



TBI

Model System Updates

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Pain after TBI: A Personal Story

In this article, Michele Kauffman shares her experience of living with and managing severe, debilitating pain as a result of a TBI she sustained on September 9, 2010. She was treated at Harborview Medical Center.

During my surgery the first day, a third of my skull was removed to lessen the swelling. After twenty-six days of ICU and intensive inpatient therapy, I was released. A couple of weeks later, I returned to Harborview to have the piece of skull bolted back on. I was sent home the next day. I was on 270 milligrams of Morphine and dozens of OxyContin a day for breakthrough pain. I know pain.

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Pain and TBI *(continued from cover)*

Five more surgeries ensued, seven in all, including surgeries that involved cutting and reattaching different back muscles to improve blood flow to my head.

I took 13 medications for disabling pain, which kept me mostly confined to my bed for six months. The pain was unbearable without my prescriptions, but I was grateful to be alive.

I had three different pains in my head that appeared one at a time or all at once. First was the “magical moving nerve” that relocated by the minute. The slightest touch could bring me to my knees. Second was the rolling mounds of skull encompassing my brain resulting from all the surgeries. This pain was dull and constant for six years. Third and lastly is a spot on the top of my head I call “the hole.”

All three of these pains still crop up once in a while, but I can deal with the pain today. Let me tell you what changed over time and what worked to help me regain control of my life and my activities.

A True Friend.

This is someone who “gets it”—and I mean really gets it— because they also live brain injury day to day. I met my true friend at a Harborview Support Group. We didn’t judge each other, we defended each other. We grew together and a decade later we are still best friends.



LIFT

I participated in the (Life Improvement Following Traumatic Brain Injury) LIFT study. The LIFT program helped me to reconnect with the joy in life I used to celebrate daily. Small steps or experiments lead to larger ones, expanding upon the week before. Learning from this brilliantly designed program to return to what makes you happy was priceless. Visit the LIFT website <https://www.liftcare.org/> to learn

about the study and treatments for depression and TBI.

Charting

This was the least favorite of my therapies for recovery from brain injury. However, it made a world of difference at doctors’ visits. I could hand the nurse my prepared chart and then concentrate on current advice and instructions for the next month.

Yoga

I attended a yoga class adapted for people recovering from brain injury for five years. The strength conditioning from the repetitive movement, peace of mind from relaxation, and being part of a healing, nurturing group of survivors helped as much as the medications. Contact the [Brain Injury Alliance of Washington](http://www.biawashington.org) (info@biawa.org, 206-467-4800) to learn more.

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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 more than 6 months ago, have had pain during the last 6 months, and receive 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.

BIAWA Walk, Run & Roll

The 2019 Brain Injury Alliance of Washington’s 9th Annual Walk Run & Roll event took place on April 27th at Green Lake Park in Seattle. The UW TBI Model System team participated in full UW colors (right) to help raise money to improve the lives of people who have had a brain injury, their loved ones and caregivers with free [Brain Health and Wellness classes](#), support groups, speakers, research and more.



Find out about the BIAWA at www.biawa.org or call toll free 877-982-4292.

Pain and TBI (continued from page 2)

Massage

My doctor referred me for massage, so it was paid for in the beginning. If you can't afford a professional massage, try a college or training school. Human touch not only brings blood to the surface, it brings energy!

Pain Clinics

Attending Harborview Pain Clinic changed my life in regard to the pain from the surgeries on my back. My doctor performed a treatment called dry needling for muscle pain.

Education

The [African Americans Reach & Teach Health Ministry](#) offered a 6 week course, "Living a Healthy Life with Chronic Pain." Epic changes came in my pain relief after taking this class. A combo of simple, fun, sitting exercises along with breathing techniques, meditation and simple willingness helped me reduce my pain medication. This was a life altering experience. Learning the difference between acute pain and chronic pain was a game changer.

After recovering splendidly from all this, I suffered a *second* traumatic brain injury on June 13th, 2014 when my car was hit by a texting driver on the freeway. Back to all thirteen medications and therapy again. Five years after the second accident, I am able to control pain with medical marijuana. I am now pain free once again most days.

