judge.

**Reflection** – healing requires turning inward. Personal reflection facilitates the searching for meaning and understanding of what has happened and how one will survive.

**Engage in life** – when the person reconnects with loved ones, friends, coworkers and community, it is a sign of healing.

Extended family, friends, and colleagues are capable of providing supports; however, professional counseling can also help. Counseling provides a safe place for people to give expression to their pain. It will assist in exploring feelings about what has happened and provide guidance to reconcile those feelings.

Remember, there is no sidestepping grief. You have to go through it to get to the other side. Doing the work will keep you safe from turning to drugs or alcohol, and it allows you to live the rest of your life to the fullest. Why? Because you deserve to … we all do!

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.lifelosses.com](http://www.lifelosses.com) and follow her blog at [www.janellebreese.blogspot.com](http://www.janellebreese.blogspot.com). She can be contacted at Janelle@lifelosses.com

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**In My Perfect World**

by Janelle Breese Biagioni, RPC

When people wonder why I do what I do, I tell them this…

Because in my perfect world, everyone would readily wear a helmet, a seatbelt, and drive their vehicle knowing the lives of many can be altered with one single moment of carelessness.

Because in my perfect world, there would never be another child to wonder why daddy can’t walk the creek bed to look for fish anymore, or wonder where his laughter has gone, or why his eyes hold the emptiness of no hope in tomorrow.

Because in my perfect world, there would be never another wife who grieves the loss of her lover, her companion, and an equal partner to walk at her side.

Because in my perfect world, families would never know the place of darkness that holds broken hearts and shattered dreams.

Because in my perfect world, government would hold the rights of people equal, knowing there is no one person deserving anything less.

Because in my perfect world, the arms of this nation would be linked together walking as a whole.

Because in my perfect world, brain injury simply doesn’t exist.


Check out our blog posts at:

[www.lapublishing.com/blog/](http://www.lapublishing.com/blog/)
Ten years ago, I got the phone call every parent dreads. My son Neil, then 17, had been hit from behind by a drunk teenaged hit-and-run driver while walking his girlfriend, Trista, home after a study date at our house. He was taken to the local hospital where he was diagnosed with a traumatic brain injury and quickly transferred to a Boston hospital’s intensive care unit. His girlfriend was not so “lucky.” She succumbed to her own massive head trauma and the next day was taken off life support.

I knew we had a long road ahead of us. Neil spent days in the ICU, months in physical rehab, and years in therapy and on anti-depressants. I grieved for everything Neil had lost: not only his girlfriend but also his memory, his concentration, his executive function, his sense of humor. What should have been the time of his life—senior prom, high school graduation, getting into the college of his choice—just turned out to be one long struggle.

When I began writing my memoir, Crash: A Mother, a Son, and the Journey from Grief to Gratitude, a friend looked at me, bewildered. “But Neil’s okay, right?” she asked. I suppose it was a legitimate question as Neil does, in fact, look “okay.” But as anyone who has suffered a brain injury or has a family member who has survived one knows, the associated losses and disabilities are often subtle or unapparent.

But with my grief came guilt. After all, my son was alive while his girlfriend was not. Even from those early days, standing over Neil shivering under a skimpy sheet on a stretcher in the emergency room, wanting to warm him, I thought of Trista’s mother, Mary, and how she would give anything to feel Trista cold and shivering instead of just plain cold. When Neil showed signs of temporal lobe agitation, lashing out at the staff and at me, it was hard to take: listening to my normally sweet-dispositioned son berating his nurses and his mother. But I thought of Mary. Wouldn’t she love to hear Trista’s voice again, even if she were yelling?

At first I thought that what I was experiencing was a kind of survivor’s guilt by extension. My son had survived a horrific accident that his girlfriend had not. But I have since learned that what I was dealing with was something more. Something called disenfranchised grief.

Disenfranchised grief

The term “disenfranchised grief” was coined by Dr. Kenneth J. Doka back in 1985. He has written two volumes on the subject and defines it as “grief that persons experience when they incur a loss that is not, or cannot be openly acknowledged, publicly mourned, or socially supported.” (Doka, K. Disenfranchised Grief: Recognizing Hidden Sorrow. Lexington Books. 1989.)

