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News, Ideas, and Resources from the Virginia TBI Model System

THE VIRGINIA TBIMS TEAM

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Problems with Perception of Time After Traumatic Brain Injury

by Kelli Williams Gary

After a traumatic brain injury (TBI), patients can experience a variety of problems. One problem that is not commonly discussed is the perception of time. This refers to the experience or awareness of the passage of time. In other words, your body has an internal clock that helps you estimate the length of a task without looking at a real clock. Imagine when you are doing something that is not interesting or boring, a few minutes may seem like an hour, but if

you are extremely focused on something that takes all your attention or brings pleasure, an hour can seem like minutes. These are examples of time perception and it is an important for many activities that are done every day.



The perception of time helps us to get up in the morning, organize how we get ready, and arrive at work or appointments at the right time. If there is a problem with time perception because of damage to the brain, people would have difficulty accurately judging how long to bathe, groom, dress, eat, and travel so they (contd. p 6)

Goodbye Dr. Lukow! In August, we will sadly say goodbye to Dr. Herman Lukow, postdoctoral fellow with the Neuropsychology and Rehabilitation Psychology service. Dr. Lukow helped the TBI Model System at VCU start two of our currently running research programs, the *Resilience and Adjustment Intervention* and the *Therapeutic Couples Intervention* (see pages 2 and 3 for study details). He served as the therapist to over 40 individuals in the Resilience study and 20 in the Couples study. In addition, Dr. Lukow published and presented research findings related to this work. In his new job, he works as a licensed marital and family therapist at Balance Behavioral Health, PLLC in Midlothian, VA. You can reach him at 804-823-5475 or herman.lukow@balancebehavioral.com.



We will miss Dr. Lukow and wish him the very best in his new clinical practice. Stay tuned though, we hope to keep Dr. Lukow involved with our research at VCU on a part -time basis!

JUST FOR FUN!

See if you can unscramble all of the words to the right. Hint: They all have to do with the 4th of July!

If you get stumped, answers are on page 7.



New Book Announcement

Back in 1977, we did not know as much about brain injury as we do today. Sara E. Lewis, of Williamsburg Virginia, has published a great book on what life was like after an undiagnosed brain injury, "*Not What I Expected: My Life with a Brain Injury (I Didn't Know I Had).*" The car accident left Sara with badly broken legs, but no one told her about the "severe concussion" briefly mentioned in the medical record. This is the story of living for nearly 30 years without knowing that you had a brain injury. The effect on relationships and her career were profound. With a wonderful and easy-to-read writing style, Sara guides us through her life, from injury to finally receiving the diagnosis of TBI, to fully understanding the impact and learning how to adapt to her brain injury.

Sara's book can be ordered through Lash and Associates at http://www.lapublishing.com/undiagnosed-tbi-brain-injury.



Adjustment and Resilience Brain Injury Study

If you have had a TBI, you may qualify for 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 education sessions. Study volunteers will be given information on brain injury, local resources, skills development, and positive coping strategies. Topics will include understanding changes that occur after brain injury, setting goals, problem solving, managing emotions and stress, and communicating well.

If you are interested in participating and 18 or older, please call Jenny Marwitz at 804-828-3704, or toll free at 1-866-296-6904, or by email at jhmarwit@vcu.edu.

Intervention for Couples After Brain Injury

Following the renewal of the TBI Model Systems grant at VCU, the research team have launched the Therapeutic Couples Intervention (TCI). The TCI is a continuation of our interest and commitment to familyfocused research after brain injury.

Often, spouses or romantic partners take on a caregiving role when their partner suffers a brain injury. As such, the TCI is designed to assist couples after TBI.