My best advice to someone who is recently injured or living with acute or chronic pain is to listen to your body. You know best.

Love and trust your doctor. If you don't, get a new one. Brain Injury Alliance of Washington has a long list of folks who understand brain injury and will help you find a compassionate, caring personal care or specialist physician. Call the Resource Line at 877-982-4292 for referrals.

Get out. Be you. Do what you love even if you have to do it differently. Attend a support group to find more like-minded individuals who also drop their fork and lose their napkin at lunch. Laugh at yourself. Watch yourself grow. Be happy!



Get out.

**Do what you
love.**

**Attend a
support group
to find others
with TBI.**



How 40 Years of NIDILRR Funding has Improved TBI Care:

Steve's Story

Adapted from remarks by A. Cate Miller, Ph.D.

2019 Brain Injury Awareness Day on Capitol Hill

The National Institute on Disability, Independent Living, and Rehabilitation Research ([NIDILRR](#)), which funds the TBI Model Systems around the country (including UW) is celebrating 40 years of TBI research funding.

What are the TBI Model Systems doing to help persons who have experienced brain injury -- and their families -- to live better with brain injury?

Let's look at how NIDILRR-funded research is making a difference by considering "Steve." Steve is a college student who is seriously injured when the car in which he is travelling is struck by another car driven by an intoxicated driver.

Health and Function

While still unable to speak, Steve's level of consciousness is assessed with a state of the art measure developed with NIDILRR funding, the Coma Recovery Scale-Revised. This helps guide his providers to the most appropriate treatments for his injury severity.

While in inpatient rehab Steve receives the medication Amantadine. NIDILRR-funded research proved that Amantadine speeds recovery of behaviors such as consistent responses to commands, intelligible speech, and reliable yes-or-no communication.

As he recovers, Steve's health care providers use specialized tools to monitor his pain, agitation, attention, neurobehavioral functioning, degree of disability, and safety risk. These ensure that Steve's progress is steady and guide his clinical care. These tools were developed with NIDILRR funding.



As his rehabilitation progresses, Steve receives treatments proven to be successful through NIDILRR funding, include interventions to improve memory, emotion regulation, resilience and adjustment, as well as decrease chronic irritability and aggression. As time passes and Steve is discharged to his parents' home, his parents enroll in a TBIMS proven telehealth intervention that provides individualized education and mentored problem-solving training.

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When returning to clinic for follow-up care, Steve's healthcare providers speak with him about a plan for maximizing his health and wellness. They are guided by TBIMS research showing that moderate to severe TBI is a chronic health condition that puts patients at-risk for certain preventable health problems, such as obesity and related conditions.

Education and Employment

As Steve makes progress in his recovery, he wants to explore employment options. He learns about an innovative demonstration project funded by NIDILRR, called "Project Career" to support the academic and career success of college students who have sustained TBI. The program merges the use of cognitive



support technology and vocational rehabilitation practices to improve academic and employment outcomes. In early results, 66% of the program's graduates achieved full-time employment, 15% are employed part-time; and 17%, although not employed, are pursuing further education on a full-time basis.

Community Living and Participation

Perhaps what Steve misses most since his injury is being out and about with his family and friends. Steve reads about the improvements in well-being and life satisfaction for those with TBI who take part in a NIDILRR-funded structured volunteer activity program. So as he continues to work toward employment, Steve decides to volunteer as an assistant Little League coach. In addition, Steve and his girlfriend enroll in the TBIMS Therapeutic Couples Intervention designed to improve the quality of couples' relationships after one partner has experienced a TBI.

While Steve continues to make improvements in most areas, he still feels as if his independence is limited. For example, his parents and his girlfriend drive for him. NIDILRR is currently funding a multi-site research project to look at "Return to Driving after Moderate-Severe TBI" which will provide valuable information to inform Steve's decisions regarding returning to driving.

Throughout his recovery, Steve and his family benefit from factsheets, info comics, videos and other resources developed by the TBI Model Systems. In fact, Steve offers some of his time to provide consumer input and to review newly drafted materials. Not only has Steve benefitted from research from the TBI Model Systems, he has contributed to this knowledge by sharing information about his recovery through periodic follow-up surveys and participating in research studies.

