



# Brain Injury Association of Texas

## *Enewsletter*

### Upcoming Events

The 2008 Walk For Thought is fast approaching! Please register your team today! The Walk will be held on November 8th at the West Campus Field on the Texas State University campus in San Marcos from noon until 6pm. Please bring your friends and family and join us for our largest fund raising event of the year! All proceeds from the walk will be used to give hope, help and a voice to the 450,000 Texans who live with a disability caused by brain injury. You can register for the Walk via our website at <http://www.biatx.org/>

BIATX's next board meeting will be October 18<sup>th</sup> from 10am to 4pm at the association's main office in Austin.

For information, contact us at:

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### *Special Veterans Issue*

#### **Coping With a Traumatic Brain Injury in the Family**

By: Angelle M. Sander, PhD  
Director, TIRR Memorial Hermann Brain Injury Resource Center  
Baylor College of medicine

If you are reading this, you probably already know that brain injury affects more than just the person with injury-it affects the entire family. While most families have faced difficulties before, they have usually never experienced anything similar to brain injury. Researchers at the TIRR Memorial Hermann Brain Injury Resource Center and the Texas TBI Model System of TIRR have talked to many family members and have spent a lot of time researching the ways in which TBI affects the family and how family members cope with TBI. Here are some of the things we have learned.

#### **Common Changes in Families After Injury**

While everyone's situation is a bit different, there are some common changes that many family members experience.

- *Less time for themselves:* Many family members say that they have little time to relax and do the things they enjoy. Much of their energy goes into taking care of their family member with injury or making sure that the household is running smoothly.
- *Financial Difficulties:* Many persons with injury are not able to return to work, so the family may be living on less money than before the injury. Families also report that they have many more medical bills than before the injury, and they have difficulty getting government aid, such as SSDI.
- *Role Changes:* After injury, family members usually don't have the same responsibilities that they did before. The family member who was injured may no longer be able to carry out the same activities as before. Other family members may try to take over those responsibilities and may become overloaded and stressed. Everyone may seem to have too much to do, or

some family members may try to do everything.

- *Problems Communicating:* Things are often so hectic after injury that family members have very little time to just be together as a family. It may seem like everything is about the injury now, and family members may not know what is going on in each others' lives. Everybody in the family probably has feelings about the injury and the changes it has caused in their lives, but they may not know how to talk to each other about it.
- *Lack of Support or Help:* Before the injury family members may have known where to go to get help with different kinds of problems, but they usually find that few people have answers for them about the injury. People that they have trusted in the past, like doctors and teachers, may not be able to help them much with the injury. Their friends and coworkers may also not understand what they are going through or be able to offer much help

### **How Do These Changes Affect Family Members?**

Here are some common feelings that family members report:

- *Feeling sad or down:* Family members may feel blue and not know why. They may have less energy and may not enjoy things the way they used to. Some people start spending more time by themselves and they may cry more easily.
- *Feeling anxious or nervous:* Some family members report being nervous all the time. They may worry all the time about such things as finances, the future, and the health and well-being of their family member who was injured.
- *Feeling angry:* Many family members feel anger. Some may be angry at doctors or other professionals whom they don't think are providing enough care. Others feel angry at other family members or at friends who give advice but don't seem to understand what they're going through. Still others are angry at their injured family member for not trying hard enough or for not appreciating what is being done to help them. Some people are angry at no one in particular, but are just angry that such a thing has happened to them.
- *Feeling guilty:* Guilt is a common feeling after injury. Some family members blame themselves for the injury, thinking they somehow could have prevented it. Others feel guilty that they cannot keep up with the things that need to be done from day to day. Some family members feel guilty about being angry, thinking that they have no right to feel that way.
- *Feeling frustrated:* Family members often have a lot of things to be frustrated about after the injury. Some of the things that frustrate people the most are: not being able to get the services they need; not having enough time to get things done; feeling that others don't understand what they're going through; and dealing with the things that their loved one can no longer do.

### **What Can Family Members Do to Cope?**

Here are some suggestions that may help to reduce your stress. Everyone is different and what works for some people may not work for everyone. Try different things and find the ones that work best for you.

- **Realize that you are not alone.** There are thousands of other family members who are going through the same thing. You may not know any of them, but you can meet them through support groups and internet sites.
- **Try not to beat yourself up about the way you feel.** The emotions you are experiencing are normal given your circumstances. Trying to ignore your feelings or telling yourself that you shouldn't have them can lead to problems like depression and

can also have a negative effect on your physical health. Instead of ignoring the way you feel, talk to someone you trust. Just saying things out loud can make a difference.

