

Traumatic Brain Injury Rehabilitation

Patient and Family Guide



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Introduction

You are receiving this book because your loved one has suffered a traumatic brain injury (TBI) and has qualified for inpatient rehabilitation in the WakeMed Rehabilitation Hospital or outpatient rehabilitation in one of WakeMed's outpatient rehab facilities. This book includes basic information about TBI, what to expect during the rehabilitation process with the WakeMed Rehabilitation team and how you can help your loved one and yourself throughout the healing process.

Follow the treatment team's recommendations to remain hopeful and positive throughout this journey of recovery. Learn all you can about your loved one's needs to help them improve.

TBI has a dramatic impact on both patients and their family members. Please know that your loved one's treatment team members are happy to answer your questions, address your concerns and offer resources to help you and your family cope with the fear, stress and emotional exhaustion that a medical crisis can cause. They are here for you and your loved one!

How serious is a traumatic brain injury?

Every brain injury is different. The severity of a TBI can vary from very mild to severe.

- A mild traumatic brain injury usually means that a patient will recover over time and may experience little to no disruption to normal activities.
- A moderate-to-severe injury will likely result in long-term changes in the patient's functioning, but the degree and type of difficulties cannot be predicted during the early stages of recovery. The long-term effects of the TBI will become more apparent over time.

What can I do to help my loved one?

Follow the recommendations of the treatment team to remain hopeful and positive. Learn all you can about your loved one's needs, so that you can help them improve over time.

Types of traumatic brain injuries

People often refer to a traumatic brain injury as a head injury. A TBI is actually a specific type of injury that results from a forceful blow to the head – a head trauma – not a stroke or brain tumor. The focus of this book is specifically on TBI.

TBIs can vary from very mild to severe.

- **Mild TBI** -- A patient will recover over time with little or no long-term side effects.
- **Moderate to Severe TBI** – The injury will have long-term effects on the way a patient functions (movement, thinking, behavior, etc.). The degree and type of difficulties a patient has cannot be predicted during the early stages of recovery. The long-term effects will become more obvious over time.

The changes a person experiences after a TBI depend on the severity, type and location of the damage to the brain. The brain works as a system; no part of the brain operates independently. Therefore, an injury to one part of the brain often affects how other parts of the brain work. For example, when one part of the brain stops working properly, other parts of the brain may gradually try to compensate – do the work for the damaged part of the brain. TBI recovery can take a long time and varies from one person to another.

Understanding the Brain: Brain Structure & Organization

It is important to first understand the structure of a healthy brain to then understand how a TBI affects a person's ability to physically, verbally and mentally function.

Left side

- Sensory stimulus from right side of the body
- Motor control of right side of the body
- Speech, language and comprehension
- Analysis and calculations
- Time and sequencing
- Recognition of words, letters and numbers



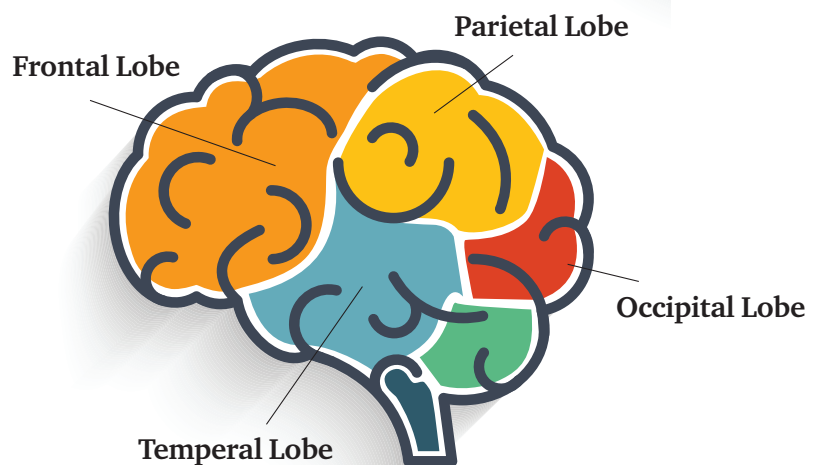
Right side

- Sensory stimulus from left side of the body
- Motor control of left side of the body
- Creativity
- Spatial ability
- Context / perception
- Recognition of faces, places and objects

Lobes of the brain

At the basic level, the brain has four distinct sections known as lobes that controls different functions:

- The **Frontal lobe**, referred to as the “executive” of the brain, oversees and controls other brain functions. When a frontal lobe is injured, we often talk about a person having “executive deficits.” This means they may have trouble with the following symptoms:
 - Difficulty paying attention, planning and organizing
 - Impulsive behavior, such as doing something without thinking about the consequences or safety of that action
 - Changes in personality or behavior, including an increase in risk-taking behaviors
 - Lack of awareness or insight into their situation and why they are acting differently
 - Changes in social skills and sexual behavior, such as making rude comments
 - Changes in emotions, such as becoming agitated more easily
 - Lack ability to “filter” what they say, leading them to say or do things out of character for them