NIDILRR-Funded TBI Resources

<https://msktc.org/tbi>

TBI Care Study

The UW TBI Model System's "TBI Care" study focuses on reducing chronic pain in people with TBI by working with a team of TBI health care experts. Participants who are randomly assigned to receive the treatment meet with a TBI care coordinator one-on-one to understand the causes and triggers of their pain and to manage their pain so they can enjoy life more.

"It's super common for people to have pain after TBI, and headaches are most common," says Mary Curran, MSW, the TBI care coordinator on the study. Curran meets with participants weekly, either in clinic or over the phone, for up to 12 sessions. "People are often overwhelmed by their pain when they start the study. We help them understand their pain and how it connects with stress and emotions. We work together to identify what they have control over or can change to reduce pain intensity and interference in life."

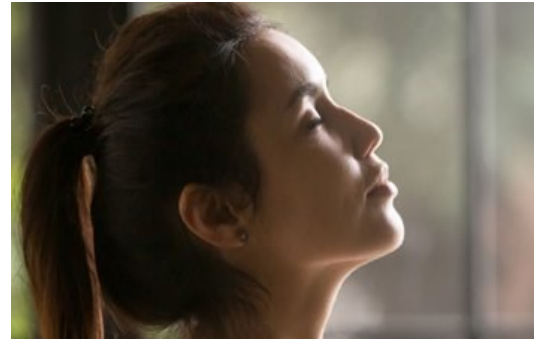
Curran uses a variety of approaches such as relaxation skills, pacing, cognitive-behavioral therapy, and goal-setting, depending on each person's individual needs and preferences. "Managing emotions that trigger or contribute to pain is key," Curran says. "Relaxation is really helpful because you can use it in the moment, stopping and taking a deep breath as soon as you become aware of stress or negative feelings."

Pain flares are a sudden, intense spike in pain that can immobilize a person with the fear of making it worse. Curran can help the person understand that flares are fairly normal, that they're not in danger, and develop a plan so when a flare starts they know how to respond and not make it worse but panicking or tensing up.

"Sometimes they are on medications that are not well-suited to someone who's had a TBI," she continues.

"Maybe their primary care doc or neurologist has prescribed meds for depression or pain that may not be recommended for someone with TBI because of its impact on cognitive function. Our medical team may suggest a different medication that targets both depression and neuropathic pain."

Everybody's situation is a little different. Curran, with input from the team of TBI experts, works with each participant to figure out what makes sense for that person in their situation, to better help manage their pain going forward.



The TBI Care study is still recruiting participants.

Please see the study announcement on page 3.



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Who's Who at UW?

Fleur Godfried is a speech pathologist in Harborview Medical Center's Comprehensive Outpatient Rehabilitation Program (CORP), where she cares for patients who have traumatic brain injuries, strokes, and other neurological conditions. Fleur started out as a student intern in 1999 and has worked across the care continuum—from newly injured patients in the hospital to those living in the

community many years after injury. She has worked as an outpatient therapist for the last 15 years.

Given the large trauma population that comes through Harborview's doors, Fleur has experience working with all levels of brain injury, from mild TBI (concussion) to severely injured patients. As a speech pathologist, Fleur addresses language, thinking and communication issues, as well as swallowing problems that are a result of brain injury.

Fleur enjoys the challenge of helping patients after they leave the safety of the hospital. Even though patients practice for the transition home, "things become very real" after discharge, she says. Working with patients to achieve their goals, whether it is returning to work or school, or just helping them achieve more independence, is "very rewarding."

Fleur participates in the annual TBI Model System Leadership Conference as part of the UW TBI Model System. Her recent presentations include topics of return to driving after TBI and showcasing case studies to improve transitions in care. Participating in these leadership conferences allows therapists to stay up-to-date on the latest best practices in the field of TBI and bring them back to their own institutions and patients.

Outside of work, Fleur enjoys spending time with her husband and two children. When not chauffeuring her kids around Seattle, she enjoys reading a good book, going to museums, and training for a 5K.



Speech pathologist Fleur Godfried with her daughter Sarah (and Pinky Bear).

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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