

TBI TODAY

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

THE VIRGINIA TBIMS TEAM

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MANAGING STRESS EFFECTIVELY AFTER TBI, PART II

In our last issue, we wrote about stress and the effects of stress on our daily lives. You may recall that we gave some signs of "stress overload":

- ▶ Disorganization (forgetting your keys, losing things, making a lot of "dumb mistakes")
- ▶ Daydreaming about spending a few days somewhere, even in the hospital - to sleep, read, be taken care of
- ▶ Trouble making even small decisions (having difficulty figuring out what to wear, feeling stumped about what to have for lunch)
- ▶ Feeling depressed (wanting to curl up on a bed, pull the covers up over your head, and sleep for a week)

What do you do if you feel overloaded with stress? Here are some ideas to help you cope with stress. Review the list and try out some of the ideas.

Take breaks often

- ✎ Famous last words, "I can't take a break. People will think I'm lazy and that I don't care."
- ✎ Realize that most family members don't give themselves enough rest

- ✎ Realize that working harder doesn't necessarily mean accomplishing more; instead, recognize that taking breaks can help you accomplish more and feel better
- ✎ Avoid the cycle of going beyond your limits, spinning your wheels, and becoming frustrated
- ✎ Take several 20 – 30 minute breaks each day, take more time if needed
- ✎ If you can't spare 20 minutes take 10, a short break is better than no break
- ✎ If you are working, make your home a more comfortable place by leaving your work at work

Make a list

- ✎ List what you need to do in the short- and long-term, and set priorities - number items by priority
- ✎ Start with number 1 and work your way down the list, crossing off each accomplished item
- ✎ Regularly review your accomplishments to help you keep a positive perspective

(Continued on page 6 - Managing Stress...)



HAVE YOU MET JENNY MARWITZ?

Jennifer (Jenny) Marwitz, M.A. is the project coordinator for VCU's Traumatic Brain Injury Model System Program (TBIMS). Having worked in the Department of Physical Medicine and Rehabilitation since 1988, she has been a VCU faculty member since 1993, holding the position of Assistant Professor since 1999.

After earning a Bachelor's degree in Psychology from the University of Wisconsin, Ms. Marwitz went on to attend graduate school at the University of Richmond where she finished her Master's degree in Psychology. Ms. Marwitz helped author the TBIMS grant and has co-authored over 30 articles for publication in numerous prestigious academic journals. Additionally, she is the technical editor for the international journal, Brain Injury.

She has found one of the biggest challenges in TBI research to

be keeping up with people after they leave the hospital. "So many patients tend to move around a lot after they leave rehab and a lot of the research depends on being able to follow-up with people through the years," comments Ms. Marwitz.

In addition to her tremendous contributions to brain injury research, Ms. Marwitz is a very committed wife and mother of two school-aged daughters, often vol-

(Continued on page 3)



PARENTING AFTER BRAIN INJURY



Parenting is an important and sometimes challenging task for every person with children. Many survivors say that parenting is even more challenging, and sometimes overwhelming, after their injury. Some survivors mention that they've noticed changes in the way they care for their children. Some describe being more strict than before. Others say they have trouble making their children behave. Sometimes survivors don't notice any changes, but their family members and friends might.

Below is a list of common parenting challenges or difficult situations that many survivors face. Check off the concerns that fit your situation.

- ▶ Being too strict
- ▶ Not being strict enough or letting your children "get away with murder"
- ▶ Having trouble deciding what "the rules" should be
- ▶ Having trouble deciding how to discipline your children when they break a rule
- ▶ Not following through with (or remembering) promised consequences
- ▶ Having your children say that you don't listen to them or understand them
- ▶ Talking to your children about **your own personal** problems
- ▶ Yelling at your children or calling them names
- ▶ Losing patience more easily or more quickly
- ▶ Forgetting to do things that your children need you to do – like preparing meals, picking them up at school, or going to important meetings
- ▶ Having trouble getting out of bed to do things for your children
- ▶ Not having enough energy to play with your children or do things with them
- ▶ Having your children laugh or make fun at you because of forgetting or making a mistake
- ▶ Laughing when trying to discipline your children

People sometimes have trouble knowing what their challenges and problems are. You may find it helpful to show your list to family and friends and see what they think.

Being an effective parent is harder after brain injury. Many families we talk to have figured out ways to successfully handle parenting challenges. The list below includes some ideas. Try them out and see if they work for you and your family.

