TBI TODAY

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

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FAMILY MEMBERS' CONCERNS ABOUT JUDGMENT AND SAFETY OF INDIVIDUALS WITH BRAIN INJURY: RESULTS FROM RESEARCH AT VCU

Lengths of stay in the hospital after traumatic brain injury are getting shorter and shorter. Survivors with brain injury are often released from the hospital before they fully recover from their injuries. They may leave the hospital in the care of family members who are unsure about the survivors' judgment and ability to live independently. Lingering problems with thinking, memory, and communication are oftentimes troubling to survivors and their family members long after hospital discharge.

Family members may worry about the survivor's ability to make good decisions and to deal with complex problems that emerge in daily life after a brain injury. Questions about ability to manage medications, prepare meals, use home appliances, make decisions about money, and drive may also come up over time.

Researchers at VCU looked at family members' responses to a questionnaire, the *Judgment and Safety Screening Inventory* (JASSI), after their relative had a brain injury. The JASSI covers nine common areas of daily living that may be of concern to family members: 1) Travel; 2) Financial; 3) Interpersonal; 4) Food and Kitchen; 5) Appliances, Tools, and Utensils; 6) Household; 7) Medications and Alcohol; 8) Fire Safety; and 9) Firearms.

The table below shows daily living problems that family members were concerned about. The percent of family members having "a lot of concern" about specific problems is also shown.

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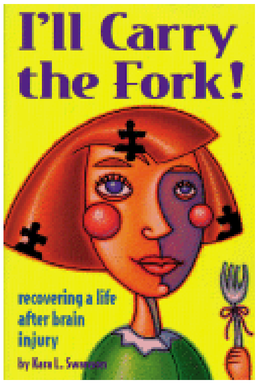
Life Area	Common Problems	% Concerned
Travel	Reacting slowly in problem situations	62%
	Being easily distracted	58%
	Driving when tired or not alert	56%
	Having accidents	56%
	Not yielding the right of way	47%
	Taking eyes off the road	47%
	Ignoring traffic signs, warnings, or signals	45%
	Trouble finding parked car	44%
Financial	Forgetting to pay bills	57%
	Failing to record checks in checkbook	54%
	Misplacing checkbook	40%
Medication	Not taking medication on schedule	49%
Appliances	Climbing unstable objects	42%
Fire Safety	Forgetting to shut off stove burners, heater, iron, or other appliances	39%
	Leaving cooking food unattended	39%

Continued from page 1

Family members may want practical advice to address their concerns about a survivor's judgment and safety after brain injury. Families are encouraged to seek out help and guidance from professionals experienced in treating individuals with brain injury. The survivor's doctor may be a good place to start for advice, or a referral to a specialist may be needed. Physiatrists, doctors specializing in physical medicine and rehabilitation, and rehabilitation psychologists or neuropsychologists can often provide the type of advice a family is seeking. Family members may also contact their state's chapter of the Brain Injury Association of America (BIAA, phone toll free 1-800-444-6443) for more ideas about getting help and information about brain injury.

This column was written by Lee Livingston, Psy.D. from the National Resource Center for Traumatic Brain Injury (NRC). The mission of the NRC is to provide relevant, practical information for professionals, persons with brain injury, and family members. For more information about helpful materials published through the NRC including the Judgment and Safety Screening Inventory (JASSI), please check our website (www.neuro.pmr.vcu.edu) or call Mary Beth King at 804-828-9055 or toll free at 1-866-296-6904 to request a catalog.



Title: I'll Carry the Fork! Recovering a Life after Brain Injury
Author: Kara L. Swanson
Publisher: California: Rising Star Press, 1999
ISBN: 0933670044
Price: $16.95 (paperback)
Description: 204 pages

"Sometimes when your life ends, you don't actually die."

"I am sitting somewhere in the bleacher seats of my mind."

"Whatever the injury has taken, you are certainly allowed to acknowledge that loss."

"That's the tragedy of brain injury. It doesn't tie up neatly in ribbons and bows. It's the guest that stays long beyond its welcome."

I'll Carry the Fork: Recovering a Life After Brain Injury is an intense read, taking readers through a roller coaster of emotions. It is a vital read for survivors, family members, and rehabilitation professionals. It provides professionals with a better appreciation of what survivors go through and can provide strength to survivors in their recovery. The quotes listed above are just a sampling of the touching words written in this memorable book.

Ms. Kara Swanson shares her personal experience with a mild TBI. She was injured in a car accident in 1996 when a minivan collided with her vehicle after running a red light.

She was taken to the hospital and released hours later. However, it wasn't until later that she was formally diagnosed with a mild TBI. But there was nothing mild about her injury.

