

# BRAIN Waves

Good Vibes for the Arkansas Brain Injury Community

VOL. 4, Issue 2, Spring 2022

## RECOVERY AFTER TBI

It is human nature to want to know what to expect after a life-changing event such as a traumatic injury. Unfortunately, for people with a brain injury that is a challenging task for several reasons. Each brain injury itself is unique. Patients may experience a wide range of medical problems related to the accident, making each situation even more different. Also, deficits can be broad, and recovery is very individualized.

One method for predicting outcome after TBI is the rate of early recovery. Those who recover quickly early on are likely to continue that path during their recovery process.

We used to tell people that good recovery only happened in the first year after their injury. After that year, progress was thought to stop almost completely. We now know this is not true. Severe impairments in the short-term do not always mean that a person will have poor outcomes in the long term.

In fact, recent studies of people with severe TBI show improvements up to 15 years post-injury. The window of improvement may be even longer, but the studies are limited past that point.

Instead of telling patients and their families that recovery will stop, we now counsel that the *fastest* recovery will happen within the first year. After that, recovery often slows.



## ASK the Specialist



Lindsay Mohney, D.O., FAAPMR, BIM  
Assistant Professor  
Dept. of Physical Medicine and Rehabilitation  
University of Arkansas for Medical Sciences

Instead of daily or weekly progress, you may notice improvements in periods of months or years.

Rehabilitation can help maximize meaningful recovery. Most people are familiar with physical, occupational, and speech therapies. Rehabilitation can also include cognitive therapy, community reintegration, vocational rehab, psychiatric or psychological care, and social support.

It is important to follow up with a physician to review medications and monitor for medical complications, which may worsen TBI symptoms. Over time, your rehabilitation program will likely change as your needs, abilities, and goals change.

I often use this analogy when discussing recovery from brain injury: It is a marathon, not a sprint! It requires work and support from those around you, and everyone's journey is a little different. There may be setbacks, and it may take a while, but don't give up!



Suggest a topic! Email us at

[trrp@uams.edu](mailto:trrp@uams.edu)

## THE TRRP/TBI-SPP TEAM



**Renee Joiner, RN, BSN**  
Clinical Program Director  
Trauma, Stroke, and SANE Programs



**Danny Bercher, Ph.D., NRP, CBIS**  
Assistant Director, TRRP



**Kristen Alexander, MPH, MPS**  
Program Manager, TRRP, ACL TBI  
State Partnership Program  
Editor, Brain Waves



**Dianne Campbell, LCSW**  
Care Coordinator, TRRP



**Amber Watson, MBA**  
Project Manager, TRRP, ACL TBI  
State Partnership Program



**Eddie Williams, RN, BSN, CBIS**  
Nurse Educator, TRRP



**Constance Tullis, LMSW**  
Social Work Volunteer

## CONTACT US

**UAMS** Institute for Digital Health & Innovation

Trauma Rehabilitation Resources Program

4301 W. Markham, #513  
Little Rock, AR 72205

**(501) 526-7656**  
**trrp@uams.edu**

**atrp.ar.gov**

**f** Trauma Rehabilitation Resources Program



## CONSTANCE TULLIS: TBI SURVIVOR AS TOLD TO KRISTEN ALEXANDER



*Constance (right) with her mom and brother in 2016*

Constance Tullis had a rough start to adulthood. She was often in trouble at school, struggled with drugs and alcohol, moved around a lot, and was in and out of substance abuse programs from the time she was 16 years old. Nothing seemed to work to get her clean. On Sept 28, 2011, her path suddenly changed when Constance was shot in the head.

Constance was transported by helicopter to Baptist Health in Little Rock, where she was given a 2% chance of survival. The bullet had damaged almost every lobe in her brain and she had high levels of alcohol in her system. A doctor was surprised she didn't die from alcohol poisoning. Constance spent almost 2 weeks in a coma, and doctors told her parents that if she did survive, she would never be able to walk or talk again. But Constance had other plans.

After a few days, her dad noticed her moving an index finger. The nurses did not believe it because the movement was so tiny. But then, Constance moved a big toe and later opened her eyes. Later she moved her right hand and arm. All Constance remembers from this time is having lots of tubes in her, changing floors a lot, and feeling like she was in a dream.