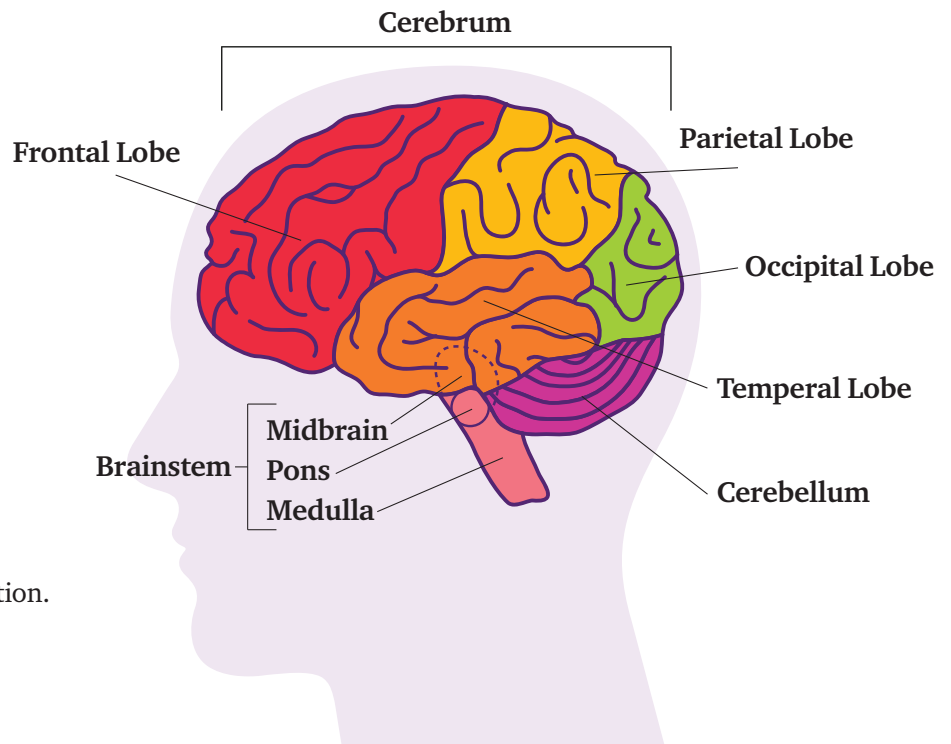


These changes are often outside the person’s control. They may not be able to understand the impact their behavior has on others.

- The **Parietal lobe** integrates our five senses: touch, smell, taste, hearing and vision. The parietal lobe helps with spatial perception, such as knowing where our bodies are in relation to other objects, perception of touch or sensations, the ability to focus visually and the ability to identify colors, shapes and sizes. Damage to this lobe can result in the following effects:
 - **Spatial inattention** – not paying attention to activity happening on the left or right side. For example, someone with left spatial inattention may not notice objects placed on the left side of a table or may frequently bump into things on the left side.
 - **Spatial localization** – difficulty visually scanning to find an object.
- The **Temporal lobe** is involved in memory, learning new information, language skills and the concept of time. Deficits due to damage to the temporal lobe vary based on whether it is the right or left side of the brain that is affected, but may include:
 - Trouble learning and recalling new information
 - Difficulty finding the right word or using incorrect words
- The **Occipital lobe** is located in the back of the brain and helps to interpret visual information and make sense of what we see. Damage to this part of the brain can result in:
 - Limited ability to identify objects that are seen
 - Visual problems, such as inability to identify colors and trouble recognizing words on a page

How the lobes of the brain function

FRONTAL LOBE	TEMPORAL LOBE	PARIETAL LOBE	OCCIPITAL LOBE
Thinking <ul style="list-style-type: none"> • Attention • Reasoning • Problem Solving • Planning • Organizing 	Hearing <ul style="list-style-type: none"> • Recognizing sounds (R) • Recognizing words (L) • Music (R) 	Feeling <ul style="list-style-type: none"> • Understanding pressure, touch, pain • Recognizing things from touch alone 	Seeing <ul style="list-style-type: none"> • Receive and interpret visual information • Recognizing simple shapes
Language (L) <ul style="list-style-type: none"> • Saying words • Stringing words together 	Language (L) <ul style="list-style-type: none"> • Hearing words • Recognizing words 	Language (L) <ul style="list-style-type: none"> • Understanding what words mean • Control of reading 	Language (L) <ul style="list-style-type: none"> • Recognizing letters and words
Doing Things <ul style="list-style-type: none"> • Initiation (getting yourself started to do something) • Doing things in the right order • Speaking (L) 	Memory <ul style="list-style-type: none"> • Remembering past events • Learning new things • Remember words or verbal information (L) • Remembering pictures or shapes (R) 	Space <ul style="list-style-type: none"> • Knowing where you are in space • Paying attention to left and right sides of space 	
Self-Control <ul style="list-style-type: none"> • Muscles • Behavior • Emotion • Frustration 			Key (L) = left side of brain (R) = right side of brain



Brainstem Structures

In addition to the four lobes that make up the “cortex” (outer area of the brain), there are additional components that can be injured during a TBI, including:

- **The Cerebellum** - involved in balance, posture, and coordination. Damage can result in:
 - Difficulty walking
 - Tremors
 - Vertigo and dizziness (even when not moving)
 - Visual difficulties such as eyes moving back and forth rapidly
 - Some aspects of attention and language
- **The Pons** - links the cerebellum to the rest of the brain and is involved in control of sleep and arousal. Damage can result in:
 - Difficulty with balance
 - Vertigo
 - Trouble swallowing
 - Uncoordinated eye movements
 - Difficulty articulating words
- **The Medulla** - controls breathing, blood pressure, heart rate and swallowing. Damage can result in:
 - Hiccups
 - Absent cough or gag reflex

Prognosis/Neuroplasticity

Recovery from a TBI also depends on neuroplasticity, the brain’s ability to form new connections and adapt to changes in the environment to compensate for the injury. Neuroplasticity involves learning based on experience. Rehabilitation therapies provide learning opportunities through structured sensory input (stimulating the senses) and motor output (movement produced as a response to sensation) that enable your brain to relearn and remap information as it heals. A rehab therapist guides your loved one’s journey on the road to recovery.

TBI recovery is a process and the focus should be on the journey of recovery – not just the final outcome.

