



TBI

Model System Updates

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TBI and Relationships: It Happened to Both of Us

Traumatic brain injury can cause cognitive, emotional and behavioral changes that have a significant impact on a couple's relationship. Lauren Schwartz, a clinical psychologist in the UW Department of Rehabilitation Medicine, has worked with many couples dealing with the challenges due to a TBI in one of the partners. "The effects on a relationship are different depending on the nature of the injury," Schwartz says. "That's important, and I start with that: helping the couple understand the specific injury and how it's affecting the behavior of the person with the injury."

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It Happened to Both of Us *(continued from cover)*

Why couples seek counseling

“Often the spouse (of the injured person) wants to get some support and education about the brain changes, to understand it from the other’s perspective, and to work on some communication strategies,” says Schwartz. They may want to talk about role changes that have happened if the injured partner needs a lot of assistance. Sometimes it’s the injured partner who initiates coming in for counseling because they are worried about the impact on their spouse.

Emotional Changes

Sometimes the person with the TBI may have more variable moods and emotions, such as being quick to anger or tears, in a way that is very different from their pre-injury self. Sometimes this is quite shocking to the spouse. “I will often start out by providing education around this common issue so they understand why it happens and why they shouldn’t take it personally,” Schwartz says. She works with them to develop coping strategies, such as decreasing stimulation and trying to help the person with the TBI not get overly tired. Over-stimulation and fatigue can increase the emotional problems.



“Even the injured partner can be shocked by the intensity of their emotions,” Schwartz says. “Often they will report feeling ‘hijacked’ by their emotions. So we work on strategies for removing themselves from the situation when this occurs and training in methods like deep breathing or brief mindfulness, taking a walk, or listening to music. The partner can encourage the injured person to use these strategies if they can see that the person is getting overwhelmed.”

Another strategy that can be useful and even add some humor to the situation is pretending the brain injury is a third party, even giving it a name — “‘Bob, that’s Bob talking.’ So we can tell ‘Bob’ to take a break, or calm down.” It makes it less personal. If the person is really struggling with strong emotional reactions after TBI, medication may be helpful.

Sometimes the opposite happens, so that the injured partner doesn’t have much of an emotional response to anything and seems to lack empathy. “Lack of empathy can be very hard on a marriage, because it feels like they don’t care,” says Schwartz. “But with lots of education and coaching you can help the patient connect with what their partner is feeling. And the (uninjured) partner can learn to be very explicit about what’s going on, and what they or others might need or be feeling.”

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Looking to get involved in TBI research?

TBI Care Study: *The Effectiveness of Collaborative Care Versus Usual Care for Pain after Traumatic Brain Injury*

We are recruiting volunteers to participate in a study called “[TBI Care](#)” to compare a collaborative care approach to pain treatment to the usual care approach. Collaborative care, may also improve treatment of other conditions that happen frequently with chronic pain, including depression, anxiety, and sleep.

You may be eligible for the study if you have had a mild-to-severe TBI, have had pain during the last 6 months, and get your care from a TBI physician at either Harborview or UW Medical Center Rehab Clinics. Participants are randomly assigned (like a coin toss) to either the TBI Care treatment group or the group receiving usual care.

For information, contact **Laurie Peabody, 206-744-3607 or lpeabody@uw.edu**

ClinicalTrials.gov Identifier: NCT03523923

All studies are voluntary and will not affect the care you receive at the University of Washington or Harborview Medical Center

March is Brain Injury Awareness Month

Brain Injury Awareness Month is in March and this year’s theme is **Change Your Mind**. The #ChangeYourMind public awareness campaign provides a platform for educating the general public about the incidence of brain injury and the needs of people with brain injuries and their families. Individuals who join us to help raise awareness with the #ChangeYourMind campaign are essential to:

- De-stigmatizing brain injury through outreach within the brain injury community
- Empowering those who have survived brain injury and their caregivers
- Promoting the many types of support that are available to people living with brain injury

More information at <https://www.biausa.org>.



It Happened to Both of Us *(continued from page 2)*

A related problem is that people with TBI can have difficulty understanding what other people are feeling. The brain injury can make it so that they are not as able to put themselves in other peoples' shoes. "In some ways they may not have access to that part of their brain in the same way anymore," Schwartz says.

Cognitive changes

As with emotional issues, couples need education about how the brain injury causes memory difficulties and other cognitive problems. The non-injured partner may need coaching to avoid interactions that could make the injured person feel tested, such as asking if they can remember what they had for breakfast. "Instead, they need to encourage the use of memory aids," says Schwartz. "Such as saying 'Let's look at your phone and see what you're doing today' rather than asking if they can remember."

Intimacy

To preserve the partner relationship and avoid a patient/caregiver relationship, Schwartz recommends that couples have someone other than the partner help with physical or cognitive support as much as possible. "The spouse may need to encourage the injured person to be more independent, do things on their own, take the bus, or be a better helper around house." The injured person working to be more of a partner helps set the stage for intimacy.