On Oct 17, Constance was transferred to Baptist Health Rehabilitation Institute (BHRI), where she stayed until just before Thanksgiving. This is where Constance's memory really started to fill in. She remembered hating the way clothes felt, so she took them off every time she was in her room. She described the therapists pushing her and working her, even when she was tired and said she didn't have the energy. "They would just never give up on me," she said.

Constance recalled learning to talk again, saying "the first word I said in speech therapy was, I whispered "Mom". I don't know how that happened."



"I went from not talking and I was able to say 'Mom' (same as when I was a baby) but that was just like remarkable to me. It was just like magic because all of a sudden I started talking and I didn't understand how. Speech therapists are amazing to me."

She tried leaving rehab several times, which is common for many patients after a brain injury. But Constance was in a wheelchair and could never quite make it out without getting caught. When Constance was discharged after a month and a half in BHRI, she still could not walk unassisted, but the therapists had taught her everything she needed to get there. She left in a wheelchair and for awhile she used a walker to get around at home and to appointments.

Constance was fortunate to have a compassionate primary care physician, Allan McKenzie, M.D., who had accepted her right out of the hospital as a Medicaid patient because he wanted to help her, and he saw it as an opportunity to learn and grow as a physician. He was sure to refer Constance to UAMS for therapies and neuropsychology. She was having major mood swings and what she calls "adult temper tantrums" from all the mental and emotional changes. She says, "I wasn't being understood and I thought I was just being normal, right? It was so frustrating!"

She struggled for a while with depression and lack of motivation. She recalled, "In the



*Constance with Chasity, who is her best friend and caregiver*

beginning I was in shock because of all the overwhelming circumstances that I was unable to handle and my inability to discuss any of it because I couldn't get my words and thoughts out of my head." Constance had been sober in the hospital, but the depression she felt when back at home led her to drink again.

**“I’m so grateful that I just kept pushing and I never gave up trying through it all.”**

She found herself slipping back into her old patterns of bad company and substance abuse. But this time it was different. "The drinking and the people I was hanging around with and everything felt gross to me," Constance said.

At some point, she had a sort of awakening. Constance realized that her disease of addiction was a life-or-death choice and

she had been given a second chance. This time she chose life. On Mother's Day in 2012, Constance got sober. Looking back on the weeks leading up to that day, she said, "I remembered my mom crying when I relapsed, and I just couldn't handle doing that

to her anymore." For the next several years, Constance treated her recovery — from both brain injury and addiction — as her full-time job. She went to more Alcoholics Anonymous (AA) meetings than she could count.

Everything was not perfect, but it was gradually improving. Getting along with her mom was really hard at that time. "I was always rightfully getting accused of wanting to relapse. I knew I wasn't [relapsing], but my precious mom didn't because I had said all that before, and nothing had stopped me [from drinking] until this traumatic event," she said. At the time, Constance denied that she had any significant cognitive problems. This is very common after a brain injury and can make it more difficult for family to get along with a survivor. Constance still had a lot of work to do, even if she could not see it.

Her neuro testing reports cited difficulties in math and writing, sustained attention, cognitive processing speed, motor functioning, and lingering word-finding problems. Constance remembers some crucial advice from Jennifer Gess, Ph.D. that, "if my seizures are controlled and I maintain sobriety, it is unlikely that I will have any cognitive decline." Constance recognized the importance of this advice for brain injury recovery. When rebuilding cognitive abilities, drugs and alcohol can impact and impair that process.

*Continued on page 4*

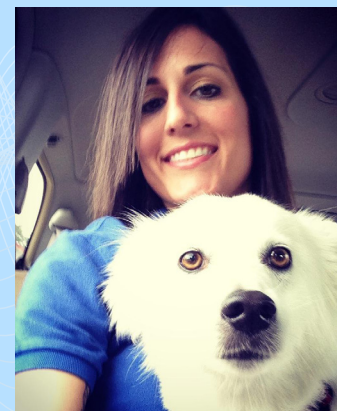
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Constance wanted to finish college, so she started working her way up to being a full-time student. She was able to get accommodations — like longer times on tests and breaks to help her focus — because of her disability. Before her injury, she was close to getting an accounting degree, but afterward she discovered she was no longer good at math. She knew she wanted to help people and she felt inspired by Kevin Navin, who was her therapist at the time, so she ended up getting her undergraduate degree in psychology in 2014. She did not walk at graduation, she says, “but I told my family I would walk across the stage whenever I finished grad school.”

