# **Sharing Scars**

**Keynote Address:** "Sharing my personal journey of challenges, traumas, and triumphs with TBI and PTSD"



By Adrienne Patterson

Art by A. Patterson

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# **BIOGRAPHY AND STORY**

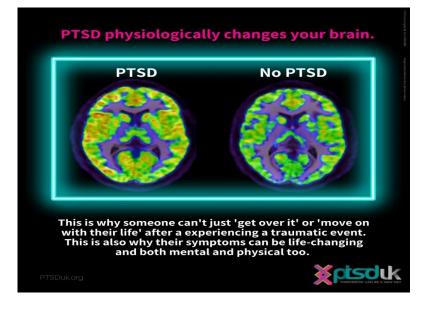
Adrienne Patterson has been an Ontario Educator for over 25 years with experience as an Elementary School Teacher, Consultant, and Administrator. Her career centered on adolescent aged students, vulnerable student populations, with specialization in Special Education and Behavioural Supports. In the course of her work, she was assaulted repeatedly over a period of time by special needs' students and sustained injuries. Having been on an extensive healing and recovery journey through Traumatic Brain Injuries and PTSD for the last decade, she has gained a great deal of insight into how difficult recovery can be and what enormous resilience, dedication, work, and support it takes to achieve even small gains.

Over the years, Adrienne's fierce determination and adhering to treatments and strategies has led to improvements in her recovery. She has learned a great deal through this journey of pain and the number of years it took to find what works best for her. Learning to live life differently with these diagnoses and health challenges has been paramount for her to be able to experience joy once again.

She shares her journey through difficult times and her belief in the importance of the therapeutic connection with providers. Her passion is giving back so that others may feel less alone. Further, that brain injury survivors, and those working with and caring for them, will find support or ideas that can aid them along their own life's journey. Adrienne demonstrates, through her story, that strong therapeutic connections impact systems of care positively.

# **INJURIES**

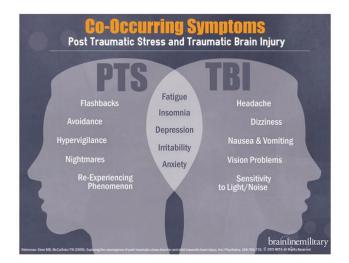
# **PTSD and Traumatic Brain Injury**



Both are brain injuries. The brain scan photo indicates physiological changes in the brain in PTSD.

# **Co-Occuring Symptoms of PTSD and TBI**

Learning how to deal with all of these symptoms and what strategies and supports worked for healing took a great deal of time and professional support.

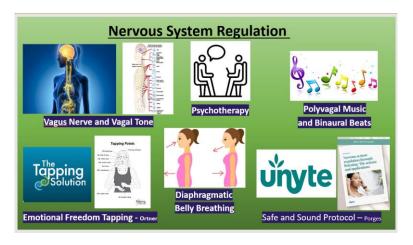


# **THERAPIES**

# **Nervous System Regulation**

The nervous system is the key to healing both the brain injuries and the PTSD. The Polyvagal Theory, by Dr. Stephen Porges,

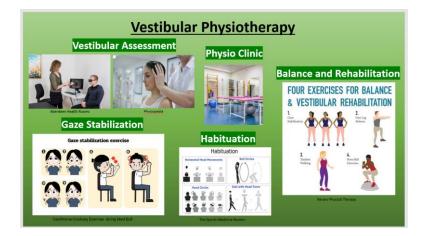
"emphasizes the role the autonomic nervous system - especially the vagus nerve - plays in regulating our health and behavior. Created and developed by Stephen Porges, PhD, the theory describes the physiological/psychological states which underlie our daily behavior as well as challenges related to our wellness and mental health. By applying Polyvagal Theory to our personal lives as well as to disciplines such as medicine, education, and management, we can understand how safety, co-regulation, and connection are paramount to a healthy human experience" (Porges Website description of the Polyvagal Theory).



# **Occupational Therapy**



# Vestibular Physiotherapy



# Pain Management and Assessments



# Lifestyle Habits, Tools, Skills, and Strategies



# **ADRIENNE'S TIPS FOR ADVOCACY AND MANAGING CARE**

Self-advocating, or by a caregiver, involves speaking up about your feelings, asking for what you need, and making sure your rights are respected, all of which can help health care providers treat you more efficiently and effectively.



