

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

THE VIRGINIA TBI MS TEAM

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NURTURING THE RELATIONSHIPS YOU NEED AFTER BRAIN INJURY, PART I

we cherish important relationships. Certain persons in our lives mean so much that we miss them when we're apart. We understand the important contributions those special people make to our lives and we have a strong desire to share our lives with them. The value of these important relationships becomes clearest when we go through a challenging time.

An accident or illness resulting in a brain injury often presents many problems for relationships. Unfortunately, many of the very skills needed to keep an important relationship, or develop a new one, are those most frequently impaired following brain injury. Let's look at the abilities that are so important for nurturing important relationships.

- Being sensitive to others' feelings and needs, not just your own
- Communication
- Remembering important anniversaries, likes and dislikes of the other person
- Self control
- Concentration

Now consider the most common problems associated with TBI:

- Attention/Concentration
- Memory
- Communication
- Self Control
- Sensitivity to other's feelings and opinions

Brain injury can complicate most kinds of relationships, for example:

- Established romantic relationships
- New relationships, dating
- Friendships
- Family relationships

Brain injury can result in the following changes to an established relationship, disturbing its balance and stability:

- Roles (e.g., who makes the decisions – who was the leader and who is the leader now?)
- Communication
- Interests
- Ability to do things together
- Behavior/self control
- Sexuality

Changes can cause distance and frustration.

WHAT CAN BE DONE?

A "partnership approach," involving positive problem solving can be helpful. With your partner, ask the following questions when a problem arises.

- What is our goal?
- How do we reach it?
- How can we work as partners toward this goal?

Make a plan of action with your partner utilizing the following tips:

- Use notebooks or calendars as memory aids
- Keep it simple
- Break plan into steps
- Use a problem-solving format as shown in the box on page 2

(Continued from page 1)

- ۲ Define the problem
- ٢ Come up with possible solutions
- Weigh advantages and dis-۲ advantages of each possible solution
- ٢ Pick a solution to try
- ٨ Evaluate the success of the solution
- ٢ Try another solution if the first one is not working

DEALING WITH CONFLICT:

Most everybody argues and has disagreements once in awhile Remember, it's not what you argue about, but how you argue that can

WE CHANGED OUR MINDS: SUCCESSFULLY SURVIVING A BRAIN INJURY

The 12 Elements of a Successful Recovery: The Caregiver's Perspective

or the past few months, we have been soliciting information from brain injury survivors and their caregivers for our book: We Changed Our Minds: Successfully Surviving a Brain Injury. Many of you have made valuable contributions to the project, which would not be possible without your support. We are very grateful. As promised, in exchange for your help, we are providing the following report, the first of three, on what we have learned thus far.

What is a Successful **Recovery from Brain Injury?**

We believe that we are surviving Jessica's TBI successfully. Despite her significant physical, cognitive, emotional, and behavioral impairments, Jessica has slowly developed a full, satisfying, and productive new life. She has developed a wide circle of warm and caring, bright and energetic friends, who through their joint activities challenge Jessica to continue her recovery every day.

Since every brain injury is different, we realize that writing a book from the narrow perspective of our own experience would be foolhardy. Consequently, we are seeking input from other survivors and caregivers. Over the past few months, we have asked the following questions:

How do you define a "successful" re-

covery from a brain injury?

- Are you recovering "successfully?"
- What is really hard about living with a brain injury?
- What advice do you have for survivors and their families who are just beginning their recovery?

Your comments show that there is much debate over the words "successfully" and "recovering." For those who equate "recovery" with "back to normal," you agree that success eludes all but a very few lucky survivors. Also, you confirm our belief that recovering from a brain injury is a lifelong process.

Many of you commented on the difficulty in defining "success." Here's what you said:

- The caregiver and the survivor must define their own success.
- What one may think successful, someone else might not.
- ✤ There are degrees of success. It depends on your current level of functionality.
- Success is fluid; it constantly changes.

Your numerous and perceptive contributions, combined with our eight years of experience living with a brain injury and our extensive reading suggest that successfully surviving a brain injury from the perspective of the caregiver has twelve elements. (Since the majority of survivors are male, we have chosen to view the caregiver in this report as a woman.)

A Caregiver Is Successfully Surviving a **Brain Injury When She...**

- 1. Is doing her absolute best to care for her survivor.
- 2. Is confident that her survivor is doing his absolute best to live within his limitations and to recover to the greatest extent possible.
- 3. Does not bear too great a portion of the care giving burden.
- 4. Is supported by family and friends who fully understand her need for help and are willing to help.
- 5. Has a family that has adjusted well to the special needs of the survivor.
- 6. Is financially secure.
- 7. Utilizes all available medical resources.
- 8. Has an understanding with her survivor as to when he should complete a task by himself and when he needs help.

harm your relationship. Here are

Be guick to forgive and apolosome tips for handling arguments and "fighting fairly".