Ms. Swanson is a humorous writer and her humor drives the book, but reading about her struggles is painful at times. Ironically, Ms. Swanson aspired to be a writer before her accident and was able to realize her dream after her injury. The recovery process is referred to as "getting on the bus," "…nobody told me that when they finished pulling me out of my car, they were putting me right on the bus." As a reader, I visualized this bus as one with no designated stops, leaving the rider uncertain of the destinations.

Ms. Swanson walks the readers through doctors appointments, tests, receiving and eventually accepting the diagnosis of mild TBI, understanding pain and suffering, grieving the loss, and learning to succeed with a brain injury. The book ends with notes from her "bookends", which she refers to as "Team Kara", the individuals who assisted her through recovery.

I'll Carry the Fork is a very enjoyable read. Within moments, you could find yourself chuckling then becoming saddened, but regardless, you leave with a deeper appreciation of TBI. *I'll Carry the Fork* is a recommended read for all because all of us have something to learn. As a rehabilitation professional, I learned even more about the perseverance and determination of many survivors and as a result, I have an even deeper respect and admiration.

Jennifer Menzel, Psy.D.

HAVE YOU MET DR. MANJULA RAMAREDDY?

Manjula Ramareddy, Ph.D. our new research associate for the TBIMS, is a native of South India and came to Virginia 1 ½ years ago. Before joining our team at VCU, she was the Assistant Director of data management at the Defense and Veterans Brain Injury Program (DVBIP) at the Walter Reed Army Medical Hospital. She is currently helping in the preparation of a new grant for the TBIMS.

Dr. Ramareddy graduated from the University of Wisconsin-Milwaukee. In her doctoral work, she examined how our balance influences visual spatial processing. After her doctorate, she completed a two-year medical psychology fellowship in the Department of Psychiatry at the Johns Hopkins Hospital. Her research interests include the public health aspects of unintentional injuries, specifically TBI and its impact.

Apart from her academic interests, she is also passionate about the environment and enjoys books and gardening. Lastly, she loves a good cup of MASALA TEA.

SUGGESTIONS WANTED!!!

DO YOU HAVE IDEAS FOR OUR NEWSLETTER?

PLEASE SUBMIT YOUR IDEAS AND SUGGESTIONS TO JCMENZEL@VCU.EDU OR CALL 804-828-9055

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

VIRGINIA UPDATING STATEWIDE BRAIN INJURY ACTION PLAN

The Virginia Department of Rehabilitative Services (DRS), Brain Injury and Spinal Cord Injury Services is in the process of updating Virginia's 2000 Traumatic Brain Injury Action Plan. In the spring of 2005, a steering committee consisting of representatives from the Brain Injury Association of Virginia (BIAV), the Virginia Brain Injury Council (VBIC), and the Virginia Alliance of Brain Injury Service Providers (VABISP) developed a work plan for this process.

During the summer of 2005, DRS hosted several brain injury town meetings across the state and invited survivors, family members, professionals, and other stakeholders to participate. Individuals unable to attend the meetings were able to submit comments to DRS via phone or mail. The purpose of the town meetings was to get feedback on the three core categories identified in the State TBI Action Plan (case management, regional resource coordination, and clubhouse/day program services) as well as community living supports and residential services. The town meeting process helped to identify and prioritize local service needs and to share information on developing and enhancing services within a local community.

The service most often acknowledged as essential was case management. Regional resource coordination (RRC) was the next most common service identified as essential. It was also noted that day programs are an important service need.

Virginia has made enormous progress in the services provided to brain injury survivors and their families over the past six years. There is a great deal we are doing right, as well as a great deal more that we want to accomplish. Our 2000 Statewide Action Plan created a vision for some of our forward movement (to view the current state action plan, visit the DRS website at http://www.vadrs.org/downloads/vatbiactionplan.doc or contact BIAV at (804) 355-5748. We want our next action plan to be even better.

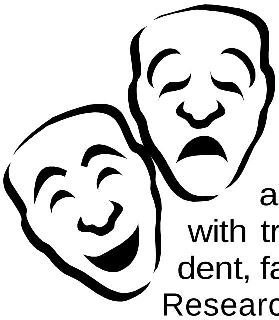
Two basic views for the development of the new action plan are to: (1) discover what we are doing right already so that we can build upon this strong foundation; and (2) review what has been accomplished so far and what is still needed. This is where you come in!

We would like your input on the following questions:

1. Where do you believe Virginia has excelled in its brain injury related efforts? Please feel free to highlight your own efforts and programs.
2. What is your dream for where we will be five years from now? Be as specific as you can.
3. What data (both existing and new sources) would you like to have included in the plan as a way of measuring our accomplishments?

