

TBI TODAY

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

THE VIRGINIA TBIMS TEAM

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Improving Relationship Intimacy After TBI: Part III

by Emilie Godwin

After brain injury, most people report big changes in intimacy with their spouse or partner. Now, here's the conclusion of a three-part series on improving intimacy after TBI.

Part III: Intimacy Isn't Just Emotional - It's Also Physical!

In our last two articles featuring tips for improving your relationship after TBI, we have focused on the parts of intimacy related to emotions and feelings. Our articles specifically have looked for ways that couples can improve their relationship by strengthening the loving and connected feelings they have with one another.

However, emotional connection is only one part of intimacy in the majority of adult romantic relationships. After TBI, most couples – when asked – say that their physical, or sexual, relationship with one another has changed in many ways. Unfortunately, few people describe being pleased with the changes.

Many changes after TBI can directly and indirectly influence a couple's sex life. However, because sex and physical intimacy can be an uncomfortable topic for many people, this common problem in TBI rehabilitation may be ignored by both couples and their doctors. Particularly, if couples do not directly bring up any sexual changes or problems, doctors may not think to ask. Yet, sex is as important of a human function as eating, sleeping and drinking; it is an instinctual drive and being sexually fulfilled is a need most adults have. Therefore, avoiding or not "working on" sexual changes and challenges during rehabilitation is NOT OK!

Many times, couples have not even discussed with one another the changes and difficulties they are experiencing with sex since the injury. This is true for both survivors and their partners. Following are some questions you and your partner may want to ask of yourself and each other. (contd. on page 2)

Dr. Kreutzer Receives Innovations in Treatment Award

Jeffrey Kreutzer, Ph.D., Project Director for Virginia Commonwealth University's TBI Model System, received the North American Brain Injury Society (NABIS) Innovations in Treatment Award at the NABIS annual conference on brain injury in September in New Orleans. The award is given annually to an individual selected by the NABIS Board of Directors for developing and implementing innovative and efficacious treatment for people with brain injuries.

(*Intimacy*, contd. from p1) Then discuss those answers and – without any judgment, or any belief that one person is “right” – talk about the similarities and differences in answers.

- ❑ Is your sexual relationship something you and your partner have talked about with one another? A good place to start is asking one another: What has changed? What do I enjoy about changes? What do I wish could be different?
- ❑ Are the changes in your sexual relationship something you and your partner have discussed – together – with your rehabilitation providers?
- ❑ Is sex something that you and/or your partner are comfortable talking about in general?
- ❑ What type of environment helps you to feel more comfortable discussing things that you find uncomfortable? Examples to consider might be: the noise level of the room (some people like a little background music as distraction; while some are unable to talk about a difficult topic with any other noise in the room; etc.); words that make you more and less comfortable when discussing intimate body parts, sexual acts, and sexual needs and interests.

In addition, many people do not know what changes their partner has noticed or is struggling with. Review the chart on page 6, paying special attention to the topics that may be true for you. After you’ve looked over the chart, discuss with your partner to find out which of these items are true – and which aren’t – for them. Share with your partner which items are true for you. (contd. on page 6)

Speaking of Relationships... there’s a new intervention for couples after brain injury! The Therapeutic Couples Intervention (TCI) is designed to assist couples after TBI with communication, stress management, goal-setting, renewing intimacy, and for some couples—parenting post-injury.

Participation is free, and study volunteers will be compensated. Please contact Jenny Marwitz at 804-828-3704, or call toll free at 1-866-296-6904. Or, send an email to jhmarwit@vcu.edu.

Around the Web

If you’ve got an internet connection, then you’ve got access to a bunch of great TBI resources!

-Check out Rosemary Rawlin’s blog, *Learning by Accident*, on brainline.org

(<http://www.brainline.org/rosemary/>) and follow her on Twitter @RoRawlins for updates!

-Our very own grant page (<http://model.tbinrc.com>) for the TBI Model Systems at VCU has tons of *free* content, including fact sheets, back issues of *TBI Today*, research updates, and more!

Mark Your Calendar!



T.G.I.F.

- ♦ **Location:** 1st Friday of each month, Belmont Recreation Center, 1600 Hilliard Rd.
- ♦ **Description:** the local departments of recreation & parks host this monthly social event for survivors of brain injury, ages 18+
- ♦ **Contact:** Call Kariayn Smith, 804-501-5135, for more information and/or to be placed on the mailing list for monthly reminders.