- **Learn as much as you can about brain injury and its effects.** There is a lot of information out there that you may not have known about.
- **Learn to relax.** Taking a few moments to relax can help you to be more ready for the things you need to do. Even when you are trying to rest you may not be in a relaxed state because you are thinking about what you need to do tomorrow or how to solve a crisis. You need to train your body and mind to get into a relaxed state.
- **Learn how to reward yourself.** Even if you have very limited time, you can find some small way to reward yourself. Promise yourself a bubble bath at the end of the day. Take a walk around the block. Or have a cup of your favorite coffee or hot chocolate. If your schedule is very hectic, you may need to write this time into it. Try to ignore the voice in your head that makes you feel guilty for taking this time for yourself. You will be able to help your loved one more if you are healthy.
- **Ask for help when you need it.** If you're like most people, you probably place a lot of value on being able to handle things on your own. But the injury is a very unusual circumstance and you need help to deal with it. You may need professional assistance, such as medical information or counseling. You may need practical help such as help getting the kids around or cleaning the house. Whatever you need, don't be afraid to ask for it. Others may want to help but not know how, and they may be glad when you tell them what you need.



BIATX would like to thank our sponsors and exhibitors who made our Houston and West Texas Seminars a great success. Our sincerest thanks go out to:

***CORE Healthcare, Dripping Springs, TX***

***ResCare Premier, San Marcos, TX***

***MENTIS Neuro Rehabilitation, Houston, TX***

***Pate Rehabilitation, Dallas, TX***

***Memorial Hermann/TIRR, Houston, TX***

***Innovative Neurotroincs, Spring, TX***

***Transitional Learning Center at Lubbock, Lubbock, TX***

**2008 National Brain Injury Caregivers' Conference**  
**June 6-8, 2008**  
**Westin Dallas/Fort Worth Airport Hotel, Dallas TX**

**Part Two**

*BIATX Board Member, Cathie Gleinser is writing a multi part series on the conference.*

The day started off with a Continental Breakfast with the Exhibitors. Every exhibitor was anxious to give as much help as they could. The first session of the day was titled TAKING CARE OF YOU: MANAGING STRESS AND DEPRESSION. This was especially interesting for me since that is something in my life that seems to creep into reality daily. There were four breakout sessions that morning. You could choose which interested you the most.

**Plenary Session**

**TAKING CARE OF YOU: MANAGING STRESS AND DEPRESSION**

**Dr. Michael E. Howard** is a clinical neuropsychologist who has been involved in brain injury rehabilitation since 1977 and has directed 6 programs in hospitals, residential settings, and communities as well as consulting at over a dozen other TBI treatment centers.

He started with Stone Age Genes VS Space Age Lifestyles. He told us that at the dawn of humankind, people lived in small bands that roamed over large areas to find food and shelter. Human population was scarce and resources were scarce yet these people were amazingly active. Traveling over 20 miles on foot in single day to visit and trade with other clans burned twice as many calories as today's American. With the Industrial Revolution came an incredible change to the lifestyle of the Americans and Europeans. Now, life is longer due to technology but exercise and dietary diversity have been lost. Fresh foods are replaced with processed foods with less fiber and vitamins but more salt, sugar, fat and calories. Sedentary living and processed food extract a health price. Increased and chronic mental stress is now a major problem. Today's caregiving lifestyles cause major risk factors for Obesity, Diabetes, Hypertension, Heart Disease, Stroke, Cancers and Alzheimer's Disease. Dr. Howard showed us how the Human Brain is really "Three Brains." The Brain Stem (Reptilian Brain), Limbic System & Thalamus (Mammalian Brain), and the Cortex (New Brain Vastly Enlarged in Humans.)

Descriptions between the Male Brain and the Female Brain were followed by footnotes. The Male Brain footnote "The "Listening to children cry in the middle of the night" gland is not shown due to its small and underdeveloped nature. Best viewed under a microscope. SEX took up the largest area of the male brain. The Female Brain was much different and had area of Shoes and Headache Generator in the same areas the males had thoughts of SEX. Chronic Stress, Burnout & Heart Disease is caused by lack of control, low rewards, low social support and long hours. Depression can cause Heart Disease. This was discovered in many studies, one is the 2004 Women's Health Initiative Observational Study.

## **Breakout Sessions**

### **1. SCHOOL ISSUES FOR CHILDREN WITH BRAIN INJURY**

**Dr. Janet Tyler** is Director of the Kansas State Department of Education's Neurologic Disabilities Support Project, a statewide program providing professional development training, consultation and technical assistance to educators serving students with TBI. Dr. Tyler has worked in the field of brain injury for the past 20 years. **Julie Peterson-Shea** has been a teacher in Kansas for 13 years and is the mother of five. In 2004 her family was in an auto accident resulting in 4 of her five children sustaining traumatic brain injuries ranging from mild to severe. Since then she has been advocating for her children and attended TBI miniteam training offered by the Kansas State Department of Education Student Support Services.

