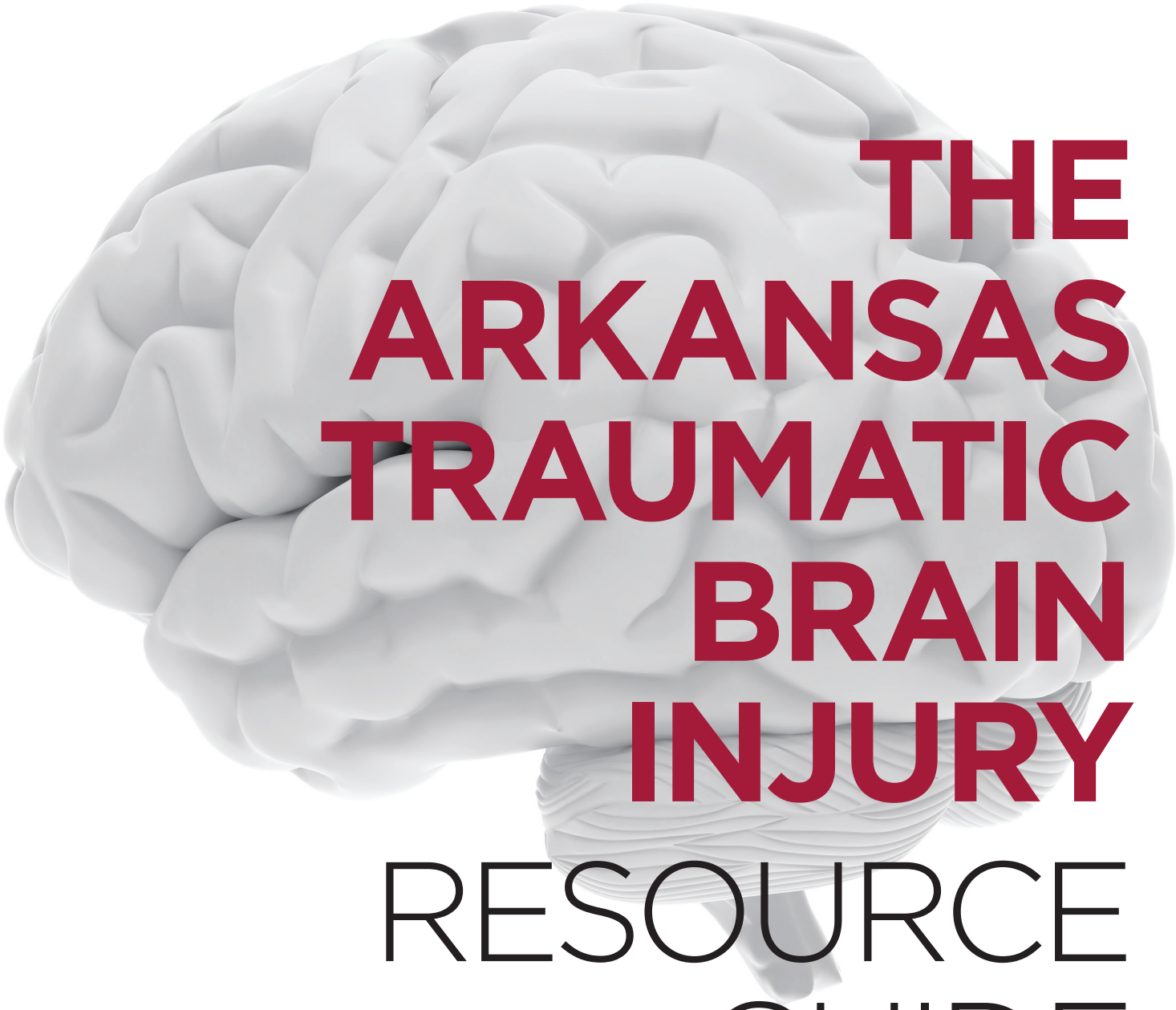


THE ARKANSAS TRAUMATIC BRAIN INJURY RESOURCE GUIDE

UAMS®
University of Arkansas for Medical Sciences

About this Guide

This guide was developed by the Trauma Rehabilitation Resources Program (TRRP). TRRP is a statewide program dedicated to helping people with traumatic injuries reintegrate into the community. We are located at the University of Arkansas for Medical Sciences, in the Institute for Digital Health and Innovation.

Our Vision: To enable every Arkansan who has sustained a disabling traumatic injury access to the comprehensive rehabilitation care he or she needs to seamlessly reintegrate into the community.

Our Mission: To increase awareness of the rehabilitation and lifelong care needs of survivors of traumatic injuries, evaluate existing programs, educate healthcare professionals, and identify vital resources for survivors of traumatic injuries.

A traumatic brain injury (TBI) is different from other traumas because it involves the most complex organ of the body, the brain. This guide is meant to help you after a TBI. To get the most from this guide, use the contents on page 3 and the tabs on the side to find the most useful information for you right now. If you see a new word you do not know, our plain language glossary in the back can help you. If at any point you feel frustrated or confused, we are here to help! Just call us at 501-526-7656 or email us at trrp@uams.edu. You may need to leave a message, but we promise to return your call in a timely manner.

You can also visit our resource website, https://atrp.ar.gov for videos, newsletters, and other helpful information.

Once the survivor is home, you may need our **24/7 nurse help line**. This resource is great for when a medical issue* arises that you are not sure how to handle. The help line can also offer you assistance with appointments, follow-ups, and even consults (this means that your primary care doctor can call for expert brain injury advice). Call toll free at 1-855-767-6983.

A note on word choice: Throughout this guide, we will refer to the person with a brain injury as “the survivor” and their family and friends as “the caregiver”. We have chosen “survivor” because brain injury is a condition that many people feel the effects of for the rest of their lives. We wish to highlight the survivor’s strength in this. We also realize that many people who care for a survivor are not always related, so we use “caregiver” to help the guide feel like it is for every reader.

**For any medical emergency, you should call 911.*

Acknowledgements

The Trauma Rehabilitation Resources Program would like to thank the following community partners and organizations for supporting us, sharing resources with us, and assisting with the creation of this guide:

Administration for Community Living Traumatic Brain Injury State Partnership Program of Arkansas

Brain Injury Association of America

UAMS Center for Health Literacy

UAMS Patient Education Department

The Model Systems Knowledge Translation Center

Jeffrey Kreutzer and Lee Livingston from The National Resource Center for Traumatic Brain Injury, Virginia Commonwealth Model Systems of Care

Arkansas Legal Services

The Brain Injury Support Group at Baptist Health Rehabilitation Institute

Nicole Thornton

Amy Goddard, MS, OTR/L, CBIS, ATP

Chrystal Fullen, Psy.D

This guide was compiled and edited by:

Kristen Alexander, MPH, MPS

Program Manager

Trauma Rehabilitation Resources Program

UAMS | Institute for Digital Health & Innovation

4301 W. Markham, #513

Little Rock, AR 72207

(501) 295-6576

www.atrp.ar.gov

Table of Contents

SECTION 1: UNDERSTANDING TRAUMATIC BRAIN INJURY 5

Brain Injury Basics 5
Functions of the Brain 8
15 Things Brain Injury Survivors Want You to Know 10

SECTION 2: THE RECOVERY PROCESS 11

Settings of Care 14

SECTION 3: TOOLS FOR FAMILY AND CAREGIVERS 21

A. Self-care Tips for Caregivers 21
B. What can I do to help? 23
C. How to ask for help: A list of things you can delegate to others 25
D. How to talk to your doctors and nurses 25
E. Self-Advocacy: Patient and Family Rights 26
F. How to Select a Brain Injury Rehabilitation Facility 28
G. Navigating Insurance Appeals 30
H. Making Health Care and Financial Decisions for Someone with a TBI: Power of Attorney, Guardianship, and Living Will 32
I. Tips From a Survivor's Wife 37

SECTION 4: LIVING WITH A TBI 39

Depression after Traumatic Brain Injury 42
Emotional Problems after Traumatic Brain Injury 46
Headaches after Traumatic Brain Injury 50
Fatigue after Traumatic Brain Injury 53
Driving after Traumatic Brain Injury 56

SECTION 5: LOCAL AND NATIONAL RESOURCES 61

Support Groups 61
Career and School Resources 62
Getting Hired 63
Caregiver Support 64
Cognitive, Behavioral, and Mental Health 64

Neuropsychology Services 66
Assistive Technology & Equipment 68
Financial Assistance & Social Services 68
Legal Services 71
Disability Organizations & Foundations 72
Trauma Survivor and Disability Publications 75
Sports and Recreation 76

SECTION 6: EASY TO UNDERSTAND GLOSSARY 77

Glossary of Medical Terms 77

SECTION 7: NOTES AND LOGS 91

Log for tasks assigned to family and friends 91
Log for communication with medical staff 92
Log for names of medical staff 93
Patient Progress log 94
Medication Log 95
Questions for the doctor: 96
Questions for the nurses 99
Insurance Log 100

Section 1: Understanding Traumatic Brain Injury

Brain Injury Basics

What is traumatic brain injury (TBI)?

Traumatic brain injury (TBI) is when your brain is damaged by a sudden force from outside your head. Not all hits to your head cause TBIs.

Symptoms of TBI can include:

- Loss of consciousness (not being awake or aware)
- Headache
- Confusion
- Feeling faint
- Feeling dizzy
- Blurred vision or tired eyes
- Ringing in your ears
- Bad taste in your mouth
- Feeling tired or sluggish
- Change in sleep patterns
- Changes in behavior or mood
- Trouble with memory, focus, attention, or thinking
- Loss of smell
- Difficulty speaking or slurred speech
- Seizures
- It is possible to have a TBI and never lose consciousness. For example, someone with a gunshot wound to the head may not lose consciousness.

What causes a traumatic brain injury?

- Many things can lead to a TBI, such as:
- A fall
- Being hit by something
- Hitting your head against something
- Another injury where an object (like a bullet) enters your head

- A car crash
- A TBI is not caused by something internal, such as a stroke, tumor, or damage to the brain caused by a lack of oxygen. Those are called non-traumatic brain injuries.

What are the types of traumatic brain injuries?

- A TBI is described as:
- **Open or closed head injury**
    - Open head injury: When there is an open wound in your skull or brain, such as a bullet wound. These injuries are often in a specific area of the brain.
    - Closed head injury: When there is no outer wound on your skull or brain. These injuries can be in a specific area or all over the brain.
- **Primary or secondary injury**
    - Primary injuries are those that happen right when you are injured. These may include:
        - Skull fractures (a break or dent in your skull)
        - Contusions (a bruise on your brain)
        - Hemorrhages (bleeding in your brain)
        - Diffuse axonal injury (stretching or tearing the cells and fibers in your brain)
    - Secondary injuries happen after you get hurt, usually within a few days. These may include:
        - Hypoxia (not enough oxygen to your brain)
        - Hypotension (low blood pressure)
        - Increased intracranial pressure (high pressure inside your skull)
        - Cerebral edema (swelling of your brain tissue)

How is the severity of a traumatic brain injury measured?

- The severity of a TBI refers to the amount of damage to your brain tissue. Your damage is based on how long you lose awareness, how much memory you have lost, and your brain scan or test results. The severity of your TBI (how bad) may be described as:
- Mild
- Moderate
- Severe

What scans or tests show traumatic brain injury damage?

- Your doctor may use 1 or more scans or tests to see if you have a TBI and check the severity:

- **The Glasgow Coma Scale (GCS)** is a test used to measure how conscious or aware you are. It is on a scale from 3 to 15. The lower the number the more severe the injury. Normally, first responders do this when they first come to treat you after your injury. To assess you, they will look at:
    - Your eyes
    - How you move your body
    - How you answer questions
- **Ranchos Los Amigos Scale (RLA Scale)** measures a survivor's recovery after a TBI by looking at how he or she interacts with the rehabilitation environment. The scale looks at the patient's interaction with their environment to show how it changes across their recovery.
- Often in intensive rehab settings, you may hear something like "the patient is still RLA 4 or RLA5" etc., so it may be helpful to understand what these numbers mean. The RLA scale ranges from 1 (no interaction) to 8 (purposeful and appropriate interaction). Scoring also considers how much agitation and/or confusion a patient is experiencing. Every time they advance a stage (even if the behaviors that come with that stage are frustrating) it means that the survivor is working towards more recovery.
- **Computed tomography (CT)** is a type of scan that is often faster and focuses on brain structure. It shows problems in your body and brain, such as:
    - Bleeding
    - Bruises
    - Blood clots
    - Swelling
- CT scans are not painful. If you have a moderate to severe TBI, you may have more than 1 CT scan while in the hospital to keep track of changes in the damaged areas in the brain.
- **Magnetic resonance imaging (MRI)** is also a scan that is used to show problems in your brain. This scan shows your brain tissue. This type of scan is more detailed than a CT scan, but it takes longer and costs more money.

What does a TBI do to my brain?

After a TBI, the neurons (tiny cells that are linked together) in your brain may die or be damaged. This can keep your body from working the way it should. Damage to certain parts of your brain can affect different functions. Some survivors have seizures that need to be managed by their doctor. This all depends on what parts of your brain are damaged and what functions they control.

What are the long-term effects of a TBI?

It is understandable to have worries about the long-term effects of TBI. Unfortunately, it is hard to say what the long-term effects will be. This is because:

- Brain injury is still a new area of treatment and research.
- We have only begun to understand the long-term effects in patients 1, 5, and 10 years after injury.
- Brain scans and other tests are not always able to show how bad the injury is. This makes it hard to know how serious the injury is early on.
- The type of brain injury and how the brain responds differs a lot for each person.
- Age and ability before your TBI also affect how well you will recover.

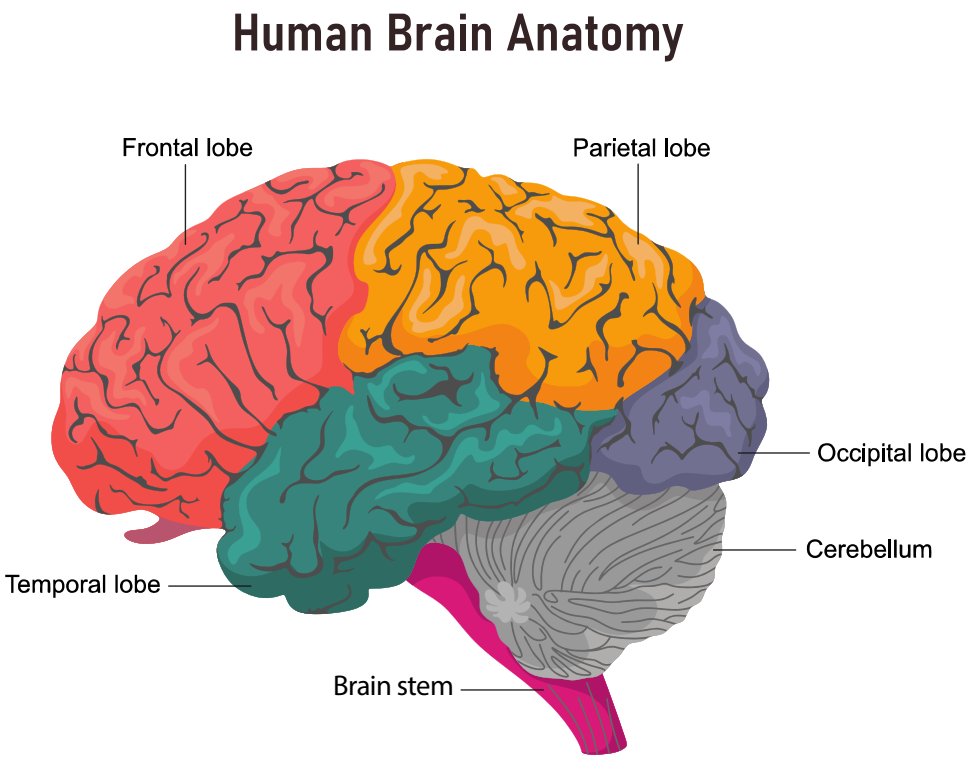
We do know that the worse your injury, the less likely you will fully heal. The length of time you stay in a coma and how long your memory loss lasts after a coma may help predict how well you will recover.

Some of this Information came from:

https://www.ninds.nih.gov/Disorders/All-Disorders/Traumatic-Brain-Injury-Information-Page

Functions of the Brain

The chart and picture below show the different parts of the brain. There is also a list of what those parts control and how damage to each part can make it hard for your body to work.



Six parts	What it controls	What May Happen After a TBI
Brain Stem	• Breathing and heart rate • Swallowing and digestion • Startle response • Awareness • Temperature • Blood pressure • Ability to sleep • Sense of balance	• Shortness of breath, leading to trouble talking • Hard time swallowing • Less aware of where you are • Problems with balance from being dizzy • Problems sleeping: insomnia (cannot sleep) or apnea (not breathing when sleeping)
Cerebellum	• When and how you move • Balance and posture (how you hold your body) • Voluntary tasks, such as walking and writing	• Hard time walking or unable to walk • Trouble picking up things • Feel shaky • Feel sick to your stomach • Slurred speech • Cannot react or move quickly
Frontal Lobe	• Awareness of self, emotions, behavior • Memory for habits and motor activities (things you do without thinking) • Change of thoughts • Reasoning • Problem solving • Creativity • Understanding ideas and words • Understanding smells	• Not able to move some body parts • Trouble with multi-step tasks, such as cooking • Hard time understanding humor or sarcasm • Stuck on single topics or thoughts • Trouble controlling reactions • Harder to plan, organize, and solve problems • Short attention span • Not able to recognize changes and limitations of self
Parietal Lobe	• Use of five senses • Awareness of what you read or see • Awareness of what you touch or feel • How you handle things	• Loss of words when writing and a hard time drawing • Trouble telling left from right • Trouble with math • Trouble with hand and eye coordination (moving together) • Trouble navigating environment • Neglecting one side of the body
Occipital Lobes	• Controls vision	• Trouble finding things and seeing colors • Seeing things that are not there or different from what others see • Not able to see movement • Some vision loss or complete vision loss
Temporal Lobes	• Hearing and speech • Memories • Knowing what is around you • Arranging things • Emotion and some behavior	• Trouble recognizing faces • Trouble understanding spoken words • Trouble knowing and talking about things • Short term memory loss • Changes in sexual behavior or interest • Talking a lot or acting aggressive • Cannot remember names of things

15 Things Brain Injury Survivors Want You to Know

By the Arkansas Brain Injury Support Group at Baptist Health Rehabilitation Institute

- Not all injuries are visible. I may look the same, but I'm not. I may look healed, but I'm not.
- Be patient. Give me more time.
- Brain injuries do not make me less intelligent.
- You may need to repeat things and check for my comprehension.
- I may lash out more than I used to.
- Brain injury impacts the **whole family**.
- It gets better, but I need you to accept the change.
- If you do not like me today, wait until tomorrow.
- This could happen to anyone at any time.
- Depression and anxiety are part of my journey, and memory loss is common.
- Technology is essential as a recovery tool.
- I may be re-learning my new self.
- I sometimes struggle with problem solving.
- I am still the same person, but I may have a different perspective, attitude, and actions than I did before.
- This is a life-long journey.