- ▶ Write down a list of "house rules." The list may include problem behaviors you often see with your children (like talking back to adults, not doing chores, or staying out after curfew) and consequences for the behaviors.
- ▶ Talk with trusted family, friends, or professionals about your list of "house rules." They may be able to help you decide if your rules are too strict or not strict enough.
- ▶ Review the "house rules" with your children and tell them that you will be following this list. Post the list where everyone in the family can see them.

RESOURCES TO THE RESCUE

BRAIN INJURY SERVICES OF SW VIRGINIA

Established in November 2000 through a Jason Foundation grant, Brain Injury Services of Southwest Virginia (BIS SWV) states its mission is to "empower survivors of brain injury and their families through individualized service coordination, education, and advocacy." Radford University and Brain Injury services of Fairfax, VA provide collaborative partnerships and mentoring. Additionally, the Roanoke Valley Chapter of the Brain Injury Association of Virginia serves as an active advisor and supporter of BIS SWV.

Residents of the Roanoke or New River Valley area, aged 16 or older with documented acquired brain injury who need assistance with certain daily living activities are eligible for services. Service Coordinators work with consumers to identify goals for increasing self-sufficiency and to develop individual service plans to meet those goals. Brain Injury survivors and active family members receive information and assistance to access services and/

or equipment needed to increase independence and quality of life.

Service coordinators assist consumers in matching their needs with area service agencies and organizations. Accessed services may include:

- ◆ Socialization and community integration
- ◆ Assistive technology and equipment
- ◆ Behavioral training
- ◆ Employment and training services
- ◆ Medical rehabilitation
- ◆ Recreation and leisure
- ◆ Residential and housing
- ◆ Transportation

For referral information please contact:

Brain Injury Services of SWVA
2036-A Colonial Ave., SW
Roanoke, VA 24015
Phone: (540) 344-1200
Fax (540) 344-9755

- ▶ Talk with other parents about how they deal with difficult behaviors. You may get some good ideas! You are likely to find that the challenges you face are very similar to theirs.
- ▶ Be consistent with rules. Try to react the same way each time your child breaks a rule.
- ▶ Be sure your requests are clear, direct, and short. Check to be sure your child understood your request by asking them to repeat the information back to you.
- ▶ Think before you react. Don't discipline your child when you're angry. Calm down first by taking a "time out" for yourself - count to 10 or leave the room.
- ▶ Try not to laugh when disciplining your child. They may think you're not being serious. Step out of the room for a moment first to try to calm down. Counting to 10 works well, too.
- ▶ Try not to yell at your children. Remind yourself that you don't want to scare your children and you want them to feel safe. If you become angry, take steps to calm down. If you can't, call a trusted family member or friend to come over and watch your children, so you can calm down.
- ▶ Make a "to do list" of things you need to do for your children and keep a calendar posted where you can see it. Review the list and your calendar several times a day.
- ▶ Setting up and sticking to routines can help avoid memory problems.

You care about your children and want the best for them. Letting your children know that you care is one of the best ways to achieve positive results as a parent.

Some positive comments you may want to use include – "Great job," "I love you," "I'm proud of you," etc.

- ▶ Think about and try to understand your child's emotions and personality. Some children are very sensitive. Some children don't seem to care, and others don't seem to listen. To communicate with your children, think about how what you say will affect them.
- ▶ Remember that children shouldn't have to deal with adult problems. If you're feeling sad or upset, talk to a trusted friend, family member, or professional who can help you feel better.
- ▶ Remember that you are part of a team. Ask trusted family and friends for help when you need it.

▶ You need a break, too. Many children enjoy being involved in activities after school and on weekends. Get them involved so you can take a break.

▶ Talk to your children's teachers to find out how things are going at school. Teachers can help identify solutions to problems and offer suggestions.

- ▶ Talk to your children. They may not understand why you're acting differently since your injury. Remind them that you'll always love them even if you're acting differently. Let them know it's okay to talk about their worries or concerns with family, friends, or teachers. You may also consider arranging for your child to talk to a counselor if they're having a hard time.

This column was written by Laura Taylor and Jeff Kreutzer from the VCU TBI Model System Family Support Research Program. For more information about the program, please contact Laura at 804 828-3703 or taylorla@vcu.edu.

MEMORY-WISE

Sometimes how you organize things can help you remember them.



Try the following the next time you need to get a few things from the store.

- ◆ Make a list of what you need. (Start with just a few things at first).
- ◆ Use the first letter of each thing you need to get.
- ◆ Then arrange the letters to come as close as you can to making one or two words. (One or two words is easier to remember than 5 or 6!)

For example:

- ◆ Say you need milk, jelly, apples, eggs, and bread.
- ◆ M, J, A, E, and B will spell JAB ME—Ouch!
- ◆ The funnier the word(s), the easier they will be to remember.
- ◆ Take the list "just in case" and test yourself using your put-together words. See how many things you remembered.