Richmond Support Group

- ♦ **Location:** 3rd Monday every month at 6 pm, Children’s Hospital Auditorium, 2924 Brook Rd, Richmond, VA 23220
- ♦ **Contact:** Call the Richmond BIAV at 804-355-5748 for more info!

Hopewell Tri-Cities Support Group

- ♦ **Location:** 2nd Tuesday every month at 6:30 pm, Nelson Library 209 East Cawson St, Hopewell VA 23860
- ♦ **Contact:** Call Mary Wallace at 804-355-5748 or email at mary@biav.net

Chesterfield Support Group

- ♦ **Location:** 2nd Monday every month at 6:30pm at the Woodlake United Methodist Church, 15640 Hampton Park Drive, Chesterfield VA 23832
- ♦ **Contact:** Call Elizabeth Perry-Varner at 804-276-5761 or email eperryvarner@verizon.net

Brain Injury Association of VA Annual Conference

- ♦ **When:** May 15, 2014
- ♦ **Location:** Westin Hotel, Richmond VA
- ♦ **Contact:** Check out www.biav.net/biav-conference.htm or call the BIAV at 1-800-444-6443 for more info!

JUST THE FREQUENTLY ASKED QUESTIONS

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.

Q: How can I help my son to better control his temper? Ever since his bike accident, John became frustrated and angered easily. His family, including his little sister, has been the target of these outbursts.

A: Anger and frustration are common reactions due to changes following a brain injury. It is understandable that you would feel overwhelmed by many problems that occurred as the result of your accident. In addition, the injured brain often has less ability to control emotions and can become more sensitive to stress.

- Help your son understand that he has the power to control his anger. Teach him that anger control is a skill which will get better with practice.
- Discourage him from saying the first thing that comes to mind. Teach him to think about other people's reactions before he speaks or acts.
- Encourage him to be positive and sensitive to other's feelings. Remind him to explain himself calmly.
- Help your son remember that controlling anger will improve relationships with family and friends.
- Encourage him to take a "time out" and try to relax when they recognize that anger is building. Helpful strategies include breathing deeply and slowly or counting to ten before speaking or acting.
- Realize that ignoring problems with anger can make things worse. Be willing to give him feedback.
- Help him develop new ways to release anger and manage stress in the long term. Examples include exercising, writing, and talking to someone he trusts.
- Identify trouble situations, people, and places that bring out anger. Make a plan to successfully deal with trouble situations and practice the plan ahead of time.
- Give praise when he controls his anger and expresses his feelings in positive ways.

Depression, Exercise, and TBI Study

A research study at VCU is evaluating the effect of exercise on depressed mood in people that have had a traumatic brain injury.

Qualified volunteers will participate in a 12 week exercise program. They will undergo study related testing before starting the exercise program and after completing the program. Testing would include paper and pencil tests, blood tests, and some participants will undergo MRI of the brain. If you choose to participate in this study, you may continue any on-going depression treatment you are already receiving.

The time commitment is 3-4 hours per week for 12 weeks, in addition to 2 entry and 2 exit appointments. Study volunteers will be compensated for their time. Study related costs, including parking, tests, and exercise sessions, will be covered by the study. If you are interested in participating, please contact: Justin Alicea 804-628-1355 or joalicea@vcu.edu, or Anne Hudak at 804-628-3962 or ahudak@vcu.edu.



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





CHAT WITH PAT

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

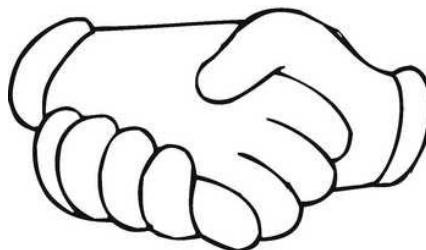
Dear Pat: I was in a horrific car accident about two years ago. My friends and I had concert tickets to see our favorite band playing at a college campus that was 4 hours away. We wanted to hang out and get good seats at the concert so we decided to leave really early that day. It was still dark outside when I left the house. I cannot tell you what happened after that. I just remember leaving to pick up my friends and then waking up in the hospital.