Examples of disenfranchised grief include loss that occurs in relationships society does not recognize or countenance, such as gay lovers or those involved in extramarital affairs. Here, the mourner herself is not recognized because the relationship is not approved by society. In other situations, the way the person died may affect how the surviving mourners are perceived and accepted. Death by suicide or homicide, drug overdose, or AIDS fall into this category of grief being somehow diminished because the death occurred in a way society may be uncomfortable with. The death of a pet is also often cited as another example of a loss society does not readily accept.

But a death need not occur in order for grief to be disenfranchised. Examples of these kinds of losses include a failed marriage or the loss of a job or the losses associated with illness or injury. This is the kind of mourning I was doing for Neil: grieving for the loss of the life we both had dreamed of for him.

A grief often misunderstood

The difficult aspect of dealing with disenfranchised grief is the misunderstanding of my suffering by so many around me. The parents of Neil’s dead girlfriend only saw in him all the things their daughter would never be: the high school graduate, the college student. Even close friends did not necessarily understand my grief after my son’s traumatic brain injury. When I began writing my memoir, Crash: A
Mother, a Son, and the Journey from Grief to Gratitude, a friend looked at me, bewildered. “But Neil’s okay, right?” she asked. I suppose it was a legitimate question as Neil does, in fact, look “okay.” But as anyone who has suffered a brain injury or has a family member who has survived one knows, the associated losses and disabilities are often subtle or unapparent.

It took me many years to let go of my guilt over the grieving of Neil’s losses: to acknowledge and own my grief as real and legitimate. And that is the first step in helping someone to enfranchise their grief: to recognize their feelings as valid and worthy. To allow them to give voice to their feelings, and to try to understand those feelings. They then must be given the time they need to properly mourn their loss.

Some with disenfranchised grief may need to seek expert counseling, but the understanding and support of family and friends can go a long way in the healing process.

Dr. Carolyn Roy-Bornstein is a pediatrician, a mother, and an award-winning writer. She is the author of Crash: A Mother, a Son, and the Journey from Grief to Gratitude (Globe Pequot Press. Sept. 2012.) Her work has appeared in the Boston Globe, JAMA, Pediatrics, Yale Journal of Humanities in Medicine, several Chicken Soup for the Soul anthologies. She has been interviewed on radio and TV and speaks regularly to doctors, nurses, college students and civic groups about traumatic brain injury.
"Either you control the memory or the memory controls you."

These words on a sign in Ron Capps’ office remind him not only of how he has learned to deal with his own past but also how his new work helps others. He deployed to wars for the U.S Army, U.S. Army Reserves, and the State Department over a quarter century, witnessing unimaginable horrors, including genocide in Rwanda and ethnic cleansing in Kosovo.

Part of his job during those years was to write factual reports of events so that analysts and policy designers and implementers in D.C. could understand the situation. As his experiences began to haunt him more and more, he started writing a second, private version that included many more horrific details he could no longer bottle up.

The private writing helped but, eventually, he says, being witness to the horror of what human beings can do to one another in war “pushed me over the edge.” Pistol in hand, he contemplated killing himself while deployed to Darfur. A fortunate phone call from his wife diverted him.

Diagnosed with PTSD, he left government service in 2008, but he still had to find a way to deal with his demons. He entered grad school on the GI Bill to get his MA in writing, knowing that writing would help him.

The power of writing

Much of the foundation for VWP comes out of research on the healing power of making art. “Writers have known that telling any story is therapeutic for about 25 or 30 years,” Capps says. “The science behind it is fascinating.”

Capps grew intrigued with this science as he was investigating art therapy. The research began in the mid-1980s with James Pennebaker, PhD, a research psychologist at the University of Texas at Austin. Pennebaker began researching how writing down one’s thoughts and feelings about traumatic experiences—what he called “expressive writing”—could help people heal from those experiences. He conducted his first study with college students, and the...
results were startling: Writing about one’s deepest feelings and thoughts about a traumatic experience—for only 15 minutes four days in a row—led to fewer illness visits to the health center over the next six months, as well as a more positive outlook, improved moods, and greater physical health. (Pennebaker, James W., PhD. 1990. Opening Up: The Healing Power of Expressing Emotions. New York: The Guilford Press)

Since that first research study, more than 200 other researchers have confirmed the power of writing about deep thoughts and feelings. The results often were the same, with benefits to physical and emotional well-being.