(Continued from page 1)

unteering her time for their school and after school activities. When she's not running her children to different activities she enjoys spending time gardening and learning to speak French with her daughters as they prepare for a foreign exchange trip to France.

1. M ____ + H ____
2. F ____ + D ____
3. L ____ + B ____
4. D ____ + P ____
5. F ____ + S ____
6. B ____ + L ____
7. K ____ + M ____



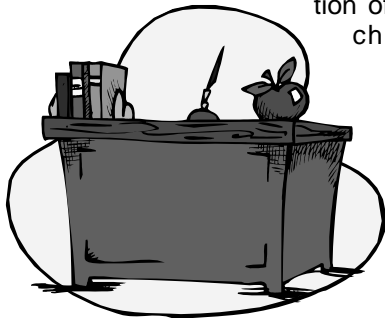
▶ Many children respond positively when you ask for their help. Like you, they want to know that their help is important. Praise them for pitching in!

▶ Be sure to praise your children and tell them positive things **often**.

JUST THE FREQUENTLY ASKED QUESTIONS

Q: What is the *public school's* obligation to help children who return to school after sustaining a brain injury? How can schools address children's needs for therapies and specialized classroom instruction?

A: The federal Individual with Disabilities Education Act (IDEA) includes a specific category for students with traumatic brain injury, recognizing that students with brain injuries may need special help in school. It is often helpful to contact the Director of Special Education of the child's



public school, or the state Department of Education, and get a copy of the guidelines on special education.

Parents may request that their child be evaluated for special education services as a result of the child's brain injury. After a formal referral is made, the school will have an educational team evaluate the child to determine his or her special education needs resulting from the brain injury. The team will develop an Individualized Educational Plan (IEP). The IEP will highlight the child's strengths and weaknesses, identify specific educational goals, and recommend services and resources. Some of these resources may include: physical, occupational and speech therapies; psychological services; counseling; further testing; transportation; tutoring; special classes; accommodations in the classroom (such as extra time for taking tests, using a computer, or having a note taker); and other services.

If the child is currently in a rehabilitation program, the *treatment* team may start the process of academic re-entry by meeting with

school personnel and planning a transition back to school. Having the child evaluated by a neuropsychologist before leaving rehabilitation can provide important information on how the injury has affected thinking and learning abilities. The neuropsychologist may also be able to help prepare school personnel to meet the child's unique academic needs.

Many educators have little experience or training in the area of brain injury. It is important for the rehabilitation staff to work with the school, helping them prepare the best plan to meet the child's special needs. The Brain Injury Association of Virginia (804-355-5748 or 1-800-334-8443 for more information) can be a valuable source of information regarding students' rights and available services.

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

MARK YOUR CALENDARS



FIRST FRIDAY OF EACH MONTH (6:00 — 9:00 PM)

Event: T.G.I.F

Location: Typically at Belmont Recreation Center, 1600 Hilliard Rd. in the Lakeside area of Henrico Co.

Description: Henrico, Hanover, and Chesterfield County Departments of Parks and Recreation host monthly social events for adult survivors of brain injury

Contact: Call 804-501-7489 for more information.

APRIL 30 — MAY 1

Event: Third Annual Brain Injury Conference for Southwest Virginia — Transcending Brain Injury

Location: Holiday Inn — Tanglewood,

Roanoke, VA

Description: Educational and general sessions with brain injury specialists and community service providers from across Virginia. Featuring a keynote address by Cathy Crimmins, author of *Where is the Mango Princess*, offers the keynote address.

Contact: Register on-line at www.radford.edu/~conf-serv or call (540) 342-9531 for information.

MAY 17

Event: Richmond BIAV Speaker Meeting

Location: Children's Hospital, 2924 Brook Rd.

Description: OT Tony Gentry presents: Consortium of Hand Held

Technology

Contact: BIAV at 804-355-5748 or 1-800-334-8443 for more information

JUNE 24 — 25

Event: 2004 Williamsburg Conference— Rehabilitation of the Adult and Child with Brain Injury: Practical Solutions to Real World Problems"

Location: Radisson Fort Magruder, Williamsburg, VA

Description: Lecture, break-out sessions, and panel discussions addressing 1) community integration 2) cognitive rehabilitation and pediatric brain injury and school reentry.

Contact: Call (703) 451-8881 for information.

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 contact Debbie West at 804-828-8797 or ddwest@vcu.edu.