I was told that it was a miracle that I survived the crash. My car had flipped in the air several times before landing on the side. I could never look at the pictures that were taken of the car and the accident scene without breaking down or crying. I was thankful that I wore my seatbelt or things could have been worse. I still got a severe head injury. I had broken my ribs and my right arm. I also had lots of bruises on my face and all over my body.

I was medflichted to the hospital and in a coma for a week. My mom said that they weren't even sure if I was going to come out of it. When I did come out of it, I did really well and was stable enough to be transferred to the rehab unit a few days later. I don't remember much about being in the hospital, except that I did a lot of different therapies. I believe I made a lot of improvements before I was sent home.

In the past two years, I worked really hard to get my life back to where it was. It's not easy. And, I've been told that it may never be the same, but I'm not ready to accept that. I know I'm better than I was after I got out of the hospital. I have reached a lot of the goals I set for myself, like driving again. I'm very grateful for my parents because they have been there for me every step of the way.

The thing that bothers me the most these days is not having any friends. My friends no longer call or come to visit. I used to be very social, going out with my friends all the time. I was a social butterfly. Now, I stay home on the weekend, watching television with parents. I do want friends, but there are a lot of days where I just want to hide in my room and spend time by myself. Please help me. I'm torn between wanting to have



friends and being left alone.

Pat's Response: Many changes occur after a brain injury, including relationships. Many survivors often feel like no one understands them or that they cannot relate to others. Social situations could be overwhelming for people with a brain injury.

They may have a hard time following conversations, listening to multiple people talking at the same time, being sensitive to loud noise, and being easily fatigued. Many survivors also feel self-conscious after their injuries because they are concerned about being different. They worried about what others think of them. Sometimes, it seems easier to be alone than to deal with all the challenges.

Building positive relationships can help with your recovery. It is important to have social interactions. For example, when faced with new challenges, it is important to be able to talk about thoughts and feelings with others. Friends can help sort out the new and difficult problems. They may even be able to help figure out solutions to the problems. Friends can also give you feedback about how you are doing. They can provide encouragements that would help you to do things for yourself. Talking with a close friend is a great way to work towards accepting injury-related changes and to cope with them. You will feel less isolated and alone by having positive relationships in your life.

(*Chat contd*) The next step is building and maintaining relationships, which can be hard. Here are some strategies that you may find useful on how to cope with feelings of loneliness and build relationships.

- ❑ **Show a commitment to helping yourself.** People will be more supportive and respectful if you do.
- ❑ **Do volunteer work.** By helping others, you are likely to meet people with a kind and giving heart.
- ❑ **Don't lose track of your faith.** You may meet understanding and kind-hearted people with similar interests and values at your house of worship.
- ❑ **Take care of your appearance.** Feelings of helplessness and discouragement can lead some people to stop taking care of themselves. No matter how you feel, don't let the basics go undone. Wear clean clothes, brush your teeth, and comb your hair. You will feel better about yourself.
- ❑ **Be careful not to be overcome by your problems and the challenges you face.** Avoid being too quick to share negative thoughts and feelings with others. Talk about things that are good in your life and in the world around you.

Lastly, getting involved with a local support group can help you to feel less alone and overwhelmed. You will have the opportunity to meet others who may be struggling with the same challenges. If you wish to get involved with your local support group to share your experience, Brain Injury Association of American has a list of support groups you and your family may attend. To contact BIAA, you may call their family helpline (1-800-444-6443) or send them an e-mail at familyhelpline@biausa.org. The website for BIAA (www.biausa.org) provides links to state chapters and additional brain injury resources. You may also write BIAA for more information at 1608 Spring Hill Road, Suite 110, Vienna, VA 22182.

Ana Mills, Psy.D. is a neuropsychology post-doctoral fellow in the Department of Physical Medicine and Rehabilitation at VCU. She is responsible for conducting comprehensive outpatient neuropsychological evaluations, providing psychotherapy services for individuals with neurologic illness, assisting with inpatient rehabilitation services, and participating in ongoing TBI intervention research projects. Currently, she is involved in the Resilience and Adjustment Intervention, a research project designed to promote resilience and coping skills in TBI survivors. She also co-facilitates the monthly Brain Injury Association of Virginia support group in Richmond. Her clinical and research interests include assessment and treatment of TBI, epilepsy, stroke, dementia, movement disorders, and psychogenic neurologic illness.