Section 2: The Recovery Process

It can be very confusing to try and figure out what the road ahead looks like, especially if you are still in acute care. This section will give you a brief overview of what recovery looks like for many people after a brain injury. Outcomes after a brain injury can be very hard to predict. Sometimes a person with a less severe injury has more deficits (limits in functioning) than a person with a more severe injury or vice versa. Some of this still remains a mystery to medical science, but there are many factors that influence each individual's recovery. Some of these factors may include:

- Age at the time of injury
- Time from injury to intervention
- Time to surgical intervention
- General health before the injury (including prior history of brain injury)
- Pre-existing medical conditions
- Area of the brain that was injured or how much damage
- Genetics
- Income and financial resources
- Insurance coverage
- Community support
- Caregivers' ability and willingness to advocate for the survivor and challenge the system.

Some people find that reading stories from other survivors helps them feel less alone, or that these stories help them understand the path ahead. The Brain Waves newsletter is an Arkansas-based resource for TBI survivors. Each issue has a survivor story. You can find all of our back issues online at http://atrp.ar.gov/education/brain-waves-newsletter/. You can also request the printed back copies and get on our mailing list by emailing us at trrp@uams.edu.

Here are other places to find survivor stories:

https://www.cdc.gov/traumaticbraininjury/tbi_stories.html

https://www.brainline.org/people-tbi/personal-stories-blogs-people-tbi

https://www.biausa.org/brain-injury/community/personal-stories

The rest of this section will go over the various stages and settings of care. There is no way to know how long a survivor will be in the hospital. The length of stay and exact order of each setting varies, depending on a person's injuries. This section will hopefully help you better understand the general sequence of recovery.

What are the common stages of recovery (healing)?

In the first few weeks after a TBI, swelling, bleeding, or changes in your brain chemistry can make it hard for the healthy parts of your brain to work well. During this time:

- Your eyes may be closed.
- You may not be aware of your surroundings.

EARLY STAGE

As swelling decreases and your blood flow and brain chemistry get better, your brain usually begins to work better. In time:

- Your eyes may open.
- You may start to sleep and wake normally again.
- You may follow commands.
- You may respond to family members.
- You may start to speak some.

Some terms that might be used in the early stages of recovery are:

Coma: When an injury makes you unconscious for a long period of time, you are in a coma. While you are in a coma:

- You are not able to respond to light or sounds.
- You are not able to communicate or show emotion.

Vegetative State: A vegetative state is different from a coma. If you are in a vegetative state:

- You are awake but not aware of anything that is happening around you.
- You go to sleep and wake up normally.
- You startle easily or focus on light, faces, or sounds for a short time.

Minimally Conscious State: After a TBI, you may be partly aware of what is happening around you. This is called a minimally conscious state. You may:

- Know where sounds and light are coming from
- Reach for objects
- Respond to commands
- Make noises like you are trying to talk
- Show emotion

A person who stays in a minimally conscious state for a period of time is often said to have a **disorder of consciousness.** If you need help navigating care for a TBI survivor with a disorder of consciousness, please reach out to our program at 501-526-7656 or trrp@uams.edu.

MIDDLE STAGE

As your brain heals:

- You may be confused.
- You may not be able to pay attention.
- You may not be able to learn.
- You may be nervous, restless, or frustrated.
- You may not sleep well.
- You may react emotionally to noise and stress.
- You may be physically violent.
- You may not follow commands all the way through. For example, you may start to follow a command to lift your leg or squeeze someone's finger and then stop.
- These symptoms may last days or even weeks. Try not to be anxious if you don't make progress for a time or get worse. Ups and downs are normal. This stage can be hard for family because you are not acting like yourself. Some days are better than others.

LATER STAGE

- As your brain heals even more, it may start to work better. Your ability to respond may get better slowly. The middle-stage symptoms will start to go away.

How long will recovery take?

- Recovery time and process can be different from person to person. But in general:
- In the first 6 months after your injury, you will have the most progress toward getting better.
- After 6 months, you may not heal as fast as you had been. You will likely keep getting better for up to 2 years, but this is different for different people.
- After 2 years, your recovery will slow down a lot. You can still keep getting better for many years after your injury. Most people still have some problems after two years, but they may not be as bad as they were.
- Recovery time can depend on your injury and your body. It is important to remember that recovery can be different from person to person.

If you have a mild TBI:

- Most of your recovery happens in the first 3 months after your injury.
- Most people are back to normal in 6 months. If you still have symptoms after 6 months, these will probably go away or get better within a year after your injury.

- Remember that recovery can be different from person to person:
- If you are under 40 years old, you may get better faster and have fewer symptoms while recovering.
- If you are over 40 years old, you may not recover as quickly and may have more symptoms.
- Recovery could take even longer if you have been in the hospital for a brain injury before. It could take 6 to 12 months even after a mild TBI.

If you have a moderate to severe TBI:

- Most of your recovery happens in the first 6 months after your TBI.
- You will keep getting better 6 months to 2 years after your injury.
- After 2 years, recovery will slow down, but you may still have some improvements for years after the injury.
- You may still have some problems, but they may not be as bad as they were right after your TBI.
- Remember that recovery can be different from person to person.

Some of this information came from: https://nurse.org/articles/glasgow-coma-scale/

https://msktc.org/tbi/

Settings of Care

This section describes the settings of care in the general order that most patients go through them. The order will vary for some survivors, but this should offer a better understanding of the process.

Acute Care (the hospital stay)

Each TBI is unique. Most people with a TBI need a combination of intensive medical treatments. These may include neurological, surgical, and rehabilitative treatment. In the acute care setting, doctors and other healthcare professionals first address life-threatening injuries. Next, they address and treat other injuries and medical problems that arise. Finally, doctors make sure the injured person is medically stable.

Once a person is stable and on the path to recovery, they will be discharged from acute care to a rehabilitation (rehab) center. Some hospitals have their own acute rehab, so the patient might just move to another building or wing. Others will need to transfer to an entirely different facility. If the patient did not have any disorders of consciousness or severe injuries, they may be able to go home from acute care (this is very rare for severe injuries).

Tips for caregivers during the acute care setting

Long-term Acute Care Hospital (often called an LTAC)

Some patients have complex medical needs that prevent them from being ready to participate in therapy, even though their condition is mostly stable. They may have a disorder of consciousness, be on a ventilator, or have other needs for more intensive treatment. These patients often spend some weeks or months in an LTAC, until they are well enough to participate in therapy. In this setting, they will have 24-hour care.

Subacute Skilled Nursing Facility (often called a SNF) or Subacute Rehabilitation Program

Patients who do not have the intense needs for an LTAC or full-on rehabilitation programs, often go to a Skilled Nursing Facility (SNF), where they can receive the right level of care for their needs. A SNF is similar to a nursing home, but often has speech-language pathologists, physical therapists, occupational therapists, and other rehabilitation professionals on staff, which is not typical for nursing homes. The average stay is 2-3 months, and patients are given 1-3 hours of therapy per day. Patients may transition from this setting to their home or a nursing home.

Acute Rehabilitation is an intensive recovery setting that usually includes some combination of physical therapy, speech therapy, and occupational therapy, under the care of specialized staff. Acute rehab often feels like a hospital setting, but it is very different. The purpose of acute inpatient rehab is to help a person recover as much as possible and as early as possible. Most patients will participate in at least 3 hours of varied therapy sessions each day, outside of their room. Patients usually stay in acute rehab anywhere from a few weeks to a few months.

In acute rehab, the care team will work with you to help you rebuild your physical and thinking abilities. Together you will set goals for the abilities that are most important to you, and then work to achieve those goals. Therapy focuses on improving bowel and bladder control, communication, mobility, basic hygiene, orientation, and learning.

A patient can usually go to rehab if:

- They are medically stable
- They are strong enough and healed enough to do 3 hours of therapy a day
- They have insurance or other payment sources

Neurobehavioral Residential Rehab

Some patients have very long-term rehabilitation needs, and will go to a post-acute, residential type setting after their inpatient rehab stay. Patients with a brain injury can receive treatment at a neurobehavioral unit if they have difficulty controlling behaviors and impulses and have the potential to continue making progress with more treatment. The goal of this highly specialized treatment is to help patients to become independent and stable and remain so in less structured environments.

Home Health or Outpatient Rehab

Not everyone with a brain injury will need intensive inpatient rehab. If a survivor has most of their pre-injury thinking skills and physical functioning, they might go home and have outpatient home health rehab instead. With home health rehab, a therapist such as Occupational, Physical, or Speech therapist will come to the home to offer sessions that help the survivor complete everyday activities. They might practice walking in the yard or cooking a meal, for example.

Tips for Caregivers During the Rehabilitation Stay

But my loved one just wants to go home, and I want them home with me!

After a brain injury, it may take some time for a patient and their family to realize that they need help with recovery. Some patients may need extra support and compassion to be aware of their own needs. You can gently remind them of their deficits, and that rehab may help them overcome those challenges.

Getting early rehabilitation can greatly influence how much a person will recover. After acute care, many people feel anxious to get home, but that may not be the best option in the long-term. If you qualify to go to rehab, it is probably in your best interest to take that opportunity.

Understanding the Care Team

Many types of healthcare providers may be involved in the recovery from a brain injury. This can be overwhelming to keep track of. The following is an overview of the health care team members who will likely be involved. Aside from providing care, the members of this team are an important source of information and support to caregivers and friends during this difficult time. Here is an overview of the various team members and their roles:

- **Surgeons:** Depending on the injuries, surgeons may be a part of the team. Examples include trauma surgeons, neurosurgeons, orthopedic surgeons, and plastic surgeons.
- **Critical care doctors:** Treat people who need intensive care. They monitor a person's medical condition closely. They also help diagnose and treat medical problems.
- **Critical care nurses:** Make frequent (in some cases hourly) rounds. They perform neurological exams, help doctors perform procedures, and are responsible for many other tasks. Because they interact frequently with the patient and family, they are often the "first line" of communication, education, and support for families.
- **Neurologists:** Evaluate and treat disorders of the brain and nervous system. They may perform tests to help determine the extent of a brain injury. They may also perform bedside evaluations to guide diagnosis and monitor neurological recovery.
- **Pulmonologists or respiratory therapists:** Diagnose and treat breathing problems. They also manage the ventilators, when needed.
- **Dieticians or nutrition specialists:** Monitor a person's nutritional status and manage their dietary needs. They may also help determine whether a feeding tube is needed.
- **Pharmacists:** Work closely with the doctors to monitor a person's medicines. They help with medicine dosing and preparing medicines. They may also offer education to the medical team and sometimes directly to families. They can explain the purpose of the medicines being given and share information on medicine side effects.
- **Physiatrists:** Diagnose and treat medical conditions—including pain, muscle, joint, and nerve problems—during the rehabilitation (rehab) process. They also direct and oversee a team of brain injury rehab specialists, including physical therapists, occupational therapists, and speech-language pathologists.

- **Rehabilitation therapists:** People with TBI may receive these rehab services while they are in the intensive care unit, acute care unit, during a rehabilitation stay, or at home with home health. There are three main categories of rehab therapists:
    - **Occupational Therapy:** In this type of therapy, the patient will practice and relearn daily activities that they need help with, such as getting dressed, brushing teeth, shopping, and driving.
    - **Physical Therapy:** These services help prevent muscle loss and keep the range of motion in arms and legs.
    - **Speech Therapy:** In addition to helping with speech, this can also help with swallowing, feeding, thinking, memory, and communication difficulties.
- **Neuropsychologists:** Evaluate and diagnose changes in behavior, thinking, and emotional responses caused by TBI. They may perform bedside assessments to help diagnose levels of consciousness. They may educate and support caregivers of people with TBI.
- **Case managers and social workers:** Coordinate the health care plan by handling insurance benefits and other financial matters as well as overseeing discharge planning. They are a valuable resource for families and can give both emotional support and information about TBI. They can also plan for future phases of care.
- **Other professionals:** A psychologist, chaplain, and patient representative may be available to offer spiritual and emotional support to people with TBI and their caregivers.

Throughout the recovery process, people with TBI undergo tests and procedures to assess the location and level of brain damage. This will help with diagnosis, prognosis, and treatment decisions. Such tests and procedures may include the following:

- **Neuroimaging studies:** These tests use computed tomography (CT scans) or magnetic resonance imaging (MRI). They help identify injured parts of the brain. Doctors can also use the results of these tests to help determine if surgery is needed.
- **Electroencephalograms (EEGs):** These tests measure electrical activity in the brain. Results of EEGs can be used to diagnose seizures, assess the level and type of brain activity, and show the location and extent of a brain injury.
- **Neurological monitoring or neuromonitoring:** Devices such as intracranial pressure monitors track the amount of pressure in the brain and help manage brain swelling. These devices require placing a tube in the brain that is attached to wires and a monitoring screen. If needed, the tube device can be used to drain excess fluid and relieve excess pressure in the brain. Neuromonitoring also helps diagnose and treat hydrocephalus (an excess of fluid buildup in the brain) and can help determine if surgical placement of a more permanent pressure valve, called a shunt, is needed.

- **Informal bedside neurological exams and formal behavior assessment scales:** Doctors may use these tests to diagnose a disorder of consciousness caused by a TBI. They can help determine a person's level of consciousness. A typical exam tests basic reflexes; doctors look at how the eyes react to light and they assess a person's response to sound, voice, touch, and pain. Doctors also look for signs of purposeful behaviors, like following a moving object with the eyes. This is called visual tracking. Other signs doctors look for are following commands and communicating.

If you would like to keep a log with the names of the care team, we have designated a space for that at the back of this guide, on page 93.

Section 3: Tools for Family and Caregivers

This part of the guide starts with self-care, because we can best take care of others when we are taking care of ourselves first.

A. Self-care Tips for Caregivers

Adapted from Jeffrey Kreutzer and Lee Livingston, The National Resource Center for Traumatic Brain Injury, Virginia Commonwealth Model Systems of Care

After a brain injury, survivors and caregivers often describe having trouble adjusting to life's changes and losses. Survivors are often faced with post-injury challenges that make recovery difficult. They may have trouble paying attention, communicating, or maintaining their balance. Going to doctor's appointments, dealing with financial issues and insurance problems, and coping with family conflict can seem to take up the majority of a survivor's time. To make matters worse, difficulties handling stress are quite common and survivors may feel easily overwhelmed.

It is common for caregivers to describe giving the majority of their energy to the survivor and others. Caregivers often find that they do not have enough time or energy to take care of themselves. Others feel guilty if they take time away from being a caregiver to do something fun. Many people put others' needs ahead of their own. They neglect their own needs and do not nurture themselves. Striking a balance between what you need for yourself and what others may need is very important for caregivers.

Realize that you need to be at your 100 percent best to deal with the many injury-related challenges. **Why is taking care of yourself so important?**

- You will be happier and healthier — and the rest of your family will be, too.
- You will be able to manage daily responsibilities more effectively and efficiently.
- Your stamina, insight, and thinking abilities will be better.
- You will get along with others more effectively.
- You will be better able to think up solutions to your problems.
- You will be able to take better care of others.

How well are you taking care of yourself? To find out, answer the True/ False questions below. Mark a ***T*** for **True** and ***F*** for **False** next to each sentence.

1. I ask others for help when I need it.
2. I have hobbies or other activities that I enjoy on a regular basis.
3. I get together with friends and family regularly.
4. I monitor my stress level and seek support when I need it.
5. I ask others to take on responsibilities when I am not able to handle them.

6. I try to get enough sleep at night.
7. I take time out to rest and relax.
8. I avoid taking on new responsibilities when I feel stressed.
9. I avoid alcohol and drugs.
10. I let others help me.
11. I talk to people I trust about my worries and concerns.
12. I set small goals for myself that are meaningful.
13. I monitor my health and seek medical care when needed.
14. I give myself credit for reaching my goals and taking small steps forward.
15. I have a fitness or exercise program.
16. I eat things that are good for me.
17. I recognize my limits and adjust my activities accordingly.

Look over your answers and count up the number of Trues and the number of Falses. The more Trues you have, the better you are doing at taking care of yourself. Good job! Keep up the good work.

If you have marked many items False, you may need to take better care of yourself. **What can you do to take better care of yourself?** We've talked to many successful survivors and families to find out ways they take care of themselves. Here are a few strategies that have worked for other people. The list below may have some options that will work for you:

- **Give yourself credit for things you accomplish.** People like to be recognized for their successes. Do not wait for others to praise you. Reward yourself when you take positive steps or reach a goal.
- **Keep track of your stress level and emotions.** Monitor them regularly, so you can get help and support as needed.
- **Set aside alone time.** We all need time alone to recharge our batteries. Take a little time out each day to do something alone — take a bath, go for a walk, write in a journal, meditate.
- **Take time out to do things you enjoy.** Read a book, go dancing, watch a movie, etc. You will be happier and better able to cope with life's stresses if you take time to do things you enjoy!
- **Protect your health.** Eat a balanced diet. Get enough sleep. Exercise regularly. Avoid alcohol and drugs. Follow up with your doctors regularly and take medicines as prescribed.
- **Remember, no man is an island.** Ask for help when you need it. Everyone needs help at times in their lives, especially when facing new challenges. Let trusted family and friends help carry the load.

- **Do not overload yourself.** When you take on new responsibilities, drop some of your old ones. Ask others to step up to the plate and help.
- **Remember that no one can do everything.** Recognize your limitations. Try to take on activities that make the most of your strengths. Ask for help with tasks that are difficult for you.
- **Be kind to yourself.** You have been through a number of very difficult situations. Give yourself credit for doing your best. It is important to remember there will be ups and downs on the path of recovery after a TBI.
- **Ask others how they've coped with similar problems.** You can learn a lot from people who have had similar experiences. Find out how others deal with problems. They may be able to save you time and pain.

