Summer 2017 VOLUME 15 NUMBER 3

# TBI TODAY



NEWS, IDEAS, AND RESOURCES FROM THE VIRGINIA TBI MODEL SYSTEM

# THE VIRGINIA TBIMS TEAM

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# Share Your Brain Injury Experiences by Mike Cerreto

After a brain injury, you enter a world in which you may feel isolated and confused. Your physical and mental challenges can cause you to feel disconnected and misunderstood by family, friends, and coworkers. Brain injury survivors may also feel embarrassed and self-conscious about their problems with attention, memory, energy, and problem solving, which lead them to withdraw from others. They can become lonely, more dependent, and stressed.

Research by both the University of Chicago and Yale University has suggested that loneliness and stress can make some medical conditions more severe. According to Sane Research, while around 10% of the population as a whole report feelings of loneliness, over two-thirds of those affected by mental challenges report feeling lonely "often" or "all the time."

Many positive things can happen when people with a brain injury get together to share their experiences and feelings. They realize that their struggles are shared by most brain injury survivors. They may become more forgiving of themselves and motivated to use methods to compensate for their brain injury.

To break free from the isolation that can occur from a brain injury, you should connect with people who are in the same situation. You can join a support group, talk with other survivors or caregivers, and meet with a counselor who can help you look at your situation in different ways.



Reach out and share your experience today to help yourself and others.

Michael Cerreto, MS, CPCRT, CSC, LDR is a Certified Cognitive Rehabilitation Therapist with **A Talented Mind Clinic** in Richmond, Virginia. He helps children, adolescents, and adults with a TBI improve the quality of their daily lives. He also facilitates **The Comeback Project** that is a free, private online community for brain injury survivors and their families. You can join the community to get the support you need at: <a href="mailto:a-talented-mind.mightybell.com">a-talented-mind.mightybell.com</a>. If you have any ideas for a future article about cognitive rehabilitation, please contact Michael at cerreto@atalentedmind.com.



# **Aphasia Support Group**

- When: 2nd Thursday of the month 6-7pm
- Location: First Unitarian Universalist Church, 1000 Blanton Ave, Richmond, 23221 in the President's Room
- Contact: Susan Hapala at (804) 908-3261 or Jan Thomas at rva.aphasia@gmail.com

# Support Group for Adults with TBI, Family, and Friends

- When: 3rd Monday of the month 6:15pm-7:45pm
- Location: Disability Law Center of Virginia, 1512
   Willow Lawn Drive, Suite 100, Richmond, 23230
- Contact: Christine Baggini at (804) 355-5748 or christine@biav.net

# Supportive Survivors

- When: 2nd, 4th, and 5th Tuesdays 6-8pm, Outings planned for the 1st and 3rd Tuesdays
- Location: Regency Mall Food Court, 1420 Parham Road, Richmond, 23229
- Contact: Ted Taylor at (804) 781-2144 or taylorted58@yahoo.com

# TGIF: Social Group for Adults with TBI and Family

- When: 1st Friday of the month
- Contact: Email Aleana McClellan at mcclellana@chesterfield.gov or call (804) 751-4134 to get on the mailing list.

# Women's Luncheon Group

- When: 2nd Tuesday of the month for lunch 11:30am
- Location: The Mill House, 7812 Shrader Road, Henrico 23294
- Contact: Jen Candela at (804) 386-0926 x 104 or jenniferc@communitybraininjury.org

Looking for a support group in your area? Check out www.biav.net/virginia-support-groups.htm for more support groups organized by region!

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.

# Sleepiness and Fatigue: They are not two sides of the same coin by Amma Agyemang

Fatigue and sleep problems are common after brain injury. As many as 73% of brain injury survivors experience fatigue while up to 50% report sleep difficulties. For some survivors, fatigue and sleep problems often go hand in hand. Although sleep problems can contribute to fatigue, the two are distinct states. Being able to tell when you are tired versus when you are sleepy can be helpful in determining the appropriate course of action; because one of the most important tenets of good sleep hygiene is to go to bed only when you are sleepy. Below are some important ways in which sleepiness differs from fatigue.

- Sleepiness is a basic biological drive; fatigue has less of a biological role.
- Sleepiness is an increased likelihood of falling asleep. Ask yourself, "If I close my eyes, will I fall asleep within 5-10 minutes?"
- Signs of sleepiness are yawning, head bobbing, decreased attention, and drooping or falling of eyelids.
- Fatigue refers to a lack of energy to begin or complete tasks.
- Signs of fatigue are muscle weakness, and decreased ability to perform physical or mental tasks.
- While sleepiness decreases after a good night's sleep, fatigue does not necessarily improve after sleep.
- Fatigue does improve after relaxation and a decrease in activities.