CHAT WITH PAT

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

DEAR PAT: Since my brain injury 2 years ago, I have had many problems that will not go away. I feel depressed and angry most of the time. I get very impatient with people. It's difficult for me to concentrate and I'm often forgetful. I couldn't keep up at work and I lost my job 6 months ago. Since then, I haven't felt like being around people much at all. The only people I have to talk to are my children. Even *they* don't understand what I'm going through. They keep telling me to "get over it" and find another job. So far, I haven't been able to do either one of those things. I feel too sad and irritable to even think about working. I finally broke down and told my doctor about how I've been feeling lately. She started me on Prozac last month. I feel a little

better, but I'm still having a pretty hard time. What else can I do to start feeling better? Are there people out there who will believe that my problems are not imaginary?

PAT'S RESPONSE: You may be surprised to find out your symptoms are not so unusual. Problems like the ones you describe are quite common after a brain injury, in fact. Many people recovering from brain trauma notice changes in their emotions and thinking. You've taken good first steps to reach out and find others who do understand what it's like to survive a brain injury.

From the letter you wrote, your doctor seems to believe that your problems are real and that they deserve treatment. Depression after a brain injury is an all too common difficulty. Reactions to loss and life changes, or changes in brain chemistry, or both may account for post-injury depression. There are many medications for depression and other emotional problems that may be helpful for you. Keep your doctor informed about how the medication is (or is not) helping. Be willing to try different medications if necessary.

If you find that medications aren't helping enough, you may want to think about other kinds of treatment or support. Many people

find individual and group therapy, for example, helps during the short and long-term phases of recovery. Your doctor may know a rehabilitation specialist in your area who provides counseling for people after a brain injury. Joining a group for survivors of brain injury is another great idea. You are likely to find the support, guidance, and advice of other people with similar experiences very helpful.

There is a community of survivors, family members and friends, and treatment professionals that will not dismiss your concerns. The Brain Injury Association of Virginia (804-335-5748 or toll free 1-800-334-8443) is a wonderful organization to contact. They are an excellent source of information about treatment specialists, programs, services, and support groups in your area.



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:
ddwest@vcu.edu



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- ✍ Realize that you can only do one or maybe two things at a time effectively
- ✍ Remember that “good” things can also be stressful; planning and having a birthday party, preparing to visit and visiting other family members
- ✍ Don’t forget activities related to helping yourself (e.g., getting rest, spending time with other family members) can also be important priorities
- ✍ Learn and recognize the difference between what you “have to” do and “want to” do

Set reasonable goals and expectations

- ⦿ Learn to recognize what you do best
- ⦿ Recognize your limitations; most relate to being human
- ⦿ Avoid letting people pressure you into taking on more than you can handle
- ⦿ Recognize what others do best and ask for their help
- ⦿ If you keep missing deadlines, be less ambitious
- ⦿ Distinguish between what you want and expect and what other people want and expect from you
- ⦿ Recognize and avoid harmful feelings like guilt and frustration

Learn and apply negotiation skills

- 🗨 Realize that few of your responsibilities are “set in stone,” and most people who expect you to do things are willing to negotiate
- 🗨 With other family members and co-workers, negotiate timelines and the amount of responsibilities you agree to take on

- 🗨 If you are afraid of negotiating, practice by rehearsing “in your head”
- 🗨 Realize that taking on too much too soon will cause failure
- 🗨 Balance wanting to please with your knowledge of what you must do to succeed

Learn and use relaxation techniques

- 🎵 Breathe slowly and deeply
- 🎵 Close your eyes and imagine yourself in a relaxing situation
- 🎵 Listen to soothing music
- 🎵 Take a walk
- 🎵 Talk to someone you like

Tell yourself things that will help

- ≥ *I’m doing the best that I can.*
- ≥ *I’m a good person, I’m trying.*
- ≥ *If I take my time I’ll do things right.*
- ≥ *Things will work out for the best.*
- ≥ *We’ve really come a long way since he was hurt.*
- ≥ *I can count on faith, my friends, and family to help me through.*

Avoid pushing yourself too hard and putting yourself down

Avoid telling yourself negative things such as:

- ⊖ *I’ve got to do more.*
- ⊖ *I’ve got to try harder.*
- ⊖ *I’ve got to get this done right away.*
- ⊖ *I should have finished a week ago.*
- ⊖ *I’m letting everyone down.*
- ⊖ *I’ll never get another chance.*
- ⊖ *I can’t believe I’m doing so bad.*

Ask for help

- 🗨 Seek help from people that have offered
- 🗨 Recognize that asking for help is better than failing
- 🗨 Don’t let your pride get in the way
- 🗨 Recognize that everyone needs help sometimes
- 🗨 Better to ask early on than right before you fail