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- Be specific about your issue and deal with it when it happens
- Don't blame the other person ٠
- Take a minute to ask why they ٠ did what they did

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- gize
- Be polite and respectful
- ٠ No name calling or cursing

Dr. Jan Niemeier

Look for Part II of Nurturing the Relationships You Need after BI in the next issue of TBI Today.

The	The problem-solving format below can help when you're making a plan of action with your partner.						
	PROBLEM	POSSIBLE SOLUTIONS	ADVANTAGES	DISADVANTAGES			

- 9. Has achieved a balance between seeking improvement and making do.
- 10. Has interests—professional, avocational, social, recreational—of her own.
- 11. Is comforted and inspired by her faith.
- 12. Accepts without bitterness that life is not fair.

Meeting all twelve of these elements is fantastical for most, if not all, of us. But we do think there is a practical purpose to compiling this list. Having a clear understanding of your objective—even if it is only partially achievable—can result in positive actions that will improve your life.

If You Would like to Read More

As we conduct our research, we are writing two series of articles that we believe will be of interest to survivors and caregivers.

The first series—Successfully Surviving a Brain Injury—will cover many aspects of recovering viewed through the eyes of both a survivor and a caregiver. The first article in this series, An Appeal to Survivors and Caregivers, now appears in a number of newsletters including TBI Today, the newsletter of the National Resource Center for Traumatic Brain Injury. The second article in the series, You Must Change Your Mind, is now available.

The second series of articles-A Slice

in the Life of a Brain Injury Survivor and Her Curious Caregiver—provide our separate perspectives on everyday activities, such as driving, that are complicated by the sequelae of a brain injury. The first article in this series, *Drinking and Driving,* will be in the Spring/Summer 2006 issue of *BRAINSTORM*, the newsletter of the Brain Injury Association of Maine.

In preparing to write our book, we are reading many of the published personal accounts of survivors and caregivers, as well as guides for families coping with a brain injury. We have learned that the quality and usefulness of these books varies considerably. Consequently, we are writing a series of reviews of those we find particularly valuable. We will post these reviews on our Website.

What Do You Think of the 12 Elements Listed Previously?

In our quest to understand better the factors that contribute to a successful recovery, we continue to ask for your help. There is a wealth of information on recovering successfully from a brain injury that we still have to learn.

At this time, we are soliciting your input and support in three areas:

1. How would you revise The Elements of a Successful Recovery from the Perspective of the Caregiver listed on

- 2. We are beginning to identify *The Elements of a Successful Recovery from the Perspective of the Survivor.* What do you think should be included in this list?
- You can support our project in a number of ways:
- Complete a questionnaire at our web site www.BrainInjurySuccess.org.
- Use our questionnaires with your support groups.
- Send us a letter or e-mail with your insights and comments.
- Consider using some of our material on your web site or in your newsletter to help us spread the word and reach more survivors and caregivers.
- Share this report with other survivors and caregivers, as well as professionals who work in the field of brain injury.

Note: Any profits derived from the sale of this book will be donated to Brain Injury Associations. Thanks very much for your support and interest in our project.

> Garry Prowe & Jessica Whitmore Info@BrainInjurySuccess.org 7025 NW 52nd Drive www. BrainInjurySuccess.org Gainesville, FL

Research Volunteers Needed VCU Acquired Brain Injury Outpatient Rehabilitation Services Program

VCU Researchers are seeking adults with acquired brain injuries (such as stroke, aneurysm, traumatic brain injury, anoxic brain injury) and their families to be part of a research study. We are evaluating the helpfulness of an outpatient rehabilitation program. During the course of 5 sessions, participants will be given information on brain injury, local resources, skills development, and positive coping strategies. Qualified volunteers will also be asked to complete several questionnaires. All participants must be at least 18 years old.

Rehabilitation services will be provided at no charge at the Medical College of Virginia Campus. Volunteers will be reimbursed for their time and effort in completing questionnaires.