To best help others, you must first take care of yourself. Sometimes it is hard to figure out where to start. If you are not sure where to begin, consider asking for ideas from someone you trust. They may be able to help you get headed in the right direction. Going to a support group is often helpful because you get the chance to hear from others who have been through similar experiences and learn about what has worked for them.

You can find information about local support groups at https://atrp.ar.gov/supportgroups

B. What can I do to help?

You may feel powerless, helpless, and afraid. But you play an essential role in the care of the survivor. You can do many things to move treatment along and support ongoing recovery:

- The survivor may not be able to make decisions about medical procedures. If you are not the legal decision maker, then find out who is. Other caregivers can support the legal decision maker during this tough and emotional time. If your survivor has an advance directive (instructions for a person's medical care if they are not able to speak for themselves), discuss their wishes about resuscitation and other treatment with the medical team.
- It might be helpful for you or someone else to become the legal guardian for the survivor. A guardian is someone the court assigns to manage personal, legal, and financial matters for a person who cannot make their own decisions. Having a guardian appointed may help when making decisions about the survivor's medical care (See page 33 for more). Elder law attorneys can assist with this process, as well as financial planning and other legal matters for people with long-term care needs.
- Be ready to answer questions from the health care team. These could be about the survivor's medicines, allergies, or other medical conditions. The more information you can give, the better prepared the medical team will be in preventing new problems.

- Learn about changes that may occur in people after a severe TBI. This will help you know what to expect through recovery. See Functions of the Brain chart on page 8 for more information.
- Learn about the skills needed to take care of the survivor. This will help you feel ready after the treatment and recovery phases.
- Family and friends are often the first ones to notice changes in a survivor's status. Noticing these changes is very helpful to the medical team. Try writing them in a notebook to keep track of progress. It is important to ask questions, raise concerns, and share your observations.
- Understanding how to interact with the survivor (see next section) may help his or her recovery. It can also help you to quickly recognize signs that may indicate a change in his or her status.

Here are some suggestions on how to interact with a survivor of a severe TBI:

- Balance periods of rest and activity. Try not to have too many distractions going at once. For example, limit the number of visitors to only a few at a time. When people are visiting, turn off the TV and make sure the room is calm and quiet. Always follow the care team's recommendations about how much and what type of stimulation is appropriate for the survivor.
- Even if the survivor cannot respond, physical contact is important. Hold their hand. If the bedside nursing staff allow it, gently massage their hands, arms, legs, or feet.
- Stimulate their senses. Offer different smells, sounds, things to look at, and things to touch. Show pictures of friends and family. Play his or her favorite music. Bring in a favorite blanket, stuffed toy, or piece of clothing.
- Talk to the survivor as if they can hear and understand you. Read them a book or news articles. Recall important, special, or funny life events; or put on their favorite TV show.
- Occasionally "test" the survivor's ability to make eye contact or watch people move around the room. Ask them to follow simple commands like "squeeze my hand," "raise your arm," or "open your mouth." Ask the survivor to answer simple "yes" or "no" questions. It may take several seconds for them to respond each time. Let them rest briefly between questions.
- Do not pressure a survivor when they do not show you the behaviors you're hoping for, or if they only show them some of the time. A brain injury survivor cannot control changes in consciousness. As recovery continues, you may see these behaviors more often.
- When your survivor regains consciousness, he or she may be confused, and behavior problems may develop. Tell them often that they are in a safe place and that people are there to help. Remind them of what happened; where they are; and

the current day, date, and time. Keep a clock and easy-to-read calendar in clear view.

- Help identify things that trigger any behavior problem for the survivor. Write down what was going on just before the problem occurred.
- Use simple language when communicating. Even if they seem to understand, survivors can struggle with complex language. Try asking yes/no questions and giving simple one-step instructions. Try to avoid abstract phrases, like "its raining cats and dogs".

Some of this information came from the Model Systems Knowledge Translation Center. Read more at msktc.org

C. How to ask for help: A list of things you can delegate to others

As a caregiver, your primary responsibility is to take care of yourself and the survivor. Let your support networks do the rest. It can be difficult to accept help from others, but this is the time to say yes when someone offers assistance. Here are some ideas of things that you can ask family, friends, and neighbors to help with. You can even keep track of who is assigned to what job.

- House or pet sitting
- Opening mail and paying bills
- Taking care of other children and family members
- Grocery shopping for your household
- Researching rehabilitation (rehab) facilities, financial assistance, public benefits
- Contacting family and friends to offer updates on the survivor's condition or setting up a secured website that will offer information
- Bringing healthy food to the hospital
- Picking up prescriptions
- Taking a shift at the hospital so you can shower, rest, and exercise
- Keeping you company and listening without offering judgement or solutions (set a regular "check-in" with someone you trust)

In the back of this guide on page 91 you will find a place to keep track of who has been assigned what tasks to help you keep everything organized.

D. How to talk to your doctors and nurses

It is important that you understand your family member's TBI and can talk to their doctors and nurses. This will help you:

- Learn about your family member's health problem
- Learn how you can help your family member get better
- Get the best care for your family member by supporting them and making recommendations
- Make the best choices you can for your family member

How can I make sure I get the most out of the visits with my family member's doctor?

Follow these tips to make sure you can get the most out of the visits with your family member's doctor:

- Write down a list of questions and concerns before you see the doctor.
- Tell your doctor how you feel or things you notice about your family member, even things that may seem unimportant or embarrassing.
- If you do not understand something the doctor says, ask questions until you do.
- Take notes about what the doctor says. There is a place for you to take notes on page 96 of this guide.
- Ask about the best way to contact the doctor. Write down their contact information in the logs on page 93

What questions might I ask my family member's doctor?

In the back of this guide, we have included some communication logs to help you keep up with answers from your doctors and nurses. Flip to page 91 to start filling these out.

Who else can I ask questions about my family member's TBI?

You can ask anyone on your family member's health care team questions. This includes their:

- Doctors
- Nurses
- Pharmacists
- Physical and Occupational Therapists
- Social workers
- Other members of the care team

E. Self-Advocacy: Patient and Family Rights

There are eight key areas related to your medical rights as a patient. If you feel that these rights have been violated, you might want to speak with an attorney or other advocate. Arkansas has free legal resources listed in the resource section of this book (page 61). Below is a list of some of your rights:

- **The Right to Emergency Treatment:** Patients have the right to emergency medical treatment even if they cannot pay.
- **The Right to Respect:** Otherwise known as nondiscrimination, this is the right to be treated with dignity and respect. Doctors cannot discriminate against a patient for any reason. This includes sex, race, age, national origin, ethnicity, religion, sexual orientation, gender identity or expression, veteran or military status, religion or any other basis prohibited by federal, state, or local law. This also means that all patients have the right to be treated humanely and never be subjected to degrading treatment by any healthcare professional.
- **The Right to Informed Consent:** The most important patient right is the right of informed consent. A patient should only give permission for a medical treatment if they have received enough information about their diagnosis and all treatment options **in terms he or she can understand**. If a patient is unable to consent, this usually falls to their next of kin. In the absence of anyone able to consent, implied consent would apply. This means that it is assumed that a person would want life-saving treatments if they were able to make that decision.
- Before a doctor can begin any course of treatment, the doctor must make the patient aware of what he or she plans to do. For any course of treatment that is above routine medical procedures, the doctor must share as much information as possible, **in terms the patient or decision maker can understand**, so the patient or caregiver may make an informed decision about his or her care.
- **The Right to Refuse Treatment:** In addition to having the right to receive medical treatment in emergency situations, mentally competent patients also have the right to refuse medical treatment. Doctors and other healthcare professionals have the duty to protect the life and health of a patient, but the patient has the final decision about the medical treatment they receive, even when it means they choose to refuse such treatment.
- **The Right to Choose Providers:** All patients have the right to choose which doctor takes care of them. Doctors and hospitals often refer patients to specialists, home health care, long-term facilities or other health care professionals for needs outside of their expertise. You have the right to choose where you want to go, within the limits of your insurance and financial resources.
- **The Right to Privacy:** One of the most basic rights that a patient has is the right to privacy. Patients have the right to decide whom, when, and to what extent their private individually identifiable health information is disclosed. This information includes, but is not limited to, medical diagnosis, treatment plans, prescriptions, health insurance information, genetic information, clinical research records, and mental health records.
- **The Right to Appeal:** Patients have the right to a fair review or appeal of any complaint against doctors, hospitals, or any other healthcare provider. The right to appeal includes complaints regarding:

- The adequacy of treatment
- The actions of healthcare personnel
- Wait times
- Operating hours
- Billing and payment issues

- **Patient Responsibilities:** It is important to acknowledge your responsibilities along with your rights. Patients have a number of responsibilities to the medical office including active participation in their treatment plan, timely resolution of their financial obligation, and respectful interaction with all staff.

F. How to Select a Brain Injury Rehabilitation Facility

This is one of the most important decisions you will have to make, and you want to be well-informed about this decision. Here are a few points to explore in your search.

- Know your options. It can be challenging to know what programs your insurance will cover. Work with your case manager and insurance company to find out all the options that are available to you. Remember that no is not always the final answer. You can make appeals and negotiate if necessary. The Brain Injury Association of America has a free guide called "Navigating the Insurance Maze" that you can access at www.biausa.org/insurance.
- Make a list and take notes on each facility so that you can compare them. Keep a summary log of your conversations, and try to get information in writing when possible. Sometimes it may be helpful to record important conversations (with permission).
- If possible, visit the facilities you are considering. If you are unable to visit, read their reviews online.
- Research or ask about their respective accreditations, classifications, certifications, awards, or recognitions.
- Learn about each facility's experience with TBI. How many TBI patients do they serve each year? Do they have physical, occupational, and speech therapists that are experienced in treating individuals with brain injuries?
- Does the center offer diagnostic services and assessments to inform treatment?
- Does the center accept Medicaid and Medicare? Even if you have private insurance, contracts with these payors can show that the program meets the national requirements for standards of care.
- What kind of outcomes can they show for their program? Can they provide references from former patients? What are their reviews like online?
- What level of participation is the family allowed or expected?

ACCREDITED FACILITIES IN ARKANSAS

The Commission on Accreditation of Rehabilitation Facilities (CARF) represents the highest level of accreditation that can be awarded to an organization and shows the organization's substantial conformance to the CARF standards. CARF is an independent, non-profit accrediting body whose mission is to promote the quality, value, and optimal outcomes of services through a consultative accreditation process that centers on enhancing the lives of those served. There are two rehab facilities in Arkansas that are accredited by CARF for their **Brain Injury Specialty Program**:

Baptist Health Rehabilitation Institute (BHRI)
9501 Baptist Health Drive
Little Rock, AR 72205
Phone: 501-202-7008
Website: http://www.baptist-health.org

NeuroRestorative Timber Ridge (TRR)
15000 Timberridge Lane
Benton, AR 72019
Phone: 501-594-5211
Website: http://www.neurorestorative.com

NATIONAL FACILITIES

If you are looking at rehab facilities out of state, it may be helpful to look at a ranked list to find the best facilities. USNews publishes an annual ranking of rehabilitation hospitals, determined entirely by expert opinion, based on responses from three years of surveys of medical specialists. The top 10 are listed here (updated in 2020). You can find the entire list at https://health.usnews.com/best-hospitals/rankings/rehabilitation

Chicago, IL	Shirley Ryan Ability Lab
West Orange, NJ	Kessler Institute for Rehabilitation
Boston, MA	Spaulding Rehabilitation Hospital
Houston, TX	TIRR Memorial Herman
Seattle, WA	University of Washington Medical Center
Rochester, MN	Mayo Clinic
New York , NY	Rusk Rehabilitation
Denver, CO	Craig Hospital
Atlanta, GA	Shepherd Center
Philadelphia, PA	Moss Rehabilitation

G. Navigating Insurance Appeals

Sometimes insurance companies may deny certain treatments, and you have the right to appeal these denials. The type and number of appeals will vary, according to your insurance plan. If the survivor is denied **necessary** treatment, it is important to identify the doctor's specialty and the state license of the doctor to see if that is affecting coverage. Steps to maximize your insurance coverage:

1. Get to know your insurance policy by:
    - Finding out what type of insurance you have.
    - Requesting a copy of the certificate of coverage from the employer.
    - Requesting a copy of the full insurance policy from the employer or insurance company.
    - Reviewing and understanding your insurance policy. Get help with this if needed. Most insurers have a hotline you can call to ask questions.
2. Get all paper copies or electronic copies of medical records for each treatment admission (some offices may charge a fee for this service).
3. Complete a HIPAA release (gives permission to share your health information) to send in with all above requests.
4. Research if any state health care mandates apply to brain injury services in your state.
    - You can check your state legislature and search for brain injury mandates.
5. Contact your insurance case manager early, and often if needed.
6. Learn key insurance supervisors and the names of your insurance plan's executives, in case you need to contact them on behalf of the survivor.
    - Your plan will often identify key officers or you can go to the insurance website.
7. Document all progress throughout the recovery process with pictures, video, and written descriptions.
8. Document every conversation you have with any person from the insurance company including the person's name and title, the date and time, purpose for the call, and details of the conversation. Use the log on page 100.
9. Save all of your claim files including any documents or records that were relied upon in making a decision to approve or deny needed treatment.

Steps to navigating the appeals process:

1. Understand each level of appeal available to the survivor through policy review. Request an explanation of each level of appeal and time frames.
2. Encourage the hospital or clinic to follow all the steps of the appeals process.

3. Write your own request to appeal any necessary treatment to benefit the survivor. Include in your request:
    - The reason for the denial
    - Reference to the plan provision on which the denial was based
    - A statement of the specific type of treatment needed
    - Written statements of support by doctors
4. Request a copy of the claim file before the appeal is decided.
5. Exhaust all levels of appeal.
6. Consider if the survivor has been discriminated against based upon his or her ability to advocate for himself or herself.
7. Speak with your family member's employer to request their help and consideration in approving needed treatment and overriding policy language.
8. If your appeals continue to be denied, consider:
    a. Filing a complaint with the Arkansas Department of Insurance, at http://insurance.arkansas.gov/pages/consumer-services
    b. Filing a claim with the Department of Managed Healthcare
    c. Contacting the media with your story
    d. Researching "brain injury stories" to find press favorable toward the cause of brain injury and the potential for successful rehabilitation
    e. Contacting the Brain Injury Association of America (BIAA) with your story
    f. Contacting local, state, and federal government officials to ask for letters of support and legislative action to help the survivor obtain the necessary treatment (search the internet for local, state, and federal legislators and government officials to learn contact information)
    g. Seeking legal advice if the terms of the policy or local laws are not being upheld.
9. When following through with any of the considerations above, consider this outline guide for your requests:
    a. State the nature of the support and need for the support
    b. State the history of the survivor's injury and treatment
    c. Summarize the history of appeals, documents, and prior letters of support
    d. Point out inconsistencies, irregularities, and omissions
    e. Conclude with specific requests

Some of this information came from: Brain Injury Association of America. To get more information, visit: https://www.biausa.org/wp-content/uploads/Navigating-the-Insurance-Maze-2018.pdf

H. Making Health Care and Financial Decisions for Someone with a TBI: Power of Attorney, Guardianship, and Living Will

When you are caring for someone with a TBI, you may need to make decisions about their health care and finances (money). To be able to make decisions for them you may need a **power of attorney**, a **guardianship**, or a **conservatorship**. Your family member may also have a **living will** that would tell you and their doctors what kind of health care they want.

ABOUT POWER OF ATTORNEY

What is a Power of Attorney?

A Power of Attorney (POA) is a legal document. It gives someone else that you choose the power to act for you when you cannot act for yourself. The person you give the power to is called your **agent**. You, or the person giving the power, are called **the principle**. This has to be set up when a person is able to make decisions for themselves.

Can I get a POA to make decisions for my family member with TBI?

If your family member is not able to make decisions for themselves now, then they cannot set up a POA for you to make decisions for them. But, you may want to think about setting up a POA for yourself or ask other members of your family to create a POA. That way you are prepared for unexpected events in the future.

What kinds of decisions does a POA allow someone to make in my place?

POA can allow someone to make a specific decision or multiple decisions about your:

- Business and money
- Health care

When does a POA end?

You can set up a POA that ends at a certain time. If there is not an end date, then the POA could end when:

- The principle dies
- The principle becomes incompetent, unless it is a durable power of attorney. A durable power of attorney is normally for someone getting medical treatment or losing mental capacity.
- The agent dies

What are the advantages of a POA?

You (the principle) can decide who can make decisions for you.

- You (the principle) can end the POA when you want to.
- You do not have to go to court to get a POA.

The court does not supervise the POA.

- It does not cost a lot of money.

ABOUT GUARDIANSHIPS

What is a guardianship?

A **guardianship** is a court order. It gives an adult (the guardian) control over another person (the ward). The guardianship may give the guardian control over the ward's property, physical person, or both.

Who can get guardianship?

Family members are often the ones to request a guardianship, but any interested adult can request a guardianship. The Department of Human Services, a corporation, or a bank can also be appointed as a guardian.

You can be a guardian if you are **all** of these:

- A resident of the state in which the ward lives
- At least 18 years old
- Competent (able to make and understand decisions)
- Not a convicted or unpardoned felon

What does a guardian do?

If you are a guardian, you have to:

- Make sure the ward is cared for (safe, clothed, and fed)
- Report how the ward is doing to the Court when the Court asks you to. This is normally once a year.
- Make decisions for the ward. There are some decisions you cannot make on your own. You may need to file a petition with the court and get permission to:
    - Deny life-saving medical treatments
    - End parental rights
    - Keep the ward from getting a driver's license

If you are the guardian of a ward's estate (including their money, property, trust, or inheritance), you have to:

- Protect and invest in the estate
- Account for the ward's estate (report all spending, selling, or investments, including income from investments)
- Give the assets of the estate back to the ward when the guardianship ends
- Make bond payments (if a judge requires it)

- Do anything else the law requires (ask an attorney what these are)

The ward or the ward's estate may sue you, the guardian, if you do not take care of them or their property.

How do I ask for a guardianship?

To get a guardianship of an adult, the ward must be incapacitated. This means the ward is not able to manage their health, safety, or financial matters because of a health problem or another reason.