**HAVE YOU
MET ANA MILLS,
PSY.D.?**

Dr. Mills recently relocated to Richmond, Virginia from Philadelphia, Pennsylvania, where she graduated in 2012 with a doctoral degree in Clinical Psychology from the Institute for Graduate Clinical Psychology (IGCP) at Widener University. She received her Master's of Science in Psychology from Villanova University in 2006 and her Bachelor's of Science in Environmental Biology from Juniata College in 1999. During her doctoral studies, Dr. Mills specialized in neuropsychology and completed a prestigious internship rotation at the Jefferson Hospital for Neuroscience in the Epilepsy Care Unit. She was also honored with the IGCP Award for Academic and Clinical Excellence and received commendations for her doctoral dissertation research, which compared cognitive profiles of Normal Pressure Hydrocephalus to Alzheimer's dementia. In her leisure time, Dr. Mills is an avid long-distance runner, horseback rider and rock climber. After completing the two-year fellowship at VCU, she aspires to obtain an academic hospital position in order to continue her clinical and research work with TBI survivors.



(*Intimacy*, contd from page 2)

Cognitive – or – ‘Thinking’ Changes:

Difficulty with planning can make sex go less smoothly.

Changes in an ability to “read” social cues, or people’s subtle hints can leave survivors feeling confused about what their partner wants and when.

This can also mean survivors may frequently miss their partner’s subtle sexual advances.

Changes in attention, concentration, and focus can make concentrating on someone else’s needs during sexual activities very difficult.

Social / Communication Changes:

Trouble with speech and word-finding can make it hard for survivors to describe what they think, feel, or want, when it comes to sex or any physical interactions with their partner.

Many people are never entirely comfortable discussing sex – even with their romantic partner. When a TBI survivor is uncomfortable they often have even greater trouble effectively saying what they want to say. This can result in avoiding any conversations about sex.

Emotional Changes:

Anxiety, depression, irritation, and having a short-temper are all common emotional concerns for TBI survivors. Each of these can lessen a person’s desire for or interest in sex.

Fatigue, depression, and anxiety – all common for survivors – are known to impact both interest in beginning to have sex and the ability to stay interested in sex.

Hormone changes that can be common after brain injury may also impact sexual interest levels. These sometimes result in either more, or less, interest in sexual activity.

Increases in Stress:

Most caregiving partners report significantly higher levels of stress after TBI. Stress impacts sex by reducing: interest or desire; ability to become or stay physically aroused; ability to stay relaxed and enjoy sexual activity.

Physical Changes:

As a result of an injury, many survivors may have physical pain that can interfere with both interest in

sex and ability to enjoy sex. This also can result in difficulty with flexibility during sexual activity, or trouble with comfortable body positioning. Difficulty with maintaining physical stimulation during sexual activity, or trouble with comfortable body positioning is also common.

Often, TBI may result in trouble with maintaining balance, coordinating body movements, or tense / rigid muscles. All of these physical challenges can make having pleasurable sex difficult.

Changing Priorities:

Partners have many new responsibilities after TBI. These new duties are often difficult to learn, and take up much of the partner’s day. These new priorities can result in a partner putting sex “on the back burner.”

Although most partners say that they would like to have a better, closer physically intimate relationship with the survivor, they also report that they do not have the time to make sex a priority.

Role Changes:

When a partner takes on the role of “caretaker” they may have difficulty then changing to the role of equal partner during sexual intimacy. Also, partners who are “in charge” of rehabilitation, but wish to be less dominant during sex, can make sex confusing. The slow but long-term improvements survivors make can result in couples not noticing when a survivor may be ready to take on more responsibilities, or try new things. As a result, many couples develop caregiver / patient roles that lessen a partner’s sexual interest, and these roles may stick around longer or more completely than necessary.

Uncertainty:

Some partners may be more comfortable hinting at sex than outright asking for physical intimacy. If survivors have trouble noticing these subtle hints, partners may be hurt, even if their partner is unaware of the advances.