> FOR MORE INFORMATION ABOUT THE PROGRAM, PLEASE CALL: JENNY MARWITZ

PHONE: (804) 828-3704 OR (866) 296-6904 (TOLL FREE)

E-MAIL: JHMARWIT@VCU.EDU

JUST THE FREQUENTLY ASKED QUESTION S

After a minor car accident, I was taken to an emergency room and given a CT scan. The doctor said the CT scan showed no brain injury. However, here I am, 8 months later, and I am still experiencing problems. I have severe headaches, periods of confusion and memory loss, and difficulty finding the words to express myself. Is it possible that I sustained brain damage that the CT scan did not show? Should I have another CT scan to see if anything shows up now?

Many brain injuries can cause serious problems without any noticeable damage that would show up on a CT scan. This is why many patients say that their biggest problem is that they look fine on the outside. Sometimes the tissue damage may be slight although still sufficient to cause problems with thinking, memory or speech. The neuropsychological evaluation can often detect brain damage even though the CT scan does not show any serious problems. Rather than get another CT scan, you would be better off getting a complete neuropsychological evaluation. If the problems persist or worsen, then another CT scan, MRI or PET may be warranted.

CHAT WITH PAT: NOT

Pat fans, don't despair. Pat is taking a well-deserved vacation. Pat will be back in full swing this fall. If you see Pat, give a nod and a wave, will you? You'll recognize Pat by the well-worn raincoat and shades. Very cool, Pat. Very cool.

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

HOUSEHOLD SAFETY: THE BATHROOM



According to the National Safety Council, the five leading causes of fatal injury outside the work-

place (i.e., in the home and community) are falls; poisoning; choking; drowning; and fires, flames and smoke. In the home, a fatal injury occurs every 16 minutes and a disabling injury every 4 seconds. The household environment can be a hazardous place, especially for individuals with TBI. Physical and cognitive challenges often impair individuals' abilities to get around and function in areas once considered harmless and safe. Problems with mobility, memory, judgment, and self-awareness represent increased risks for accidents in many areas in the home such as the kitchen, bathroom, basement, laundry room, garage and workshop. Survivors and caregivers should be aware of these potential household dangers and make modifications where necessary to reduce the risk of re-injury.

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The bathroom is potentially a very dangerous place and is typically a primary focus for healthcare providers performing home safety assessments. Listed below are various items that pose safety hazards in the bathroom.

LOW TOILET SEATS make transfers difficult for individuals with poor balance and weakness in arms and legs. Individuals with physical challenges could easily fall and hurt themselves again.

RECOMMENDED SAFEGUARDS

Use a raised toilet seat (available at medical supply stores) to make transfers to and from the toilet easier.



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



- * Install grab bars near the toilet to provide a stable surface for transfers.
- * Consider using bedside commodes to avoid having to walk to bathroom when sleepy or groggy.

EXCESSIVE CLUTTER is hazardous, especially for persons with poor vision and limited mobility. Clutter makes getting around more difficult and can cause one to slip and fall.

RECOMMENDED SAFEGUARDS

- Consider using plastic shelves and storage containers to store bathroom accessories.
- Consider using a shower caddy for storing toiletries.
- Make sure the area is well lit.

THROW RUGS constitute a major falling risk for individuals with balance problems or those using assistive devices. Unsecured throw rugs move easily, particularly on a wet floor.

RECOMMENDED SAFEGUARDS

- Remove all throw rugs, if possible, or secure throw rugs with adhesive.
- Consider installing grab bars.

BATHTUBS can be extremely dangerous for individuals with disabilities. The water, slippery surface, and high tubs make transfers and taking showers risky for individuals with weak arm and leg strength, poor endurance, or poor vision. Hot water poses a risk of burns.

RECOMMENDED SAFEGUARDS

* Place a rubber mat on or affix non-slip adhesive decals or strips (available at most home supply and hardware stores) to tub floor.

- A handheld shower can help one control water flow with minimal movement.
- Immediately wipe up any water spilled on the floor to avoid slips and falls.
- Avoid tub doors with mirrors or other hard materials.
- * For persons with permanent mobility problems, consider installing a level-access shower with shower seat.
- * Consider fitting tub and shower with thermostatic or anti-scald devices. These devices, made by all shower valve manufacturers, protect against unpleasant and po-

Average temperature	2nd Degree burn¹	3rd Degree burn ²	
113°F	2 hours	3 hours	
117°F	20 minutes	45 minutes	
118°F	15 minutes	20 minutes	
120°F	8 minutes	10 minutes	
124°F	2 minutes	4.2 minutes	
131°F	17 seconds	30 seconds	
140°F	3 seconds	5 seconds	
1 - no permanent tissue damage; 2 - tissue destroyed			

tentially dangerous temperature changes.

Make sure your water heater is set to a safe range (below 120[°]F). The accompanying chart indicates the time in which one can burn with home hot water heaters set at various temperatures.