With a severe brain injury, your family member may meet the criteria for needing a guardian. This depends on the damage that their TBI caused. A court will decide whether the ward can take care of themselves, their finances, and their property. Not managing money well is normally **not enough** for the court to give you guardianship.

Follow the steps below to request guardianship. Get an attorney to help you do these steps.

- **File a petition with the Probate Clerk at the County Clerk's Office in the county where the ward lives.** Your petition must include this information:
- About the ward:
    - Name and age
    - Post office address and home address
    - How much money the ward has and a description of their property. This includes any money they make, pension, insurance, or allowance.
- About the guardianship you are asking for:
    - Why you are trying to get guardianship
    - What type of guardianship you are asking for (person, estate, or both)
    - How long you think the guardianship should last
- About you:
    - Post office address and home address
    - Whether you are a guardian of others, and, if so, their names and addresses
- About others who may be involved in the ward's care:
    - The names and addresses of:
        - Anyone related (by blood or marriage) to the ward
        - The person or organization that has custody of the ward, if a minor
        - The ward's current guardian, if there is already one
    - A list of any group that gives services to the ward, and a statement that you have told them you are asking for guardianship

- **After the petition is filed, the ward must be:**
    - Served (legally delivered) the petition, given notice of the hearing, and told their rights.
- **After the petition is served, you will need to file proof with the Court that the petition was served to the ward.**
- **Call the Judge's office to get a date set for a hearing.**
- **The Judge will order a professional evaluation** unless the ward has had one within 6 months of the hearing. An evaluation is when a doctor, psychologist, or social worker checks the ward's condition. They will report this to the court.
- **After the Court sets a hearing date, let those involved know the date.** You can ask the Probate Clerk to create and serve a Notice of Hearing. This is a legal document that tells individuals and groups who may be involved in the ward's care:
    - The name of the Judge
    - Where the hearing is
    - The date and time of the hearing

What happens at the hearing?

At the hearing, the ward has a right to have an attorney to:

- Show evidence
- Question witnesses
- Have the person who did the ward's evaluation testify (talk about in front of the court) about their health problems

The Judge will:

- Ask questions about the guardianship
- Listen to the witnesses
- Review the evidence

Anyone who does not want you to get guardianship will also be able to tell the Judge why they are against it. After the Judge has heard from everyone, they will decide:

- If there is something else that might help the ward besides a guardianship
- If a guardianship is needed
- What kind of a guardianship to grant if one is needed

What happens if the Judge gives me guardianship?

If the Judge decides to give you guardianship, then they will create an Order to the Guardian. This document explains exactly what you, as guardian, can and cannot do with the ward and their property.

The Probate Clerk will then give you the Letters of Guardianship. These letters are what you will show to other people so you can take care of the ward and their property.

When does a Guardianship end?

A guardianship can end for many reasons. These include:

- The ward dies or moves out of state
- The Judge finds that the ward is competent
- The Judge finds that the guardianship is no longer in the ward's best interest

What are the drawbacks of a guardianship?

Applying for guardianships can be expensive and time consuming. Guardianships also mean that the ward loses the ability to care for themselves.

ABOUT CONSERVATORSHIPS

What is a conservatorship?

A conservatorship is like a guardianship but where the "ward" allows someone to handle their property for them. It is voluntary and the ward does not have to be declared as incapacitated.

How do I get a conservatorship?

You can get a conservatorship just as you get a guardianship. But you will not need an evaluation, so it costs less money.

ABOUT LIVING WILLS

What is a living will?

A living will is a legal document. It states what you want your family and doctors to do if you need medical treatment that will save your life. It is not like a real "will." It is not meant to tell your family or friends what you want to do with your property after you die. It only applies to health care decisions and only becomes effective if the doctor taking care of you decides any of the following:

- You are so sick that you cannot get better.
- You will not wake up. (This only applies if you are not conscious.)
- You are not able to make decisions for yourself.

How do I get a living will?

You can get forms from your doctor.

Some of this information came from: Arkansas Legal Services: They have legal services for those that qualify based on income. To get more information visit https://www.arlegalservices.org/guardianship or call 1-800-952-9243.

I. Tips From a Survivor's Wife



Written by Nicole Thornton, whose husband Tony survived a head-on collision in 2018. You can read Tony's story in the Brain Waves issue from Autumn 2019 at https://atrp.ar.gov/education/brain-waves-newsletter.

- Have the nurse print off or write down the details of the injuries - that way you can communicate the correct info with others and ask questions on exactly what is going on. With TBI there are usually lots of doctors with all different messages, so the details are easily lost in translation. I asked for this daily and it was so helpful!
- Request a child life counselor to speak with young children who may be affected by the injury, such as the survivor's kids or siblings.
- Keep a journal of the survivor's daily progress. This is helpful to encourage you on the journey as the days, weeks, and months go by.
- Get an organizational binder and keep every document, receipt, paperwork, anything you've signed - labeled and organized.
- When looking at rehab facilities - many facilities offer housing, food assistance, or other programs for families (where that may be a deal breaker if they are long distance), so make sure to ask about those programs they may offer.
- If you are a member of an air ambulance agency (air evac, survival flight, etc.) many of them offer inner faculty transport at no cost to members, be sure to check before you fly.
- If you have to travel on a plane with the survivor, call the airline in advance and request disability services to assist you through the airport and onto the plane. Also, be sure to explain if you are traveling with medical equipment, as they cannot charge you baggage fees for bags containing these items.
- When applying for Social Security Disability, we found it helpful to go through an agency. Allsup is who we used. Our social worker at Pate Rehab recommended them to us and they have about a 98% first time approval rate for SSDI. We got it within three weeks of applying and on the first try. It was easy to get our questions answered and we had our own legal rep for assistance. They do take a percentage of your first check, but it was completely worth it.

Section 4: Living with a TBI

Community reintegration is probably the most important goal for any TBI survivor. However, complications from a TBI can be hard for survivors and families to cope with. Recovery from a TBI should be considered more of a process rather than a destination of 100% recovery and/or function. It is often said that TBI recovery is more of a "marathon rather than a sprint." This section offers some basic advice on coping with common issues after a brain injury. Some of this information was adapted from fact sheets compiled by the Model Systems Knowledge Translation Center (MSKTC), a leading source of information on traumatic brain injury. If you don't find what you are looking for here, there are many more fact sheets online at https://msktc.org/tbi/factsheets.

Disclaimer:

This information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

- How Traumatic Brain Injury (TBI) Can Affect the Patient
- Depression After Traumatic Brain Injury
- Emotional Problems after Traumatic Brain Injury
- Headaches After Traumatic Brain Injury
- Fatigue After Traumatic Brain Injury
- Driving After Traumatic Brain Injury

How Traumatic Brain Injury (TBI) can Affect the Survivor

Your brain is the control center for all activity, including activities of your body (breathing and moving) and your mind (thinking, judgment, and emotional reactions). A TBI limits the way your brain normally works. When nerve cells in your brain are damaged, they can no longer send information to each other in the normal way. This causes changes in how you act and what you are able to do.

The injury may cause other problems, too, depending on how your brain was damaged. No one can tell which problems you will have after a TBI. Problems normally get better as you recover, but this may take weeks or months. If your injury is severe, it may take many years to recover. There are three types of problems you can have after TBI:

- Physical
- Cognitive (Thinking)
- Emotional or behavioral

Physical Problems

Most people with TBI are able to walk and use their hands within 6-12 months after injury. In some cases, your physical problems will not keep you from going back to work or

driving. If you would like to drive again after your TBI, please read, “Driving After Traumatic Brain Injury,” page 56.

You may have some physical problems for the rest of your life. TBI may lower your ability to control your body, make you weak, or make it hard to balance. For example, you may have trouble playing sports as well as you did before the injury. You may also have trouble doing other activities for very long because of fatigue. (For more information on how fatigue might affect you, please read, “Fatigue After Traumatic Brain Injury” on page 53)

Cognitive (Thinking) Problems

If you have a mild TBI (concussion), it may be hard to:

- Focus
- Be alert
- Remember things
- Think quickly
- Reason or think through ideas
- Plan
- Problem-solve

If you have moderate to severe TBI, the thinking problems listed above may be worse and last longer. You may also have problems with:

- Talking, writing, or getting others to understand you
- Seeing things correctly
- Seeing how close or far something is (depth perception)
- Knowing that you have thinking problems

What can I do to help with my thinking problems?

- Limit distractions in your environment. For example, try not to have the television or other noises going in the background.
- Do one thing at a time (no multi-tasking).
- Use visual cues like pictures or words to help you remember tasks.
- Start a memory notebook to keep track of things you remember or want to remember.
- Keep a calendar visible with today’s date and upcoming appointments listed.
- Make sure you get enough rest.
- Try doing mindfulness or relaxation exercises to slow down your brain and help you relax.

EMOTIONAL AND BEHAVIORAL PROBLEMS

It is normal to have behavioral and emotional problems after TBI. These can be caused by:

- Damage to your brain: If you had damage to your frontal lobe (a part of your brain that controls emotion and behavior) you are more likely to have trouble with behavior and emotion.
- Thinking problems: If you cannot focus enough to keep up with what someone is saying, you may get frustrated and upset.
- Changes in your life because of your injury: You may feel frustrated or depressed because you cannot do some things that you used to before your injury.

What other changes might happen?

TBI can cause upsetting new behaviors or change your personality. These changes are very hard on you and your family. TBI may make you:

- Restless
- More dependent on others
- Have mood swings
- Lose the energy to do things
- Get angry easily
- Be hostile to others
- Lethargic (feeling tired or sluggish)
- Act in ways that do not fit the situation
- Unaware of what you are doing or saying

What can I do about these changes?

With rehabilitation training, therapy, and other support, you can learn to manage these emotional and behavioral problems. For more information on how TBI can affect your mood, please read, “Emotional Problems after Traumatic Brain Injury.” on page 46.

You may not see that you have changed or have problems. It is very common for TBI survivors to be unaware of their own changes in thinking or acting. This is often called anosognosia. It can be caused by the brain damage itself or by denial of what’s really going on in order to avoid fully facing the seriousness of your condition.

There are 3 levels of awareness that this condition can affect:

- **Intellectual Awareness:** You are aware that you have problems with some functions.

  Ex. **a.** I know I have a problem with my temper

  b. I know that I have some cognitive changes since my TBI

- **Emergent Awareness:** You are aware of your limited ability while it is happening. This requires already having intellectual awareness.

Ex. **a.** I can see myself getting angry and out of control

b. I realize I have forgotten what I was supposed to practice after therapy

- **Anticipatory Awareness:** You can anticipate that you will have trouble with an activity and then plan to use strategies to help prevent problems.

Ex. **a.** I know when I am tired after therapy, I always lash out at my mom. So this time I am going to listen to my favorite music on the way home to help keep me calm.

b. When getting instructions for homework, I recognize I may forget later, so I use a notebook to help me copy down important details.

Depression after Traumatic Brain Injury

What is depression?

It is normal to feel sad after TBI. However, if you feel sad for a long time or stop enjoying things you used to enjoy, you may be depressed. Depression is a feeling of sadness, loss, despair, or hopelessness that does not get better over time. Symptoms of depression include:

- Feeling down, sad, blue, or hopeless
- Loss of interest or pleasure in usual activities
- Feeling worthless, guilty, or like a failure
- Changes in sleep
- Changes in how hungry you are
- Hard time focusing or thinking
- Not wanting to be around other people
- Tiredness or lack of energy
- Moving or speaking more slowly
- Feeling restless or fidgety
- Thoughts of death or suicide

These feelings can upset your daily life. If you feel depressed or lose interest in your usual activities several days per week for more than two weeks, you should talk with your doctor.

How common is depression after TBI?

Depression is a common problem after TBI. About half of all people with TBI have depression within a year after injury. Even more (nearly 2 out of 3) have it within 7 years after injury.

This is much higher than the normal rate of depression. In general, fewer than 1 in 10 people have depression in a year. More than half of the people with TBI who are depressed also have high anxiety.

What causes depression after TBI?

There are many causes of depression after TBI. These can be different for everyone. Causes can include:

- **Changes in the brain from your injury:** Depression can be caused by damage to the areas of your brain that control feelings (emotions). Changes in the levels of chemicals in your brain can also cause depression.
- **Your response to your injury:** You may also feel depressed if you are going through changes caused by TBI. Changes could include: short-term or long-term disability, your role in your family, and your role at work or outside the home.
- **Reasons not related to your injury:** Some people are more likely to be depressed because of their genes or their personal history. Those with a history of depression can have a relapse or worsening of their depression. This can happen because of chemical changes in the brain or the stress of adjusting to the brain injury.

What can be done about depression after TBI?

If you have symptoms of depression, it is important to get help as soon as possible. This will keep your depression from getting worse. You can:

- Find a doctor who knows about TBI that can help you
- Take antidepressant medicines as they are prescribed to you
- Go to counseling (psychotherapy treatments)

If you have thoughts of hurting yourself or others, get help right away! Call a local crisis line.

- Call 911.
- Call the 24-hour National Crisis Hotline at 800-273-8255.
- Go to an emergency department.

What medicines are usually prescribed to help with depression?

Always talk to your doctor before taking any medicines, whether prescribed or over the counter. Be sure to keep a record of what you took and when, to avoid accidental overdose. Never take more than instructed. See page 95 for a helpful way to track your medicines.

To treat depression you can take antidepressants. There are many different types or "classes" of antidepressants. Some types are better than others for people with TBI.

- Selective serotonin reuptake inhibitors (SSRIs) are often the best antidepressants for people with TBI. These medicines, sertraline (Zoloft®) and citalopram (Celexa®), have the fewest side effects and may even help your ability to think.
- Serotonin-norepinephrine reuptake inhibitors (SNRIs) are newer medicines that may also be a good option for people with TBI. These include meds such as venlafaxine (Effexor®).

There are some types of antidepressants that you should not take if you have TBI. They can have bad side effects. These include:

- Monoamine oxidase inhibitors (MAOIs)
- Tricyclic antidepressants (TCAs) in high doses. A low dose of TCAs can be safely used to help with sleep or pain.

What do antidepressants do?

Antidepressants are a type of medicine that help balance chemicals (neurotransmitters) in your brain. They are not addictive. They can also help you have:

- More energy
- Better focus
- Better sleep
- Better eating habits
- Less anxiety

What will happen if antidepressants are not working for me?

If you are having problems with your medicine, talk with your doctor about:

- Changing your dose (the amount you are taking)
- Switching you to a different medicine
- Taking two different antidepressants, if a single medicine is not working

How long will I have to take antidepressants?

After starting antidepressants, it can take a few weeks to start feeling better. Even if antidepressants help with depression, they usually do not have to be taken forever. Sometimes, it will balance your brain's chemistry in 6 to 12 months. Then you may be able to wean off of them (with your doctor's instructions). However, each person's brain and brain injury are different. Stopping antidepressants suddenly or not taking them as directed can have dangerous side effects. You should always talk with your prescriber before starting or stopping antidepressants.

How should I take antidepressants?

It is important to take your antidepressant every day, even if you are feeling better. Do not suddenly stop taking it. In most cases, your doctor will tell you to take it for at least several months.

What are the best kinds of counseling for depression?

For people that are depressed, the best types of counseling focus on how you act and think:

- Cognitive-behavioral therapy (CBT) helps people learn how to change the way they act, think, and feel about things that happen to them, and the way they see themselves. CBT has lowered depression for many people. There is good evidence that the structure and repetition in CBT can help patients with TBI, even if they are having memory and attention problems.
- Behavioral activation therapy helps people that are depressed become more active and enjoy activities again. This should help improve mood. A professional counselor can help you set up a routine of activities you enjoy. This is often used as part of CBT treatment.
- The major difference between these two therapies is that CBT focuses on how your thoughts and ways of thinking make you feel, while behavioral activation therapy focuses on you being more active in your life through behaviors (e.g., engaging in activities you enjoy) and being more involved in your environment.

Remember, many people do best with a combination of approaches, such as antidepressant medicine plus sessions with a trained counselor.

What else can I do about my depression?

There are other ways to treat depression, such as:

- Exercising
- Acupuncture
- Biofeedback (electronic monitoring)
- Treating anxiety or pain
- Going to brain injury support groups to get information and support

You should ask your doctor or another health care profession that treats TBI if these treatments are right for you.

Who should I ask to help me with depression?

When you can, you should get treatment from a brain injury rehabilitation program that can address all aspects of TBI recovery. Many doctors can help you with depression, such as:

- Psychiatrists: Doctors with special training in medicine management and counseling for depression.
- Psychologists: Doctors trained to counsel people with depression.
- Some social workers and licensed professional counselors (LPCs) are trained to help with depression.
- Some doctors and neurologists have experience treating depression.
- Some nurse practitioners (NPs) have experience in treating depression.

What else do I need to know about depression?

Depression is not a sign of weakness. It is not anyone's fault. Depression can be a medical problem, just like high blood pressure or diabetes. You cannot get better from depression by simply wishing it away, using more willpower, or "toughening up."

For more information about depression, contact the National Institute of Mental Health:

- Call 1-866-615-6464.
- Go online https://www.nimh.nih.gov/health/topics/depression/index.shtml

Some of this Information came from:

Fann, J.R., Hart,T., Schomer, K.G..Treatment for Depression after Traumatic Brain Injury: A Systematic Review. Journal of Neurotrauma 26:2383-2402, 2009

Emotional Problems after Traumatic Brain Injury (TBI)

A brain injury can change the way you feel or express emotions. After a TBI, you may have several types of emotional problems.

What emotional changes can I expect after a TBI?

After a TBI, you may not be able to control your emotions, and you may have:

- Mood swings
- Anxiety
- Depression

It is important to talk with your doctor and caregivers about how they can help you manage any of these changes.

Mood swings

- You may feel emotions that are not expected, very strong, and go away quickly.
- You may get angry easily but get over it quickly.
- You may feel like you are happy one moment, sad the next, and then angry.
- You may start crying or laughing for no reason.

These emotional changes are called mood swings.

What causes mood swings?

- Mood swings are often caused by damage to the part of your brain that controls emotions and behavior (the way you act). In some cases, your emotions may not match the situation (such as laughing at a sad story).

- Normally, there is no one event that will trigger a mood swing. This may be confusing for family members who may think they accidently did something that upset you.

What can I do about mood swings?