An injury to a child's brain may cause long-term cognitive, psychological, sensory-motor, and language deficits which adversely affect the child's educational performance. Upon discharge from rehabilitation schools need to know many *practical ideas before re-entry to public school. Make friends with someone instrumental in making decisions for your child. Request that your child* be tested, prioritize what you wish to accomplish, be patient yet focus on goals and find out where special education services originate. *Cognitive Deficits Following TBI* can include memory, focusing, delayed response time, organization, generalizing, flexible problem solving, perceptual/spacial functions and judgment. Memory Strategies include repetition, relate information, mnemonics, verbal rehearsal, assistive devices and go over information at home.

A PARENT'S JOB is to support your child, be realistic but optimistic, know your child, give yourself a break, and find a support system.

### **2. HOW DOES TRICARE WORK**

**Lisa Silver is a Transitional Assistance Advisor for the West Virginia National Guard.**

As part of her job, she provides information and assistance to service members and their families in accessing benefits and services through Veterans Affairs, the military health care system, and community resources. Ms. Silver also provides education to the State Leadership as to the entitlements available through Veterans Affairs. Ms. Silver has been assisting soldiers for 23 years with their entitlements and benefits. She is married to an active duty Special Forces Officer and has 3 children ages 19, 15, and 12.

The Program Overview about the Military Health Plan was extensive. The options of TRICARE are TRICARE Prime, TRICARE Prime Remote, TRICARE Standard and TRICARE Extra, TRICARE Reserve Select, Transitional Assistance Management Program and Pharmacy. Cost-effective, managed care option available in TRICARE prime service areas. Most care received from Primary Care Manager at a military treatment facility or in the TRICARE civilian network. Transitional Assistance Management Program allows up to 180 days transitional health care to qualified service members separating from active duty and their families. TRICARE Pharmacy allows generic medications when available, prior authorization may be required for certain medications, certain brand name medications dispensed when no generic is available or when medically necessary and TRICARE Mailorder Pharmacy available when there is no other RX insurance.

### **3. COMPLEX MILD TRAMATIC BRAIN INJURY II: APPROACHES TO TREATMENT**

**Thomas Kay, Ph. D.**

Dr. Kay received his bachelor's degree in English Literature from Dartmouth College and

Master's Degree from University of Rochester, and Ph. D. from Emory University. He did his internship at The University of Washington Medical Center, and post-doctoral fellowship at NYU Medical Center. He spent over 20 years at NYU Research and Training Center on Head Injury and Stroke. Currently in full-time private practice and is the recipient of the 1990 Clinical Services Award from the Brain Injury Association of America for his work on minor head injury. He has over 200 international presentations, as well as a book, two dozen chapters and articles in professional journals.

His presentation was toward a Neuropsychological model of functional disability after a mild traumatic brain injury. Can there be functional disability after MTBI: false dichotomies? Is there a real neurological brain injury or is this a psychological exaggeration? Requirements for a Neuropsychological Model of functional disability after MTBI was explored.

Acknowledge the potential contribution of both neurological and psychological factors in determining functional outcome. Allow that the relative weight of each will differ from individual to individual. Describe a process in which multiple factors interact to determine the functional capacity of each individual.

Neurological Factors are two-fold. Pre-existing factors are age, brain integrity (genetic or developmental), previous damage (overt or covert) AND injury related factors, cell loss, non-structural disruption and seizures. Physical factors are pain, fatigue, sleep disruption, sensory / motor disorders, vestibular disorders, visual disorders and medication effects. Psychological factors are psychological overlay, trauma response (PTSD), emotional destabilization, personality style and needs, family dynamics, vocational demands, litigation/insurance conflicts and effort (conscious vs unconscious.)

### **Plenary Session**

#### **UNDERSTANDING THE LONG TERM DEMANDS OF CAREGIVING**

**Richard Bonfoglio, MD**

**Michael Davis, CBIS**

The survival of persons with severe brain injuries during the acute medical phase requires intensive and extensive medical, surgical, and rehabilitative care. The health care system generally provides extraordinary support for these injured persons. During the acute crisis, extended families often pull together to rally around the injured person. However, for those surviving a catastrophic brain injury, these are often longterm personal, interpersonal, vocational, financial, and health consequences. The current health care system is not geared to thoroughly address these long term implications for individuals surviving serious brain injuries and family and friends often fatigue or fall away due to the extensive ongoing needs of the brain injury survivors. Therefore, an increased focus on the longterm consequences for those that have suffered a serious brain injury is paramount to enhancing the quality of life over their remaining decades. Developing an ongoing program of care that includes case and medical management and life care planning is an important part of the solution to current system failing for persons with severe brain injuries.