So, the next time you find yourself saying, "I'm tired, I'm going to bed," ask yourself a follow-up question, "Am I sleepy or am I tired?" If you are sleepy, then sleep is what you need, but if you are tired instead, then sitting down and putting your feet up to do something relaxing may be the better solution.

# **DEAR PAT,**

My husband, Steve, was in a bicycle accident about four months ago. He was hit by a car early in the morning when he was out on a long ride with his friends. He luckily survived the crash, but life has been chaotic in our household since that day. We have two young sons and I work full-time as a nurse at a local hospital. I went back to work a week after his accident because we couldn't afford for both of us not to work. I've been trying to juggle everything between work and taking care of Steve while he recovers. Steve and I used to have a pretty even division of responsibilities at home. Well, I had to take over his part after the accident. I'm not sure how long I can continue like this. I really need help dealing with this enormous stress that I find myself under. I was pretty good at handling stress before this but this accident has pushed it to another level.

# **PAT'S RESPONSE:**

It is obvious that your family is very important to you and that you want to care for your husband and sons. Oftentimes, people forget about themselves when they are in a caretaking position. You are so used to taking care of others' needs that you forget about your own, especially as a nurse. You will not be able to care for your family if you are ill.



Pat answers your personal questions about brain injury with compassion and practical advice. However, advice from Pat's column should not be substituted for consultation with a doctor or rehabilitation specialist. The identity of individuals submitting questions to "Chat with Pat" is kept strictly confidential.

Here are some suggestions to help you cope with stress:

- Breathe slowly and deeply
- \* Take time for yourself and do something enjoyable...listen to soothing music, take a long bath, go for a walk, or read a book.
- \* Close your eyes and imagine yourself in a pleasant situation.
- \* Set reasonable goals by reviewing your husband's recent progress.
- \* Think positive thoughts and try to keep a good sense of humor.
- \* Avoid comparing your husband's behavior with his functioning before the injury.
- \* Avoid putting yourself down or pushing yourself too hard.
- \* Seek support and help from trusted friends and family members and ask them for feedback about how you are handling stress.
- \* Share the burden of caregiving with trusted family and friends, and consider respite care services.
- \* Keep up a healthy lifestyle by exercising, eating healthily, and avoiding caffeine, alcohol, drugs, and tobacco.
- \* Be patient with yourself. Recovery is a long process and solving big problems takes time.
- \* Focus on accomplishments and progress instead of failures.
- \* Remember that you will run the risk of emotional collapse and health problems if you do not take breaks.

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# **Summer Word Scramble**

Unscramble the summer-themed words below, then use the highlighted letters to figure out the secret message. You can find the answers on page 7!

# JUST FOR FUN

**MESSAGE:** 

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1. SRSTHO	
2. C A B E H	
3. IACNOTVA	
4. NDAS LCESTA	
5.GINSIHF	
6. E N S R S E C U N	
7. O A D M L N E E	
8. CNPICI	
9.ACMINGP	
10. W T E A R	
11. H T E A	
12. CEI RAEMC	
13. S N I H E N U S	
14. R B U E E C B A	
15. W R T N O L E A E M	

# Frequently Asked Questions

THE INFORMATION PROVIDED IN THE FAQ IS INTENDED TO FAMILIARIZE THE PUBLIC WITH ISSUES RELATED TO TBI. NO INFORMATION PROVIDED HEREIN SHOULD BE CONSTRUED AS THERAPEUTIC ADVICE OR AS A SUBSTITUTE FOR CONSULTATION WITH A COMPETENT MEDICAL OR MENTAL HEALTH PROFESSIONAL.

# **QUESTION:**

Since my brain injury, my co-workers and casual acquaintances have asked me a lot of questions about my accident. I'm sure some are out of genuine concern but I think some people are just nosy. I'm not sure how much information to share, especially when the questions seem intrusive. Any suggestions?

# **ANSWER:**

People are very curious beings and I do not think there is any way to prevent people from asking these questions. However, you *can* have control over the type and amount of information you communicate and *how* you communicate it.