- Usually, you cannot control these emotions on your own. The good news is that this situation often gets better in the first few months after TBI. People often go back to having normal emotions.
- If you are having problems controlling your emotions, you should talk with your doctor or a psychologist (a doctor who treats mental and emotional problems) to find out the cause and maybe get treatment.
- Counseling for your family can help them cope better, too. Several medicines may improve or control your mood. You should talk with a doctor that knows about emotional problems caused by TBI.

How can my caregivers help me with mood swings?

Ask your caregivers to:

- Keep calm and do not react emotionally if you get overly emotional
- Make sure you get plenty of breaks throughout the day.
- Avoid things that are known to trigger or upset you, when possible.
- Use hand signals or agreed upon cues to measure your level of upset. For example, asking "how upset are you on a scale of 1-10 right now" can help you build awareness over time.
- Take you to a quiet area to help you calm down
- Accept your feelings and give you a chance to talk about them
- Give you gentle feedback and support after you gain control
- Turn your attention to a different topic or activity

Anxiety

Anxiety is a feeling of fear or being nervous that is not fitting for the situation. After a TBI, you may feel anxious but do not know why. If you have anxiety you may:

- Be worried about making mistakes or failing at a task
- Feel people are complaining about you
- Have a sudden rush of anxiety, called a panic attack
- Have a stressful event (such as the one that caused your injury) play over and over in your mind, called posttraumatic stress disorder (PTSD)

What causes anxiety after TBI?

Many situations can cause anxiety. Having a TBI can make them even harder to handle. Anxiety can be caused by:

- Being in crowds
- Feeling rushed or hurried
- Sudden changes of plans
- Being in a stressful situation
- Heavy traffic
- Noisy children
- Pressure to be on time
- If you have a TBI, you may have trouble solving problems because it is hard for you to focus or think clearly. This can make you feel overwhelmed, especially if you are asked to make decisions.
- Anxiety often happens when there are too many demands on you, such as going back to work too soon after injury.

Since each form of anxiety calls for a different treatment, anxiety should always be diagnosed by a mental health professional or doctor.

What can I do about anxiety?

- Try to reduce unnecessary stress and the situations that demand a lot from you.
- Ask for help with the things that are bothering you. You can ask someone you trust to talk or work with a counselor or therapist.
- Add structured activities into your daily routine, such as exercising, volunteering, church activities, or self-help groups.
- Make sure you are taking time to relax. Listening to music, taking hot baths, meditating, and doing breathing exercises can all help with anxiety.
- Anxiety can be helped by certain medicines, by psychotherapy (counseling) from a mental health professional who is familiar with TBI, or a combination of medicines and counseling.

How can my caregivers help me with anxiety?

- Ask them to reassure you and help calm you.
- Ask them to give you time for your feelings of anxiety to go away.

Anxiety and mood swings can also be caused by over stimulation since injured brains have a slower processing speed and may not be able to multitask. Initial treatment can include decreasing the stimulation. This can be done by turning off lights and sound sources such as TV or radio and limiting guests in the home.

Trouble with a Bad Temper

Many patients with a TBI become upset easily. For example, you may:

- Get angry easily
- Feel that others are getting on your nerves
- Have a quick temper
- Use bad language
- Throw objects
- Slam doors or punch things
- Threaten or hurt family members or others

What causes temper problems?

A bad temper after TBI is likely caused by:

- Injury to the parts of your brain that control emotions
- Frustration or unhappiness with the social changes caused by the injury, such losing your job or being dependent on others
- Feeling alone, depressed, or not being understood
- Trouble thinking, focusing, remembering, expressing yourself, or talking with others
- Getting tired easily
- Pain

What can I do about temper problems?

- Reduce triggers for bad tempers by lowering stress and leaving situations that can be irritating.
- A psychologist or other mental health professional familiar with TBI can help you learn some basic anger management skills such as:
    - Self-calming strategies
    - Relaxation methods
    - Better communication methods
- Certain medicines can help you control your temper. Talk to your doctor about which meds might help you.

How can my family members help me with my temper after TBI?

Talk with your family about the following:

- They need to understand that being irritable and getting angry easily is due to the brain injury. Ask them to try not to take it personally.
- Ask them to try not to argue with you when your temper is bad. Instead, they should let you cool down for a few minutes first.

- Ask them not to try to calm you down by giving in to your demands.
- Ask them to set some rules for communication. They should remind you that it is not okay to yell at, threaten, or hurt others. They should refuse to talk with you when you are yelling or throwing a temper tantrum.
- After your bad temper is over, they should talk with you about what might have caused it. They should encourage you to discuss the problem in a calm way. They can suggest other outlets, such as leaving the room and taking a walk (after letting others know when he/she will return) when you feel anger coming on.

If you have anxiety, feelings of sadness or depression, irritability, or mood swings, ask your doctor:

- Would counseling be helpful?
- Would an evaluation by a psychiatrist be helpful?
- Are there medications that can help?

Peer and other support

Remember, too, that not all help comes from professionals! You may get help from:

- A brain injury support group — Some support groups are specialized for people with TBI, others are for family members, and others are open to everyone affected by brain injury. See page 61 for more information about local support groups.
- Peer mentoring – A person who has coped with brain injury for a long time gives support and suggestions to people who are struggling with similar problems.
- Friends, family members, a member of the clergy, or someone else who is a good listener.

Headaches after Traumatic Brain Injury

Headache is one of the most common symptoms after a TBI (often called “post-traumatic headache”). More than 3 in 10 people with a TBI say they still have regular headaches long after injury.

Why are headaches a problem after a TBI?

You may have regular headaches for more than a year after your TBI. Headaches can make it hard for you to live like you used to. And they can make it hard to think and remember things.

What causes headaches after a TBI?

After a severe TBI, you may have headaches because of the surgery on your skull. Headaches could also be caused by small collections of blood or fluid inside your skull.

Headaches can also happen if your TBI is only mild or moderate, or if your severe TBI is healing. These headaches can have many different causes, including:

- A change in the brain caused by the injury

- Neck and skull injuries that are not fully healed
- Tension and stress
- Side effects from medicine

What kinds of headaches could I get after TBI?

Although there are many types of headaches, migraines, tension, secondary, and rebound headaches are the most common. You may get more than one type of headache. You may be more likely to get a certain kind of headache, such as a migraine, if one or more people in your family also had them.

Migraine headaches

You may get migraine headaches because an area of your brain becomes too sensitive. This sends a pain signal that spreads out to other parts of your brain. If you have a migraine you may:

- Have a dull, throbbing feeling, usually on one side of the head
- Feel sick to your stomach or throw up
- Be sensitive to light and sound
- Have moderate to severe pain
- Get a warning signal that a migraine is coming, such as seeing spots or bright lights. This is called an “aura.”

Tension headaches

Tension headaches are caused by stress, muscle tension, or muscle spasms. If you have a tension headache you may:

- Have a tight, squeezing feeling, around the entire head or on both sides
- Have mild to moderate pain
- Have them later in the day

Cervicogenic (secondary) headaches

Secondary headaches happen when you have an injury to the muscles and tissues in the back of the head, neck or spine. They are called “secondary” or “referred” because you feel the pain in your head even though the injury is somewhere else. There are many nerves in the tissues and bones of the neck. These nerves have branches that travel to the skull and scalp and can result in pain. If you have a secondary headache:

- You may have pain that starts in the neck, shoulders, and back of the head. Sometimes it travels over the top of the head.
- Neck movement or changes in position makes the pain worse.
- You should not have nausea

Rebound headaches

Sometimes the medicines used to treat headaches can cause headaches. If you take pain medicine every day, missing one or two doses can cause a headache.

You can also get a rebound headache if you lower the amount of caffeine you have. For example, if you normally drink a lot of coffee or energy drinks and then skip a day, you may get a headache.

When should I be concerned about a headache?

Most headaches are not dangerous. In the first few days after a concussion or head injury, you will likely have headaches. You should see a doctor who treats TBI patients if any of the following happens:

- Your headache gets worse
- You have nausea or vomiting while you have a headache
- Your arms or legs get weak while you have a headache
- You have problems speaking while you have a headache
- You feel more tired than normal while you have a headache

Do I need special tests to diagnose a headache?

Brain scans or other tests are not normally used to diagnose your headache. Instead, your doctor will use your history and symptoms to decide what kind of headache you are having and how to treat it.

How can I help prevent headaches?

Many times, your daily habits can cause headaches or make them worse. Making simple changes can often make a big difference in whether or not you have headaches. Try to:

- Get enough sleep.
- Get daily exercise. Exercises like walking and stretching often help to prevent headaches by helping you sleep and lowering stress. If your head hurts worse after any exercise, check with your doctor.
- Avoid caffeine (coffee , sodas with caffeine, or tea).
- Avoid certain foods that may cause a headache like red wine, MSG (monosodium glutamate, a common food additive), or certain cheeses.
- Avoid taking pain medicines on a daily basis unless your doctor prescribes it.

How can I treat my headaches after TBI?

Always talk to your doctor before taking any medicines, whether prescribed or over the counter. Be sure to keep a record of what you took and when, to avoid accidental overdose. Never take more than instructed. See page 95 for a helpful way to track your medicines.

- Over-the-counter pain medicines like acetaminophen (Tylenol®) or ibuprofen
- Therapy or meditation to help you relax
- Biofeedback therapy: a technique that enables an individual to learn how to change physiological activity for the purposes of improving health and performance.
- Stretching and self-massage
- Acupuncture
- Local injections (numbing medicine or steroids) to muscles, nerves or joints of your neck
- Massage
- Heat or ice packs
- Medicines for migraine headaches, like sumatriptan (Imitrex®), that your doctor prescribes
- Keep a headache diary of your symptoms and how well different treatments work. Here is an example:
    - When did it start?
    - How intense was it?
    - Symptoms (dull, sharp, part of head)
    - When did I notice it was over?
    - How I treated it: Did it help?

Some of this information came from:

Hoge CW, McGurk D,Thomas JL, Cox, AL, Engel CC, Cas- tro C A (2008). Mild traumatic brain injury in U.S. Soldiers returning from iraq. N Engl J Med, 358(5), 453-463.

Lahz S, Bryant RA (1996). Incidence of chronic pain fol- lowing traumatic brain injury. Arch Phys Med Rehabil, 77(9), 889-891.

Lew HL, Lin PH, Fuh JL,Wang SJ, Clark DJ,Walker WC (2006). Characteristics and treatment of headache after traumatic brain injury: A focused review. Am J Phys Med Rehabil, 85(7), 619-627.

Fatigue after Traumatic Brain Injury (TBI)

What is fatigue?

Fatigue is the feeling of being tired, drained, or not having enough energy. There are different kinds of fatigue, such as:

- **Physical fatigue** is when you feel like your body is tired and needs to rest. This normally happens because you have been physically active for a long time.
- **Psychological fatigue** is when you do not feel like doing anything, or are not motivated. This usually happens because you have had extra stress or problems that keep you from making progress.

- **Mental fatigue** is when you cannot think well or clearly for a long period of time. This normally happens because you have been thinking hard for a long time.

After a TBI, you may have more than one kind of fatigue.

Why does it matter if I'm feeling fatigued?

When you are feeling fatigued:

- You may not be able to think clearly, focus, or remember
- You may not be able to communicate well
- You may not have the energy to:
    - Take care of yourself
    - Go to work
    - Exercise or be physically active
    - Do the things you enjoy
- You may be in a bad mood
- Certain activities (such as driving) may be more dangerous

How common is fatigue after TBI?

Fatigue is normal for anyone after hard work or a long day. But if you have a TBI, you will often feel fatigued more quickly and more frequently than normal. It is one of the most common problems people have after a TBI. Around 7 in 10 people with a TBI complain of mental fatigue.

What causes fatigue after TBI?

The cause of fatigue after TBI is not clear, but it may be due to the extra work your brain has to do even for simple activities such as walking or talking clearly. Your brain may be less "efficient" than before your injury (it may take more energy to do the same work). Here are some examples:

- **Physical fatigue can come from muscle weakness.**
    - Your body needs to work harder to do things that were easy before the TBI.
    - Physical fatigue gets worse in the evening and normally gets better after a good night's sleep.
    - You will normally have less of this kind of fatigue as you get stronger, get more active, and get back to your old life.
- **Psychological fatigue is often caused by depression, anxiety, or other psychological conditions.**
    - This type of fatigue gets worse with stress.
    - Sleep may not help at all, and the fatigue is often at its worst when you wake up in the morning.

- **Mental fatigue comes from the extra effort it takes to think after TBI.**
    - Many common tasks take much more focus than they did before.
    - Working harder to think and stay focused can make you mentally tired.
- **Certain medical conditions can cause or increase fatigue:**
    - Depression
    - Sleep problems, such as sleep apnea
    - Allergies
    - Hypothyroidism (your thyroid gland doesn't do enough) or other gland disorders
    - Breathing or heart problems
    - Headaches
    - Sitting all day and evening (lack of exercise)
    - Not getting enough vitamins or the right nutrients
    - Stress
    - Low red blood cell counts (anemia)
    - Medicine commonly used after TBI, such as muscle relaxers and pain medicines

What can I do to lower fatigue?

- **Pay attention to what causes you fatigue.**
    - Learn to notice the early signs of fatigue, such as becoming easily upset or distracted.
    - Stop what you're doing before you get tired.
- **Get more sleep.**
    - Set a regular sleep schedule by going to bed and waking up at the same times every day.
    - Start taking regular breaks or naps. Only nap for 30 minutes or less. Avoid taking evening naps.
    - This will make your body and mind work better.
    - If you have insomnia (cannot sleep), tell your doctor. You may have a health problem causing this. Your doctor can tell you about helpful treatments.
- **Improve your time management:**
    - Plan and follow a daily schedule. Use a calendar or planner to help manage mental fatigue.
    - Do the most important activities first.

    - Do things that take the most physical or mental effort earlier in the day, when you have more energy.
    - Try not to do too much in one day.
- **If visitors make you tired, limit time with them.**
- **Resume activities gradually, over weeks or even months.**
    - Start with normal, easy tasks at home or work that you can complete without fatigue.
    - Gradually increase the complexity of each task, taking breaks as needed.
- **Exercise daily.**
    - Research has shown that people with TBI who exercise have better mental function and alertness.
    - Over time, exercise helps lower physical and mental fatigue and builds stamina.
    - Exercise may also lower depression and help you sleep better.
- **Avoid:**
    - Alcohol
    - Marijuana
    - Caffeine (coffee, tea, soda) after lunch, if you have problems sleeping
- **Talk with your doctor about:**
    - Problems that may be causing fatigue
    - All of the medicines you are taking
    - Feelings of depression
    - Blood tests that could show what is causing your fatigue

Some of this information came from: Model Systems Knowledge Translation Center. Fatigue and Traumatic Brain Injury. Retrieved from http://www.msktc.org/lib/docs/Factsheets/TBI_Fatigue_and_TBI.pdf

Driving after Traumatic Brain Injury

Driving is an important part of a person's independent lifestyle and integration into the community. Because we take our driving skills for granted, it is easy to forget that driving is the most dangerous thing we do in our everyday lives. A brain injury can affect the skills needed to drive safely. If and when you may safely return to driving should be addressed early in recovery. The survivor, family members, and health professionals should all be included in this important decision. If anyone has concerns that driving may put a survivor or others in danger, health professionals may recommend pre-driving testing.

How can a TBI affect driving ability?

A brain injury can disrupt and slow down skills that are essential for good driving, such as:

- Ability to stay in one lane
- Seeing well
- Keeping concentration for a long time
- Remembering directions
- Figuring out solutions to problems
- Hand-eye coordination
- Reaction time
- Safety awareness and judgment

Studies have shown that even mild thinking difficulties, which may not be recognized by the TBI survivor, may add to increased risks while driving.

Warning signs of unsafe driving

- Driving too fast or too slow
- Not obeying signs or not noticing traffic signals
- Mis-judging distance when stopping or turning
- Being slow to make decisions
- Becoming easily frustrated or confused
- Having accidents or near misses
- Drifting across lane markings into other lanes
- Getting lost easily, even in familiar areas

How often do TBI survivors return to driving?

Between 40 and 60 percent of people with moderate to severe brain injuries return to driving after their injury. To lessen the risk of crashes, survivors may limit their driving habits. They may drive less often than they did before the injury or drive only at certain times (such as during daylight), on familiar routes, or when there is less traffic. Having experienced a seizure after the TBI may keep someone from driving. States often require that a person be free of seizures for a period of time, such as 6 months, before resuming driving. People who want to return to driving need to check the laws in their state.

Driving evaluations and training

A driving evaluation is a crucial step in determining a person's ability to drive following recovery from a TBI. Research shows that most TBI survivors are not thoroughly evaluated for driving skills before they begin driving after the injury, and this may put TBI survivors at risk for a crash.

While there is no standardized assessment test or process, a typical driving evaluation has two parts:

- **Preliminary Evaluation:** A review of cognitive (thinking) abilities, including reaction time, judgment, reasoning and visual spatial skills. Recommendations on the need for adaptive equipment and additional skills training are based on the results of the evaluation.
- **On-the-Road:** A test of driving abilities, either using a driving simulator or driving a vehicle with an evaluator. This test is used to judge safe driving skills in various traffic environments, as well as basic driving skills for people using adaptive driving equipment.

Current research shows that many survivors of TBI can become good, safe drivers with the proper training. Training helps improve specific driving skills. Sometimes this involves practicing driving with a driving evaluator. In other cases, a training program might focus on specific skills such as quickly processing visual information.

Evaluations and training are often provided by professionals certified through the Association for Driver Rehabilitation (ADED). A list of certified professionals may be found on the ADED website, https://www.aded.net/search/newsearch.asp.

Vehicle modifications

Survivors who have physical disabilities but no cognitive (thinking) disabilities may be able to resume driving with adaptive equipment and/or other modifications to the vehicle.

Recommendations for adaptive equipment and modifications could include:

- Hand-controlled gas and brake systems
- Spinner knobs for steering
- Left foot accelerator
- Lifts for entering and exiting the vehicle

A person who wishes to resume driving must have a valid driver's license. In some states there must be a formal evaluation performed by a licensing bureau before resuming driving after a brain injury. Insurance is also required. The person should check local regulations relating to licenses and insurance.

Other transportation options

Accessible and reliable transportation is the most critical part of community integration following a TBI. If a person is not able to drive, there may be other options for transportation. Family members can provide transportation, and public transportation such as buses can be used. Some communities provide public transportation specifically for disabled riders.