ELECTRIC DEVICES in 🚬 the bathroom can be very hazardous, especially for individuals with poor judgment, memory, vision, and limited mobility because of the possibility of electrocution or electric fire.

RECOMMENDED SAFEGUARDS

- Keep all electrical equipment away from water and post signs on mirrors for reminders.
- Use surge protectors to prevent overloading electric circuits
- Consider using batteryoperated devices instead of electric ones.
- Make sure bathroom electric outlets meet safety standards.

FYI Burn Facts

Courtesy of Shriner Burns Hospital

- ✤ Hot water scalds account for 20% of all burns
- ✤ More than 2,000 children in American are treated for scalds each year
- Scalding accidents occur most frequently in the bathrooms and kitchens where they are most preventable
- Scalding leads to additional injuries such as heart attacks, shock, falls, and serious broken bones, particularly among the elderly
- Scalding and other burns require the most expensive treatments: long hospital stays, costly skin grafts, and plastic surgery
- Most U.S. states now require by law some form of anti-scald measures in buildings

For additional information about safety in the home, visit the National Safety Council Website at www.nsc.org.

Kelli Williams



JENNIFER MENZEL?

Dr. Jennifer Menzel is a postdoctoral fellow in Neuropsychology Rehabilitation Psychology. and She received her bachelors and masters degree in psychology from Loyola College in Maryland and received her doctoral degree in clinical psychology from Indiana University of Pennsylvania. Dr. Menzel completed a one-year predoctoral internship with a concentration in neuropsychology at the North Florida/South Georgia Veterans Healthcare System in Gainesville, Florida. In addition to neuropsychology and rehabilitation psychology, Dr. Menzel is also interested in geropsychology.

At VCU Medical Center, Dr. Menzel is involved in clinical work, completing neuropsychological evaluations, and outpatient therapy. As part of her fellowship, she is also involved in several research projects focusing on TBI in the geriatric population, depression following TBI, and family intervention. Dr. Menzel serves as Project Coordinator for the Brain Injury Family Intervention (BIFI) project.

In her spare time, Dr. Menzel enjoys attending baseball games, traveling, shopping, and going to the movies. In fact, she considers

herself to be quite the movie buff. She also plays softball for a local coed softball team. Dr. Menzel recently took up running and completed her first 5K and 10K races in May 2006. You can also find Dr. Menzel studying for her licensure exam at Café Gutenberg or taking in a show at the Landmark Theater.

Dr. Menzel is "mom" to an adorable Jack Russell Terrier, Emmett, and enjoys spending time with her favorite four-legged companion. A little known fact about Dr. Menzel is that she played the played clari-

net for 10 years and performed has at ' Oriole Park at Camden Yards and the Meyerhoff Symphony Hall in Baltimore.



NOW WHAT DID I COME IN *HERE* FOR? STRATEGIES FOR REMEMBERING WHAT YOU'RE LOOKING FOR

Walking into the kitchen, Wallace stopped dead in his tracks, scratched his head, and wondered, "What the heck am I doing in here?" Last he remembered, he was sitting in front of the TV. "This is crazy," he thought. "I know I came in here for something, but for the life of me, I can't remember what it was."

Wallace is in good company. Forgetting what you are looking for is a common problem reported by persons who've had a brain injury. What can be done to remedy this frustrating problem?

- Avoid trying to do too many things at once. It's much easier to forget or get confused when you are trying to do different things at the same time.
- Repetition, Repetition, Repetition. Repeat the name of the object of your search over and over until you find it.
- Write down what you're looking for. Even just one word may be enough to trigger your recall.
- If paper isn't handy, write on your arm or hand.

- If a pen isn't handy, "write" with your finger.
- Take something with you to remind you what you're looking for. For example, if you're looking for your checkbook, take the bill you intend to pay.
- "Retrace your steps." For some, going back to the "scene of the crime" helps them recall what they're looking for.
 - Walk back to the last place you remember being. Look all around.
 - Try to form a picture in your mind of what you were doing. Were you sitting or standing? Were you alone or with someone?
 - Pantomime or "act out" what you were doing (e.g.,

writing something down, opening a drawer, leafing through a book).

Wallace returned to the den and noticed his half-eaten bologna sandwich. Pickles, he thought to himself, smiling. As he returned to the kitchen, Wallace repeated "Dill" over and over again until he

got to the fridge. Pickle jar in hand, Wallace strutted back into the den to, well,... relish his victory.