Severe TBI

The most severe TBIs are often referred to as “disorders of consciousness” or lacking awareness of self and environment. There are a number of terms used to describe reduced levels of consciousness and severe brain injury:

- **Coma** is the most severe level of impaired consciousness. Patients do not open their eyes, follow commands or display purposeful movement or behavior.
- Patients in a **vegetative state** can have open eyes and their sleep/wake cycle may be active. They do not respond, either spontaneously or to stimulation, follow commands, communicate or display purposeful movement or behavior. They may show reflexive movements such as posturing (involuntary muscle contraction) or withdrawal.
- **Minimally conscious state** is when patients begin to display meaningful and purposeful responses. This state is often first observed as a response to a command that can be clearly repeated. These patients are still extremely limited in their ability to communicate or move in a normal capacity.

Possible Medical Complications

Other medical issues may occur with a TBI, including:

- **Cardiovascular issues** - related to the heart and blood flow
- **Seizures** - abnormal electrical activity in the brain
- **Infections** - contamination with an infectious agent
- **Hydrocephalus** - increased fluid on the brain

The treatment team can provide more information about complications, including how they are treated and how they affect recovery.

Medications for TBI

During the recovery process, physicians may prescribe a variety of medications for different purposes. Some are prescribed for medical purposes, such as to control seizures, while others may be prescribed to manage TBI symptoms, such as agitation, uncontrolled emotions or alertness. Here are some types of medications that may be recommended. Speak to the attending physician if you have questions about the medications prescribed for your loved one.

Medications Used during Recovery after Traumatic Brain Injury

TYPE OF MEDICATIONS	EXAMPLES	PURPOSE
Anti-depressants	Prozac, Zoloft, Lexapro, Paxil, Celexa, Wellbutrin, Effexor, Cymbalta, Luvox & more	Helps to stabilize mood by increasing available neurotransmitters in the brain which can be decreased after brain injury
Anti-psychotics	Haldol, Abilify, Risperal, Zyprexa, Seroquel & more	Manage agitation following brain injury
Mood Stabilizers	Depakote, Tegretol, Lamictal & more	Manage agitation and aggression following brain injury
Stimulants	Ritalin, Provigil, Nuvigil & more improve focus and concentration	Increase alertness, manage fatigue and improve focus and concentration
Anti-convulsants	Depakote, Lamictal, Dilantin, Keppra	Manage seizures, have a calming effect and minimize agitation

Understanding Changes after TBI

Patients may experience many physical, cognitive, behavioral and emotional changes after a TBI. Some symptoms improve as the brain heals; others may not. Every patient recovers differently. Complete recovery, meaning the patient returns to the level of functioning and independence they had before the TBI, is often unrealistic. It is very difficult for rehabilitation professionals to predict how well a person will recover after a TBI because the brain is so complex. How well a patient recovers after TBI depends on many factors such as:

- Severity and location of the injury
- Pre-injury condition
- Personality
- Learning style
- Family dynamics
- Relationships

In any case, we know the recovery process is slow and requires patience.

Here are some of the changes your loved one may experience throughout their recovery.

Physical Changes

The most common physical changes that occur after a TBI are related to the patient's:

- **Balance** - the ability to stay upright without falling over
- **Strength** - muscle power
- **Coordination** - multiple body parts smoothly working together in harmony

Other, less outwardly visible physical changes can also occur:

- **Fatigue** – Fatigue is especially common in the early stages of recovery. For some people, staying awake can be challenging. Others may be inattentive or drowsy. The ability to pay attention and alertness typically improve as the brain recovers.
- **Sensory Changes** – Sound, touch, taste and smell may be different after a TBI. Vision changes may also occur. Double vision (seeing two images of the same thing) and trouble with peripheral (side) vision are common after a TBI.
- **Spasticity** – The brain sends messages through the spinal cord and nerves. These messages then reach the muscles, causing them to contract or relax. After a TBI, the messages exchanged between the brain and muscles can get mixed up, causing unwanted muscle contractions known as spasticity. People with spasticity may feel like their muscles have contracted and will not relax or stretch. They may also feel muscle weakness, loss of fine motor control (the inability to make small, exact movements, such as picking up small objects) and overactive reflexes.

Cognitive Changes

Cognition is a term used for thinking skills, which include memory, language skills, the ability to pay attention and more. Cognitive changes are usually present after TBI and may include problems with:

- **Memory**
 - Short-term, day-to-day memory is poor. Long-term memory (recalling things from the past) is usually good.
 - Learning new information
 - Filling in memory gaps with incorrect information (seems like they are making things up)
- **Language**
 - **Expressive language** – cannot “find the correct words” or uses the wrong words
 - **Receptive language** – slower or unable to understand what someone is telling them
 - **Processes language at a slower rate** – trouble understanding when others express long or complex thoughts

- **Visuospatial**
 - Difficulty making sense of what they see
 - Spatial orientation – unable to understand where they are in their current environment
- **Executive**
 - Trouble paying attention or blocking out distractions
 - Mental flexibility or ability to manipulate information is impaired
 - Cannot plan and organize
 - Processes new information more slowly
 - Slower verbal and physical/movement responses

These cognitive changes can be frustrating and challenging for both the patient and family members. We also find that persons with moderate to severe brain injuries often mentally fatigue easily, so we encourage maintaining a low-stimulation environment: low light, quiet environment (no video, music, loud voices, etc.) and limited distractions and visitors. If this is appropriate for your loved one while in the hospital, the physician will put in an order for a Low Stimulation Environment (LSE), so that all staff will work with you to minimize noise and distractions as much as possible in the hospital. In an outpatient setting, this means that the staff will try to work in a quieter environment whenever possible.

Behavioral and emotional changes

Behavior or how one acts or conducts oneself, can change dramatically after a TBI. Changes in how a person behaves toward others is often the most apparent. These changes may be a temporary part of the recovery process or they may be longlasting.