Step-by-Step: Should you be driving?

- Discuss your ability to drive with your healthcare team and family members

- Get a professional evaluation to determine your driving ability
- Based on your evaluation you may be allowed to drive, need training or vehicle modification before returning to driving, or will need to use other transportation options

Recommended resources

Brain Injury Association of America. *www.biausa.org*

State Vocational Rehabilitation Offices. *www.jan.wvu.edu*

Association for Driver Rehabilitation Specialists. *www.driver-ed.org*

National Mobility Equipment Dealers Association. *www.nmeda.org*

Some of this information came from:

Eby, D.W., Molnar, L. J. (2010) Driving Fitness and Cognitive Impairment. JAMA. 303(16):1642-1643.

Section 5: Local and National Resources

Don't see what you are looking for? Our website, https://atrp.ar.gov/resources/resource-links/ includes many other resources and a searchable resource map at https://atrp.ar.gov/places-home/.

Support Groups 61
Career and School Resources 62
Getting Hired 63
Caregiver Support 64
Cognitive, Behavioral, and Mental Health 64
Neuropsychology Services 66
Assistive Technology & Equipment 68
Financial Assistance & Social Services 68
Legal Services 71
Disability Organizations & Foundations 72
Trauma Survivor and Disability Publications 75
Sports and Recreation 76

Support Groups

Most people feel anxious about attending a support group, and that is normal. But many survivors have found that this kind of community is helpful. Visiting a support group regularly may help you feel less alone, because you can meet others who have gone through similar experiences.

Find the most up-to-date information at https://atrp.ar.gov/brain-injury-support-groups/. **Meeting details sometimes change. Please verify meeting details before your visit.**

Online Support Groups & Communities

There are online support groups and communities available for those who live outside these areas or those who prefer to connect from home.

Faces of TBI

Their mission is to be a voice for Traumatic Brain Injury (TBI) and bring awareness to the world, through educating survivors, caregivers, friends and family, as well as the medical community. This group has regular Zoom meetings online. Search for @facesofTBI on Facebook.

Facing Disability

Their mission is to connect families dealing with spinal cord injuries with the life experiences of others, and to offer medical information and resources. https://facingdisability.com/join-the-conversation

Mobile Women

mobileWOMEN.org is the creation of women in wheelchairs. Their mission is to bring together current and accurate information on issues of interest to the community including health, fashion and other topics.www.mobilewomen.org or search for "MobileWOMEN.org" on FaceBook..

TBI Talk

A community and network for TBI survivors that includes articles, testimonies, and tips about TBI. http://www.tbitalk.com

Trauma Survivors Network

This is a community of patients and survivors looking to connect with one another and rebuild their lives after a serious injury. The underlying goal of their resources and programs is to ensure the victims of trauma a stable recovery and to connect those who share similar stories. https://www.traumasurvivorsnetwork.org

Career and School Resources

Arkansas Department of Education Brain Injury Support Program

The state consultant for students with brain injury offers support and improved access to educational services in the schools. This includes consultation and technical assistance, professional education, and information about the latest researched-based practices and methods for students with brain injury.

Office Phone: (501) 319-7333, ext. 124

Fax: (501) 379-8387
Email: amy.goddard@arkansas.gov

Arkansas Rehabilitation Services

https://arcareereducation.org/about/arkansas-rehabilitation-services

Arkansas Rehabilitation Services provides a variety of FREE training and career preparation programs for people with intellectual, physical, and sensory disabilities. They can help you return to work, start a new career path, or help you access accommodations at your current workplace. Contact ARS at (800) 330-0632 or (501) 296-1600 to find out how they can help you.

You can also reach out to your local office and ask for intake paperwork. They will then send you some forms and set up an intake appointment. Here are the offices by region:

Region 1

Fayetteville: (479) 582-1286
Harrison: (870) 741-7153

Region 2

Jonesboro: (870) 972-0025
Batesville: (870) 793-4153
Searcy: (501) 268-4542

Region 3

West Memphis: (870) 735-4725
Helena: (870) 338-2753

Region 4

Fort Smith: (479) 755-3300
Booneville: (479) 675-3835

Region 5

Russellville: (479) 890-5751
Conway: (501) 730-9725

Region 6

Hot Springs: (501) 623-4479
Benton: (501) 317-1390

Region 7

Little Rock: (501) 686-2800
North Little Rock: (501) 833-1490

Region 8

Texarkana: (870) 773-2807
El Dorado:(870) 862-5451

Region 9

Pine Bluff: (870) 534-2404
Monticello: (870) 367-9669

Getting Hired

Getting Hired is a recruitment solution dedicated to helping inclusive employers hire professional individuals and veterans with disabilities. https://www.gettinghired.com/

Job Accommodation Network (Jan)

JAN helps people with disabilities enhance their employability, and shows employers how to capitalize on the value and talent that people with disabilities add to the workplace. If you have questions about what types of accommodations you are entitled to, JAN can help you find resources. https://askjan.org/

Project Awin

Project AWIN services are designed to help Arkansas residents with disabilities understand and use the work incentives provided by the Social Security Administration. You can call for more information, Toll Free at (888) 284-7521.

T.E.E.M Academy

T.E.E.M Academy prepares young men and women for satisfying careers in a variety of fields. They offer practical, hands-on instruction with live online training that allows students to see and hear their teachers. (877) 933-9595
http://teemacademy.org/

Ticket To Work

Ticket to work is a free employment program run by Social Security. Use this website to learn about the program and get started. If you are interested in job accommodations, please visit https://choosework.ssa.gov/.

Caregiver Support

Arkansas Long Term Care Ombudsman Program

The mission of the Arkansas Ombudsman Program is to ensure that long-term facility residents have the right to live their lives with dignity and feel free to voice complaints or concerns without fear of backlash. The Ombudsman strives to be a trusted advocate for all residents by educating them regarding their rights, investigation of complaints and empowering residents to speak for themselves. The Ombudsman offers support for those who feel they do not have a voice. https://www.arombudsman.com/

CareLink

CareLink's mission is to connect homebound older people and their families with resources to meet the opportunities and challenges of aging. https://www.carelink.org (800) 482-6359

Caregiver.com

Provides an online home for caregivers including tips sections, discussion lists, breaking news, topic specific channels, expert answers and email newsletters.www.caregiver.com

Caregiver Action Network (CAN)

Caregiver Action Network (CAN) is the nation's leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for patients with chronic conditions, disabilities, disease, or the frailties of old age. https://caregiveraction.org/ (855) 227-3640

Family Caregiver Alliance

Family Caregiver Alliance is the first community-based nonprofit organization in the country to address the needs of families and friends providing long-term care for patients at home. https://www.caregiver.org (800) 445-8106

National Respite Network

This website has resources about respite for caregivers and professionals. Follow this link to see respite programs in Arkansas: https://archrespite.org/respite-locator-service-state-information/136-arkansas-info

VA Caregiver Support

The Caregiver Support Program offers training, educational resources, and multiple tools to help you succeed. Please contact the Caregiver Support Line for advice on being a caregiver. https://www.caregiver.va.gov/ (855) 260-3274

Cognitive, Behavioral, and Mental Health

Mental Health Providers

If you are looking for mental health care, this website offers extensive search options:

- PSYCHOLOGYTODAY.COM

You can also call the **ARConnect Call Center** to have someone assist you with finding mental health support. (501) 526-3563 or (800) 482-9921.

Arkansans struggling with mental illness but unable to find a suitable provider and resources in their community no longer have to go lacking for professional care. AR-Connect provides assistance via telephone and tele-video virtual visits that can be accessed 24 hours a day, 7 days a week. No referral is necessary; anyone needing help will find it only a phone call away.

Crisis Stabilization Units

If you or your survivor is experiencing a mental health crisis and is at risk of incarceration, you may find help at one of these units:

Pulaski County (at UAMS)

Serves Pulaski, Perry, Saline, Lonoke, Jefferson and Grant counties.
Address: 3001 W. Roosevelt Road, Little Rock, Arkansas
Phone: (501) 340-6646

Sebastian County

Serves these counties: Sebastian, Crawford, Franklin, Logan, Scott, and Polk.
Address: 3113 South 70th Street, Fort Smith, Arkansas
Phone: (479) 785-9480

Washington County

The CSU offers an alternative to jail when someone appears to be in a mental-health crisis.
Address: 105 N Mill Ave Fayetteville, Arkansas
Phone: (479) 316-7100

Craighead County

Serves Clay, Craighead, Crittenden, Cross, Greene, Fulton, Independence, Izard, Jackson, Lawrence, Lee, Mississippi, Monroe, Phillips, Poinsett, Randolph, St. Francis, Sharp, White, and Woodruff counties.
Address: 837 Willett Road, Jonesboro, Arkansas
Phone: (870) 393-5335

Neuropsychology Services

Many people with brain injuries can benefit from seeing a neuropsychologist to evaluate brain functioning and address their unique needs. Many of these clinics have waiting lists, so do not put off setting up your appointment.

Arkansas Families First

Arkansas Families First is a multidisciplinary behavioral health care group that offers a variety of health services for children, teens and families in Central Arkansas.
4004 McCain Boulevard, North Little Rock
(501) 812-4268

Arkansas Neuropsychology and Behavioral Health

Gives comprehensive diagnostic examination, psychotherapy, and medicine management in one convenient location.
6020 Warden Road Suite 210, North Little Rock
(501) 537-1388

Clinical Neuropsych and Associates, PA

Neuropsychology examines how you think, learn, comprehend, move and behave to determine whether your brain is functioning correctly or if you have a brain-based disorder or disability affecting your behaviors. For more information, please call St. Bernards Healthline at (870) 207-7300.
Located at: Encompass Rehabilitation Hospital of Jonesboro, 1201 Fleming Avenue, Jonesboro
Phone: (870) 933-5174

The Fowler Institute

The Fowler Institute is a private practice that specializes in a broad range of services for individuals, families, groups and organizations. Assessment, psychotherapy and corporate training are among the services offered.
415 North McKinley Street, Little Rock
(501) 664-6632

Integrated Neuropsychological Services

Integrated Neuropsychological Services is dedicated to providing research-based, personalized, and confidential psychological services to the Northwest Arkansas community and surrounding areas.
86 West Sunbridge Drive, Fayetteville
Phone: (479) 435-6360

NEA Neuropsychology

NEA Neuropsychology, PLLC, is independently owned by licensed board-certified neuropsychologist Kristin Addison-Brown, PhD, ABPP-CN. NEA Neuropsychology gives psychological and neuropsychological assessment services to the Northeast Arkansas and Southeast Missouri areas.

304 Southwest Square, Jonesboro
(870) 203-6085

UAMS Neuropsychology at PRI

The Psychiatric Research Institute's Neuropsychology Service offers neuropsychological assessments to adolescents and adults with various conditions. They also provide individual cognitive rehabilitation for TBI patients.

4224 Shuffield Drive, Little Rock
(501) 526-8200

PASSE (Provider-led Arkansas Shared Savings Entity)

The Provider-led Arkansas Shared Savings Entity (PASSE) is a new model of organized care that will address the needs of certain Medicaid beneficiaries who have complex behavioral health and intellectual and developmental disabilities service needs. The PASSE model is a Medicaid-funded program. It does not change a person's eligibility for Medicaid, but it changes the way services are paid for by Medicaid for certain eligible individuals.

https://humanservices.arkansas.gov/about-dhs/dms/passe

For network lists, visit:

https://humanservices.arkansas.gov/programs-services/services-by-group/disabled-and-mental-health

- **Arkansas Total Care: (866) 282-6280**
- **Empower Healthcare Solutions: (866) 261-1286**
- **Summit Community Care: (844) 405-4295**
- **DHS PASSE Provider Line: (888) 889-6451**

Assistive Technology & Equipment

AbleData, Tools & Technology to Enhance Life

AbleData is the premier source for impartial, comprehensive information on products, solutions and resources to improve productivity and ease with life's tasks They give information to assist customers, caregivers, and professionals regarding assistive technology (AT) options and programs available. https://abledata.acl.gov/

Arkansas Relay Service

Arkansas Relay Service is a statewide service that connects standard (voice) telephone users with deaf, hard-of-hearing, deaf-blind, speech-disabled, or late-deafened people who use text telephones (TTYs) or voice carry-over (VCO) phones.http://www.arkansasrelay.com
(800) 676-3777 (TTY/Voice)
(800) 676-4290 (Español)
(877) 787-1989 (Speech-to-Speech only)

Easter Seals Short-term Equipment Loans

Easter Seals offers short term equipment loans for students. Visit https://eastersealsopts.org/short-term-equipment-loan/ to browse their equipment library.

iCAN

iCAN (Increasing Capabilities Across Network) is the Arkansas statewide assistive technology program designed to make technology available and accessible for everyone who needs it. They offer free equipment loans from their equipment library. They have a very helpful and knowledgeable staff to help you find the right equipment for your needs. https://ar-ican.org/ (800) 828-2799

Telecommunication Access Program (TAP)

The Telecommunication Access Program (TAP) gives specialized telecommunication equipment to eligible Arkansans who are deaf, hard of hearing, deaf-blind, or who have a speech, visual, mobility, or intellectual impairment. The equipment that TAP gives remains the property of the State of Arkansas for two years and then becomes the property of the recipient of the equipment. https://arktap.org/ (800) 981-4463

Financial Assistance & Social Services

Access Arkansas

Visit this page to learn what state financial benefits you might qualify for, including Arkansas Works (AR Medicaid), ARKids First, SNAP, Child Care Assistance, Pregnant Woman Coverage, and others. https://access.arkansas.gov/

Arkansas 211
2-1-1 is a free, confidential referral and information helpline that connects individuals in need to important community services in Northwest Arkansas. 2-1-1 is the direct link between people who need help and people who can give help. The 2-1-1 call center serves Benton, Carroll, Madison and Washington counties. https://arkansas211.org/

Arkansas Department of Human Services
The Department of Human Services (DHS) is Arkansas' largest state agency, providing a safety net for our most vulnerable residents. People needing support will find at least one local DHS office in each of the state's 75 counties.

Arkansans may apply for a vast array of services at their local county office as well as online. Services include ARKids First health insurance for children, the Supplemental Nutrition Assistance Program (SNAP, formerly known as food stamps), Transitional Employment Assistance (TEA) and Medicaid. https://humanservices.arkansas.gov/ (800) 285-1131 or dial 711 for Arkansas Relay Service

Arkansas Food Bank Locator Map
Quickly and easily find the closest food pantry to you with the Agency Locator Map. https://arkansasfoodbank.org/who-we-serve/service-map/

Assisted Living
This website offers helpful information about assisted living facilities in Arkansas. https://www.assistedliving.org/arkansas/

Arkansas Long-Term Care Ombudsman Program
This organization advocates for residents of long-term care facilities, to ensure they can voice complaints without fear of retaliation. Find your regional office at https://www.arombudsman.com/

Arkansas Medicaid
Gives financial assistance for some disabilities in the state of Arkansas https://medicaid.mmis.arkansas.gov/

Choices in Living
People who are nursing home-eligible and wish to reside in an assisted living facility may qualify for the Choices program. Choices In Living is a Medicaid waiver which allows for 24-hour personal care services to be covered for a limited number of people, helping nursing home-eligible recipients avoid being institutionalized. Apply at your local Department of Human Services office, or the process can be initiated over the phone by calling the Choices in Living Resource Center at (866) 801-3435.

Financing and Grants for Equipment, Vehicle, & Home Modifications
Modifications and equipment are expensive, but there are options to help. For a list of some of the local options available, visit https://atrp.ar.gov/financing-grants/

Medicare
The official U.S. government site for Medicare. This site gives you access to your Medicare plan, costs, coverage, claims, forms, and more. https://www.medicare.gov/

Miracles for Mary
Providing compassion and alternatives for care in overcoming the effects of traumatic brain injuries. This includes providing love and comfort to families who are suffering through the anguish of a life changing injury, enabling alternative treatments for the injured, and providing education and support to those who suddenly find themselves in the role of caregiver. https://miraclesformary.com/

Modest Needs
Modest Needs assists "low-income workers who are struggling to shoulder the burden of a short-term emergency expense." The main type of assistance they give is called a Self-Sufficiency Grant. These funds are given as grants, not loans, meaning the money does not need to be repaid by recipients. Self-Sufficiency Grants are intended to help people who work and earn an income, but live just above the poverty level and are therefore unable to take advantage of any social assistance programs. These people may be just one paycheck away from financial disaster, and that's where a grant can help.
https://www.modestneeds.org/for-applicants/

Social Security Administration: SSI & SSDI
The Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that give assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits under either program. https://www.ssa.gov/disability/

Taxpayer Advocate Service
An independent organization within the IRS, TAS is here to protect your rights as a taxpayer, and help you with tax problems you cannot resolve on your own.
https://taxpayeradvocate.irs.gov/ Phone: (501) 396-5978

Veteran Resources
Please visit https://atrp.ar.gov/veteran-resources/ to view financial resources for veterans and their families.

Legal Services

Arkansas Crime Victims Reparations Board

The Arkansas Crime Victims Reparations Program, administered by the Department of Public Safety on behalf of the Crime Victims Reparations Board, gives financial compensation to victims who have suffered personal injury or death as the result of violent crime. Eligible victims may be awarded reparations regardless of whether there has been an arrest or conviction related to the crime.
(501) 682-1020

https://portal.arkansas.gov/agency/department-of-public-safety/crime-victims-reparations-board/

Arkansas Legal Services Online

This site gives information, resources and links that can assist you in helping to find the legal assistance you need. These free resources are offered by the Center for Arkansas Legal Services and Legal Aid of Arkansas. Together, these two non-profit law firms offer free civil legal assistance to eligible low-income people throughout the state. They serve all Arkansas counties. Call their helpline to learn more: Helpline: (800) 9-LAW-AID (800-952-9243) or (501) 376-3423

Arkansas Workers' Compensation Commission

Workers' compensation insurance protects employers, employees, and their dependents from financial burdens resulting from job-related injury and disease. Arkansas law states that employers in categories that are not specifically exempted must provide this insurance coverage for employees and cover costs of job-related accidents and disease.
http://www.awcc.state.ar.us
(501) 682-3930

Disability Rights Arkansas

DRA is an independent, private, nonprofit organization dedicated to advocating for and protecting the rights of people with disabilities. https://disabilityrightsar.org/
(800) 482-1174

Legal Aid of Arkansas

Legal Aid is a 501(c) 3 nonprofit organization that offers free legal services to low-income individuals residing in the state of Arkansas in civil (non-criminal) cases. Legal Aid serves 31 of the 75 counties in Arkansas. Legal Aid assists thousands of clients every year in priority areas, such as family law, consumer issues, bankruptcy or evictions. https://arlegalaid.org/
(870) 972-9224

Lawhelp.org

LawHelp helps people of low and moderate incomes find free legal aid programs in their communities, answers to questions about their legal rights and forms to help them with their legal problems.