The counseling setting can give couples a safe place to talk about sex and any problems they may have with reduced sex drive or physical impairments secondary to the injury. "Sometimes spouses express being worried that they may hurt the injured person during sex or bring on seizures" says Schwartz. "We also talk about creating time to be intimate. There may be times of the day that are better for intimacy. People don't like the idea of making appointments for sex, but it can be useful in this situation, especially if there are pain, fatigue or caregiver issues at certain times of the day. Intimacy is about communication."

Recovery and hope

Doctors often say most recovery happens by 12 months after injury, but many patients experience ongoing improvements for two years or sometimes longer. Although the changes later on are likely to be more subtle. Couples often ask her, "is this the new normal?" If it's past two years, she says "probably, but learning to cope with things as they are is a good place to start."

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When the injured person works to be more of a partner, it helps set the stage for intimacy.
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Getting help

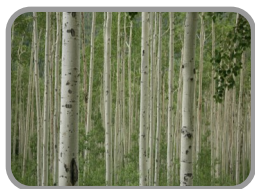
Counseling can be tremendously helpful, and it's important to find a therapist who understands TBI. "Some people with TBI appear normal, and their problems may not be apparent in an initial one-hour session," says Schwartz. She has known couples who have had negative experiences with more general couples therapists who didn't understand TBI. "They can end up giving the couple unhelpful strategies, and the spouse may not feel validated." If you are not able to find an experienced brain injury therapist, find one who is open to learning about TBI and willing to read up on current information. A therapist with medical rehabilitation or health psychology experience is a good place to start.

Brain Injury Alliance of Washington offers information, classes, support groups, and local resources for individuals with TBI, partners, family members. Go to <https://www.biawa.org/> or call 877-982-4292.

For those outside Washington State, the **Brain Injury Association of America** offers information about TBI and a directory of resources in each state. Go to <https://biausa.org> or call 800-444-6443.



Personal Stories



A severe TBI derails lives—and relationships—in an instant.

Angela, injured nine years ago, says she "had to learn how to do everything all over again—sit up, walk, talk, eat, bathe, get dressed" after her injury. Emotionally, "I was very focused on myself only." This makes sense in the hospital, but it's "not so much how the real world is, especially relationships." Her emotional struggles—with frustration, anger, sadness, hopelessness, and loss—also strained her relationships.

She worked hard to regain as much as possible physically and cognitively, and has learned strategies for dealing with her emotions. "I consider others now and even work to try to anticipate how my actions and words (or lack thereof) may affect others." In individual counseling she learned how to identify and evaluate her own thoughts. In couples counseling, she and her husband learned to use a "true bucket," where they put statements they agreed were true about their relationship, such as their love and hopes for each other. "We made a physical 'true bucket' and wrote out our truths and pulled out slips of paper and read them when times got tough." This practice has helped to strengthen their relationship and deepen their intimacy.

Angela recommends that couples seek out a variety of resources to see what helps them, "whether it's religious faith, church, a support group, counseling, a hotline, a 'true bucket' or a doctor. What works for you may look different than what works for others. Keep at it. It's worth the fight."

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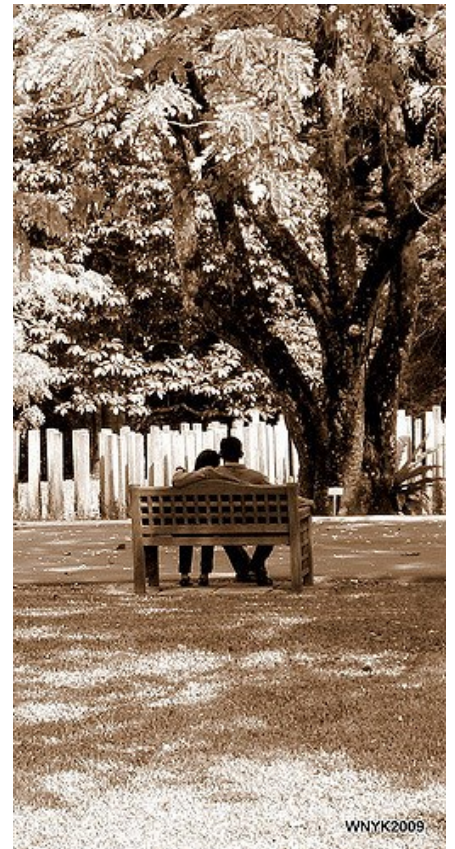
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Daniel believes that love and hope saved his life, helped his recovery, and has kept his marriage strong since his injury seven years ago. Like Angela, he had to relearn how to sit, walk, climb stairs and do other physical activities after the injury. His biggest struggle has been with his emotional and cognitive changes. “My personality changed,” he says. “I had no idea what was going on, and couldn’t grasp what had happened to me.”

Daniel was overwhelmed, frustrated and suffered disturbing emotional fluctuations. His memory was unreliable—large segments of time were lost completely, while false “memories” of things that never happened were vivid in his mind—and this made him anxious and confused. His wife has helped by providing “reality checks,” as well as pointing out when he is starting to get overwhelmed or nervous.