Topics covered in the TCI program include:

- What is normal for brain injury? Common problems after TBI
- How are we different now? Common relationship changes after TBI
- * Communicating in a 'new' relationship
- * Managing stress effectively
- * Setting reasonable goals
- * Solving problems effectively
- * Establishing emotional intimacy
- * Renewing physical intimacy
- Parenting 101: parenting education and skills (optional material for couples who are parents)
- Parenting after TBI: Common hurdles to effective parenting (optional material for couples who are parents)
- * Taking care of yourself and your relationship
- * Focusing on gains and looking forward

Participation is free, and study volunteers will be compensated for their time. If you are interested in participating, please contact Jenny Marwitz at 804-828-3704, or toll free at 1-866-296-6904. Or, send an email to jhmarwit@vcu.edu.



Supportive Survivors

- When: Tuesdays 6-8pm
- Location: Usually at the Regency Mall Food Court (Richmond)
- Contact: Contact Ted Taylor at (804) 852-6644 or taylorted58@yahoo.com

Richmond Area Support Groups

- Location: 2nd Monday every month at 6:30pm, Woodlake Methodist United Church, 15640 Hampton Park Drive in Chesterfield
- Contact: Liz Perry-Varner at 804-276-5761
- Location: 3rd Monday every month at 6 pm, Children's Hospital Auditorium, 2924 Brook Rd.
- **Contact:** Call the Richmond BIAV at 804-355-5748 for more info!

Richmond Aphasia Support Group

- When: 2nd Thursday of the month from 6-7pm
- Location: Epiphany Lutheran Church Price Hall
- Contact: Call Lynn Burris, (804) 439-2657 or email at rva.aphasia@gmail.com

October 12, 2015

- Event: 11th Annual Golf Classic
- Location: Salisbury Country Club, Richmond VA
- Contact: Email steve@biav.net or call the Brain Injury Association of VA for more info. Participants are encouraged to register in advance for fundraising!



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: jhmarwit@vcu.edu

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



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.

DEAR PAT: It has already been 10 months since my son fell off a ladder at work. He had to move in with me and his father after he got out of the hospital because he couldn't take care of himself with all the broken ribs and leg. He also had a brain injury. Bobby was in really bad shape. I was so scared when he was in the hospital. I didn't know if he would be able to walk or talk again. My poor baby is only 25! He had so much going for him.

Luckily, Bobby recovered from most of his physical injuries. He is walking on his own without any assistance, but has a lot of soreness and pain so he hasn't started exercising yet. It seems like he was mad all the time when he had to use the wheelchair to get around. Anyway, once he was able son. I just want to be prepared for to move around, his mood got better but you'll still catch him swearing often. Not moving around in the same way as he used to really frustrates him. My son was very active before the accident. He was always on the go and hates sitting still.

I think Bobby is 85% better than where he was after the accident.

It's amazing to see how far he has come. Even his doctors were surprised. Of course, it hasn't been easy. But, my son has worked very hard and refused to give up. There were some tough days but he kept going. I went through some roller coasters with him and it hasn't been easy on me either. I had to put my life on hold while helping him recover. I'm not complaining though, mind you. I would do anything for my son. What I'm worried about now is his memory and attention. Bobby gets distracted easily. I can be talking to him about something and he'll randomly ask me a question because it popped up in his head. He has many unfinished projects all around the house that drive me crazy. It is also very upsetting to see him struggle to get the right words out and say what he wants to say. He forgets things too and I have to remind him to take his medications. He just doesn't seem to be able to get it together to complete simple tasks. These problems haven't gotten any better. I'm scared that he's going to have to stay here with us for the rest of his life because he won't be able to live on his own.

Pat, will my son ever return back to the way he used to be before the accident? I'd like to see him return to work. What kind of expectations should I have? I would love him no matter what since he's my whatever it is ahead of us.



PAT'S RESPONSE: Feelings of frustration are common when you see your loved one struggle and experience difficulties. It is obvious that you care about your son and want the best for him. You wish you could do something to help him. Most people wish improvements could occur over night; yet, things don't seem to happen fast enough.

Recovery from brain injury varies from person to person. Depending on the severity of the injury, the location of the injury, and age, the recovery process can range from months to years. Most physicians will tell you that the greatest recovery takes place in the first three to six months after the injury. However, it is difficult to predict exactly when things are going to happen.