The National Domestic Violence Hotline

The Hotline is the only 24/7 center in the nation that has access to service providers and shelters across the U.S. Call (800) 799-7233/(800) 787-3224 (TTY). Online chat is also available 24/7/365.

Office for Victims of Crime (OVC)

OVC channels funding for victim compensation and assistance throughout the United States, raises awareness about victims' issues, promotes compliance with victims' rights laws, training, technical assistance, publications, and products to victim assistance professionals. https://www.ovc.gov/

Prosecuting Attorney Victim and Witness Program

The Prosecutor's Victim and Witness Program is designed to assist victims of crime through the criminal court system. Our Victim and Witness Coordinators offer a variety of informational, referral and personal support services to crime victims in court related cases. https://pulaskipa.org/victim-witness-program/ (501) 340-8000

UALR Bowen School of Law Legal Clinics

The Bowen School of Law offers various legal clinics and workshops to assist you with court cases, housing and credit issues, tax issues, legal disputes, and small business matters. See their website for more information. https://ualr.edu/law/clinical-programs/legal-clinic-services/ (501) 915-5492

Disability Organizations & Foundations

After the Injury

Resources for parents to help children recover from an injury.
https://www.aftertheinjury.org/

The American Association of People with Disabilities (AAPD)

The American Association of People with Disabilities (AAPD) is a convener, connector, and catalyst for change, increasing the political and economic power of people with disabilities.
https://www.aapd.com/

Amputee Coalition

Amputee Coalition's mission is to reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention. https://www.amputee-coalition.org/

Brain Injury Association of America

Everyone in the U.S. who sustains a brain injury is diagnosed, treated, and accepted. The mission is to advance awareness, treatment, and education and to improve the quality of life for all people affected by brain injury. https://www.biausa.org/

Brain Trauma Foundation
For over 30 years, Brain Trauma Foundation has been conducting innovative clinical research and developing evidence-based guidelines that improve outcomes for the millions of people who suffer from traumatic brain injuries every year.
http://www.braintrauma.org/

Christopher & Dana Reeve Foundation
The Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy. https://www.christopherreeve.org/. Their Paralysis Resource Guide is an essential tool for everyone living with or impacted by paralysis. The Paralysis Resource Guide third edition is currently available in digital and print – English or Spanish. For a FREE copy of the Paralysis Resource Guide, please call (800) 539-7309 or visit www.ChristopherReeve.org/Guide

Disabled American Veterans
DAV is a nonprofit charity that offers a lifetime of support for veterans of all generations and their families, helping more than 1 million veterans in positive, life-changing ways each year. The organization gives nearly 615,000 rides for veterans attending medical appointments and assists veterans with more than 250,000 benefit claims annually.
https://www.dav.org/

Facing Disability
FacingDisability.com connects families who are suddenly learning to cope with a spinal cord injury to people who have already been there. https://facingdisability.com/

Limbs for Life Foundation
The Limbs for Life Foundation is dedicated to providing fully-functional prosthetic care to individuals who cannot afford it and raising awareness of the challenges facing amputees.
http://limbsforlife.org/

Love your Brain Foundation
LoveYourBrain is the message that embodies a positive approach to brain injury prevention and healing. Their programs are designed to build community, foster resilience, and help people understand the importance of loving your brain. They offer a free 6-week yoga series at Blue Yoga Nyla in North Little Rock. The class takes place 4 times a year, and is open to anyone with a brain injury or concussion, or their caregivers.
https://www.loveyourbrain.com/

Miracles for Mary
Providing compassion and alternatives for care in overcoming the effects of traumatic brain injuries. This includes providing love and comfort to families who are suffering through the anguish of a life changing injury, enabling alternative treatments for the injured, and providing education and support to those who suddenly find themselves in the role of caregiver. https://miraclesformary.com/

Mobility International USA
Mobility International USA (MIUSA) is a disability-led non-profit organization advancing disability rights and leadership globally. MIUSA is a cross-disability organization serving people with a broad range of disabilities. https://www.miusa.org/

Model Systems Knowledge Translation Center
A national center that helps facilitate the knowledge translation process to make research meaningful to those with Spinal Cord Injury, Traumatic Brain Injury, and Burn Injury. https://msktc.org/

National Association of State Head Injury Administrators (NASHIA)
NASHIA is a voluntary membership organization established by State government employees to help one another plan, implement, and administer public programs and services for individuals with brain injury and their families. http://www.nashia.org/

National Center on Physical Activity and Disability (NCHPAD)
NCHPAD is a public health practice and resource center on health promotion for people with disabilities. NCHPAD seeks to help people with disabilities and other chronic health conditions achieve health benefits through increased participation in all types of physical and social activities, including fitness and aquatic activities, recreational and sports programs, adaptive equipment usage, and more. https://www.nchpad.org/

National Organization on Disability
NOD focuses on increasing employment opportunities for the 80% of working-age Americans with disabilities who are not employed. https://www.nod.org/

National Rehabilitation Information Center (NARIC)
The National Rehabilitation Information Center (NARIC) is the library of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). They collect, catalog, and disseminate the articles, reports, curricula, guides, and other publications and products of the research projects funded by NIDILRR. https://naric.com

Shepherd Center
Shepherd Center, located in Atlanta, Georgia, is a private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury, brain injury, multiple sclerosis, spine and chronic pain, and other neuromuscular conditions.

Shepherd Center offers free videos to learn more about brain and spinal cord injuries. These videos are available to view online:

Understanding Brain Injury (Video Series) http://www.braininjury101.org/

Understanding Spinal Cord Injury (Video Series) http://www.spinalinjury101.org/

Southwest ADA Center
The Southwest ADA Center is the Southwest's leading resource on the Americans with Disabilities Act and related disability rights laws. The Center's mission is to promote voluntary compliance with the Americans with Disabilities Act (ADA) by providing three core services — technical assistance, training and materials dissemination.
http://southwestada.org/index.html

SOURCES for Independent Living
SOURCES offers services, support, and advocacy for individuals with disabilities, their families and the community. They are dedicated to consumer-directed services. If you are in the Northwest Arkansas area, this is the place to call. They have a support group, offer home modifications, and are extremely knowledgeable about local resources.
http://www.arsources.org/ (888) 284-7521 TDD: (479) 251-1378

UNITED STATES ACCESS BOARD
The U.S. Access Board is a federal agency that promotes equality for people with disabilities through leadership in accessible design and the development of accessibility guidelines and standards for the built environment, transportation, communication, medical diagnostic equipment, and information technology. Their website offers resources for filing a complaint about non-accessible federal buildings. https://www.access-board.gov/

Trauma Survivor and Disability Publications

There are so many great magazines and publications for people living with brain injuries, their caregivers, and the professionals who serve them.

Brain & Life – The American Academy of Neurology's patient-education magazine, available free to patients, caregivers, and all interested in neurology for everyday living.
https://www.brainandlife.org/

Brain Injury Hope Magazine – HOPE Magazine is a publication that supports the brain injury and concussion community. Subscribers will receive a monthly email with a free digital copy of HOPE Magazine as well as the option to purchase the magazine in print on Amazon. http://www.tbihopeandinspiration.com/

Brain Injury Professional – an official publication of the International Brain Injury Association and North American Brain Injury Society. It is published quarterly. Although this publication is marketed to professionals, survivors, caregivers, and their community may find it useful as well. The issues may be viewed online for free.
https://braininjuryprofessional.com/

Brain Waves – A newsletter for Arkansans living with traumatic brain injury and their caregivers. Send your mailing or email address to trrp@uams.edu to receive this free quarterly newsletter. View and download all editions online at
http://atrp.ar.gov/education/brain-waves-newsletter/

New Mobility – "The magazine for active wheelchair users". https://www.newmobility.com/.

Spinal Connection – A quarterly newsletter for Arkansans living with spinal cord injury. https://www.spinalcord.ar.gov/programs-and-services/spinal-connection/

Sports and Recreation

If you are an athlete who was injured in your sport, or if you are an aspiring athlete who would like to pursue an active lifestyle, there may be additional resources for you. Visit https://atrp.ar.gov/recreation/ to see what may be available to you.

Section 6: Easy to Understand Glossary

Glossary of Medical Terms

This is only a partial list of the hundreds of terms and specialties associated with brain injury, spinal cord injury, and limb amputation. Are you having trouble understanding these words? Have you found a word you need help with? Call our team and have all your questions answered: (501) 526-7656.

A

Acalcula: When a person cannot perform simple math problems.

Acuity: Describes how sharp or accurate a person's thought, vision, or hearing is.

Active Range of Motion (AROM): The amount of joint movement a person can make using their only muscle strength (without assistance). Also see "Passive Range of Motion".

Activities of Daily Living (ADL's): Also called ADL's, or daily living skills. These are routine activities carried out for personal hygiene and health such as eating, dressing, grooming, shaving, etc. Nurses, occupational and physical therapists are the main coaches for these.

Acute: 1. Sharp or severe. 2. Severe symptoms that come on quickly and only stay for a short time. 3. The early stages of an injury (as opposed to chronic, which is long term).

Adaptive or assistive equipment: Any equipment that helps with self care, work, play or leisure activities.

Advocacy: When a person offers support, assistance, or help for a specific cause.

Affect (n.): The outward signs of a person's emotions. For example, the phrase "flat affect" might be used to describe someone showing no emotion.

Agitation: When a person seems upset or bothered, often shown through restless activity, pacing, crying, or laughing with or without an apparent reason, pulling at clothes or people, and not being able to stay still.

Agnosia: When the brain does not process the senses, which may keep a person from being able to recognize objects, people, or sounds.

Agraphia: When a person cannot write.

Alexia: When a person cannot read, often because they cannot process words.

Alertness: Being awake and able to respond to stimulation.

Ambivalence: A lack of feelings or conflicting feelings about an object, person or action, emotion, idea, situation, etc.

Ambulate or ambulation: To walk.

Amnesia: Lack of memory about events occurring during a particular period of time.

Pictured: Brain aneurysm

Aneurysm: Abnormal balloon-like deformity in the wall of a blood vessel, usually an artery, that weakens the wall of the vessel. If the size increases, the wall weakens as the balloon grows larger, and may eventually burst, causing a hemorrhage.

Anomia: Unable to remember names of objects.

Anosmia: Loss of the sense of smell.

Anoxia: When there is no oxygen to the brain. Cells of the brain need oxygen to stay alive, so this damages brain cells.

Anterior: Front.

Anterograde Amnesia: When someone cannot create new memories (can be partial or complete loss), but they are still able to remember things from before the event that caused the amnesia.

Anterolateral: Front and side.

Anteroposterior: Both front and back.

Antibody: An immune response the body creates to attack bacteria or viruses. It is carried in the blood as a type of protein.

Anticonvulsant: Medicine used to help prevent seizures (e.g., Dilantin, Phenobar, Mysoline, Tegretol).

Antidepressants: Medicine used to treat depression.

Anxiety: Feelings of fear, panic, apprehension, uneasiness, agitation, uncertainty. Anxiety can cause irritability, confusion, and bodily reactions such as increased heart rate, increased blood pressure, fatigue, sweating, sleep issues, and muscle tension.

Apathy: Indifference or lack of emotion, concern, or interest.

Aphasia: Partial or total loss of the ability to use words and/or to understand language.

Apraxia: A motor disorder that limits a person's control of certain movements, even though their muscles are fine. This can limit certain movements, such as those that involve facial muscles, or it can keep a person from moving their arms or legs. This condition can vary by type, but mostly affects planning motor movements. For example, dressing apraxia or constructional/drawing apraxia.

Aprosodia: When a person cannot perform or understand parts of language such as rhythm, pitch, or intonation.

Arachnoid Membrane: The middle three membranes (layers of tissue) that protect the brain and spinal cord.

Arousal: When a person is waking.

Arterial line: A thin tube inserted in an artery that gives constant blood pressure readings and allows blood samples to be taken for analysis.

Articulation: Movement of the lips, tongue, teeth, and palate into specific patterns for speech (Also, a movable joint).

Aspiration: When fluid or food enters the lungs through the windpipe (trachea). This can cause a lung infection or pneumonia.

Ataxia: Loss of full control of bodily movements caused by damage to the cerebellum (the part of the brain that controls muscle coordinations). This can limit a person's ability to walk, talk, eat, and to perform other self-care tasks.

Atrophy: A weakening in muscles, tissues, organs, or part of the body caused by lack of nourishment, underuse, neglect, or loss of nerve supply.

Attention or Concentration: The ability to focus on a given task or set of stimuli for an appropriate period of time.

Augmentative and Alternative Communication: Use of forms of communication other than speaking, such as: sign language, "yes/no" signals, gestures, picture board, and computerized speech systems to compensate (either temporarily or permanently) for severe expressive communication disorders.

Automatism: A person is in a trance-like state but appears normal, and performs actions without thinking or knowing what they are doing. Can last for minutes or days, often associated with severe emotional distress or a type of epilepsy.

Axon: The nerve fibers that carry instructions and sensory feelings in the body.

B

Balkan Frame: A rectangular frame placed over a bed to help with position and movement. Loops or bars can be hung from the frame to help with therapy activities or getting in and out of bed.

Bed Mobility: A person's level of movement in bed, such as rolling over, scooting, sitting up, and lying down.

Behavioral inflexibility: When a person behaves or completes tasks the same way and cannot change or adjust these patterns.

Bilateral: Meaning both the right and left sides of the body.

Bio-feedback: Technology that uses sensors and visual cues or sounds to give information about bodily functions, to help a person to learn control over them. This can be used for relaxing muscles, reducing pain, lowering heart rate or blood pressure, and relieving stress.

Brain Injury, Acquired: Any brain injury or brain damage that occurred after birth.

Brain Injury, Closed: When a blow or jolt to the head or sudden motion causes the brain to hit the skull and causes damage to the brain.

Brain Injury, Mild: When a brain injury causes the Glasgow Coma Scale to fall between 13-15, and at least one of the following happens: 1) any period of loss of consciousness, 2) any loss of memory for events immediately before or after the accident, 3) any change in mental state at the time of the accident (e.g., feeling dazed, disoriented, or confused), 4) brain, nerve, or spinal dysfunctions which may or may not fade.

Brain injury is only mild where the severity of the injury does not exceed the following: a) loss of consciousness of approximately 30 minutes or less; b) after 30 minutes, an initial Glasgow Coma Scale score of 13-15; c) Post Traumatic Amnesia not greater than 24 hours.

Brain Injury, Traumatic: Damage to living brain tissue caused by an external force. It is usually characterized by a loss of consciousness (amnesia or coma) that can be very brief (minutes) or very long (months or indefinitely). The term does not include brain injuries that are caused by insufficient blood supply, lack of oxygen to the brain, toxic substances, growths or tumors, disease-producing organisms, birth trauma or defects, or degenerative processes.

Brain Stem: The lower part of the brain that connects to the spinal cord. Controls functions that are necessary for survival (breathing, heart rate) and for arousal (being awake and alert).

C

Catheter: A flexible tube inserted into the body. Catheters are used to move fluids into and out of the body or to take measurements.

Central Nervous System: The brain and spinal cord.

Cerebellum: Located in the back of the head; the part of the brain that helps with coordination, accuracy, and timing of movement.

Cerebrospinal Fluid (CSF): A colorless liquid that protects the brain and spinal cord from physical impact or shock. Fluid increases and decreases as space in the skull changes. To make diagnoses, a lumbar puncture (spinal tap) is used to draw CSF for analysis. Some TBIs also require an external ventricular drain to drain excess CSF.

Cervical: The upper part of the spine, located in the neck. This part of the spine sends messages from the brain to control all aspects of the body.

Circumlocution: The use of many words to describe something that could be described with less words. May be used when the specific term is forgotten.

Clonus: Muscle spasm involving repeated, often rhythmic, contractions.

Closed head injury: A trauma to the brain in which the brain is not penetrated by any object.

Cognitive Impairment: Difficulty with basic thinking functions like perception, memory, attention or reasoning.

Cognitive Process: Higher mental functioning such as learning, memory, imagination, comprehension, and decision making. Or, the way an individual becomes aware of people, objects, and situations in the environment and their meaning.

Cognitive Rehabilitation: Provided by a speech pathologist, occupational therapist, or a neuropsychologist. This type of therapy helps to improve independence in daily living skills by teaching patients strategies to overcome thinking difficulties caused by their TBI.

Coma: State of unconsciousness from which the patient cannot be awakened or aroused, even by powerful stimulation; lack of any response to one's environment; defined clinically as the inability to follow a one-step command consistently (Glasgow Coma Scale of 8 or less).

Combativeness: The act of being especially argumentative, fighting off help or medical care, or starting fights.

Communicative Disorder: Problems processing or using hearing, language, and/or speech processes.

Cognitive Dissonance: Inconsistent thoughts, beliefs, attitudes or behavior.

Comprehension: Ability to understand spoken, written, or general communication.

Concentration: Keeping attention on a task over a period of time.

Concrete Thinking: Literal thinking that is focused on the physical world, such as facts about the here and now, physical objects, and literal definitions.

Concussion: Temporary unconsciousness resulting in confusion, altered mental state, or other effects from a blow to the head or sudden jolt of the head. Sometimes the terms "concussion" and "mild TBI" are used to mean the same thing.

Confabulation: Talk about people, places, and events with no basis in reality. May seem to be "made up stories", but this is often an effort to make sense of the environment.

Confusion: A state in which a person is bewildered, perplexed, or unable to self-orient.

Conjugate Movement: Both eyes move simultaneously in the same direction. Convergence of the eyes toward the midline (crossed eyes) is a disconjugate movement.

Continence: The ability to control urination and bowel movements.

Contracture: Loss of range of motion in a joint due to abnormal shortening of soft tissues.