#### 1. Listen to your body's cues

- Don't ignore symptoms and patterns.
- Ignoring symptoms and pain, can cause them to worsen.

- Get in tune with your body in order to start identifying problematic symptoms.
- If people who care about you give you feedback or are concerned, pay attention to what they are saying, as they may notice cues or behaviours that may indicate a need for medical supports.

### 2. Assess needs

- Pay attention and assess needs in the following categories: physical, psychological, logistical and support.
- Keep track of patterns, issues, and methods or interventions already tried and keep track of the data and details.
- Review your notes at regular intervals to see what is working and what isn't and what may need further support.

### 3. Reach out, speak up, be honest

- Be honest about symptoms and seek support from various groups of providers or resources (ie. caregiver, family, friends, medical and health providers, support groups).
- Without being honest about symptoms, feelings, and behaviours, accurate assessment will be difficult and possibly make you feel worse.
- Speak your truth and don't hide it, even when it is difficult to share your reality, from your providers as it makes it more difficult for them to make sound decisions and recommendations regarding medications, referrals, and treatment protocols.

### 4. Prepare for appointments

- Know what you need help with, have all the information compiled and ready to give to your provider so important details don't get missed in the rush of the appointment.
- Call ahead if you're struggling so supports can be prepared and to find out information like parking or expectations of the appointment like wearing appropriate clothing for a treatment or assessment.
- Have all your personal and medical information ready to provide to the medical professional.
- It is very helpful, especially for those with complex needs, to have things prepared. Keeping an up-to-date record of medications, supplements, and treatments on a print out and as a document in your phone. Prepare a list of surgeries and medical procedures/treatments, a list of medications, and also, a list with contact information of all providers. It is helpful at appointments for the administrator of the provider, your provider, and for your significant people (like partner, friend or Powers of Attorney) to have to help advocate for you, or if you can't speak for yourself. This is also helpful as forms to be filled out often don't have enough space on them to write everything you might need to tell your provider and can take more time than you have at the appointment.
- Keep track of all medications and supplements every day and when they are taken so that patterns and trends can be analyzed and compared with treatments, rest, exercise, and pain levels, etc. It becomes useful for the provider to help decide if treatment protocols need to change or remain the same. It is also helpful to keep track of when medication was taken in case you forget.
- Bring a support person if needed.
- If you're having a rough day and know you'll struggle at check in, call the office in advance and explain the situation. Often, the office will have suggestions on how things might be made easier or at least they will have a heads up that you may need support when you arrive, before you have your appointment.
- Wear or bring the appropriate clothing to appointments like physiotherapy, so that exercise or acupuncture needles can be placed more easily (ie. shorts).
- Find out where the parking is located and what will be needed when you get there...also be aware of stairs, elevators, or long walks. Ask for instructions on how to locate an office or clinic if you've never been before. Then you'll be on time and less stressed.

- Keep a note in your phone attached to the date of the appointment that has your questions and concerns already written down to discuss.
- Bring needed items such as: water, ear filters, headphones, ice pack, medications, proper clothing and footwear, a book or something to keep you occupied if you have to wait. Also bring Fitness Tracker data, notes made, questions for provider, and medication tracking.

### 5. Be clear about what you need

- When talking with the professional, try to provide examples, descriptions, and provide any data as these are helpful for the professional to understand what you are trying to explain.
- Ask them to slow down if you don't understand and take notes of advice given (or your chaperone/caregiver can).
- Jot notes in your phone or on paper to keep track of what was discussed and what your instructions are. That is why it is helpful to have a chaperone for complex or difficult appointments, as they not only help to make you feel supported, but they can help keep track of details also. It helps to ensure greater accuracy.
- If you know what helps you then that can be provided or if you have it with you, they can help. For example: In a panic attack, an ice pack, a cold glass of water, quiet or physical space can help you regulate much quicker. Although the providers you see are experts in their field, you are the expert about you. They give better care when they already know what works.

### 6. Establish relationships with your providers and their administrative staff

- Even though it should be the professional and their staff that form relationships with you and are responsible for their environment and their support of you, it is human nature that if you consider that these professionals are human too, then making an effort to connect to them will only help yourself and your care in the long run. It helps to establish rapport and consistency.
- Know their names, keep them recorded in your contact information in your phone, so if you forget, you can refer to your phone and still use the person's name...you'd be amazed how often that helps the worker, especially if they are having a tough day....
- It helps to establish rapport and consistency. It is extra helpful that when you're struggling and may not be able to converse as you normally do, that they already know you and how to support you better.
- It is really helpful that providers know your patterns and how hard you work. This is great so that when you may need to be squeezed in for an appointment, the providers will know that you only call when you've exhausted all other resources first.

### 7. Set realistic goals with your provider and make adjustments

- Attempt to do what is asked of you, yet if you notice that it is too hard or causes symptoms to flare too greatly, accommodate yourself, allowing more time to achieve if success is not immediate. Getting a 'win' leads to greater successes over the long term.

### 8. Follow through on the advice, skills, and treatments

- Without a solid attempt to try, it is difficult for providers to alter the plan or make other decisions. It is frustrating that often things take time to work or to be dismissed if they don't, but without trying, you're simply stuck.

### 9. Research treatments, diagnoses, and options given

- Taking the time to understand your conditions and treatments helps you to make better decisions, reduces anxiety, and often deepens your resolve to stick with a particular treatment, when research indicates its efficacy.

- Research allows you to discover questions you may want to ask your provider.
- Sometimes, research and bringing this up with your provider may remind them of an aspect of your case

that may have slipped their mind in the moment and can bring a better depth to your care.

#### 10. Keep a regular routine for follow up with your essential providers

- It helps with your own consistency, stability, and access to supports.
- Your body will also adjust to the routine and this consistency helps to know when things continue to worsen, or a new symptom (or side effect) may crop up that need addressing.

#### 11. If things go wrong at an appointment, address them

- Take time to reflect on what happened so you can be clear about the changes to be made. Without
  addressing issues that the professional may have missed, been unaware of, or they may have been having
  a bad day...the issue will grow and this impacts your recovery. Reach out to Patient Services'
  Departments or contact the colleges that govern certain Professions when necessary, which when done,
  positive changes can be made.
- Addressing issues, allows things to improve, or a new way can be found to solve a problem, or it helps others as it brings an issue to light that may have been overlooked.

#### 12. Don't be afraid to try alternative approaches to health

- Do your homework and investigate its efficacy and manage your expectations of how they can help and tell your medical providers what you are trying or doing as it can impact medication regimens, or treatment protocols.

#### 13. Adopt a management philosophy

- There are no quick fixes and slacking off sets you backwards. Keeping regular routines helps stability, including planning for and following through with rest and recovery time.

#### 14. Try to only change one major treatment or medication at a time

This allows you to monitor its effectiveness. Changing too many things all at once makes it difficult to discern what is working and what is not and leads to frustration and often an exacerbation of symptoms.

# **BUILDING STRONGER SYSTEMS OF CARE**

#### "It is the therapeutic connection, when honed and nurtured, that we strengthen systems of care."

- Adrienne Patterson

# **Professional Therapeutic Relationships**

Advocating for oneself and ensuring adherence to treatment plans and working with a variety of professionals in the pursuit of health and safety is paramount to good care...let's not forget that often patients are vulnerable, ill, injured, lack experience and expertise and that they rely on the system to aid them in their hours of need. Yet, this is not always how it works. Therefore, providers need to understand that while their respective discipline is important and necessary for the patient, it is a fraction of the entire puzzle. Each provider needs to understand the grander context for the patient.

# Adrienne's Providers' Conclusions

Here are the main learnings that came out of the interviews with providers:

- One main provider who sees the big picture of overall health and what the priorities for healing and specialized treatments are. He stated that, "Your organization, self-advocacy, research, and questions has aided not only your recovery, but enhanced our therapeutic connection. Your suggestion for more regular check-ins allows me to keep up more regularly on your case and needs and has created a more fluid consistent approach to managing other healthcare needs that pop up. I now use this strategy with other complex patients".
- "Listen with humility and let symptoms lead the path to treatment."
- "Don't confuse our professional goals with that of the patient. Align treatment goals with what the patient wants. Be open and human, with professional boundaries."
- "Stay committed, break the case down into component parts, start somewhere and see how it evolves. Always inform the patient what you are doing. Listen, think, and select evidence-based treatments, ensuring the patient understands and will follow through."
- One provider, who has worked in a hospital care setting for over 30 years, says, "Let's put the 'care' back into Healthcare". She further states, "As Professionals, we actively seek to be inspired by the folks we work with and to recognize that we are a small part of their Post Traumatic Growth or recovery".
- "There is power in creating a therapeutic connection. Be authentic, be consistent, and create the therapeutic space. The relationship is the key. If approached with honour and humility, by bearing witness, and by not getting overwhelmed...this shifts the paradigm which creates an authentic place where understanding and awareness grows."

# **Compassionomics**

The relationship between provider and patient is crucial in building stronger systems of care and helps to guard against **Vicarious Trauma** (Compassion Fatigue or Empathic Stress) and actually supports <u>Vicarious Resiliency</u>.

In a TEDxPenn talk about the "**compassion crisis**," Dr. Stephen Trzeciak, a critical care Doctor at Cooper University Health Care in Camden, N.J. shared his research and scientific study on compassion, which he dubs, **'Compassionomics'**. This experiment and review of articles, literature, and medical studies indicated that a <u>lack of compassion</u> in healthcare tops the long list of challenges facing health care for not only patients but also the health of the provider...and "The absence of compassion can lead to devastating, and even fatal, consequences." – *'Compassionomics'* p. viii.

The books 'Compassionomics' and 'Wonderdrug' by Doctors Trzeciak and Mazzarelli, further explains that,

"it takes as little as 40 seconds of undivided attention for providers to connect with their patients and improve health outcomes".

# Compassion Can Improve Our Healthcare System

# "Compassionomics provides the evidence that one simple tool, compassion, can affect not only the outcomes for our patients, but also the financial health of our organizations and the well-being of our providers."

- Dr. Donald Berwick, M.D. - President Emeritus, Institute for Healthcare Improvement

There is hope for the future and we all need to turn our attention to our daily interactions in our work and with each other, that do make a difference for patients, their caregivers and families and for the professionals themselves as burn out is real and can happen to the best-intentioned worker. The symbiotic relationship of the care provider and the patient, if managed with compassion, strengthens outcomes for patients and reinvigorates the professional, as they see and feel that what they do...<u>does</u> make a difference. The individual's commitment and accountability sets this chain of engagement and therapeutic rapport into action, thus strengthening systems of care.

# **CONCLUSION**

To quote Martin Luther King Jr.,

# "Life's most persistent and urgent question is, 'What are you doing for others?"

We are all grappling with and being inspired to do just that.

Adrienne's challenge to you all is...

# What will YOU do with your 40 seconds?

Thank you! Adrienne Patterson

# **RECOMMENDED RESOURCES**

#### Brain Injury and Post Traumatic Stress Disorder

- Centric Health LifeMark Health Group (2015). Vestibular Rehabilitation Outcome Measures, Lifemark.ca
- Dallaire, Romeo (with J.D. Humphreys), (2016). *Waiting For First Light My Ongoing Battle with PTSD*, Penguin Random House.
- Doidge M.D., Norman, (2015). The Brain's Way of Healing Remarkable Discoveries and Recoveries from the Frontiers of *Neuroplasticity*, Penguin Group
- Douglas J. Mason PYSD (2004). *The Mild Traumatic Brain Injury Workbook: Your Program for Regaining Cognitive Function and Overcoming Emotional Pain*, New Harbinger Publications
- Fleury, Theo (with Kristie McLellan Day), (2009). *Playing with Fire*, Harper Collins Publisher Ltd.
- Fleury, Theo, & Barthel, Kim, (2014). Conversations with a Rattlesnake Raw and Honest Reflections on Healing and Trauma, Influence Publishing.
- Graham, Linda, (2013). Bouncing Back Rewiring Your Brain For Maximum Resilience and Well-Being, New World Library.
- Hanson, Rick, & Mendius, Richard, (2009). *Buddha's Brain The Practical Neuroscience of Happiness, Love, & Wisdom*, New Harbinger Publications.
- Harris, Natalie, (2017). Save-My-Life-School A First Responder's Mental Health Journey, Wintertickle Press.
- Kain, Kathy L., Terrell, Stephen J., (2018). *Nurturing Resilience Helping Clients Move Forward from Developmental Trauma, An Integrative Somatic Approach*, North Atlantic Books.
- Komer, Dr. Lawrence D., & Komer, Joan Chandler (2016). *New Hope for Concussions TBI and PTSD*, Peak Performance Publishing.
- Levine, Peter A. PhD (2010). In An Unspoken Voice How the Body Releases Trauma and Restores Goodness, ERGOS Institute Press.
- Lumosity.com Brain Games
- Porges, Dr. Stephen, The Polyvagal Theory, 2011. https://www.stephenporges.com/
- Porges, Dr. SW (2017). The Pocket Guide to the Polyvagal Theory: The Transformative Power of Feeling Safe, W. W. Norton & Company.
- Rosenberg, Stanley, (2017). Accessing the Healing Power of the Vagus Nerve Self-Help Exercises for Anxiety, Depression, Trauma, and Autism, North Atlantic Books.
- Schiraldi, Glenn R., (2021). The Adverse Childhood Experiences Recovery Workbook Heal the Hidden Wounds from
   Childhood Affect Your Adult Mental and Physical Health Powerful new strategies to overcome low self-esteem, shame,
   depression, anxiety, emotional trauma, and other long-term effects of toxic childhood stress, New Harbinger Publications.
- Van Der Kolk, Bessel, (2014). The Body Keeps The Score Brain, Mind, And Body In The Healing Of Trauma, Penguin Books.

#### **Mindfulness and Pain Management**

- Gardner-Nix, Dr. Jackie, (2009). The mindfulness solution to pain Step-by-Step Techniques for Chronic Pain Management, New Harbinger Publications.
- Germer, Christopher K., (2009). The mindful path to self-compassion Freeing Yourself from Destructive Thoughts and Emotions, The Guilford Press.

- Kabat-Zinn, Jon, (1990). *Full Catastrophe Living Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*, Bantam Books (Random House).
- LeFort, Sandra, et. al., (2021). Living a Healthy Life with Chronic Pain Getting Your Life Back, Bull Publishing.
- Neff, Kristin, (2011). Self-Compassion Stop Beating Yourself Up And Leave Insecurity Behind, Harper Collins.
- Stahl, Bob, & Goldstein, Elisha, (2010). A Mindfulness-Based Stress Reduction Workbook, New Harbinger Publications.
- Teasdale, John, Williams, Mark, & Segal, Zindel, (2014). *The Mindful Way Workbook An 8-Week Program to Fee Yourself from Depression and Emotional Distress*, The Guilford Press.
- Treleaven, David A., (2018). *Trauma-Sensitive Mindfulness Practices for Safe and Transformative Healing*, Norton and Company.

#### Psychology, Healthcare & Well-Being, Alternative Health

- Brach, Tara, (2003). *Radical Acceptance Embracing Your Life With The Heart Of A Buddha*, Bantam Dell (Random House).
- Brown, Brene, Daring Greatly (2012) *How the Courage to Be Vulnerable Transforms the Way We Live, Love, Parent, and Lead*, Penguin Random House.
- Brown, Brene, (2015). *Rising Strong How the Ability to Reset Transforms the Way We Live, Love, Parent, and Lead*, Penguin Random House.
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- Brown, Brene, (2018). Dare to Lead Brave Work, Tough Conversations, Whole Hearts, Penguin Random House.
- Brown, Brene, (2021). *Atlas of the Heart Mapping Meaningful Connection and the Language of Human Experience*, Penguin Random House.
- Cameron, Julia, (1992). The Artist's Way A Spiritual Path to Higher Creativity A Course In Discovering And Recovering Your Creative Self, Penguin Books.
- Kaufman, Scott Barry, & Gregoire, Carolyn, (2015). *Wired to Create Unraveling the Mysteries of the Creative Mind,* Perigee (Random House).
- Mate, Gabor, (2003), When The Body Says No The Cost Of Hidden Stress, Vintage Canada.
- Millman, Dan, (1980). Way of the Peaceful Warrior A Book that Changes Lives, New World Library.
- Millman, Dan, (1991). Sacred Journey of the Peaceful Warrior, New World Library.
- Millman, Dan, (2006). Wisdom of the Peaceful Warrior A Companion to the Book that Changes Lives, New World Library.
- Trzeciak, Dr. Stephen, & Mazzarelli, Dr. Anthony (2019). *Compassionomics The Revolutionary Scientific Evidence That Caring Makes a Difference*, Studer Group.
- Trzeciak, Dr. Stephen, & Mazzarelli, Dr. Anthony (2022). **7** Scientifically Proven Ways That Serving Others Is the Best Medicine for Yourself Wonderdrug, St. Martin's Publishing Group.