Please send your thoughts and ideas to BrainInjuryVirginia@comcast.net.

Ann Deaton, Ph.D.



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

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 individuals submitting questions to "Chat with Pat" will be kept strictly confidential.

DEAR PAT:

I was in a car accident over a year and a half ago when someone rear-ended me at a stoplight. I was pretty shaken up from the experience, but luckily I didn't have any broken bones or other major injuries. At the hospital, the doctor told me that I had a concussion and would be back to "normal" in a few months. Things didn't get better and I'm still having many of the problems I had initially, like headaches, being tired, difficulty concentrating, and memory problems. I had to stop working because I can't function the way I used to. I was an organized person and my life was very structured and now, it takes me hours to get myself together to leave the house. How can I get to the point where I can function like a regular person? Can you still get better after one year? Is there any hope for me to get back the skills that I lost?

PAT'S RESPONSE:

Feelings of frustration and disappointment are common when accident-related problems don't resolve within a year or two. What you are describing is frequently reported by other brain injury survivors. Most people want improvements to occur quickly so they can return to their lives before the accident. Impatience can set in and lingering problems begin to take their toll on emotional well-being after a while.

Course of recovery is different for everyone and it is difficult to predict when things are going to happen. However, improvements can continue to occur even after one year. From working with many brain injury survivors, we have found key factors that can help to make certain that your improvement continues. 1) Ability to Learn: Learning allows you to do things better and more efficiently. 2) Practice and Training: Mental and physical exercise can help you to make gains. 3) Ask for Help: Learn when and how to ask for help from other people.

Tips for making progress:

- Keep trying to develop more effective strategies for doing things.
- Stop doing things that don't work.
- Focus on your primary goals, monitor progress, and stick with plans that work.
- See what works for other people and what doesn't.
- Listen to other people's ideas.
- Exercise your body and mind.
- Learn from your mistakes.
- Ask people that care about you for feedback.

You may wish to contact the Brain Injury Association of Virginia (BIAV), located in Richmond, for information about services for persons with brain injury in the state. Local offices often have listings of professionals who specialize in working with brain injury survivors. You may wish to seek individual assistance from an occupational therapist or a rehabilitation psychologist to work on areas of difficulty. Contact BIAV by phone (804-355-5748 or toll free 800-334-8443) or email (info@biav.net).

JUST THE
FREQUENTLY ASKED QUESTIONS

Q: I was diagnosed with a brain injury eight months ago after a fall. My husband repeatedly tells me that I get angry more easily than I used to and I can be difficult to live with. Is anger common after a brain injury? And what can I do to improve my behavior?

A: Anger, irritability, and frustration are common after brain injury. You are likely experiencing anger and frustration because you feel overwhelmed by the changes that have resulted from your injury. Following an injury, you may be more sensitive to stress and feel less in control of your emotions.

Even though a brain injury can bring on changes in managing your emotions, the most important thing to keep in mind is that you *still have control over your emotions*. But, it will likely take more effort than before.

Managing anger and other intense emotions is a skill to be learned and practiced. Instead of saying the first thing that comes to your mind, counting to ten and breathing slowly and deeply can be very helpful. If you have something to say to others, explain yourself calmly. By doing this, people are more likely to listen and understand your point of view. Finally, talking to a trusted family member or friend or seeking professional help from a psychologist or counselor can help you cope with and express your feelings appropriately.

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.

Questions for Pat or the FAQ column are welcomed.
Send them to: "ASK PAT" OR "FAQ"
P.O. BOX 980542. RICHMOND, VA 23298-0542

We Changed Our Minds: Successfully Surviving a Brain Injury

We continue to solicit information from people living with a brain injury and those who care for them. The information we collect will be used in our forthcoming book, *We Changed Our Minds: Successfully Surviving a Brain Injury.*

“Survivor” Versus “Person with a Brain Injury”

“Person-first” language is a recent and welcome trend in terminology for individuals living with a disability. Rather than saying “a brain-injured person,” it is preferable to say "an individual living with a brain injury," because such folks are people first, with all of the countless characteristics that make each of us unique. Only one of these traits, albeit an important one, is their brain injury.

Even so, the large majority of individuals living with a brain injury dislike the *“person-first” language*. They prefer to be called "survivors." Many wear this label as a badge of the courage and determination they display every day of their lives. Recognizing that we are unable to satisfy all of the people all of the time, we use the two terms interchangeably.