Personality can also affect a patient’s predisposition to feel certain emotions. After injury, a patient in recovery may have more trouble controlling emotions or instead show little emotion (referred to as flat affect). Common emotional and behavioral changes include:

Depression	Feeling sad, down or irritable
Anxiety	Feeling nervous, agitated, jittery or worrying
Flat Affect	Showing little or no emotional expression
Emotional Lability	Crying or laughing easily, but the person does not feel the emotion as strongly as they are showing it
Decreased Frustration Tolerance	Getting upset easily when things do not go smoothly, often out of proportion to the situation
Impatience	Easily upset when there is a slight delay
Short-temperedness	Getting angry more quickly than usual
Impulsivity	Taking action or making decisions without awareness of or thinking about safety or consequences
Disinhibition	Lacking a filter or understanding appropriate behavior
Aggression	Either physically or verbally attacking
Understanding Emotions	Being able to recognize and appreciate what others are feeling

How the Treatment Team Communicates

As mentioned, numerous changes can occur after a TBI. To help the treatment team track a patient's cognitive and behavioral recovery, the rehab staff uses a tool to communicate some of these changes: the Rancho Los Amigos Scale of Cognitive Functioning, often referred to as the Rancho Level or RLA. The treatment team uses the Rancho Level Scale as an easy way to tell other team members about a patient's current response level.

The Rancho Los Amigos Scale of Cognitive Functioning

Rancho I	Does not respond to external stimuli when IV sedation is paused.
Rancho II (Total Assistance)	Generalized responses to external stimuli.
Rancho III (Total Assistance)	Localized response to stimuli. Increased periods of being awake.
Rancho IV (Maximal Assistance)	Confused/Agitated. Short attention span. Easily distracted.
Rancho V (Maximal Assistance)	Confused/Inappropriate/Non-Agitated. Short-term memory is poor; may fill in gaps with inaccurate information. Agitated when over stimulated. May be impulsive and/or overestimate independence.
Rancho VI (Moderate Assistance)	Confused/Appropriate. May remain impulsive. Easily confused by changes in routine. May require help to perform ADLs. May have trouble organizing thoughts or remembering new information.
Rancho VII (Minimal Assistance for Daily Living Skills)	Automatic/Appropriate. Cognitive function intact for simple activities, but memory or other cognitive issues likely persist. Learns information at a slower rate.
Rancho VIII (Stand-by Assistance)	Purposeful/Appropriate. Oriented, able to recall/integrate past and present events. May overestimate or underestimate abilities. Needs some help recognizing the need to learn ways to compensate for their deficits.
Rancho IX (Stand-by assistance by request)	Purposeful/Appropriate. Asks for help as needed. Aware of deficits and able to correct/compensate, but needs assistance to anticipate problems.
Rancho X (Modified Independent)	Purposeful, Appropriate. Can multitask, but needs periodic breaks. Recognizes impact of areas of impairment and can independently compensate for shortcomings or ask for more time. Estimates abilities accurately.

Some patients may move quickly from one Rancho Level to the next or can demonstrate characteristics of more than one level at a time. Depending on the extent and severity of injury, they may remain at one level for an extended period of time or never move past a level. Not everyone starts at Level I (one) nor does everyone make it to Level X (ten).

Safety after a TBI

Many changes that occur with brain injury can at times cause safety risks to the individual and others. Some TBI patients lack awareness or understanding of how their brain is different. After a TBI, they can act in ways that are impulsive or put them at risk, such as trying to leave the hospital. If this occurs and we feel that the individual is not capable of making the decision to leave, we can implement some safety features. In the

rehabilitation hospital, we may use Safety Awareness for Everyone (SAFE). The SAFE system allows us to more closely monitor TBI patients to assure they do not attempt to leave the hospital. An electronic bracelet sounds an alarm if a patient goes past certain exit points.

During hospitalization, constant observers (commonly referred to as “sitters”) may be used to ensure patient safety. This service is useful for patients who are physically able to move around easily, but are still confused or don’t understand the seriousness or the safety factors associated with their condition. For those who are more limited physically but need to be monitored for safety purposes, we use an electronic remote constant observer called AvaSys. An AvaSys is simply a camera in the patient’s room. A staff member in another part of the hospital monitors the patient to make sure they are safe.

Rehabilitation Services for TBIs

WakeMed’s rehab programs are based on person-centered care, a treatment philosophy that gives patients and their families the ability to help guide the rehabilitation team so they can focus on what is important to the patient based on values, preferences and desired outcomes.

One symptom of brain injury is impaired self-awareness or lacking the ability to recognize deficits or problems caused by the injury. This lack of awareness makes rehab challenging because it can cause some patients to resist treatment or refuse therapy. Therefore, part of the focus of rehab is to help improve this self-awareness to help the patients understand the importance of actively participating in their own person-centered care.

All members of the rehab team (nurses, therapists, physicians, case managers, neuropsychologists and other specialized providers as well as the patient and family) work together to provide the best possible care. When the rehabilitation process begins, each team member will meet with the patient or family member to do an initial assessment and develop specific goals. The team then develops an individualized treatment plan to help patients reach their goals. As part of the person-centered care, we encourage the patient and family to provide input on goals.

TBIs in Children and Adolescents

Just like adults, outcomes after a TBI in children and adolescents depend on many factors. For pediatric patients, the age at the time of injury and the child’s level of development are important factors, as well as the nature and extent of the injury.