#### **5. TEACHING SELF REGULATION AS A POSITIVE BEHAVIORAL SUPPORT**

**Tim Feeney, Ph. D.**

Dr. Feeney is the Executive Director of the Community and Support Services, and for the past 13 years, the Project Director of the New York Neurobehavioral Resource Project at STIC, a NYSDH grant funded program developed to support individuals with brain injury. He has been responsible for the procurement and coordination of over \$10 million dollars in grant-funded programs serving individuals with brain injury and other challenging behaviors. Over 50 scholarly journal articles and book chapters have been co-authored by Dr. Feeney as well as the book Collaborative "*Brain Injury Intervention: Positive Everyday Routines.*"

Communication ---> Behavior ---> Cognition EQUALS Goal of Intervention

Successful intervention is about establishing a respectful relationship with someone who's doing his or her best to tick you off. It's important to have fun with and create opportunities for fun and to laugh a lot even in the face of significant challenges. Three beliefs that will affect the likelihood that you'll be successful are:

1. Optimism & Hope. Evident in the problems the language that is used when describing the individual and when interacting with the individual.
2. Appreciating the Influences of Contextual Factors on Behavior. Requiring an understanding of the setting events of ones behavior.
3. Applied Pragmatism. Recognizing there is no *single "right" solution and getting everyone* involved in the intervention.

Another goal of intervention is that the individual not only behaves in ways that are acceptable but chooses to behave in ways that are acceptable. A goal without a plan is just a wish is credited to Larry Elder. "Much of our cognitive *life may be the product of highly automated routines*" says Gerald Edelman. Constructing an identity that is meaningful and sustainable is a primary goal of intervention.

Other topics for Saturday included:

PSYCHOSOCIAL ISSUES FOR THE WHOLE FAMILY

Dr. James Mikula

PRACTICAL STRATEGIES FOR MANAGING DAY TO DAY BEHAVIOR

Carolyn Rocchio

LEGISLATION AFFECTING MILITARY PERSONEL WITH BRAIN INJURY

Laura Schiebelhut

THROUGH OUR EYES: LIFE ENHASING TIPS FROM A PARENT AND A SPOUSE

Peggy Burns Keener, RN

Faye Eichholzer

PLANNING FOR THE TRANSITION FROM SCHOOL TO ADULTHOOD

Dr. Janet Tyler

Linda R Wilkerson MEd

VISUAL CHANGES AFTER BRAIN INJURY

Dr. Penelope Suter, OD FCOVD

NAVIGATING THE VETERANS ADMINISTRATION SERVICES

Tina M. Trudel, PhD

VOCATIONAL OPTIONS AFTER BRAIN INJURY

Brandy Reid, CRC, CBIS

Kellie Manderfeld, MA

GETTING THE HELP YOU DESERVE: GOVERNMENT PROGRAMS THAT CAN SUPPORT YOU AS A CAREGIVER

Bill Ditto, MSW

CAREGIVERS AND SURVIVOR AGING: HOW TO PREPARE FOR TRANSITIONS

Tina M. Trudel, PhD

## **Houston Seminar Wrap-Up**

*"I am proud to say that the Houston Seminar was a huge success for the fact that we had a respectable turn out, a great line of speakers and people that wanted to be educated about Traumatic Brain Injury, TBI. We were able to reach people from as far away as Weimar down to Victoria. We had the pleasure of having the following talks: "How to be an Effective Consumer of Neuropsychology Services", Keeping Relationships Alive After TBI",*

*“Managing Spasticity and Post-Traumatic Movement Disorders”, “The Story of HB 1919: Brain Injury, Insurance and Rehabilitation”, “Brain Injury and Depression”, “Neuroanatomy of Behavior After Brain Injury or ‘You Don’t Like my Behavior? You’ll Have to Discuss That With My Brain Directly’”, “Interventions to Improve Social Communication After TBI”, and “Post Traumatic Stress Disorder and Traumatic Brain Injury.” We would not have been able to make it happen without our sponsors CORE Healthcare, ResCare Premier, MENTIS Neuro Rehabilitation, Memorial Hermann/TIRR, Pate Rehabilitation and Innovative Neurotronics. I heard nothing but positive feedback on everything.”*

*Jason Ferguson  
Houston Regional Seminar Chair*

## **Have You Been Denied Insurance Coverage for Brain Injury Rehabilitation? We Want to Hear Your Story**

The Brain Injury Association of Texas is seeking out individuals with brain injury who have been denied cognitive rehabilitation benefits through their insurer on health benefit plans issued or renewed on or after January 1, 2008. In some cases this may be a violation of [HB 1919](#) which was passed in the last Texas legislative session. The Association is encouraging members and their families to file a complaint with the Texas Department of Insurance (TDI) directly.

TDI's website links for filing complaints:

1. Go to <http://www.tdi.state.tx.us/>
2. Click on “Online Services”
3. Click on “Online Services-Complaints”
4. Follow Instructions

General Information on Complaints:

<http://www.tdi.state.tx.us/pubs/consumer/cb003.html>