You probably felt disappointed when Bobby's problems persisted beyond six months. Then, the fear of not knowing if it will get better sets in. There are things you can do to help your son to continue to make progress. Keep working to help your son develop more effective strategies for doing things. For example, create a calendar to keep track of all his appointments and events. Learning from others who have similar experiences will provide you with ideas of what works for other people and what doesn't. Support groups are generally a good place to gather this information. Most important of all, learn from mistakes and stop doing things that don't work. And, keep doing things that do work. Also, give Bobby constructive feedback and ask others for feedback.

"Successful" recovery is relative. It means different things to different people. It may mean returning back to work. Or, it may mean being able to manage (contd. p5)

your finances by yourself. For others, it may mean being able to walk independently and go to the store. Continually judging Bobby's progress by comparing to how he was before the injury can bring on disappointment. Also, if you focus too much on what he still needs to do, you can easily lose sight of what has been accomplished. Instead, think about the progress that has been made since his injury. Encourage him to do the same.

It is often hard to judge how much progress has been made. Progress can be very slow, and slow changes are harder to recognize. Progress also requires a lot of effort from the injured person and family members. Sometimes, you take one or two steps back when you take two steps forward. Regularly, you and your son should assess the progress he has made. It is often helpful to visually see the progress using charts or graphs. Celebrating progress, whether it is big or small, is essential to building Bobby's sense of accomplishment.

If you wish to get involved with your local support group to share your experience, Brain Injury Association of America has a list of support groups you and your husband may attend. To contact BIAA, you may call their family helpline (1-800-444-6443) or send them an e-mail at familyhelpline@biausa.org. The website for BIAA (www.biausa.org) provides links to state chapters and additional brain injury resources. You may also write BIAA for more information at 8201 Greensboro Drive, Suite 611, McLean, VA 22102.

JUST THE

FREQUENTLY ASKED QUESTION S

THE INFORMATION PROVIDED IN THE FAQ IS IN-TENDED TO FAMILIARIZE THE PUBLIC WITH ISSUES RELATED TO TBI. NO INFORMATION PROVIDED HEREIN SHOULD BE CONSTRUED AS THERAPEU-TIC ADVICE OR AS A SUBSTITUTE FOR CONSULTA-TION WITH A COMPETENT MEDICAL OR MENTAL HEALTH PROFESSIONAL.

Q: My best friend has been "out of it" ever since she fell from roller skating and hit her head. What are the signs of a concussion?

A: It is important that your best friend be seen by a physician to determine if she does have a concussion. Here is a list of symptoms that patients commonly have weeks or months after a concussion. Have you noticed your best friend having any of them?

- Headaches
- Dizziness
- □ Feeling tired
- □ Moving slowly
- □ Trouble falling asleep
- Nightmares
- Feeling frustrated
- □ Impatience
- □ Irritability or short temper
- □ Feeling sad or blue

- □ Misplacing things
- Losing train of thought
- □ Thinking slowly
- Poor concentration
- □ Forgetting if you have done things
- □ Forgetting what you read
- □ Forgetting names or phone numbers
- □ Trouble following instructions
- □ Trouble following conversations
- □ Trouble coming up with the right word



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: jhmarwit@vcu.edu



(*Time,* contd) could arrive at work on time. This results in not being performed (e.g., eating breakfast) and/or consistently being late. Difficulty with the perception of time can cause the following problems:

- Slowness in completing specific tasks in a daily routine
- Issues with following a timed schedule
- Problems with ordering smaller activities to complete a larger task
- Difficulty with completing multiple tasks within a given time frame
- Misjudging how long a certain task will take

It is important to understand that problems with the perception of timing of events can be as disabling as not being able to complete the steps of the task itself. To improve independence in daily activities, the focus should not just be placed on relearning a task. There must also be focus on increasing the ability to complete the task in a reasonable length of time and with fewer prompts or cues. Let's consider the following scenario:

Prior to his TBI, Joe worked as Head Chef in a fine dining restaurant. He spent three weeks in the hospital and had one month of outpatient rehabilitation. His physical recovery was quick, but he continued to have problems with memory and concentration. After a short time at home, Joe wanted to return to cooking at the restaurant. His boss agreed to let him come back part time, assisting another chef instead of being in charge.

Before his injury, Joe was able to successfully prepare multiple, complex meals under very tight time demands. Post-injury, he had difficulty establishing a consistent routine to cook even simple meals. He struggled with multi-tasking and time-sensitive aspects of his job. His slowness in completing tasks and difficulty recalling cooking instructions added to his frustration. What could Joe do to try and fix this?

- He made a plan with his boss to make sure he wasn't overworked. Before as Head Chef, Joe did everything! Instead, he stuck with simpler tasks and a set amount of meals per hour.
- Joe had to relearn things he had done previously without much thought. Setting timers when he would start certain tasks helped him stay focused and not get distracted.
- Other staff were patient with him and helped him review his new methods for staying on task prior to working on a busy Friday night.
- After a while, Joe didn't need the prompts or timers as much as when he first returned to work.

Perception of time plays a significant role in everyday life. Disruption in accurately estimating time can likely cause frustration in real word situations (e.g., cooking, dressing, shopping, etc.). There are steps that can be followed to help with time perception by establishing basic routines, breaking down tasks, and establishing prompts to promote accuracy with time.



Set Boundaries With Others to Ease Your Mind

by Michael Cerreto, MS, CPCRT, CSC, LDR

After your TBI, do you feel frustrated by people who refuse to acknowledge that you have different challenges and needs? Do you feel mentally overwhelmed by all of the information and requests from others you have to respond to throughout your day? Do you wish you could say "no" to others at times to simplify your life and ease your mind?

While people with a TBI may appear at times as if their lives are getting back to normal, their minds are not. Their changing mental capabilities can impact their self-image and relationships with others. Your family, friends, and coworkers may have their own difficulty coming to grips with who you are after a TBI. They want you back to what they consider "normal" and they may not know how to adjust their behavior to reduce the load on you.

As a result, some people with a TBI respond by hiding parts of themselves, withdrawing, and pretending nothing is wrong. This can lead to more personal problems, hopelessness, and unhappiness.

There is a way to set boundaries with others to ease the burden on you. When someone is doing something that overwhelms you mentally, you can give them an alternative behavior you want to see from them.

For instance, if someone at work continually interrupts you to get non-urgent information, you can say, "I would really like to provide you with that information but I am right in the middle of something. Can you please send me an email about what you need and I will reply tomorrow?" By responding in this way, you set a boundary with the person. It communicates clearly that you don't want to be interrupted and explains how you want that person to behave so life is easier for you. This is just one example. You can use this technique with any relationship in your life.

By recommending alternative behaviors in order to set boundaries with others, you assure that people always know what you need, and you simplify your life to ease the burden on your mind.

Michael Cerreto, MS, CPCRT, CSC, LDR is a Certified Cognitive Rehabilitation Therapist with A Talented Mind Clinic in Midlothian, Virginia. He helps children, adolescents, and adults with a traumatic brain injury improve the quality of their daily lives. He is also the coauthor of the book Journey Back From Chemobrain that is now available on Amazon. If you have an idea for a future article about cognitive rehabilitation, please contact him at cerreto@atalentedmind.com.

Word Scramble Answer Key

Here are the answers for the puzzle on page 2. How'd you do?

14. England	R. America
13. Philadelphi	6. ମାୟପ
12. Barbeque	5. Parade
11. Patriotic	4. Liberty
10. Summer	3. Independer
9. July	2. Freedom
mədtnA .8	1. Fireworks



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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 edu-

cate 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.



The Voice of Brain Injury: Help, Hope & Healing