Despite not being totally confident that she was capable of graduate school, Constance set her mind to it. “I looked at it as something that I couldn’t achieve and so that would make me try even harder,” she said. Kevin warned her that grad school would be aggressive, but that did not stop her. She applied to the UA Little Rock School of Social Work and was denied multiple times because they did not think she would be able to pass the licensure exam. Constance’s mom went to the school in person to ask them to just give her a chance, which worked! She was accepted after that.

In 2019, Constance graduated with her master’s in social work. Then came the dreaded licensing exam. She failed it several times, and then started working with Chrystal Fullen, Psy.D., a neuropsychologist at UAMS. Dr. Fullen gave her a regimen to follow for her studies. She would study for 45 minute chunks with a 15-minute break. This worked really well for Constance, who followed it to a T. She also learned to use word association to remember the meaning behind hard words like hippocampus, for which the association goes; “if you see a hippo on campus, you will never forget it, so that part of the brain is for memory.”

It wasn’t long after she finished school that Constance realized she wanted to work with others like her; people who had survived a brain injury. Rani Lindberg, M.D., who had known Constance for years, sent emails to TRRP (the organization behind this newsletter)



Constance and her dog in 2013

suggesting that she get involved with the program. Dr. Daniel Bercher, Ph.D. jumped on the opportunity and invited her to join the Arkansas Brain Injury Council. Then in January, she started volunteering part-time with the team!

These days, Constance knows what she needs to do to stay sober and healthy. She walks her dog every day at lunch, rain or shine, a routine that protects her peace. She attends AA meetings regularly and participates in the virtual brain injury support groups that are held every Tuesday. She can’t run yet, but she is getting close! She works on her yoga and does other workouts, and she tries to eat healthy food. She talks a lot about the power of gratitude, which is a practice she was not always good at. She says she learned a lot from watching gratitude videos.

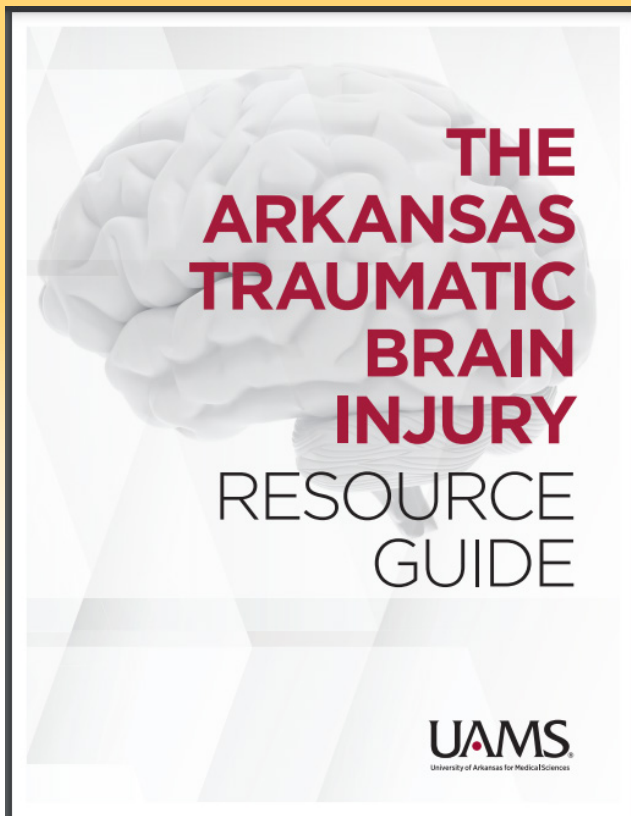
Constance says, “A grateful heart is like a magnet for the miracles. If I treat every day like it’s my first day and my last day to be alive, that’s staying in the present. Yesterday’s the past, tomorrow is the future but today is the present. Took me years to figure that out.” It is amazing to hear her say it, but Constance is grateful for her brain injury. “I’m so glad now that everything played out the way it did. I’m so grateful that I just kept pushing and I never gave up trying through it all. I just persevered.”

When asked about her advice for other survivors of brain injury, Constance had one tip: “just keep trying and do the very best you can each time. Never stop trying!”

We want to hear your story! Email us at

 [trrp@uams.edu](mailto:trrp@uams.edu)

# RESOURCE HIGHLIGHT



## FREE Resource Guide

We are excited to announce Arkansas' new guide for people living with brain injury. This comprehensive guide can be used as a tool to help patients and families navigate the journey from injury to community.

To view online: Visit <https://atrp.ar.gov>, click the "education" tab, and then click "The Arkansas Traumatic Brain Injury Resource Guide." Or, type this link into your browser: <https://atrp.ar.gov/wp-content/uploads/sites/24/2021/12/Arkansas-Traumatic-Brain-Injury-Resource-Guide.pdf>

From there, you can browse the guide online, download it to your computer, and even print it.

To receive a copy by mail, email your name and address to us at [trrp@uams.edu](mailto:trrp@uams.edu) with the subject line as "**Resource Guide Request**" or call us at 501-526-7656.

### What will I find inside the guide?

Our guide is easy to understand and has seven sections. Here is a brief description of them:

- **Understanding Traumatic Brain Injury:** A simple guide to the basic parts and function of the brain, with helpful diagrams and charts to understand how different injuries might affect a person's body or behavior.
- **The Recovery Process:** This section helps with understanding the different settings and facilities after a TBI and how they work.
- **Tools for Family and Caregivers:** Here you will find self-care guides, communication and advocacy tools, and legal information that puts complex topics in simple language.
- **Living with a TBI:** Get advice about common issues that survivors face, such as depression, headaches, fatigue, and emotional challenges.
- **Local and National Resources:** A long list of places you can go for help.
- **Easy-to-Understand Glossary:** Easily look up medical terms to better understand their meanings.
- **Notes and Logs:** A place to keep track of things like the names of your medical staff, medications, recovery progress, and other important items.



# A SUPPORT GROUP FOR EVERYONE!

Our partners at Sources for Community Independent Living in Northwest Arkansas have been working hard to offer support group access for every member of the family. We are excited to share that we now have THREE categories of support groups, with hopefully more to come in the future!

Support groups are a positive place to meet people who understand your struggles, whether you are a survivor or a caregiver. They can also be a good place to learn new skills and strategies for living with your (or your loved one's) injury. The great thing about these groups is they are all online, so you can join from anywhere! Here are our current options:

**For Adults with Brain Injury: Every Tuesday at 1 p.m.**  
**For Caregivers: 1st Monday of every month at 2:30 p.m.**

## To Join:

Download RingCentral Meetings to your computer or smartphone, click Join Meeting and type the meeting ID: 894 179 693

-or-

Type this link into your browser:

**<https://meetings.ringcentral.com/join?jid=894179693>**

No internet? No problem: Call +1 (650) 242-4929, type the above meeting ID then press #.

For more information contact NeCol Whitehead at [nwhitehead@arsources.org](mailto:nwhitehead@arsources.org) or call/text 479-802-3903.

## For Teens (ages 14-18) with Any Disability

Meets the 2nd & 4th Thursday of the month from 4:30-5:30 p.m.

- Know yourself, what you need, and how to get it
- Build relationships with peers who have similar experiences
- A safe place to talk about struggles and challenges

To sign up, contact Kasi Miller at [kmiller@arsources.org](mailto:kmiller@arsources.org) or 479-802-3907 (calls or texts welcome)





## Social Security/ Disability POINTERS

# SOCIAL SECURITY CAN HELP YOU START OR RETURN TO WORK

By Tonya Cater, Social Security Public Affairs Specialist

If you rely on Supplemental Security Income (SSI) payments or Social Security Disability Insurance (SSDI) benefits and want to start or return to work, we can help.