Pennebaker’s research and writing became the keystone of VWP’s work. All the participants at Walter Reed have read his work, and Pennebaker went to Walter Reed to help the program directors structure the program.

There is a major difference between expressive writing as studied by the researchers and creative writing. With expressive writing, a person simply writes, as in a journal, with no concern about structure or the fine points of writing. It’s private writing, simply to get the words out. Creative writing, on the other hand, includes the additional steps of shaping, revising, clarifying, and editing to produce literature to be read by others. These additional steps add to the healing power because the writer can gain distance from the event by shaping and reshaping the experience, transforming it into a memory that no longer hurts. Interestingly, this is true for writing both fiction and nonfiction.

Bearing witness

As Capps wrote in his curriculum guide, Writing War: A Guide to Telling Your Own Story, the aim of VWP is for participants to write from first-hand experience to “create a literature of war rather than a literature about war”—to write about the entire military experience so that those with little knowledge of military life can learn and understand.

Capps explains that after World Wars I and II there was “an explosion of writers” who told their stories in now-famous novels, memoirs, and poetry collections. Yet during those wars and through Korea and Vietnam, the draft sent tens of millions of people to war, creating a better understanding of war and military life throughout the nation. Now, with less than 1 percent of our population in the volunteer military during the last 12 years of war, that widespread understanding is missing. Therefore, says Capps, it’s important for those who have lived the military experience, whether or not they have ever left the States, to bear witness. “We have the responsibility to bring back our reports of what happened,” says Capps.

This tradition goes back to ancient Greece, he explains: “The whole town would listen to the soldiers’ stories. It was hugely healing for the warriors and crucial for others to understand what war is like.” Today, writing offers the storytelling avenue that leads to healing in the writers and increases understanding in those who read it.

VWP is “creating an archive of literature written by, about, and for the military community,” says Capps. It publishes a literary journal, O-Dark-Thirty, and is gearing up to publish books through its BCG Books. Most VWP workshops and seminars now take place in the Washington, D.C., area, but they are expanding to the New York and Boston areas, and he “would love to go out west,” says Capps.

The VWP is funded through donations and sponsorships; no government funds are used. See more at the website. (veteranswriting.org) 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. www.barbarastahura.com
Writing has been something I have done off and on since about 5th grade or so. I wasn’t all that good at it in the early years of my life, even through high school. I would do some creative writing for English class if I needed to, or to try and impress a girl. Nothing really too deep or too touching. I look back at it now and see what I was missing.

The element of my muse I was searching for with my writing was...pain, suffering, rock bottom, I suppose. Being deployed to Iraq gave me these things. I had stopped writing for about six years after high school until I had a chance to share my story. Melanie Davis reached out to a few disabled veterans through the Wounded Warrior Regiment with the Marine Corps. She was writing a book of veteran stories, and she wanted us to share our stories of triumph and our pain. Being a personal historian, she is very interested in preserving our heroes’ stories. I expressed my interest in writing my story about my military career, and with Melanie’s help I got my chance. After some writing and many phone calls, we started to piece together my story.

Through writing about my life during my time in the Marine Corps and after, I started to get in touch with the deep down, raw emotions of the darkest corners of my mind. They truly scared me, and I really did not know what to do with them. With encouragement from my wife and some pushing from Melanie, I started to express these emotions on paper, in ways I never had before. The power of releasing those emotions was amazing. I started to feel the stress of the hard times in my life beginning to fade. They never will go away, because they are part of me, but they started to fade. I just started writing, and my writing became free form poetry.

