Support for Caregivers as They Navigate Changing Family Dynamics after Brain Injury

by Katherine Walker

When a loved one suffers a brain injury, the shift in family dynamics can be sudden and difficult to navigate. New challenges arise, dependent on the nature of the injury, and may include communication difficulties, dependence in previously independent activities (such as bathing and dressing), and physical limitations. A parent or spouse may need to quickly assume the role of primary caregiver for their loved one. Family members both young and old may struggle to understand the complexity of the injury and recovery process, and relationships may be strained by stress and the emotional toll of coping with so many unexpected changes. Listed below are several ideas to help caregivers and family members cope with the many changes following a loved one’s brain injury.

- Be patient and kind to yourself and others. Adjustment to change does not happen overnight and it will take time to adapt to family life after a brain injury.
- Try to make reachable goals by breaking down large goals into smaller steps. That way, when a smaller goal is reached, you feel that you have achieved something and are now one step closer to the long-term goal.
- Focus on accomplishments and goals reached rather than failures. Do not try to compare your family member to who they were before they were hurt. Rather, think of the gains they have made since the brain injury.
- Seek the help of friends and extended family members, as well as members of your place of worship, if applicable, to help with tasks such as meal delivery, transportation, or household chores in order to support your family and to avoid caregiver burnout. You also may wish to consider respite care services as an additional option for helping hands.
- Take time for yourself after caring for others. Practical self-care activities may include exercising, journaling, reading, or setting up a social outing with friends.
- When stressed or irritable, it may be helpful to remove yourself from a situation until you cool down, and then re-address the issue when all parties are feeling more relaxed. Other strategies to de-escalate stressful interactions include counting to 10 or taking deep breaths to help calm yourself and others.
- Strengthen relationships by planning special activities to participate in as a family. You might wish to host a family movie or board game night, assemble puzzles together, go for walks or hikes, or plan a day trip to visit a local park or museum.
- Commit to staying positive and keeping a sense of humor. Encourage and compliment one another. Sometimes the little things help make someone’s day brighter.
- Check in with family members on a daily basis to keep communication lines open and make all individuals feel supported and heard.
- Participation in therapy with a provider who specializes in working with families after brain injury would further support the changing family relationships and dynamics.
- Get involved with a local support group so that you can build relationships with others in the community and share experiences. For more information on support groups offered by the Brain Injury Association of Virginia, visit: https://www.biav.net/support-groups/

Katherine Walker is a psychometrist in the Department of Physical Medicine and Rehab at VCU
Project Overview:

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

Greetings! COVID-19 may have slowed us down, but we are now providing our parenting workshops online! Our next session is November 4 & 11 from 11:30—1 PM. A stipend will be provided. To register contact: TBIParenting@gmail.com

Virginia Commonwealth University received a grant from the Commonwealth Neurotrauma Initiative (CNI) to provide positive parenting skills for families affected by a parent's TBI. VCU researchers found that families have an overriding concern about how to handle the added anxiety and uncertainty after an injury. Families want to know, “How can we address the injured parent’s needs, while also helping our kids understand and adjust?”

Targeted Parent Training/Supports
Children who experience a parent’s brain injury have themselves experienced a traumatic event. The Substance Abuse and Mental Health Services Administration (SAMHSA) found that child-focused services enhance the well-being of trauma-exposed youth. Even when supports are targeted toward parents only, children are the beneficiaries of more family harmony and a better day-to-day life at home. There were improvements in parenting skills and mental health, along with decreases in child behavior problems.

Project Objective/Goals
Unfortunately, researchers have not looked at the effectiveness of parent training programs specifically for parents with TBI and their non-injured partners. VCU’s Positive Parenting Project is evaluating a specialized program of TBI/positive parenting education and resources (i.e., workshops, written materials, peer networking). Project goals include:

⇒ Enhance positive parenting skills for families affected by a parent's TBI. Online Positive Parenting workshops will be address relationships, communication, and coping strategies. Participants receive a notebook of workshop content, information on resources and supports, and a gift card.

⇒ Increase the capacity of community TBI professionals to provide positive parenting information and support. Develop a train-the-trainer workshop for community providers that work with families affected by TBI.

⇒ Increase awareness of, and strategies for, addressing common issues parents face after a parent's TBI. Develop and share newsletter articles, fact sheets, and tip sheets. Connect families using social media. Project materials will be posted online.

Consumer/Family Involvement
Parents with TBI (consumers) and non-injured parent partners (family members) serve on an advisory board. Members and workshop participants give feedback on workshops and resource materials. Consumers/family members also contribute to “family to family” informational tip sheets as a peer resource for parents with TBI.