Previously children were believed to “bounce back” more easily than adults after a TBI. However, we now realize this may not be true. While children can be quite resilient and may recover previously learned skills quite well, they may struggle more with skills that they have not acquired yet. For example, a 5-year-old with a moderate-to-severe TBI who has mastered tying her shoes before the TBI may easily recover that skill. But learning a new skill after suffering from a TBI can be more challenging, such as learning motor skills to play soccer. This is thought to be due to the relation between brain maturity and injury.

For children with mild traumatic brain injury or concussion, returning to play in organized sports requires medical clearance by a physician. For children with a moderate-to-severe TBI, this holds true as well but may require more attention and time from the rehabilitation staff and neuropsychologist who is working with the child.

Return to school or “return to learn” refers to when a child is ready to resume school-related activities. The timing will vary based on the child, their injury and recovery. While it is important for children not to fall behind in school, we also want them to be ready for academic studies. The rehab team and neuropsychologist provide guidance about when a child is ready to return to school.

Impact on family members

Traumatic brain injuries can affect the patient's entire family. Many family members and friends struggle emotionally during the early stages of recovery after a loved one suffers a moderate-to-severe brain injury. Frustration, anger, sadness and denial are all common reactions. Feelings may be overwhelming. A sense of isolation is also common, despite having support of other family members and friends. Your loved one's treatment team members understand these feelings and can help.

Expect both good and bad days. Several days of progress may be followed by days of agitation, confusion or medical complications. Try to stay positive on the bad days and know that better days will come.

Your Role in Your Loved One's Recovery

People cope with stressful situations differently. What works for one person may not work for another. We hope some of these suggestions will help you get through this difficult time.

- **Contact person** – Select a primary contact and identify that person to the staff so decisions about medical care, permission forms and information are guided appropriately through a central source. This procedure will help ensure privacy as well as accuracy of information shared.
- **Express your feelings** – You will draw more support from those around you than you realize. Talk about both positive and negative feelings with family, friends and staff. Discuss your loved one's progress with staff and feel free to ask questions.
- **Be kind to yourself** – Take time for a walk outside or leave the hospital for lunch or dinner with a friend. Go home for a restful night's sleep. By taking care of yourself, you'll be better prepared to care for your loved one.
- **Journal or notebook** – Write important information or thoughts in a journal or notebook. Also, try to keep records and information together in a single file for easy access. After recovery, patients and family often find this information helps put their situation in perspective.
- **Rotate family visitation** – If you need or want to leave the hospital, you could ask a friend or family member to stay with the patient. Also, remember to limit visitation at the advice of the staff, especially if the patient is agitated or restless.
- **Voicemail/ social media updates**– Change the message on your voicemail or home answering machine to include updates for friends, church members or family. You may want to consider having a friend or family member set up an email or website to communicate information to loved ones and friends or provide frequent updates on social media depending on the patient's comfort level with sharing of their information.
- **Talk positively to your loved one** – When speaking, assume the patient can understand what you are saying. Speak in a comforting and familiar way, even if the patient is “unconscious.” Tell stories about family activities, like the children at school, fun things they are doing, etc. If your loved one has a favorite location or a restful place, like the beach or mountains, talk about it in very descriptive words. Read to them from favorite books.
- **Touch** – Touch is a very personal and meaningful therapy, especially the touch of a loved one. It can be relaxing and therapeutic. You can rub your loved one's hands and feet with lotion which the staff will give you.
- **Pictures** – Bring pictures of your loved one so that the staff will know how they looked before the injury. You may also bring pictures of family and friends to place on the patient's board. Please label the pictures with names so the staff can use them to talk with your loved one and call people by name.
- **Music/messages** – As the patient becomes more stable, music has been found to be soothing. You could bring in some favorite music or you could record messages from family members, including small children, for your loved one to hear.

Understand that every patient is different and that staff is trying their best to adapt to your loved one's needs. We respect your knowledge about the patient's emotional and physical needs and encourage your participation.

There are many services available to you and your family for support, including nurses, physicians, social workers, chaplains, trauma specialists and child life specialists. We can help you contact any of these staff members as needs arise.

How Families Can Help

Family involvement throughout the patient's medical and rehabilitation journey is important. The following guidelines will be particularly helpful for during the early stage of rehab:

- **Avoid overstimulation:** This is especially important in the early stages. A person who is tired or physically weak fatigues quickly and overstimulation may increase agitation and confusion. A low stimulation environment promotes recovery.
- **Use the familiar:** Patients with short attention spans are more likely to focus on something familiar and comfortable rather than something new and strange. Play familiar music or bring in objects or pictures that will be familiar to your loved one.
- **Be consistent:** Develop a routine as much as possible. Following a daily routine in the early phase of recovery can be challenging in a hospital setting but may help your loved one become better oriented to their environment and feel more secure.
- **Wash hands:** The risk of infection is high for TBI patients. Please help us reduce the risk of infection by washing your hands before you touch your loved one. Avoiding visiting if you are sick and ask others to do the same.
- **Stay calm:** Be the role model for your loved one. Interact with your loved one and staff in a calm manner, even when situations become frustrating. If you become upset, this may trigger your loved one to become agitated as well.
- **Peer support:** A visit from someone who has experienced or has a loved one with a TBI can be helpful for some patients. If you are interested, talk with your treatment team about WakeMed's Peer Support Program.
- **Education:** Educate yourself about TBIs and the impact on the person and the family. WakeMed had written materials available (ask any member of your treatment team) as well as a class that meets in the 2C Dining Room of the rehabilitation hospital.

TBI Resources

Books That May Help You Understand TBI:

Where Is the Mango Princess: A Journey Back from Brain Injury

By Cathy Crimmins

A Hard Chance: Sailing into the Heart of Love

By Tom Gallant

No Stone Unturned: A Father's Memoir of His Son's Encounter with Traumatic Brain Injury

By Joel Goldstein

Life Out of Order

By Sally Laux

Rise and Shine

By Simon Lewis

Head Cases: Stories of Brain Injury and Their Aftermath

By Michael Paul Mason

Over My Head: A Doctor's Own Story of Head Injury from the Inside Looking Out

By Claudia Osborn

Successfully Surviving a Brain Injury: A Family Guidebook, From the Emergency Room to Selecting a Rehabilitation Facility

By Garry Prowe

Learning by Accident

By Rosemary Rawlins

Crash: A Mother, a Son and the Journey from Grief to Gratitude

By Carolyn Roy-Bornstein

To Love What Is: A Marriage Transformed

By Alix Kates Shulman

I'll Carry the Fork

By Kara Swanson

In an Instant: A Family's Journey of Love and Healing

By Lee and Bob Woodruff

If you would like more info regarding resources, talk with the Case Manager. In addition, there is a list of books on the Brain Line website (www.brainline.org).

Other Resources

Brain Injury Association of North Carolina

Brain Injury Association of North Carolina (BIANC) has five regional Brain Injury Resource Centers. Support groups across the state offer persons with brain injury and their family members opportunities to meet others in similar circumstances.

Contact BIANC to locate a support group near you.

NC Family Hotline BIANC: 1-800-377-1464 Website: www.bianc.net

Brain Injury Resource Center - Raleigh

P.O. Box 97984

Raleigh, NC 27624

919-833-9634

Brain Injury Resource Center - Charlotte

Carolinas Rehabilitation

1100 Blythe Boulevard

Charlotte, NC 28203

704-960-0561

Brain Injury Resource Center - Greenville

P.O. Box 2743

Greenville, NC 27836

252-717-3347

Brain Injury Resource Center – Asheville

CarePartners Rehabilitation Hospital

68 Sweeten Creek Rd.

Asheville, NC 28803

828-277-4868

Brain Injury Resource Center – Winston-Salem

Wake Forest Baptist Health
Sticht Center - 3rd Floor
Medical Center Drive
Winston-Salem, NC 27157
336-713-8582

Brain Injury Association of America

1608 Spring Hill Road, Suite 110
Vienna, VA 22182
National Family Helpline: 1-800-444-6443
www.biausa.org

Triangle Brain Injury Support Groups**TBI/ABI/Stroke Support Group Cary, NC**

1st Monday of each month
6:30 – 8 pm
WakeMed Cary Hospital
Conference Center Board Room
1900 Kildaire Farm Road
Contacts: Norman Case:
(919) 244 – 6221 norman.case.soaringeagle@gmail.com and Brooke Hinnant brookewhinnant@gmail.com

Triangle Brain Injury Support

WakeMed Raleigh Campus
3000 New Bern Avenue
Raleigh, NC 27610
Conference Dining (1st floor)
3rd Tuesday of each month
6:30 – 8 pm
Contact: Chelsea Gettle
(919) 781 – 3616 x227 cgettle@communitypartnerships.org
Note: this group has a Brain Injury Family/Caregiver Group that meets at the same time.

- Resources for Seniors (919-872-7933) maintains a list of caregiver and other specific support groups. Call for more information.
- TapNet (919-800-8047) www.aphasiaproject.org
Support group for families/caregivers of individuals with aphasia.

National Support and Education Organizations

While You Are Waiting

www.waiting.com

Basic education about traumatic brain injuries. Helpful for families during early stages of medical care. Excellent resource for friends and relatives at home waiting for news.

Model System Knowledge Translation Center

Learn about new research findings and TBI education.

www.msktc.org/tbi/factsheets

National Information Center for Children and Youth with Disabilities

www.nichcy.org

Information for parents on federal laws for special education, including rights and responsibilities of parents. Has a fact sheet on traumatic brain injury and listing of resources for North Carolinians. Many pamphlets are free.

The Perspectives Network

www.tbi.org

Information and support for persons with brain injury and their families, including personal stories and medical articles.

Traumatic Brain Injury Resource Guide

www.neuroskills.com

Articles and information on traumatic brain injury research as well as products relating to brain injury. Includes an online bookstore. Organized by Center for Neuro Skills.

Traumatic Brain Injury Survival Guide

www.tbiguide.com

Online book about brain injury in clear and easy to understand language written by Dr. Glen Johnson.

Brainline

www.brainline.org

Brainline is a free educational website that provides valuable information about brain injury. Updated list of books, apps and multiple resources regarding TBI.

Center for Disease Control (CDC)

www.cdc.gov/TBI

The CDC conducts research and programs while working to prevent TBIs and to help people recognize, respond and recover if a TBI occurs.

Traumatic Brain Injury, LLC

www.traumaticbraininjury.com

This website is a resource for education, advocacy, research and support for brain injury survivors, their families and medical and rehabilitation professionals.

Rehab Abbreviations and Levels of Assistance

Rehab professionals use a lot of terms or shorthand ways of talking. Here's what they mean:

ADL: Activities of daily living such as dressing bathing, brushing your teeth, etc.

Assistive Devices:

SPC	Single Point Cane
SW	Standard Walker
RW	Rolling Walker
PRW	Platform Rolling Walker
HW	Hemi-Walker
W/C	Wheel Chair
SB	Slide Board
BSC	Bedside Commode
DABSC	Drop Arm Bedside Commode
SC	Shower Chair
TTB	Tub Transfer Bench
RSC	Rolling Shower Chair

Braces: Devices used to restrict or assist in body movement.