I let my issues become the paper’s issues as I spilled my passions, anger, remorse, and sadness on the blank, white page. It left me drained but somehow mentally satisfied. The more I wrote, the stronger some of the emotions got. I began thinking that I can’t be the only veteran who feels this way. So I took a huge step and started to share my words with the world via social media, friends, and some online publications. The feedback I have been receiving from other veterans has been a large outpouring of support. My writing is shared from the veteran to a loved one or another veteran and sparks conversations that might never have happened without a little push from my writing.

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.
Lash & Associates Publishing/Training Inc.

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Clinical Corner

Talking with Your Spouse or Charlie Brown’s Teacher?

Miscommunication in Couples after Brain Injury

by Dawn Neumann, PhD

The dam finally broke for Christine as she shared with the group her mounting frustrations towards her husband, Mark. “Since his car accident, every time I talk with my husband I get the impression I must sound like Charlie Brown’s teacher,” she said. “Repeatedly, I try to explain my thoughts and feelings to him, trying to make him understand what I’m going through. I feel that I must be insane. Otherwise, why would I keep doing the same thing over and over expecting to get a different response? I’ve explained a million times how I feel, so why won’t he change? I can only assume from his lack of a response, he must not love me anymore because if he cared, he would try to make me happy.”

Anyone ever feel like Charlie Brown’s teacher when talking with your spouse or partner?

No doubt you have heard before that good communication is the foundation for a good relationship. Without good communication, relationships are as vulnerable as a house of cards, struggling to withstand even the slightest breeze. Communication is often a challenge for most couples, but after a brain injury, couples are even more susceptible to problems with miscommunication. Largely, the miscommunication we often see after brain injury tends to revolve around the couple’s inability to share and understand each other’s emotions and needs.

“When we can talk about our feelings, they become less overwhelming, less upsetting, and less scary. The people we trust with that important talk can help us know that we are not alone.” — Fred Rogers

Christine was trying to share her fears and needs with her husband, looking for him to communicate support and understanding, only to be met with a blank stare. Christine felt very alone in their relationship. Instead of soothing her emotions, they were only worsened.

“The void created by the failure to communicate is soon filled with poison, drivel and misrepresentation.” — C Northcote Parkinson

Mark’s silence and lack of response falsely communicated to Christine that he didn’t care about her. If asked, Mark would say he loved his wife very much, that she meant the world to him and he’d be distraught without her. So why didn’t he respond to her? After Mark’s injury, his ability to experience and express certain emotions, like fear or sadness, changed. For the most part, he was a happy go lucky guy; he could no longer experience or relate to the emotional concerns expressed by his wife, and as a result, was unable to empathize. He couldn’t infer her needs or detect the urgency or seriousness of the matter.

“Assumptions are the termites of relationships” — Henry Winkler

Because Christine did not realize Mark’s brain injury made it difficult for him to relate to her emotions, she began to make assumptions about what he was thinking and feeling. She assumed he no longer loved her because her emotions seemed to mean nothing to him. She asked, “Would he even be upset if I left? I really don’t know.”

“To effectively communicate, we must realize that we are all different in the way we perceive the world and use this understanding as a guide to our communication with others.” — Anthony Robbins

Mark and Christine were not seeing each other’s side. Unfortunately, the ability to think of things from another person’s view point is often greatly diminished after a brain injury. We cannot assume our spouse is going to interpret or understand our feelings, anticipate our needs, or respond to a
situation the way we would expect most people to. It is also difficult for a person without a brain injury to imagine how someone who has a brain injury sees the world.

“Remember not only to say the right thing in the right place, but far more difficult still, to leave unsaid the wrong thing at the tempting moment.” - Benjamin Franklin

One of Mark and Christine’s interactions ended with him saying, “Christine, you’re overreacting like you do about every little thing.” She responded, “You are such a jerk. Maybe it’s time I found a new man to care about my needs.” For both partners after a brain injury, it can often be hard to know the right thing to say in a given situation, and it can become even more difficult in the heat of the moment to fight the impulse to say very hurtful things to our loved ones. When angry, we respond with a kneejerk reaction that really doesn’t communicate to our partner how we really feel or what we want.

But there is hope for good communication after brain injury. Here are some important communication tips:

• Be explicit. Tell your partner when something is truly important to you.