Our Project

Through questionnaires, workshops with support groups, appearances at conferences, and via our website, we have spent the past year asking hundreds of survivors and caregivers the following questions: How do you define a "successful" recovery 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 beginning their recovery? We have conducted workshops with 23 support groups in four states: Florida, Georgia, Alabama, and Ohio. We have received 339 completed questionnaires from support group attendees and visitors to our website. We are members of three internet support groups, from which we gain valuable insights into the challenges faced by survivors and caregivers.

We maintain a mailing list of 464 survivors, caregivers, and health professionals who participate in the project. At times, we pose questions to these folks. At other times, we share with them some of our preliminary conclusions for comment. We presented some of our conclusions and met many survivors and caregivers at the annual conferences of the Brain Injury Associations of Indiana, Ohio, and Wyoming.

What Is a Successful Recovery from a Brain Injury?

There is much debate over the words "successful" and "recovery." 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 of defining "success." Here's what you said: caregivers and survivors must define their own success, what one may think successful, someone else might not, there are degrees of success, and success is fluid; it constantly changes.

Only the survivor and caregiver can define a successful recovery. There is one certainty. A successful recovery is not a full recovery. Even the survivor and caregiver may differ on definitions of success. A teenager may define success as getting back behind the wheel. The caregiver, however, may define success as the day their teen recognizes that limited attention span means he/she shouldn’t drive.

Success changes over time. Initially, success may be opening your eyes or speaking for the first time. A few weeks or months later, success may be completing inpatient rehabilitation and returning home. Years later, success may be volunteering at the local animal shelter. The only common denominator is that every survivor must have new goals to accomplish to continue growing.

We continue to recruit new participants for the project. If you might be interested, please visit our website (www.BrainInjurySuccess.org) or send us an e-mail: GarryandJessica@BrainInjurySuccess.org). We will treat any information you provide with complete confidentiality. We will donate any profits from this book to those brain injury organizations that participate in this project, though we hardly expect this work to generate much money. For us, it is a labor of love. Thanks very much for your support and interest in our project.

Garry Prowe & Jessica Whitmore

THE ROAD NOT CHOSEN

Two roads diverged.

And that was years ago. Like the poet, I chose the less-travelled path. I never liked crowds and have always wanted to make my own choices, to do “my thing” regardless of what others did.

I was happy with that choice and with my life. Because of that narrow road, I encountered a number of different opportunities. Many were challenging, but all were in some way personally fulfilling.

So, life went on. That road seemed the right one for me and for those I met along the way. And life went on . . . and on.

Then, suddenly, there was another road. This road was even narrower, certainly lonelier than the first. And this road was not chosen.

A curious thing perhaps, that this journey actually began on a literal road. Uncontrolled intersection, late afternoon, sun in the other driver’s eyes (I suppose), and I was hit.

Then later, just more than a month, I was thrust upon the longer road. Emergency surgery, subdural hematoma, walk a straight line, touch your finger to your nose. What happened? Do you remember?

So now, what am I to do about this unchosen road? I am here; this is not a choice. I can withdraw. I can rebel. How could this happen to me? I had plans, goals, ambitions.

However, life goes on. Yes, life goes on all around me and I, a spectator far too often, see things happening and want to join in. But, somehow, I have trouble connecting.

Life does go on though. Life at a slower pace, life in a different direction. And I, now walking along the other road, narrower than the one before, begin to see the beauty.

There are joys. There are challenges and, yes, there are friends. I’ve lost some friends and gained some others. The companionship of those who also walk this path is good. No, more than good. It is precious.

I am learning to move along the new road and in spite of the past, in spite of sorrow, in spite of myself, to enjoy it. Many, probably most, of the previous goals are changed.

Ambition? Sure! Some days simply to survive. Other days to learn, to grow, and to enjoy life.

I took the less travelled, the unchosen road, and that has made all the difference.

Larry Carlson

WHO’S WHO IN THE VCU TBI MODEL SYSTEM ??

Jeffrey Kreutzer, Ph.D.

Jennifer Menzel, Psy.D.

Kelli Williams, MPH, MS, OTR/L

William Walker, M.D.

Janet Niemeier, Ph.D.

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2

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Answers to Who's Who from page 7

1. Jennifer Menzel, Psy.D.
2. Jan Niemeier, Ph.D.
3. William Walker, M.D.
4. Jeffrey Kreutzer, Ph.D.
5. Kelli Williams, MPH, MS OTR/L

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GET *TBI TODAY* E-MAILED STRAIGHT TO YOUR COMPUTER !!!

Contact Jenny Marwitz at
jhmarwit@vcu.edu or 804-828-3704
to sign up for our *TBI Today* mailing list.

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