VCU’s Positive Parenting Project
This project is funded by Commonwealth Neurotrauma Initiative Grant #A262-80329, “Enhancing Parenting Skills of Civilians and Veterans with Traumatic Brain Injury and Their Noninjured Partners” awarded to VCU Departments of Rehabilitation Counseling & Physical Medicine & Rehabilitation.

If you have an upcoming event of interest to the Brain Injury community in Virginia, we would be glad to consider including it here. Please call (804) 828-3704 or email jennifer.marwitz@vcuhealth.org.
Do you live in Virginia? Have you had a TBI? If yes, we want to hear from you!

VCU researchers are seeking adults with traumatic brain injuries who live in Virginia to answer a 5-minute survey regarding pain and opioid use. All participants must be at least 18 years old.

The survey will not identify you in any way and all information will be kept confidential.

To answer the survey, please go to:

go.vcu.edu/tbi-and-pain

If you would like more information or if answering the survey questions over the telephone or by regular mail would be easier, please contact:

Laura Albert at (804) 828—2377
Laura.Albert@vcuhealth.org

This study is funded by the Virginia Department of Aging and Rehabilitative Services (DARS), award number A262-80504

So far we have heard from around 250 Virginians! We will be collecting responses until Friday, December 11th. If you're interested in helping us with our project, please visit the link above by that date.

Connect the dots to see a spooky friend.
(check your answer on page 7)
DEAR PAT,

I am in a 3-year relationship with my boyfriend who has a TBI. He introduced himself to me as someone that sustained these injuries when he was 19 years old (he is now 45). I immediately began to search for information about TBI so that I could understand it and how it affects a person. As we moved further into the relationship, the things I noticed in him made me also search out information on how to be in a relationship with a person with a TBI. I am at my wit’s end now, doing my part to be a supportive girlfriend, but I am not going to keep letting him belittle me. He discredits my research and even my education (I have a BA in Psychology and I am in school for my Masters in Mental Health Counseling). I do not know what to do to make this relationship work. I fear it will be over soon. Please help.

PAT’S RESPONSE:

First of all, I commend you for taking the initiative to understand TBI and its impact on relationships. You obviously care a lot about him and want this relationship to work. I also applaud you for reaching out for help.

One of the most distressing problems reported by loved ones following brain injury is personality change. Personality change is a common occurrence after brain injury. Family members and their loved ones often describe survivors as “different,” and typically have a difficult time coping with the personality change. Although you did not know your boyfriend preinjury, the behaviors you noticed in him could be the direct result of the head trauma.

Whether your boyfriend’s behaviors are the consequence of his TBI or not, it does not excuse him from engaging in inappropriate behaviors. It is his responsibility to address and/or remedy the behavior. Often this includes seeking out treatment with a psychologist who specializes in working with people with TBI.

To help start you in the right direction, here are some suggestions for you to help him manage his anger:

⇒ Discourage your boyfriend from saying the first thing that comes to mind. Teach him to think about other people’s reactions before he speaks or acts.

⇒ Encourage your boyfriend to be positive and sensitive to other’s feelings. Remind him to explain himself calmly.

⇒ Encourage your boyfriend to take a “time out” and try to relax when he recognizes that anger is building. Helpful strategies include breathing deeply and slowly counting to ten before speaking or acting.

⇒ Help your boyfriend develop new ways to release anger and manage stress in the long-term. Examples include exercising, writing, and talking to someone he trusts.

⇒ Identify trouble situations, people, and places that bring out irritability, anger, and frustration. Make a plan to successfully deal with trouble situations and practice the plan ahead of time.

⇒ Give praise when he controls his anger and expresses his feelings in positive ways.

However, you are not his therapist and it is not your job to be his therapist. You are his girlfriend. Therefore, you and your boyfriend might also want to consider seeing a family/marital therapist who specializes in working with individuals with TBI and their partners to improve your communication and learn ways of supporting each other. Finally, it is important that you make sure to take care of yourself. You have to decide if this relationship is healthy for you.
1. What’s a witch’s favorite subject in school?