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With the authors' permission, this article was taken from the book *Memory Matters: Strategies for Managing Everyday Memory Problems* by Deborah West and Jan Niemeier. For more information about this book and other helpful resources, visit the National Resource Center for TBI Website at www.neuro.pmr.vcu.edu or call (804) 828-9055 to request a catalog.

U.S. EDUCATION OFFICIAL SURVEYS VCU TBI MODEL SYSTEM

On Friday, April 21, an important visitor from the federal government came to VCU Medical Center. Mr. John Hager (former Lieutenant Governor of Virginia and current U.S. Assistant Secretary of the Department of Education Office of Special Education) came to see what the TBI Model System program at VCU



is all about. Mr. Hager met with university and hospital leaders, toured the Neuroscience Intensive Care Unit and Rehabilitation Units, and met with a group of survivors and their family members. Jim Rothrock, the Commissioner of the Virginia Department of Rehabilitative Services, and Anne McDonnell, Executive Director of the Brain Injury Association of Virginia, also joined the meeting. Mr. Hager reportedly enjoyed the opportunity to talk with people about their needs, opinions, and the types of services they've received as a result of our grant funding.

Jenny Marwitz



David Cifu, Dean Jerome Strauss, and Jenny Marwitz



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TBI TODAY **VOLUME 4 NUMBER 2 GRANT WILL FUND STATEWIDE EFFORTS TO** STRENGTHEN BRAIN INJURY SERVICES IN VA

n April 2006, the Virginia De-partment of Rehabilitative Services received a TBI Act State Implementation Grant from the US Health Resources Services Administration and will be collaborating with the Brain Injury Association of Virginia on Project SOS:BIS (Strengthening Our Statewide Infrastructure for Brain Injury Services). The goals and objectives of the grant center around five areas: data, advocacy, capacity building, education, and outreach.

The first goal focuses on data collection and use. Data from various sources across the state will be used to provide a basis for policy and program decisions to meet the needs of survivors throughout Virginia. Objectives include researching and improving outreach efforts, exploring the prevalence of brain injury, and developing a mechanism for improving brain-injury related data collection and analysis.

The second goal concerns advocacy efforts across the state. Survivors, caregivers, and other interested parties will be provided with the necessary tools to speak up for themselves and for needed services within the state.

The third goal, capacity building, involves maintaining and strengthening Virginia's basic brain injury service system by revising its Brain Injury Action Plan. Broadening funding sources for brain injury programs and services is planned. Capacity building will also strengthen relationships among current and potential public and private brain-injury service providers.

Goal number four addresses education and will focus on expanding the range of and access to brain injury related educational opportunities for survivors, family members, and professionals. Specialized educational materials will be provided, including "train the trainer" packets and annual conferences to increase the knowledge and skills of brain injury services providers, survivors, and family members by providing annual conferences.

The final goal will focus on outreach to increase knowledge of and access to quality brain injury support, services, and information for all Virginians. Existing resource materials will be adapted for at-risk and minority populations. Further, the needs of native Virginia tribes relative to brain injury will be investigated. Outreach will involve increasing the public's awareness of the incidence, prevalence, effects, and prevention of brain injury. In addition, help obtaining information on brain injury will be provided.

BIAV is excited to be involved in this collaboration with DRS and we look forward to working with individuals and organizations across the state as we strive to meet all of the goals.

Anne McDonnell Executive Director Brain Injury Association of Virginia



HAD A BRAIN INJURY? FEELING DOWN OR SAD?

If so, then you might qualify to participate in a study of depression medications for people with traumatic brain injury (TBI) from a car accident, fall, assault, or sports injury.

Researchers are comparing Effexor (a medication to help with depression) to a placebo (sugar pill). If you qualify to be in this study, you will be seen by a doctor regularly for 12 weeks. There are no charges for the doctor's visits or the study medications, and you will receive up to \$55 for your time and effort. You must be 18 years or older to participate.

This study is conducted by the VCU Department of Physical Medicine & Rehabilitation. Contact Jenny Marwitz for more information. Phone: (804) 828-3704 or (866) 296-6904 (TOLL FREE); E-MAIL: jhmarwit@vcu.edu; USPS: VCU Department of Physical Medicine & Rehabilitation, Box 980542, Richmond, Virginia 23298-0542

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to sign up for our TBI Today mailing list.





JUST FOR FUN! Picture This! By Debbie West

Can you solve the following pictogram (rebus) puzzles? Each picture represents a saying (see example, below). You may have to look in between the lines, literally! Answers are on page 7, but try not to peek unless you have to! For more fun word games, visit www.fun-with-words.com.



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