• Share and validate each other’s vulnerable emotions. For example: “I can see how you might feel worried and afraid, and I’m sorry you are feeling that way.”

• If you don’t understand your partner’s emotions, or you don’t know how to respond, then ask your partner for guidance: “Please, I’m having trouble understanding what you mean. Can you try to explain it differently?” or “Tell me what I can do to help you feel better.”

• Role-play and try to put yourself in your partner’s shoes. Think about where your partner is coming from, and what your partner could relate to. Use this understanding to explain your situation in a manner he or she could better understand.

• Because people with brain injury may have difficulty knowing how to respond to your emotional needs, tell your partner what you would like to be done.

• If you have trouble experiencing emotions the way you used to, think back to your emotional experiences before your injury. Act out emotions in the mirror. These exercises could help ignite your emotions.

• Avoid making assumptions. Realize your thoughts are not facts, so verify your thoughts with your partner.

• Before responding harshly to your partner, try to figure out why you feel so angry. When we feel angry, there are often more vulnerable emotions at the root of that anger, such as feeling hurt, afraid, or disrespected. Try to communicate what you are really feeling. For example: “It hurts my feelings when I express my fears to you and you don’t try to comfort me.” Refrain from blaming, name calling, attacking, and “I told you so’s.”

Dr. Dawn Neumann is an Assistant Research Professor at the Indiana University School of Medicine in the Department of Physical Medicine and Rehabilitation, and Clinical Research Faculty at the Rehabilitation Hospital of Indiana. She has her M.A. in Psychology from Rutgers, NJ, and a Ph.D. in Rehabilitation Science from the University at Buffalo, SUNY. Dr. Neumann’s research focuses on understanding and treating a variety of emotional problems after brain injury, including impaired social cognition and nonverbal communication, empathy loss, irritability and aggression, and poor interpersonal/marital relations. She is the Chair of the Early Career Networking Group (EC-NG) for the American Congress of Rehabilitation Medicine (ACRM) and serves on ACRM’s Board of Governors as their Early Career Member-at-Large.
Kids' Club

EXECUTIVE SKILLS IN CHILDREN AND TEENS WITH BRAIN INJURY

by Janet Tyler, PhD

Tom, 13, isn’t buckled up when his friend loses control of his car, and his head slams into the dashboard during the crash. Sierra, 10, is kicked in the face by a horse while visiting a stable. While having a fun day of sledding, Taylor, 16, runs headfirst into a tree. All three of these children sustain traumatic brain injuries that affect their frontal lobes.

Sitting behind the forehead, the frontal lobes are often injured during a traumatic brain injury (TBI). They play an important role in directing and regulating our thoughts and actions. They are responsible for allowing us to carry out complex mental functions such as paying attention, planning, organizing, problem solving, controlling behavior, setting goals, and self-evaluating. These high-level skills are known as “executive functions” or “executive skills” and a brain injury that affects them can have a strong impact on cognition, emotion, and behavior.

Fortunately, the right interventions can help students with brain injury function better in school and at home.

Executive skills

Impairments in executive skills can show up in the classroom and at home for children and teens with brain injury. Here is a list of these skills and examples of each.

Initiation - Allie sits at her desk doing nothing while everyone else has begun the assignment. Sam takes so long to decide which game to play his free time is over.

Planning/Prioritizing - Miguel waits until the last minute to begin his school projects and when he does start, he first does the tasks he enjoys instead of the most important ones.

Organization - Taylor, who was very organized before his accident, now comes to class without the right materials and chronically loses his belongings.

Problem Solving - Madison cannot solve problems of many kinds, and she refuses to consider suggestions from others.

Sustained Attention - Diana is easily distracted and once interrupted cannot get back on task. Marcus starts projects with enthusiasm but quickly loses interest.

Impulse Control - Tom now blurts out irrelevant or random comments in class, and he cannot wait to hear all the instructions before beginning an assignment.

Goal-Oriented Behavior - Jared can no longer create short- or long-term goals. He desperately wants to be part of the baseball team but does not follow through with practicing.