- Keep in mind that you can make choices about what you tell others about your injury. You can always change the topic to something you feel more comfortable talking about.
- Before giving out personal information, ask the other person to agree to keep what you say in confidence.
- You should only tell people what they need to know and what you feel comfortable telling others.
- Keeping answers short, simple, and to the point is another good rule of thumb.
- It is also important to know how to answer questions without becoming upset *or* making the person asking the question uncomfortable.
- Politely decline answering questions if you feel uncomfortable. For example, you could say, "I appreciate your concern, but I'd rather not talk about it right now."
- Talking to other survivors about how they deal with difficult questions is another recommendation.
- It is important to disclose only the most personal information to people you really trust such as family members, close friends, doctors, and therapists.
- Practice answering questions (role playing) with trusted family members and friends. This can give you additional confidence in how to address the situation with your colleagues.



Questions for Pat or the FAQ column are welcomed.

Send them to:

"ASK PAT" OR "FAQ"

P.O. BOX 980542. RICHMOND, VA 23298-0542

or e-mail: jennifer.marwitz@vcuhealth.org



# What is Participation?

# by Kristin Graham

What is participation? Merriam-Webster defines participation as "the act of participating." Participation is an active word. Generally it means you are engaged in some activity. In rehabilitation and after brain injury, participation is defined as involvement in a life role, such as working, going to school, or parenting.

There are many changes and challenges after a brain injury. You may find that you have trouble paying attention, your balance may be off and you use a cane to walk, or you find yourself feeling more down or depressed. All of the changes and challenges experienced after brain injury can impact the way someone participates. Going back to the same job, driving, or attending classes might not be possible. But there are plenty of people and organizations that can help you get back to doing the things you want to do or even find new ways to participate. Below are some resources:

# Work

- ◆Department for Aging and Rehabilitative Services:<u>www.vadars.org</u>
- School

  ◆Teachers, guidance counselors, school counselors
  - ◆ Office of Disability Support Services (name may vary from school to school)

# Social

- ◆Support Groups Brain Injury Association of Virginia: www.biav.net
- ◆Adaptive Sports Sportable: www.sportable.org

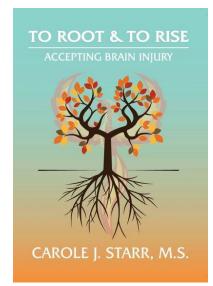
Each of us may define participation a little differently and that's because we all do it differently. How do you define participation?

# TBI Survivor Book Announcement

Brain injury survivor Carole Starr has written about her experience in her new book, *To Root & To Rise: Accepting Brain Injury*. A teacher and amateur musician, Carole's life drastically changed when she was broadsided on the driver's side by another car going about 50 miles per hour. While she shares the journey she took to accept her brain injury throughout her book, she has also structured it to be a workbook, allowing those with brain injury to take steps toward acceptance. With short chapters, large text, and flexible ways to navigate through it, her book is designed with brain injury survivors in mind.

Carole was recently interviewed by Diane Atwood on a local Maine podcast about her story and her book. To listen, visit <a href="http://dianeatwood.com/to-root-and-to-rise-accepting-brain-injury/">http://dianeatwood.com/to-root-and-to-rise-accepting-brain-injury/</a>.

To read more about Carole, read an excerpt, or purchase her book, visit CaroleJStarr.com. *To Root & To Rise* may also be purchased at Amazon.com



# Join a Supportive Online Community for TBI Survivors and Families

The Comeback Project is a free, private online community for survivors of brain injury and their families to help you get your life back after a brain injury. You can join the community to share and get the support you need at: a-talented-mind.mightybell.com.

The community is provided by A Talented Mind Clinic in Richmond, Virginia, that provides cognitive rehabilitation therapy to brain injury survivors and families. For more information, you may also email Mike Cerreto at cerreto@atalentedmind.com.

# **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

TBI Today, VCU P.O. Box 980542 Richmond, VA 23298-0542



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	AETER	.01
	САМРІИС	.6
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	FEMONADE	٦.
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# SKILL-BUILDING, SUPPORTIVE AND EDUCA-TIONAL PROGRAM FOR COUPLES AFTER BRAIN INJURY PARTICIPANTS INVITED!

Are you in a relationship? Have you or your partner had an acquired brain injury?
You May Qualify for an Ongoing Research Study!

Virginia Commonwealth University researchers in the Department of Physical Medicine and Rehabilitation are seeking adults with brain injuries to be part of a research study. We are evaluating the helpfulness of an outpatient rehabilitation program to help couples adjust to brain injury. Qualified volunteers will participate in five to six support and education 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

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