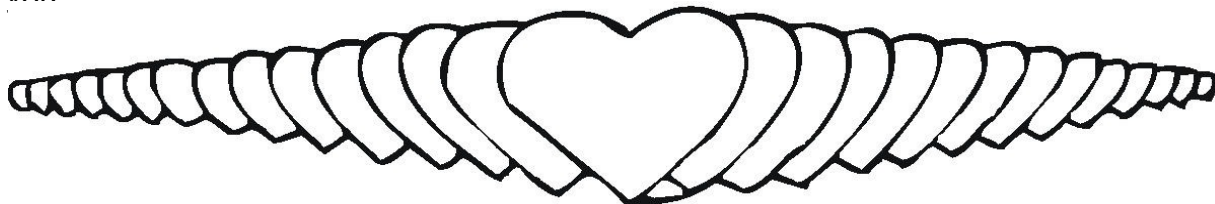
Research shows that many partners report that they are unsure how their partner is satisfied with their post-injury sex life or not, but are nervous about or uncomfortable with bringing up the subject.

When someone is not certain if their partner likes or wants sex, they are likely to use caution and not make advances.

Once you and your partner have discussed the questions listed above, reviewed the table, and discussed which challenges you each notice, use these tips to work on improving the physical connection in your relationship. With your partner, make “improving our sex life” a top-priority goal in your long-term plan for rehabilitation.

Better Sex Tips After TBI:

- ❑ **No more sex Wait, what??** This may seem like the opposite of what you should do! But, for many people, pressure to perform can be the biggest obstacle to good sex. Agree to no sex for a month, but schedule times at least once a week when you and your partner will be physically intimate without intercourse. Be creative, and discover new ways to physically connect without sex. This will increase both people’s comfort, desire, and willingness to have sex when the month is over.
- ❑ **Plan! Do not depend on being spontaneous.** Survivors often have challenges getting things started, and most couples who are nervous or uncomfortable with sex will avoid the subject without something to prompt them. Talk about how, when, and where these things will happen.
- ❑ **Consider timing.** Survivors likely have times of the day when they are more tired, and times they have more energy. Spouses are usually exhausted by their many responsibilities by the end of the day. Schedule times for physical intimacy when you will both have more energy - - Think about having sex in the morning.
- ❑ **Lower Distractions.** Extra stimulation can be distracting and tiring for TBI survivors. When being intimate: reduce background noise; turn lights down low; avoid perfumes, candles, or adding other pleasant smells to the room. Make the main focus of your interactions each other.
- ❑ **Feel safe.** After TBI, both people in a relationship are often intimidated by physical intimacy. Create rules to “make sex safe.” Agree that: No one will ever criticize any sex acts, and any feedback will be given thoughtfully and respectfully; “Arguments stay out of the bedroom” – no disagreements while being physically intimate; and “The bedroom stays out of arguments” – when disagreeing or arguing with your spouse, never bring the topic of sex into the discussion.
- ❑ **Be open.** Most things must be done differently after TBI. Sex is no different. Use this time to learn who your partner is in bed now. Create the excitement and energy of a new sexual relationship by getting to know each other sexually like it’s the first time.
- ❑ **Explore positive touch.** Every part of the body can generate a physical connection to your partner. Take turns exploring each other’s bodies with “gentle touch” while also saying kind and loving things you feel about your partner. Schedule a “Positive Touch Date.” Write out what you will each say in advance. Take turns. Sexual intercourse is not the goal. Create a connection for your partner through your touch and the positive things you think about them. Let them do the same for you.



Survivor Stories Wanted!

Recovering from a brain injury can be very difficult. Sometimes, one of the most helpful and inspiring things is simply hearing from other survivors who have gone through recovery and faced the same challenges. Are you a survivor with a story you’d like to share? If so, then we’d like to hear it, and it might get into a future issue of TBI Today!

Submit to: jhmarwit@vcu.edu

or

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Founded in 1983 by families and concerned professionals, the Brain Injury Association of Virginia is the only statewide non-profit organization in Virginia exclusively devoted to serving individuals with brain injury, their families, and those that care for and about them. Over 10,000 people find help from BIAV each year.

BIAV is a chartered state affiliate of the Brain Injury Association of America and exists to be the voice of brain injury through help, hope and healing for Virginians with brain injury and their families. We educate human service professionals and the community on the risks and impact of brain injury and advocate for improved medical and community-based services. Many of our staff members are Certified Brain Injury Specialists (CBIS Certified).

To find out more information about BIAV, contact us at 1-800-444-6443 or 804-355-5748. Or visit our website at www.biav.net.



The Voice of Brain Injury: Help, Hope & Healing