AFO	Ankle Foot Orthotic
PRAFO	Pressure Relief Foot Orthosis
TLSO	Thoracolumbosacral Orthosis
D or Dep	Dependent
Extremities	(Arms and Legs)
L	Left
R	Right
B	Bilateral (both)
UE	Upper Extremity
LE	Lower Extremity

Levels of Assistance

CGA	Contact Guard Assist: Person requires helper to have hands on them for safety.
DEP or D	Dependent: (helper does 100% of the task)
I	Independent: Person does 100% of task without assistance.
Mod I	Modified Independent: Person is independent with the task but needs an assistive device.
MAX A	Maximum Assist: Person only performs 25% of task.
Min A	Minimum Assist: Person performs 75% of task.
Mod A	Moderate Assistance: Person performs 50% of the task.
S	Supervision
Set-Up	Person can do task after someone sets up everything for them.
SBA	Stand By Assist: Helper needs to stand close by the person for safety.
WFL	Within Functional Limits: Person is able to function in the environment.
WNL	Within Normal Limits: Person is functioning at a normal level for age or developmental stage.

Glossary of Terms

Acute Rehabilitation Program: Early phase of rehabilitation beginning as soon as a patient is medically stable. Includes an interdisciplinary team of professionals.

Abstract Thinking: The ability to apply knowledge to different tasks.

Acquired Brain Injury: An injury to the brain occurring after birth that is not hereditary, congenital or degenerative.

ADLs: Activities of Daily Living such as dressing, bathing, toileting, eating, etc.

AFO: Ankle-foot orthosis or short leg brace.

Agitated: Person is easily upset, irritated or angered. May kick, hit or bite. Many patients who suffer from TBIs go through this recovery stage.

Amnesia: Loss of memory.

Aneurysm: A balloon-like deformity in the wall of a blood vessel. The wall weakens as the balloon grows larger and may eventually burst, causing a hemorrhage (severe blood loss).

Anticonvulsant: Medication used to decrease the possibility of seizures.

Anoxic Brain Injury: Injury to the brain that occurs due to lack of oxygen to the brain.

Aphasia: A loss of the ability to express oneself and/or understand language. It is caused by damage to brain cells.

Apraxia: A motor disorder caused by damage to the brain, in which the individual has difficulty with the motor planning to perform tasks, speech or movements when asked.

Aspiration: Fluid or food enters the lungs through the windpipe. It can cause a lung infection or pneumonia.

Ataxia: A problem with muscle coordination caused by an injury to the brain, usually in the cerebellum or basal ganglia. Can interfere with a patient's ability to walk, talk, eat and perform self-care.

Attention: The ability to stay focused on an activity or conversation without being distracted by external stimuli.

Awareness: The acknowledgement, observation or recognition of one's own actions and the drawing of conclusions about their effects.

BIANC: Brain Injury Association of North Carolina.

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

Brain Injury: Damage to the brain that results in impairments in one or more functions.

Burr Hole: A surgical procedure in which one or several small holes or openings are made in the skull to remove blood clots near the brain under the dura, the protective covering of the brain.

Clinical Case Manager: The team leader or liaison for the patient, the family and the treatment team. They help with personal, financial, emotional and social concerns that may arise as a result of illness or injury.

Cerebral Spinal Fluid: The fluid that bathes and protects the brain and the spinal cord.

Clonus: Uncontrollable jerking movement of muscle, often seen in wrist and ankle.

Coma: A state of unconsciousness from which a person cannot be aroused.

Comprehension: Understanding spoken, written or general communication.

Cognition: Thinking skills, including memory, attention, perception, making decisions, problem solving and reasoning.

Cognitive Impairment: Difficulty with thinking skills such as perception, memory attention, problem solving, decision making or reasoning.

Concussion: The common result of a blow to the head or sudden deceleration sometimes causing confusion and/or altered mental state, either temporary or prolonged.

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

Confabulation: False memories which the person believes to be true. It is an attempt to fill in memory gaps.

Craniectomy (bone flap removal): A surgical procedure in which part of the skull is removed to allow a swelling brain room to expand without being squeezed and causing more damage. Usually the flap is eventually replaced.

Craniotomy: A surgical procedure in which the skull is opened to relieve causes of increased intracranial pressure, by fractured bones or blood.

Cue: A signal or direction to help a person perform an activity.

Decubitus: Discolored or open area of skin caused by pressure.

Depressed Skull Fracture: A breakage in which pieces of skull press into the tissues of the brain.

Diffuse Axonal Injury (DAI): Damage to the pathways that connect different areas of the brain, caused by individual nerve cells stretching and breaking.

Diplopia: Double vision.

Disinhibition: Inability to control (inhibit) impulsive behavior and emotions.

Deep Vein Thrombosis (DVT): A blood clot deep within a vein.

Dysarthria: Difficulty forming words or speaking because of weakness or lack of muscle coordination used in speech.

Dysphasia: Difficulty swallowing.

Edema: Collection of fluid in the tissue (swelling).

Electrocardiogram (ECG/EKG): A procedure that uses electrode pads on the chest to monitor and record heart rate and rhythm.

Electroencephalogram (EEG): A procedure that uses electrodes on the scalp to record electrical activity of the brain.

Electromyogram (EMG): A procedure that inserts needle electrodes into muscles to study and record electrical activity of muscle and nerve fibers.

Emotionally Labile: Involuntary uncontrolled laughing or crying. May change quickly without reason.

Executive Functions: Skills involved in anticipating, setting goals, planning, self-regulating, incorporating feedback and completing an intended activity.

Extremity: An arm or leg.

Flaccid: Lacking normal muscle tone; limp.

Flexion: Bending a joint.

Functional: The ability to use skills in useful activities in a reasonable amount of time.

Gait Training: Instruction in walking, with or without equipment.

Hematoma: A collection of blood in tissues or a space following a rupture of a blood vessel.

Hemianopsia: Loss of half the visual field in one or both eyes.

Hemiparesis: Weakness of one side of the body.