Common sense strategies can help you be strong

- 🗨 Focus on one thing at a time
- 🗨 Work on your hardest responsibilities at times when you feel most fresh and rested
- 🗨 Have “quiet times” for everyone, noise can increase stress and reduce productivity

Have a back-up plan

- 🗨 Failing and not knowing what to do next is a bad situation
- 🗨 Any time you plan something, have a back-up plan
- 🗨 Recognize your human imperfections; most people fail sometimes
- 🗨 When your first approach doesn’t work, go to your back-up

Recognize that life has many challenges

- ▶ Brain injury or not, many people struggle to enjoy successful lives
- ▶ Recognize that many of the issues you face are faced by others
- ▶ Be patient; everyone finds obstacles on the road to success
- ▶ Recognize that persistence, faith, and your good character will help you to succeed in time

TBI TODAY presents its newest feature, Inspiration Point: a forum for readers to express their creativity. Readers are encouraged to send their contributions of original writing to the editor (see below "Just for Fun").

This poem was written by a patient diagnosed with brain cancer. Ten years after being told she had only months to live, she's still going strong.

6-9 Months

Sometimes one is informed
 The options of life;
 Our hearts can be torn;
 And other days become so bright.
 There is living with hope,
 But realize we could lose.
 The burdens we cope,
 Oh Lord, what does one chose;
 Only you can decide.
 6-9 months, yea, that's what we're told,
 This human body has just to stay alive.
 CANCER, that word, it's so cold.
 My Father in Heaven, I want to survive,
 6-9 month?? It's just not fair:
 I'm falling apart:
 But I know you're here.
 Oh GOD, the things you can do,
 Those 6-9 months, turned to "8" years!
 My miracle, "Father God," that
 can only be from you!

The following poem was shared with us by a young woman who experienced a moderately severe brain injury in a car accident. Despite having a lot of trouble with her memory since her injury, Ms. Hathaway is working.

Untitled

Do you ever blame yourself
 All day, every day?
 For something that your memory
 will not able you to say?

You spend your days thinking
 of ifs, ands, even buts.
 You ask yourself how you'll get out
 of these deep, dark dampened ruts.

"What ifs" seem like
 natural thoughts to you.
 You analyze people and objects
 until there is nothing left to do.

If you aren't keeping yourself
 in a productive blame,
 Then you are turning your
 own happiness into shame.

"Why did I" or "Why do I" are
 a few questions you begin to ask.
 You really should ask yourself
 what frightens you the most
 Why play the role of your own worst enemy
 when you can live a very happy life?
 And, to this, I ask for a toast.

Christina Hathaway

Reader contributions are welcome! Send your ideas for "Just for Fun" or contributions to "Inspiration Point" to Debbie West at Box 980542, Richmond, VA 23298-0542 or e-mail to ddwest@vcu.edu.

**JUST
 4 FUN!**

Working word puzzles can help keep you sharp. Try your hand at the word puzzles below. Use the clue to solve the riddle, forming a rhyming word pair. For example, "an automobile saloon?" would be a "car bar." First letter hints are at the bottom of page 3. Answers are on page 8. The first 4 are all one syllable words. The last 3 are all two syllable words. Good luck!

1. A rodent's home? _____ + _____
2. A plate for the trout? _____ + _____
3. The final explosion? _____ + _____
4. Gherkin flavored medicine? _____ + _____
5. It's raining daisies? _____ + _____
6. Improved mailer? _____ + _____
7. Gloves for Tabby? _____ + _____



RESEARCH TO UNDERSTAND EMOTIONAL ADJUSTMENT AFTER BRAIN INJURY

People have a lot of emotional changes after brain injury. Researchers at the TBI Model System want to understand some of the emotional changes. Doctors often have difficulty deciding whether people's symptoms are due to the brain injury, depression, adjustment to losses and changes, or a mixture of these things. We are looking for people with brain injury to participate in an interview about emotional changes and coping.

To date 52 individuals have enrolled in our study. We are hoping that we can get at least 50 more volunteers before October 2004. People who have had a traumatic brain injury and are at least 18 years old can participate in the study. People do **not** have to feel depressed to be in the study.

If a person agrees to be part of the research, he or she will come into the clinic two times (3 months apart), and answer questions about emotional problems. Volunteers can get paid up to \$55 for being in this study. For more information, call Jenny Marwitz at 804-828-3704 or toll free at 866-286-6904 or email jhmarwit@vcu.edu.

1. Mouse house
2. Fish dish
3. Last blast
4. Dill pill
5. Flower shower
6. Better letter
7. Kitten mitten

PUZZLE ANSWERS

JUST FOR FUN

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