2. Which Jack has a head but no body?

3. Why didn’t the Mummy have any friends?

4. How do you fix a jack-o-lantern?

5. What room do ghosts avoid?

6. Why did the vampire take art class?

7. Who was the most famous skeleton detective?

8. What do you call a witch that lives on the beach?

9. What’s a ghost’s favorite place to vacation?

10. Why are skeletons always so calm?

11. What’s a ghoul’s favorite make-up?

12. What do you call two witches living together?

**BONUS CHALLENGE:**

13. I’m tall when I’m young, I’m short when I’m old— and every Halloween, I bring carved gourds to life. What am I?

**ANSWER KEY:**

1. Spellings
2. Broomstick
3. Jack-O-Lantern
4. Vampires teeth got stuck
5. The living room
6. They wanted to learn to draw blood
7. She took Bones
8. Sand Witch
9. Malibu, FL
10. Because nothing gets under their skin
11. No Snake
12. She took Brooms
13. A candle
Frequently Asked Questions

**QUESTION:** I have been a mess since my car accident 6 months ago. I have nightmares, I can’t sleep, and I’m afraid to leave my house. I’m constantly worried that something bad is going to happen to me again. I refuse to get in a car now. A friend mentioned that I might have PTSD. How do I know if I have it and what can I do about it?

**ANSWER:**

Post-Traumatic Stress Disorder (PTSD) is a trauma reaction. Persons who have experienced a traumatic event, such as a car accident, can develop symptoms of PTSD, which include the following:

- Recurrent, intrusive distressing memories of the event
- Recurrent, distressing dreams of the event
- Acting or feeling as if the traumatic event were happening again, as if one was reliving it
- Efforts to avoid thoughts, feelings, or conversations associated with the trauma
- Efforts to avoid activities, places or people that remind one of the traumatic event
- Reduced interest and/or participation in significant activities
- Difficulty falling or staying asleep
- Irritability or outbursts of anger
- Difficulty concentrating
- Hypervigilance — extreme sensitivity to environment (smell, sight, sound and touch)
- Exaggerated startle response, or overly “jumpy”

If you answer yes to several of the above difficulties, you might meet the criteria for a diagnosis of PTSD. The diagnosis can be made by a psychologist, psychiatrist, or physiatrist.

The good news is that you don’t have to live with the symptoms. There is treatment to address the problems. Consideration should be given to seeking help from a mental health professional, such as a psychologist, who has experience working with persons with trauma and specializes in treatment of PTSD. In addition, you may wish to consider psychopharmacological intervention. Discussing the options with your treating healthcare provider will be important.
Survivor Stories Wanted!

Recovering from a brain injury can be very difficult. Sometimes, one of the most helpful and inspiring things is simply hearing from other survivors who have gone through recovery and faced the same challenges. Are you a survivor with a story you’d like to share? If so, then we’d like to hear it, and it might get into a future issue of TBI Today!

Submit to: jennifer.marwitz@vcuhealth.org or TBI Today, VCU P.O. Box 980542 Richmond, VA 23298-0542

Resilience and Adjustment Study for Adults with Traumatic Brain Injury
Participants Invited!

Have you had a traumatic brain injury (TBI)? You May Qualify for an Ongoing Research Study!

Virginia Commonwealth University researchers in the Department of Physical Medicine and Rehabilitation are seeking adults with traumatic brain injuries to be part of a research study. We are evaluating the helpfulness of an outpatient rehabilitation program to help people adjust to having a brain injury. Qualified volunteers will participate in seven rehabilitation and education sessions and possibly three additional sessions. Study volunteers will be given information on brain injury, local resources, skills development, and positive coping strategies. Volunteers will also be asked to complete several questionnaires. Participants must be at least 18 years old. There is no charge for services and volunteers are compensated for their time.

If you are interested in participating, please call Jenny Marwitz at 804-828-3704 or toll free at 866-296-6904 or email jennifer.marwitz@vcuhealth.org

Our team has been hard at work developing our new website! Come visit us at tbims.vcu.edu.

You can view the archive of our newsletter issues at the new website in the “Newsletters” section.

Did you Know? You can subscribe to TBI Today by email and get every issue sent directly to your computer, tablet, phone, or any other device that supports PDF. Best of all, it’s free! Email Jennifer.Marwitz@vcuhealth.org to be added to the list!
Founded in 1983 by families and concerned professionals, the Brain Injury Association of Virginia is the only statewide non-profit organization in Virginia exclusively devoted to serving individuals with brain injury, their families, and those that care for and about them. Over 10,000 people find help from BIAV each year.

BIAV is a chartered state affiliate of the Brain Injury Association of America and exists to be the voice of brain injury through help, hope and healing for Virginians with brain injury and their families. We educate human service professionals and the community on the risks and impact of brain injury and advocate for improved medical and community-based services. Many of our staff members are Certified Brain Injury Specialists (CBIS Certified).

To find out more information about BIAV, contact us at 1-800-444-6443 or 804-355-5748. Or visit our website at www.biav.net.