Fatigue is still a major issue. Always an active man, he’s had to accept that he needs to plan his activities carefully and pace himself, knowing that doing too many things in a day will have an emotional and physical cost. The adjustment continues, but the struggle has brought him and his wife closer together than ever.

He shared three important lessons he has learned for keeping the relationship strong. First, accept the fact that the TBI changed everything, including both partners and the relationship. Second, be very open to each other and tell the other person directly and immediately what you are feeling. And third, reach out to peers. TBI is largely an invisible disability, and the rest of the world just doesn’t get it. Others who have had similar experiences are the ones who will understand, validate your feelings, and provide encouragement.





Sleep after TBI: How the TBI Model Systems Have Advanced the Field

By Kathleen Bell, Tamara Bushnik, Kristen Dams-O'Connor, Yelena Goldin, **Jeanne Hoffman**, Anthony Lequerica, Risa Nakase-Richardson, and **Jennifer Zumsteg**. This study was published in the peer reviewed journal *NeuroRehabilitation*. 2018, Vol. 43, No. 3, pages 287-296.

Good sleep is important for recovery and ongoing health after a traumatic brain injury. Sleep problems such as insomnia, sleep apnea and disruptions of the normal sleep-wake cycle, are common after TBI, however. These disorders often lead to fatigue, difficulty concentrating, mood changes, and other problems that can interfere with independence and quality of life.

UW TBIMS researchers **Jeanne Hoffman, PhD**, and **Jennifer Zumsteg, MD**, along with other TBI Model Systems colleagues across the country, have made it a priority to advance understanding of sleep problems in TBI and to identify treatment and prevention approaches that address the needs of the TBI population. This article explains how the different TBIMS centers work together to combine data and conduct research, and describes several ongoing studies that are already showing promise in improving the ways sleep problems are identified and treated.



Announcements & Awards

Adler Endowed Fund for Traumatic Brain Injury Research

Dr. C J Plummer, TBI Fellow at Harborview, has been awarded the first Adler Endowed Fund for Traumatic Brain Injury Research. The award was created by Seattle attorney Richard Adler and the Adler Giersch Law firm in 2018 to support research in TBI rehabilitation care at UW and Harborview Medical Centers. The research grant awarded to Plummer will expand a student-centered return-to-learn protocol for high school students who have had a concussion. This project will help identify students with concussions and provide a pathway for returning to school safely. The grant is awarded for a one-year period.

American Psychological Association Rehabilitation Psychology 2019 Rosenthal Memorial Lecture Award

Dr. Jeanne Hoffman, director of the UW TBIMS, received the **2019 Rosenthal Memorial Lecture Award** from the American Psychological Association's Division of Rehabilitation Psychology. This award recognizes Dr. Hoffman's achievements, contributions, and leadership in improving rehabilitation care for individuals with TBI. Her accomplishments in rehabilitation psychology have made a lasting imprint on the field. Dr. Hoffman will present the her award lecture at the Rehabilitation Psychology Conference on February 7-10, 2019 in Orlando, Florida.



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Who's Who at UW?



Sara Sullivan is a Physical Therapy Clinical Specialist in Harborview's Inpatient Rehabilitation Unit, where she cares for patients who have traumatic brain injuries, spinal cord injuries, stroke, and other neurological conditions.

Sullivan's first exposure to physical therapy came after getting injured during a sumo wrestling activity (in foam suits) at her high school graduation party. She ended up sustaining a cervical compression fracture and concussion, and found that PT gave her a sense of

ownership and control over her own recovery. She pursued this interest at the University of Nevada and earned a Master's degree in PT in 2004.

Sullivan always had a particular interest in treatment of brain injury and is especially fascinated by the brain's amazing capacity for recovery. "Recovery from brain injury is very personal," she says. "What works for one person may not work for another." To pursue this interest, she moved to Philadelphia in 2007 to complete a neurologic PT residency at Moss Rehab. The following year, she became a board certified clinical specialist in neurologic physical therapy.

Coming to Harborview was the first time Sullivan worked in a mixed-diagnosis rehab unit. Working with several diagnoses has been "a strength for my practice," she says. "For example, my improved knowledge about seating and positioning from work with spinal cord injury has made an impact on my ability to prescribe appropriate seating to individuals following TBI." This expertise led to a presentation at the 2018 TBI Model Systems Leadership Conference in Charlotte, NC titled "Considerations for Power Wheelchair Prescription in the Brain Injury Population." These leadership conferences allow participants to stay abreast of the latest best practices in the field of TBI and bring them back to their own institutions and practices.

Outside work, Sullivan enjoys traveling, hiking, kayaking, and generally getting into the outdoors with her new husband and two stepsons.

The Washington Traumatic Brain Injury Resource Center

BIAWA is first and foremost a source of support for those affected by Brain Injury, of which the Resource Center is a critical part.

[Brain Injury Alliance of Washington](http://www.biawa.org/): www.biawa.org/

[BIAWA Support Center](http://www.biawa.org/getsupport.php): www.biawa.org/getsupport.php



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