Self-Evaluation - Tameka can no longer identify successful classroom behaviors. Neither can she correctly estimate the time it will take to complete a task well.

Children and teens with frontal lobe injuries may have impaired functioning in some or all of these areas. As they grow older, these impairments may worsen. As they face increased academic, cognitive, behavioral, and social demands, their deficits become more noticeable.

These impairments can have a far-reaching impact on students’ overall performance. Even if they are able to learn to read, do math problems, and master job-related skills in the classroom, those skills will be of little use outside of school unless they can apply that information to unique situations. To be successful in the real world, students also need to be able to solve problems, manage their own behaviors, plan, and achieve goals.

Helping students with executive skill impairments

For most children, normal maturing of their brain and ongoing interactions with parents, teachers, and other adults help develop their executive skills. But children with frontal lobe injury may need closer direction to improve those skills. Once specific areas needing improvement are identified, teachers and parents can make adjustments in the classroom and at home, teach specific skills, and give children better opportunities to evaluate and improve their own executive performance.

For example, Miguel has weak planning and prioritizing skills, so he can use step-by-step instructions to make these skills conscious and deliberate. At school, teachers can walk him through various schoolwork tasks, using as many cues as needed. At home, his parents can have him help plan activities such as a party or family trip.

Diana has difficulty paying attention, so her teachers can break her assignments into smaller pieces and give her focusing cues until tasks are complete. At home, her
parents can provide a specific area for homework, free of distractions, to help her stay on task. Taylor, who now struggles to stay organized, can benefit from a daily morning session with his teacher to review the day’s schedule and gather materials for each class. At home, Taylor’s parents can create a checklist of chores, including the steps required for each one, to help him complete them successfully.

Specifically teaching executive skills and making adjustments in the home and classroom setting can help address areas that are weak. The eventual goal is for the child’s own executive skills to become strong enough so that the external supports can fade away.

**Strategies for better executive skills**

Having a frontal lobe injury often means that children can find it difficult to judge and evaluate their own performance. Fortunately, they benefit from learning how to do this through “metacognitive strategies,” or easy-to-follow procedures that help them understand their own cognitive (thinking) processes. These procedures have several steps:

- identify a goal
- plan how to reach it, and
- keep track of the process.

Along the way, children ask themselves questions such as, “Am I following the plan” or “How am I doing?” to give themselves feedback to keep improving. At first, teachers and parents model procedures for them and offer cues for using them. By practicing on everyday tasks with adult supervision, children with frontal lobe injury find that procedures become automatic, and eventually they can work on their own. By using metacognitive strategies regularly, children can practice setting goals, planning, predicting, organizing, problem solving, self-monitoring, and self-evaluating.

**For more information on executive skills see:**

cbrt.org/tbi-education/executive-functions/

www.brainline.org/content/2011/02/executive-functions-and-communication-in-adolescents_pageall.html

As a special educator, Dr. Janet Tyler has not only worked directly with students with TBI, but she also trained educators to serve those students. For 23 years, she directed an innovative statewide program in Kansas that provided training and consultation to educators serving students with TBI and their families. She is now in private practice providing educational consultation and training services to school districts, lawyers, medical personnel, and parents of children with TBI. Dr. Tyler can be reached at jtyler@kstbi.org

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MEDITATIONS ON BRAIN INJURY

by Mike Strand

Reviewed by David Grant

Sitting down to read this short volume of essays, I wasn’t quite sure what to expect. Over the years since my own brain injury, I have read many titles about learning to live this new life, some by survivors and others by the medical community.

To say that Meditations on Brain Injury offered more real-life practical insight about rebuilding a life after brain injury than most any title I have read is a vast understatement.

Mike Strand holds the proverbial “Keys to the Kingdom” as he openly and from the heart shares on a wide range of topics including rebuilding relationships and embracing acceptance after a brain injury. Between the covers of his book, Mike lays out a veritable road map on how to not only live life with a brain injury, but on how to embrace life and actually thrive in the often confusing post-injury world.

His candor and quick wit are refreshing as he draws upon more than two decades of real-life experience living with his own brain injury. This is not a one-time book to read, only to be put on a shelf to gather dust. As a member of the human family living daily with this injury, I’ll be referring back to this powerful volume regularly.

In a perfect world, Meditations on Brain Injury would be requisite reading for anyone affected by a TBI. My only regret is in not having found this book earlier in my recovery.


Item: MEDIT, 65 pages, softcover, $10.00

www.lapublishing.com/brain-injury-survivor

CRASH: A MOTHER, A SON AND THE JOURNEY FROM GRIEF TO GRATITUDE

by Carolyn Roy-Bornstein, MD

Reviewed by Marilyn Lash, MSW

This book is a gem; I was hooked after the first chapter. Factually, it is a story all too familiar. A teenage boy and his girlfriend are hit by a drunk driver while walking home on a dark night. Both are seriously injured; she dies, he survives.

Carolyn Roy-Bornstein is a pediatrician, yet she is as unprepared as the rest of us for the trauma of brain injury when it is her son Neil. Negotiating the medical care system is one thing; navigating the emotional devastation of a mother’s grief and loss is another.

Readers will appreciate the complexity of a parent’s anguish and fears, the hopes and pitfalls for recovery. Grateful that her son has survived, she is caught in conflicting emotions of guilt and gratitude as she struggles to mourn what her son has lost while she witnesses his struggles to not only survive but to live again.

This book follows her son’s difficult return to school as he struggles socially and cognitively to fit in and keep up. An adolescent’s brain is still developing, so an injury at this critical stage can have many consequences. Neil’s story will be an eye opener for many educators and counselors on the many and often subtle cognitive, behavioral, and social changes caused by brain injury. As Carolyn follows her son’s life after high school and his struggles to hold a job and build a career, readers will appreciate the lifelong impact that a brain injury can have in ways that are often invisible and immeasurable.

There is no going back. Life is never the same again. This book gives readers insights into the perilous journey of brain injury that is traveled not only by the survivor but by parents and siblings as well. You are not alone.

Order Crash at www.carolynroybornstein.com/memoir/
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Lash & Associates realizes how necessary (and functional) a collection of books like this could be - and the positive emotional impact they could make on families that really need them most...our veterans, their families, and caregivers of wounded service men and women everywhere.

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http://usbia.org/

Brain Injury Association of America
http://biausa.org

INTERNATIONAL RESOURCES

International Brain Injury Association
http://www.internationalbrain.org

Brain Injury Australia
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Headway United Kingdom
www.headway.org.uk

ORGANIZATIONS BY STATE

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www.ahif.org/

Alaska Brain Injury Network
http://www.alaskabraininjury.net/

Brain Injury Alliance of Arizona
http://biaaz.org/bia/index.aspx

Brain Injury Alliance of Arkansas
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http://braininjurynm.org/

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http://www.bianc.org/

Head Injury Association of North Dakota
http://www.braininjurynd.com/

Brain Injury Association of Ohio
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Brain Injury Association of Oklahoma
http://www.braininjuryoklahoma.org/

Brain Injury Alliance of Oregon
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Brain Injury Association of South Carolina
http://www.biausa.org/SC/

Brain Injury Alliance of South Dakota
http://www.braininjurysd.org/

Brain Injury Association of Tennessee
http://www.braininjurytn.org/

Texas Brain Injury Alliance
http://www.texasbias.org/

Brain Injury Assoc. - Texas Division
http://www.biausa.org/Texas/index.htm

Brain Injury Association of Utah
http://biau.org/

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http://www.biavt.org/

Brain Injury Association of Virginia
http://www.biav.net/

Brain Injury Services (Virginia)
http://braininjurysvcs.org/

Brain Injury Association of Washington
http://www.braininjurywa.org/

Brain Injury Alliance of West Virginia
http://www.biawestvirginia.org/

Brain Injury Alliance of Wisconsin
http://www.biaw.org/

Brain Injury Resource Center of Wisconsin
http://www.bircofwi.org/

Brain Injury Alliance of Wyoming
http://www.projectbrainofwyoming.com/

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http://www.afterdeployment.org/

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