Hydrocephalus: Excessive accumulation of fluid in the brain.

Hypoxia: Decreased amount of oxygen getting to the brain.

Impulse Control: The ability to withhold verbal or motor responses or anticipate consequences while completing a task.

Incontinent: Inability to control bowel or bladder functions.

Increased Intracranial Pressure (ICP): Increased pressure on brain tissue caused by the skull being overfilled with swollen brain tissue, blood, cerebral fluid or spinal fluid.

Information Processing: Regulating incoming information organizing and storing it and regulating the response.

Initiation: Starting a physical or mental activity.

Judgment: The ability to make appropriate decisions based on available information and expected consequences.

Lability: Notable shifts in emotional state (such as uncontrolled laughing or crying).

Lethargic: The person awakens with stimulation; drowsy but awake.

Long Term Memory: The ability to easily recall feeling, events, ideas and other information from a long time ago, usually prior to the traumatic brain injury.

Medication Induced Coma: The process of giving patients medicine to induce a deep sleep to help decrease more swelling or damage to the brain.

Memory: The ability to store, retain and retrieve information.

Mental Flexibility: The ability to shift from one idea to another.

Meningitis: Inflammation of the membranes of the brain and spinal cord, collectively known as the meninges.

Muscle Tone: The tension in resting muscles and the amount of resistance felt when muscle is moved.

Neglect: Paying little or no attention to a part of the body.

Neurologist: A physician who specializes in the nervous system and its disorders.

Neuropsychologist: A clinical psychologist who specializes in understanding how thinking skills, behaviors and emotions might be different after a brain injury.

Neurosurgeon: A physician who specializes in the diagnosis and surgical treatment of disorders of the nervous system, including the brain and spine.

NPO: Nothing by mouth (from Latin phrase nil per os). Patient cannot have any food or liquids due to the inability to safely swallow or in preparation for tests.

Occupational Therapist: A therapist that focuses on helping patients regain skills of activities of daily living, upper extremity function, visual skills, thinking skills and pain relief.

Orientation: Knowing who you are, where you are and the current time.

Orthosis: A splint or brace designed to improve function or provide stability.

Percutaneous Endoscopic Gastrostomy (PEG) Tube: A tube inserted through a surgical opening into the stomach. Places liquids, food and medication into the stomach when a person is unable to take them by mouth.

Perception: The ability to make sense of what one sees, hears, feels, tastes or smells. Perceptual losses are often very subtle and the patient and/or family may be unaware of them.

Perseveration: Uncontrolled, involuntary repetition of speech, an idea or an activity.

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

Physical Therapist: A therapist who focuses on helping patients regain skills and physical function and pain relief.

Post Concussive Syndrome: A group of symptoms after a concussion that may include memory changes, mood swings, poor concentration, headache, dizziness, depression and anxiety.

Posturing: An involuntary flexion or extension of the arms and legs, indicating severe brain injury.

Premorbid: Before disease or injury.

Problem Solving: Recognizing a problem, defining a problem, identifying alternative plans, selecting a plan organizing steps in a plan, implementing a plan and evaluating the outcome.

Prognosis: Prospect for recovery from a disease or injury based on the nature and symptoms of the case.

Rancho Los Amigos Scale of Cognitive Functioning: Often referred to as Rancho scale, it is used as a shorthand way to describe a person's current level of functioning after a traumatic brain injury. Ranges from Level 1 (coma) to 10 (purposeful, appropriate modified independent).

Range of Motion (ROM): Active (person does themselves) or passive (someone else does for person) movement of a joint.

Reasoning: The ability to solve problems and make safe decisions.

Recreation Therapist: A therapist who develops a program to help persons with disabilities plan and manage leisure activities.

Restless: Feeling the need to move, trouble staying still.

Secondary Brain Injury: An injury that occurs after the initial trauma. It is usually caused by increased pressure inside the skull as the brain swells and presses against it. Fluid and blood can also build up in the brain.

Seizure: Also called convulsions, seizures are the result of erratic electrical activity in the brain. They may appear as jerking movements of the arms and legs followed by a period of deep sleep, slight tremors of the face or just staring for a long time.

Sensation: A physical feeling or perception of feeling resulting from something that happens to or comes into contact with the body.

Self-Monitoring: Awareness of one's behavior and the accuracy or appropriateness of one's performance.

Sequencing: Keeping track of the correct order of events for body movement and language.

Shunt: A surgically placed tube running from the ventricles of the brain to divert excess fluid into the abdominal cavity, heart or large vessel in the neck.

Skull fracture: Broken bones surrounding the brain. In a depressed skull fracture, the broken bone puts pressure on the brain.

Social: The ability to relate to and effectively work with others; interpersonal behavior.

Spasticity: An involuntary increase in muscle tone that occurs following injury to the brain or spinal cord, causing muscles to resist being moved.

Speech and Language Pathologist: Therapists who work to prevent, assess, diagnose and treat speech, language, social communication, cognitive-communication and swallowing disorders in children and adults.

Storming: A disturbance of the autonomic nervous system which may include changes in heart rate, blood pressure or temperature. The person may also sweat a lot and appear flushed and have posturing.

Tracheostomy: A tube that is placed through the neck into the trachea (windpipe). This procedure is done to reduce damage to the throat and trachea from long-term intubation.

Ventriculostomy: A catheter placed into the ventricles of the brain (fluid filled central area) and connected to a drainage bag to assist in draining extra fluid to help control intracranial pressure. It is also used to measure the intracranial pressure.

Verbal-abstract Reasoning: The use of language for communication and problem solving.

Important Numbers

Information from your Treatment Team



www.wakemed.org

Raleigh Campus • Cary Hospital • North Hospital
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