Coup/Contrecoup: Coup is bruising or tissue damage at the point of impact, while Contrecoup is damage to brain tissue on the opposite side from the impact.

Contusion: Bruised or injured tissue or skin.

Cortical Blindness: Full or partial loss of vision from damage to the brain's occipital cortex. This can happen even if the eye is undamaged and functioning normally.

CT Scan/Computerized Axial Tomography: A series of X-rays taken at different levels of the body. For head injuries, it's used to assess the brain, skull, and intracranial structures. A scan is often taken soon after the injury to help decide if surgery is needed. The scan may be repeated later to see how the brain is recovering.

D

Decerebrate Posture (Decerebrate Rigidity): An abnormal body posture, usually from severe brain damage, that involves the arms and legs being held straight out, toes pointed down, and the head and neck arched backward. Muscles are tight and rigid.

Decreased Insight: Patient may not recognize problems he is having or may attempt to rationalize or minimize problems.

Decubitus: Pressure area, bed sore, skin opening, or skin breakdown caused by pressure. The area may be discolored or an open wound.

Demyelination: The loss of nerve fiber "insulation" from trauma or disease, causing issues with nerve impulses and neurological problems.

Depression: A mood disorder that causes a person to be sad, tired, or less motivated to participate in their daily activities.

Diffuse Brain Injury: Injury to a widespread area of the brain.

Diplopia: Seeing two images of a single object; double vision. See also vision after head injury.

Disinhibition (Lack of inhibition): Inability to control impulsive behavior and emotions.

Disorientation: Not knowing where you are, who you are, or the current date. Health professionals often speak of a normal person as being oriented "times three", which refers to person, place, and time.

DLS: Daily Living Skills: Also called Activities of daily living. These are routine activities carried out for personal hygiene and health such as eating, dressing, grooming, shaving, etc.

Dorsiflexion: Bending the ankle to bring the foot back (opposite of pointing the foot and toes).

Dura Mater: The tough outer membrane that covers and protects the brain and spinal cord.

Dysarthria: Difficulty in forming words or speaking them because of weakness of muscles used in speaking. Speech may be slurred and very slow. Voice quality may be abnormal, usually more nasal; volume may be weak; drooling may occur. Dysarthria may accompany aphasia or occur alone.

Dysphagia: Difficulty in swallowing. It also includes difficulty in moving material from the mouth to the stomach. This also includes problems in positioning food in the mouth.

E

Edema: Collection of fluid in the tissue that causes swelling.

EEG (Electroencephalogram): A procedure that uses electrodes on the scalp to record electrical activity of the brain. Used to detect epilepsy, coma, and brain death.

EMG (Electromyography): A test that measures muscle and nerve activity by recording the response to electrical stimulation.

Emotional Lability: Rapid, drastic changes in emotional states. For example, inappropriate laughter, crying, or getting angry for no apparent reason.

Endotracheal Tube: A tube inserted through the patient's mouth or nose. It passes through the throat and into the air passages to help breathing. To do this it must also pass through the patient's vocal cords. The patient will be unable to speak as long as the endotracheal tube is in place. It is this tube that connects a ventilator to the patient.

Euphoria: Exaggerated sense of well-being that may not be based on reality.

Exacerbate: To make something worse.

Executive Functions: The abilities needed to formulate, plan, and carry out actions and self-regulate.

Extended Care Facility-Basic: Residential facility that offers 24-hour nursing, supervision, and assistance with activities of daily life.

Extended Care Skilled Facility: Offers 24-hour nursing, supervision, and assistance with ADLs, as well as various types of therapy and rehabilitation.

Extremity: Describes the outermost, or farthest points. May mean arms and legs, or especially hands and feet.

F

FIM (Functional Independence Measure) Score: A score that describes a person's degree of disability. The scores are often used to track changes during rehabilitation.

Flaccid: Lacking normal muscle tone; limp.

Flexion: Bending a joint.

Foley Catheter: A tube inserted into the bladder for urine collection.

Frontal lobe: Front part of the brain, which is involved in planning, organizing, problem solving, selective attention, personality, and other "higher thinking functions".

Frustration Tolerance: The ability to complete a task despite apparent difficulty. Individuals with a poor frustration tolerance will often refuse to complete tasks which are the least bit difficult. Angry behavior, such as yelling or throwing things while attempting a task, can show poor frustration tolerance.

G

Gainful Occupation: Any type of employment for which compensation is received, including work for which payment is "in kind" rather than in cash.

Gait Training: Gait is another word for walking, so gait training offers instruction on walking (can be with or without assistance or equipment).

Generalization: Being able to take learning from one setting into another (learning to transfer from the wheelchair to the bed in the hospital; then being able to do the same at home).

Gastrostomy Tube (G-Tube): A tube inserted through a surgical opening into the stomach. It is used to introduce liquids, food, or medicine into the stomach when the patient is unable to take these substances by mouth.

Glasgow Coma Scale (GCS): A system used to assess the degree of brain impairment and to identify the seriousness of injury in relation to outcome. The system involves three measures: eye opening, verbal responses and motor response. These three measures are given a score that tells the level of consciousness and degree of dysfunction. Scores range from a high of 15 to a low of 3. Persons are considered to have experienced a 'mild brain' injury when their score is between 13 and 15. A score of 9 to 12 is considered to reflect a 'moderate' brain injury and a score of 8 or less reflects a 'severe' brain injury.

Grief Process: Emotional responses to grief which progress from alarm to disbelief and denial, to anger and guilt, to finding a source of comfort, and finally to adjustment.

H

Hematoma: Collection of blood clotting in tissues following the rupture of blood vessels.

Types include:

- ***Epidural Hematoma—***outside the brain and its fibrous covering but under the skull.
- ***Subdural Hematoma—***between the brain and its fibrous covering (dura).
- Intracerebral Hematoma—in the brain tissue.
- ***Subarachnoid Hematoma—*** around the surface of the brain, between the dura and arachnoid membranes.

Hemianopsia/Hemianopia: Loss of vision for one half of the field of vision, not from actual blindness but from processing problems in the brain. The issue is not for the entire right or left eye, but for the right or left half of vision in each eye.

Hemiparesis: Weakness, paralysis or loss of movement on one side of the body.

Hemiplegia: Paralysis to one side of the body, due to injury of the neurons that carry signals to the muscles from the motor areas of the brain.

Hemorrhage: A ruptured blood vessel that causes heavy bleeding.

Heterotopic Ossification (HO): Extra knot-like bone that sometimes forms in the soft tissue after an injury. It can decrease range of motion and flexibility or it can cause pain.

Hoyer Lift: A type of equipment used to transfer a person from a bed to a wheelchair or commode.

Hydrocephalus: Too much fluid in the brain, causing increased pressure in the skull.

Hypoxia: A decrease in the amount of oxygen reaching the tissues of the body.

I

Impulsivity: Acting without thought or acting too quickly, which can lead to errors, difficulties, or accidents.

Incontinence: When a person cannot control bowel and bladder functions. Many people who are incontinent can improve control with training.

Informed Consent: The patient's right to know the risks and benefits of a medical procedure.

Intracranial Pressure (ICP): The pressure inside the skull, around the brain. Too much pressure can be life-threatening.

Intracranial Pressure Monitor: A device used to measure the ICP (pressure in the skull) with a small tube (catheter) attached to the skull and a transducer to register the pressure.

Ischemia: Low blood flow to an organ or part of the body that may cause an oxygen shortage, resulting in tissue damage.

J

Judgment: Using information to make a decision that is safe and appropriate for the situation.

K

Kinesthesia: Awareness of how body parts feel as they move.

L

Emotional Lability: Obvious, sometimes extreme or sudden changes in a person's emotional state (e.g., uncontrolled laughing or crying)

Lack of Inhibition: Some brain injuries impair the systems that monitor the brain. A person may no longer seem to care about society's idea of proper behavior, or they may be very angry and hostile, use profanity frequently, or make inappropriate sexual remarks.

Lack of Initiation: The person may find it very difficult to initiate action, even though he may know what to do.

Lateral: Side.

Leg Bag: A small, thick plastic bag that can be tied to the leg and collects urine. It is connected by tubing to a catheter inserted into the urinary bladder.

Lesion: Another word for bruise or wound.

Locked-in-Syndrome: A disconnection of the motor cells in the lower brain stem and spinal cord from controlling signals issued by the brain leaves the patient completely paralyzed and mute, but able to receive and understand sensory stimuli. Communication may be possible by code using blinking or movements of the jaw or eyes.

Lumbar: The lower part of the spine, below the thoracic.

M

Magnetic Resonance Imaging (MRI): A machine that uses electromagnetic energy to create pictures of a person's soft tissue, central nervous system, and musculoskeletal systems.

Malingering: To pretend to be unable to do something to avoid work or duties.

Memory: Knowing information from the past and day-to-day. Problems with memory are common after head injury

Memory, Episodic: Memory for ongoing events in a person's life. Sometimes this is more easily impaired than semantic memory, perhaps because it has been repeated less.

Memory, Immediate: The ability to recall numbers, pictures, or words immediately following presentation. Patients with immediate memory problems have difficulty learning new tasks because they cannot remember instructions.

Memory, Long Term: In neuropsychological testing, this refers to recall thirty minutes or longer after presentation. This type of memory requires mental storage and retrieval of information.

Memory, Semantic: Part of the long-term memory that recalls ideas and concepts that are common knowledge, such as the names of colors, the sounds of letters, the capitals of countries and other basic facts acquired over a lifetime.

Memory, Short Term: Primary or 'working' memory, its contents are in conscious awareness—A limited capacity system that holds up to seven chunks of information over periods of 30 seconds to several minutes, depending upon the person's attention to the task.

Motor Control: The ability to contract or relax a particular muscle or group of muscles.

Muscle Tone: The amount of tension in a muscle at rest. Tight muscles are described as having high muscle tone, and floppy muscles are described as having low tone.

Myelin: The fatty white material that insulates nerves and is essential for proper nervous system function.

N

Nasogastric Tube (NG tube): A tube placed through a person's nose and throat to the stomach. This tube allows for direct "tube feeding" to maintain the nutritional status of the person or removal of stomach acids.

Neglect: Paying little or no attention to something. This could refer to a person, place, or even a particular part of the body.

Neologism: Nonsense or made up words, often unrealized by the speaker.

Neurogenic Bladder: A lack of bladder control due to brain, spinal cord, or nerve damage, which may be the result of disease or injury.

Neuropsychologist: A psychologist who specializes in evaluating the brain and behavior and planning training programs to help the survivor of brain injury return to normal functioning. Often works closely with schools and employers as well as with caregivers of the injured person.

Non-ambulatory: Unable to walk.

Nystagmus: Involuntary movement of the eyes.

O

Pictured: Occipital Lobe

Occipital Lobe: The back region of the brain, which processes visual information. Damage to this lobe can result in vision issues.

Olfactory Stimulation: When the sense of smell is stimulated (when a person smells an odor, whether pleasant or foul).

Orientation: Awareness of one's environment or situation and the ability to use this information appropriately in a functional setting. Ex., knowing who you are, where you are, what day it is, etc.

P

Paraplegia: Lower body paralysis. Loss of function begins below the cervical spinal cord, while the upper body is still completely or mostly functional. Degrees of lower limb paralysis may still vary depending on the severity of spinal cord damage.

Parietal Lobe: Part of the brain at the upper back area of the head. It is very involved in processing information from the five senses.

Passive Range of Motion: The amount a joint can move when someone else is moving your limb.

Percutaneous Endoscopic Gastrostomy (PEG) Tube: A tube surgically placed in the stomach for feeding.

Perception: To be able to make sense of what one sees, hears, feels, tastes, or smells.

Perseveration: Repeating a word, gesture, or phrase. This may mean answering a question that is not being asked anymore or responding to something that is no longer happening. It may also mean to ask the same question over and over.

Physiatrist: A doctor who specializes in physical medicine and rehabilitation.

Plateau: When a person gets better for a period of time and then stays the same.

Plasticity: The way that the nervous system can rewire itself to get back to normal levels of action after an injury.

Post-Concussion Syndrome: Persistent emotional and thinking problems after a mild TBI that continue past what would normally be expected in recovery. Symptoms may include difficulty thinking and knowing things that a person would have known before the injury, mood changes, sensitivity, anxiety, and physical symptoms, such as headache and dizziness.

Post-Traumatic Amnesia (PTA): A period after a brain injury when the patient loses their short-term memory. They may remember things from before the injury but not new information. This means they cannot learn anything new. Memory of this period is never stored; therefore, things that happened during that period cannot be recalled. See also Anterograde Amnesia.

Posture: The way a person holds their body when standing or sitting.

Pre-morbid Condition: Describes a person before the disease or injury occurred.

Pressure Sore: A discolored or open area of skin damage caused by consistent pressure to an area. Common areas most prone to breakdown are buttocks or backside, hips, shoulder blades, heels, ankles, and elbows.

Problem-Solving: Ability to consider the possible outcomes of different solutions to a problem and to select the most advantageous solution. Individuals with deficits in this skill may become "immobilized" when faced with a problem. In other words, by being unable to think of possible solutions, they may respond by doing nothing.

Prognosis: A doctor's prediction about how the patient will recover from a disease or injury.

Prone: Lying on stomach.

Proprioception: The way people know what the body is doing without thinking about it. For example, if your legs are crossed or your hand is raised, you know that without looking. Damage to the brain can interrupt this sense.

Prosody: Patterns of speech such as rhythm and tone.

Q

Quadriparesis: Weakness in the limbs that causes partial loss of function in all four limbs of the body.

Quadriplegia: Total loss of function in all four limbs of the body. Also referred to as Tetraplegia.

R

Rancho Los Amigos Scale: Measures the level of awareness, behavior, and thought function in a brain injury survivor.

Range of Motion (ROM): The amount a person is able to move any part of the body in any direction.

Reasoning: Ability to think and process information. Processing involves taking in information from the environment, remembering it, understanding it, breaking it down into parts and using these parts separately or in combination with other knowledge.

Reasoning, Abstract: Ability to think and process words with multiple meanings, or to process ideas or information about something that cannot be seen.

Reasoning, Concrete: The ability to understand the literal meaning of a phrase.

Reasoning, Sequencing: The ability to organize information or objects in the mind. Nearly every activity, including work and leisure tasks, requires sequencing. For example, when cooking certain foods, ingredients must be added and mixed in a specified order; in dressing, undergarments must be put on prior to outer garments.

Regeneration: The regrowth and healing of nerves. This can help a person restore function after a brain or spinal injury.

Respite Care: When someone takes care of a person temporarily, to give the usual caregiver time off or time to rest.

S

Seizure: A sudden increase in electric activity in the brain, which changes how someone looks or acts for a period of time. Seizures can take different forms, such as violent shaking, repeated movements, or even just a period of "zoning out" or looking blank.

Selective Attention: Being able to focus on one thing even when several things are happening at the same time.

Selfishness: Injury may cause the person to be very wrapped up in themselves, often to the point that caregivers think the patient is unfeeling.

Sensation: A physical or emotional feeling.

Sensorimotor: Refers to all aspects of movement and sensation and the interaction of the two.

Sensory Integration: Interaction of two or more sensory processes in a manner that enhances the adaptiveness of the brain.

Sequencing: Reading, listening, expressing thoughts, describing events or contracting muscles in a certain order or meaningful manner.

Shunt: A tube used to drain fluid from the brain or to balance pressure around the spine.

Spasticity: When muscles have more tone and tightness, causing them to react strongly to reflexes. This may make movements appear jerky.

Spatial Ability: Skills that help people to understand the spatial relationship between objects and oneself. Includes being able to visualize objects, understand distances between objects, and one's own placement in a space.

Subdural: Beneath the dura (tough membrane, shell), which covers the brain and spinal cord.

T

Tactile Defensiveness: Being overly sensitive to touch by withdrawing, crying, yelling, or striking when one is touched.

Temporal Lobes: The parts of the brain on either side near the ears, which help with smell, sound, language, emotion, and short-term memory.

Thoracic: The part of the body between the neck and belly.

Tilt Table: A table that can lower or raise a person from standing to lying down or vice versa. Often used to diagnose fainting or balance issues.

Tracheostomy: An opening cut into the front of the throat to help with breathing.

Tracking, Visual: Visually following an object as it moves through space.

Tremor, Intention: Trembling or shaking of a part of the body when making a difficult or precise movement.

Tremor, Resting: A shaking of the limbs, even when a person is at rest.

Trunk Control: The ability to move the head, shoulders, and pelvis in and out of various postures or to simply keep them aligned.

U

Unilateral Neglect: Paying little or no attention to things on one side of the body. This usually occurs on the side opposite from the brain injury. In extreme cases, the patient may not bathe, dress, or acknowledge one side of the body.

V

Ventilator: Machine that helps an individual to breathe and gives oxygen to the body.

Verbal Apraxia: When a person loses some or all control of proper sequencing of the muscles used in speech (tongue, lips, jaw muscles, vocal cords). These muscles are not weak, but their control is defective. Speech is labored, characterized by sound reversals, additions, and word approximations.

Vestibular: Describes issues in the inner ear, which helps with balance and movements of the head.

W

Whiplash Injury: An injury to the neck from a violent back and forth movement of the head and neck such as in a rear end car collision. Such injuries sometimes cause brain damage.

Withdrawal: A response to physical danger or severe stress characterized by a state of apathy, lethargy, depression, and retreat into oneself.

X

Y

Z

Information contained in this resource guide is not meant to replace or substitute advice from a medical professional. Always consult your doctor and qualified health care professionals regarding specific medical concerns or treatment.

Section 7: Notes and Logs

We have set aside a place for you to keep track of important information. The first few pages are pre-made logs, and then you will find blank space where you can create your own lists.

Log for tasks assigned to family and friends

Task	Assigned to	Date	Status

Log for communication with medical staff

Question	Answer	date/name of staff

Log for names of medical staff

Staff name	Title/ Responsibility	Best contact	When/how often they visit

Patient Progress log

Date	What did you observe? Where did it take place?	Date reported to staff

Medication Log

It may be helpful to keep track of all medications in one place. You may want to track what is given by nurses in the hospital, so you are able to ask questions about changes. You may want to continue to use this list at home and take it to doctors appointments.

Date	Name of Med	Dosing and special instructions	Take until	Side effects

You may have other questions you want to ask your family member's doctor. Use the table below to write them down to help you remember.

Your question	Answer from the doctor: