

Self-Care Tips for Families Affected by a Parent's TBI

Coping with family trauma like a brain injury can be difficult. It is helpful to practice selfcare. What does that mean?



Set up a regular schedule for hygiene, mealtimes, chores. Plan weekly family events such as "Movie Mondays" or "Super Sunday" outings)

Spend time outdoors on a regular basis, even a 15-minute stroll in the evening is beneficial.

Talk about important topics when everyone is awake and alert, not tired and grumpy.

Be aware of noise levels in the house as blaring TV or radio can be jarring and distracting for someone with TBI

Learn about ways to help you and others relax (sitting quietly / meditation, spoken tapes, soothing music, special breathing exercises, walking)

FACT SHEET #2

POSITIVE PARENTING SKILLS FOR FAMILIES AFFECTED BY A PARENT'S TRAUMATIC BRAIN INJURY 09/20

Figuring out the "new normal" after a parent's traumatic brain injury (TBI) is not easy for a family. Fortunately, there are resources available. Families can use this fact sheet as a starting point to get through unfamiliar waters.

TRAUMATIC BRAIN INJURY (TBI)

Our amazing brain controls all aspects of our existence, similar to the command center of a spaceship. Although the whole brain works together to get things done, different parts are responsible for many different tasks. When the brain is injured – either from an external event like a car crash or assault, or from an internal event like a stroke or tumor – the



effects can range from mild / temporary to severe / long-term. Everyone's "command center" is unique, which means that every brain injury and every recovery from a brain injury are unique to that person. Changes after a brain injury are affected by factors such as severity of injury, areas of the brain injured, and an individual's overall health and motivation.

Common issues resulting from a brain injury include:

- **Physical / Sensory / Medical:** balance, walking, headaches, fatigue, seizures; seeing, hearing, smell, taste, touch; chronic pain
- Cognitive / Thinking: memory, learning and understanding new information, concentration and attention, word-finding, judgment and decision-making, problem-solving, planning and organizing
- Emotional / Psychological / Behavioral: irritability, depression, anxiety, mood swings (laughing, sadness, anger), acting without thinking, post-traumatic stress disorder (PTSD)

Physical	Cognitive	Emotional	Sleep
· Headache	· Feeling Mentally "Foggy"	· Irritability	· Drowsiness
· Nausea	· Feeling Slowed Down	· Sadness	· Sleeping Less Than Usual
· Vomiting	· Difficulty Concentrating	· More Emotional	· Sleeping More Than Usual
· Balance Problems	· Difficulty Remembering	· Nervousness	· Difficulty Remembering
· Dizziness	· Forgetful of Recent Info		· Trouble Falling Asleep
· Visual Problems	· Confused re Recent Events		
· Fatigue	· Answers Questions Slowly		
· Sensitivity to Light	· Repeats Questions		
· Sensitivity to Noise			
· Numbness or Tingling]		
· Dazed or Stunned			Source: CDC Facts for Physicians

Try Calming Breath: Sit or lie down with eyes closed.
Breathe in through nose for 4-6 counts, then breathe out through mouth for 4-6. Do a minimum of four times. You can do this anywhere, anytime, and often!

Arrange living space to minimize obstacles and to make it easy for family members to get what they use every day

Make sure there is good lighting (fluorescent or too-bright lighting can be bothersome after an injury, while brighter lights are needed if there are visual issues)

Participate in a support group, either in-person or on-line (for survivors, caregivers, veterans)

Take advantage of available help and resources, like those listed here!



Self-Care for Families

emotional	physical	spiritual
watch a good movie write each other positive notes verbalize and talk about feelings draw self portraits Say" I love you" spend time writing have a sing-a-long tell jokes try a new craft	dance party go for a walk family bike ride take a hike play kickball tag roller skating go to the pool jumprope kids yoga wii fit games	a gratitude list go outside talk about forgiveness write thank you's volunteer spend time outside or with nature practice positive self-talk plant a tree
read together draw or write stories kids meditation find shapes in clouds practice beligb heraths go on a walk to find new things make vision boards try Headspace for kids create mandalas make mindfulness jars play mind strepth games like memory	practical clean updeclutter oid toys _assign choees _make a grocery list together _learn about money _make a weekly budget check-in _make a weekly cleaning check-in _homework/study _have a moraling & _might require	Social play in the park call or visit relatives have family dinner play boardgames host a sleepover invite friends over plan a bbg join a team do a neighborhood food drive have talks about friendship and how to be a friend.

One of the keys to recovering after a TBI is to identify problems that are not getting better, and then finding ways to manage these challenges long-term. *Nowhere is this more important than in parenting issues following a TBI.* Changes in a parent and in the household after a brain injury may be hard for children to accept. They may not understand that a parent's behavior is not fully under their control (irritability, memory issues). What are some effective ways that a family can deal with these changes?

COMPENSATORY STRATEGIES can help with some of the long-term problems you may see in your loved one. Compensatory strategies –or "finding new ways to do old things" – uses a person's skills and strengths to successfully function day to day – including parenting. The great thing

about using these strategies is that they can be used with all family members! We all use these methods in our lives: writing things down in notebooks, post-it notes on the refrigerator, or carrying a pocket calendar; some can be more complex, like smart phone apps (appointments, reminders, anger management techniques, etc.), medication



alarms, home management devices (Alexa, OK Google).

Compensatory strategies do not fix the underlying problem, but can "make up for" some losses experienced after an injury. When used consistently in a supportive environment, such strategies can play an important role in helping the entire family function more successfully.

GUIDELINES FOR COMPENSATORY STRATEGIES

- Remember to focus on your loved one's strengths and skills. It is natural that everyone pays attention to the person's injury and how it has disrupted the family. However, make an effort to notice the good things that are there progress in recovery, how family and friends face a challenge together.
- Learn special techniques and approaches ("compensatory strategies") to help



with memory or language problems, organization, medication management, etc. A speech language therapist, occupational therapist, or a brain injury rehabilitation specialist can work with the person with TBI and the family.

• Changes in a person's environment,

including use of compensatory strategies, must be done with everyone's participation and approval. When family members are supportive of a change, it is more likely to be successful. Through trial and error, you will find the ones that work well, and others that were not effective for the person or the situation.

- Brain injury, including concussion, can cause fatigue, pain, and anxiety. Match activities to an individual's energy level. Although each person is different, a rule of thumb is to schedule mentally demanding tasks early in the day.
- Family members may need extra time to perform routine tasks, and new events may add stress and frustration (e.g., graduation, wedding, vacation). Plan ahead and schedule plenty of extra time to reduce disruption. The family should jointly prioritize tasks and events that are most important.

Most of us probably grew up with authoritarian (or conventional) parenting, which is based on fear. Authoritarian parenting is based on the *child's fear of losing the parent's love*. Some of us may have grown up with permissive parenting, which is also based on fear. Permissive parenting is based on the *parent's fear of losing the child's love*. **Connection parenting is based on love instead of fear.**



-Pam Leo, Connection Parenting, 2007

PARENTING is the process of providing protection and nurturing that allows children to grow into responsible and healthy adults. Parenting is difficult under the best of circumstances, and parents often seek help during difficult times. Outside support, along with self-care and compensatory strategies, are useful for all families, and are especially important for families after a parent's brain injury. Following a brain injury, a parent's actions and reactions may be different and perhaps hurtful (e.g., irritability, shouting, isolation).

Positive Parenting provides families with an excellent roadmap for parenting after a brain injury – or any time!



POSITIVE PARENTING "is not just permissive parenting; permissive parents do not set and enforce limits, positive parents do. Positive Parenting is a philosophy rooted in connection." -Rebecca Eanes, 2016. Positive Parenting can help families avoid some of the pitfalls and frustration following a parent's brain injury. Positive Parenting is about building and keeping a deeper connection between parents and kids, which adds to better life at home.

Positive Parenting versus Conventional Parenting (Eanes, 2016)

Positive (Connection) Parenting		Conventional (Authoritarian) Parenting	
Parent	Child	Parent	Child
Love-based connection and attachment between parent and child; feels warm bond with child	Emotionally secure; good coping skills and response to stress; positive relationships; feels warm bond with parent	Fear-based disconnection and detachment between parent and child; feels distant toward child	Insecure; poor coping skills and response to stress; relationship difficulties; feels distant toward parent OR may strive ceaselessly for parent's love and approval
Proactive: gives ongoing feedback to child on both positive and unwanted behavior	Proactive: receives ongoing feedback from parent to guide both positive and unwanted behavior	Reactive: gives feedback only when unwanted behavior occurs, while positive behavior is ignored ("good behavior is expected")	Reactive: receives feedback from parent only when unwanted behavior occurs, while positive behavior is ignored ("good behavior is expected")
Empathetic and compassionate leadership; feels warmth and respect for child; values the dignity of the child	Feels warmth and respect for parent; responds with willingness, cooperation, unity	Harsh and controlling leadership; values obedience to parent over dignity of child	Feels separation from parent; responds with resentment, resistance, rebellion OR may become extreme "people pleaser"
Positive discipline, praise for desired behavior, appropriate consequences for unwanted behavior; emphasis on learning new skills	Understands expectations; learns skills to help control impulses and unwanted behavior; better problem- solving	Harsh discipline, little praise for desired behavior; severe consequences for unwanted behavior; little emphasis on learning new skills	Does not understand expectations; does not learn skills to help control impulses and unwanted behavior; poorer problem-solving



RESOURCES ON TBI AND PARENTING

General On-Line Information and Resources

Brain Injury Association of America (BIAA). https://www.biausa.org

Brain Injury Association of Virginia (BIAV). https://www.biav.net

Centers for Disease Control and Prevention (CDC), U.S. Department of Health and Human Services (HHS).

- Positive Parenting Tips: https://tinyurl.com/CDCPositiveParenting
- TBI: Get the Facts. https://www.cdc.gov/traumaticbraininjury/get_the_facts.html

Defense Veterans and Brain Injury Center (DVBIC), U.S. Military Health System.

- Talking With Children About Moderate or Severe TBI (free booklet). https://dvbic.dcoe.mil/material/talking-children-about-moderate-or-severe-tbi-booklet
- TBI Basics (article). https://dvbic.dcoe.mil/article/tbi-basics
- The TBI Family Podcast for Caregivers (podcast). https://dvbic.dcoe.mil/training/podcasts/tbi-family-podcast

Model Systems Knowledge Translation Center (MSKTC). (Funded by <u>National Institute on Disability</u>, <u>Independent Living</u>, and <u>Rehabilitation Research</u> (NIDILR), Administration for Community Living (ACL), U.S. Department of Health and Human Services.)

- <u>Cognitive Problems after TBI</u>. <u>https://msktc.org/tbi/factsheets/Cognitive-Problems-After-Traumatic-Brain-Injury</u>
- Couples' Relationships after Traumatic Brain Injury (TBI Fact Sheet): https://msktc.org/tbi/factsheets/relationships-after-traumatic-brain-injury#Couples)
- Parenting after TBI in the Family (Hot Topics Series Video): https://msktc.org/tbi/hot-topics/relationships/parenting-after-tbi-in-the-family

Books

Rebecca Eanes. <u>Positive Parenting: An Essential Guide.</u> 2016. Penguin Random House: NY. (Positive-Parents.org https://www.rebeccaeanes.com/)

Jo Johnson, Ph.D. My Parent Has a Brain Injury. 2012. Lash & Associates Publishing, Inc., Youngsville, NC.

Pam Leo. <u>Connection Parenting: Parenting Through Connection Instead of Coercion, Through Love Instead of Fear.</u> 2007. Wyatt-MacKenzie Publishing: Deadwood, OR.

Lea Waters, Ph.D. <u>The Strength Switch: How the New Science of Strength-Based Parenting Can Help Your Child and Your Teen to Flourish</u>. 2017. Penguin Random House: NY.

Articles

Alex Goody. Parenting After Brain Injury. 2017. Headway: Nottingham, UK.

Maria Konnikova. *How People Learn to Become Resilient*. 2016. (https://www.newyorker.com/science/maria-konnikova/the-seret-formula-for -resilience)

Susan M. Pollak, Ed.D. Self-Compassion for Parents: Nurture Your Child by Caring for Yourself. 2019. Penguin Random House: New York.

Susan M. Pollak, Ed.D., *Why Parents Need a Little Self-Compassion*. 2020. Greater Good Magazine (https://tinyurl.com/ParentCompassion). University of Berkeley: CA.

The Brain Injury Guide & Resources. <u>Compensatory Strategies</u>. 2012. A Collaboration of the Missouri Department of Health and Senior Services and the MU Department of Health Psychology. https://bit.ly/2FPeFND

Audiovisual for Self-Care

Guided Imagery is a gentle but powerful technique that focuses the mind in positive ways.

- A Guided Meditation for Traumatic Brain Injury (TBI): Guided Imagery and Affirmations to Relieve Concussion Symptoms and Restore Healthy Function. Belleruth Naparstek, 2012. Healthjourneys.com.
- Caregiver Stress: A Guided Meditation, Belleruth Naperstek, 2009. Healthjourneys.com.
- Healing Trauma: A Guided Meditation for Postttraumatic Stress. Belleruth Naparstek, 1999. Healthjourneys.com.
- Positive Parenting: Meditations for Staying Cool, Calm, & Collected, Roberta Shapiro, 2018. Healthjourneys.com.



Want to know more about VCU's Positive Parenting Project? Contact Carolyn Hawley, Ph.D. at TBIParenting@gmail.com. for more information on workshops and resources.

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