Ticket to Work (Ticket) is a program that supports career development for SSDI beneficiaries and SSI recipients who want to work and progress toward financial independence. The Ticket program is free and voluntary. Learn more about the Ticket to Work program at [www.ssa.gov/work](http://www.ssa.gov/work) or call the Ticket to Work Help Line at 1-866-968-7842 or 1-866-833-2967 (TTY) Monday through Friday, 7 a.m. to 7 p.m. CST.

In addition to the Ticket to Work program, the Plan for Achieving Self-Support (PASS) program also helps people with disabilities return to work. A PASS allows you to set aside resources and other income besides your SSI for a specified period. With a PASS, you can pursue a work goal that will reduce or eliminate your need for SSI or SSDI benefits.

### How does a PASS help someone return to work?

- We base SSI eligibility and payment amounts on income and resources (items of value that the person owns).
- PASS lets a person with a disability set aside money and items they own to pay for items or services needed to achieve a specific work goal.
- The objective of the PASS is to help people with disabilities find employment that reduces or eliminates the need for SSI or SSDI benefits.

You can read all about the PASS program at [www.ssa.gov/pubs/EN-05-11017.pdf](http://www.ssa.gov/pubs/EN-05-11017.pdf).

The PASS must be in writing and we must approve the plan. To start, contact your local PASS Cadre or local Social Security office for an application (Form SSA-545-BK). You can also access the form at [www.ssa.gov/forms/ssa-545.html](http://www.ssa.gov/forms/ssa-545.html). Ticket to Work service providers, vocational counselors, or a representative or relative can help you write a PASS.

For more information about PASS, read The Red Book - A Guide to Work Incentives at [www.ssa.gov/redbook](http://www.ssa.gov/redbook). Your job isn't just a source of income — it can be a vehicle to independence or the beginning step to fulfilling your dreams. Let our Ticket to Work program or PASS program help you achieve your goals.

Suggest a topic! Email us at

 [trrp@uams.edu](mailto:trrp@uams.edu)

**Trauma Rehabilitation Resources Program**

4301 W. Markham, #519-4  
Little Rock, AR 72205

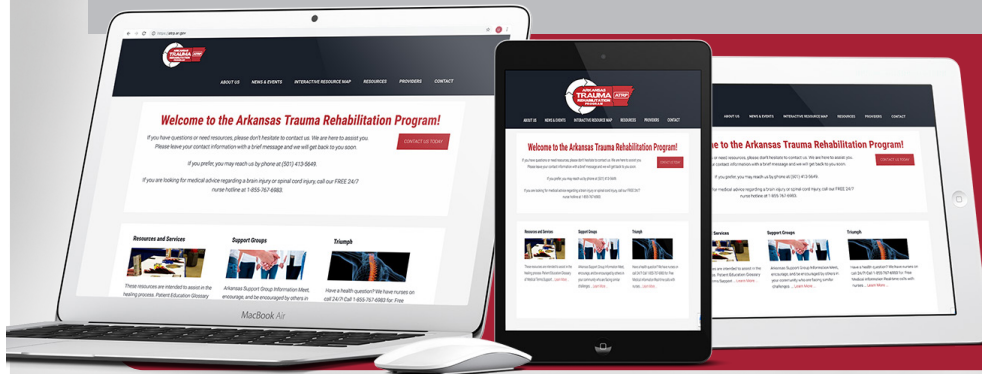
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The Trauma Rehabilitation Resources Program offers a disability resource website to connect those with trauma-related disabilities to helpful resources and organizations in the community.

To access the disability resources website, go to:  
**<https://atrp.ar.gov>**

We also offer a 24-hour nurse call center for people with a brain or spinal cord injury, their caregivers, or medical providers. Call anytime with questions about your health, symptoms, or medical care.

To access the call center, call:  
**1-855-767-6983**



For more information about the disability resource website or the nurse call center, call (501) 295-6576 or email [trrp@uams.edu](mailto:trrp@uams.edu)

*The nurse call center is a partnership of the UAMS Institute for Digital Health & Innovation and the UAMS Department of Physical Medicine and Rehabilitation, and is funded by the Trauma Rehabilitation Resources Program.*

