

# Anoxic Brain Injury

## Patient and Family Guide



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## Introduction

You are receiving this book because you or your loved one has suffered an anoxic brain injury 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 anoxic brain injuries, what to expect during the rehabilitation process with the WakeMed Rehabilitation team, and how you can help your loved one and/or 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 or your loved one's needs to promote improvement.

Anoxic brain injuries are serious, and they have a dramatic impact on both patients and their support networks. Please know that the treatment team involved in your care are happy to answer your questions, address your concerns, and offer resources to help you and your supports cope with the fear, stress, and emotional exhaustion that a medical crisis like this can cause. They are here for you and your loved ones!

## What is an anoxic brain injury?

An anoxic brain injury occurs when there is a complete loss of oxygen flowing to the brain, often as a result of reduced blood flow. Oxygen provides the brain with the energy it needs to function properly. A disruption of oxygen to the brain starves it of its main energy source, and without it, the brain cells can die. If there is only a partial lack of oxygen to the brain, this is called a *hypoxic* brain injury. You will sometimes hear the term cerebral hypoxia used to represent an anoxic brain injury.

## Causes of Anoxic Brain Injuries

Anoxic brain injuries result from a variety of causes. These can include:

- Cardiac or respiratory arrest
- Heart attack related complications
- Complications from anesthesia
- Suffocation
- Choking
- Strangulation
- Near drowning
- Drug overdose
- Exposure to high altitudes
- Carbon monoxide inhalation
- Smoke inhalation
- Poisoning
- Electrical shock
- Extreme blood loss
- A severe asthma attack

## Understanding the Brain: Brain Structure & Organization

It is important to first understand the structure of a healthy brain to then understand how an anoxic brain injury affects a person's ability to function from a physical, cognitive (thinking skills), and emotional/behavioral standpoint.

### 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

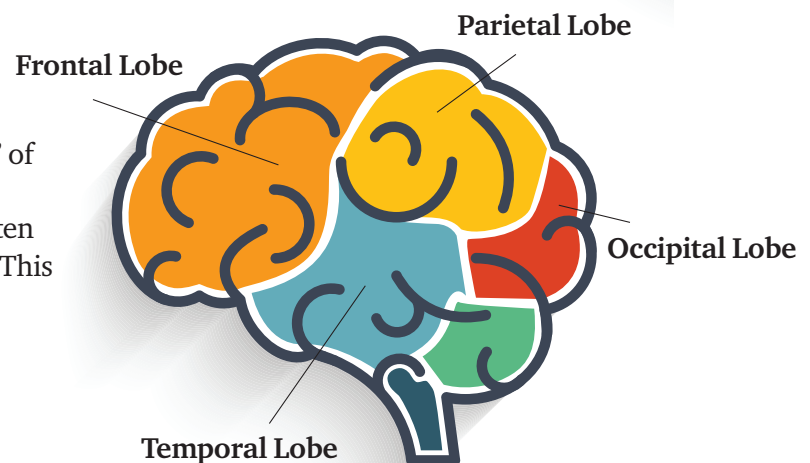
## Lobes of the Brain

At the basic level, the brain has four distinct sections, known as lobes, that control 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 struggle 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 the 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

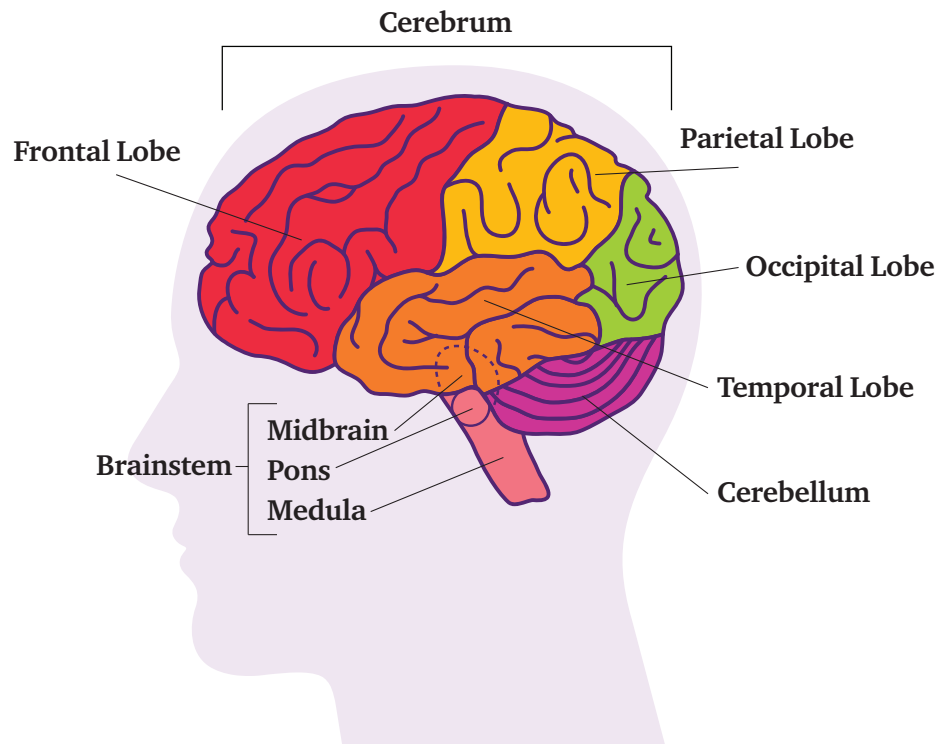
The **Occipital lobe** is located in the back of the brain and helps to interpret visual information and make sense of what we see. Damage to this part of the brain can result in:

- 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
<b>Thinking</b> <ul style="list-style-type: none"> <li>• Attention</li> <li>• Reasoning</li> <li>• Problem Solving</li> <li>• Planning</li> <li>• Organizing</li> </ul>	<b>Hearing</b> <ul style="list-style-type: none"> <li>• Recognizing sounds (R)</li> <li>• Recognizing words (L)</li> <li>• Music (R)</li> </ul>	<b>Feeling</b> <ul style="list-style-type: none"> <li>• Understanding pressure, touch, pain</li> <li>• Recognizing things from touch alone</li> </ul>	<b>Seeing</b> <ul style="list-style-type: none"> <li>• Receive and interpret visual information</li> <li>• Recognizing simple shapes</li> </ul>
<b>Language (L)</b> <ul style="list-style-type: none"> <li>• Saying words</li> <li>• Stringing words together</li> </ul>	<b>Language (L)</b> <ul style="list-style-type: none"> <li>• Hearing words</li> <li>• Recognizing words</li> </ul>	<b>Language (L)</b> <ul style="list-style-type: none"> <li>• Understanding what words mean</li> <li>• Control of reading</li> </ul>	<b>Language (L)</b> <ul style="list-style-type: none"> <li>• Recognizing letters and words</li> </ul>
<b>Doing Things</b> <ul style="list-style-type: none"> <li>• Initiation (getting yourself started to do something)</li> <li>• Doing things in the right order</li> <li>• Speaking (L)</li> </ul>	<b>Memory</b> <ul style="list-style-type: none"> <li>• Remembering past events</li> <li>• Learning new things</li> <li>• Remember words or verbal information (L)</li> <li>• Remembering pictures or shapes (R)</li> </ul>	<b>Space</b> <ul style="list-style-type: none"> <li>• Knowing where you are in space</li> <li>• Paying attention to left and right sides of space</li> </ul>	
<b>Self-Control</b> <ul style="list-style-type: none"> <li>• Muscles</li> <li>• Behavior</li> <li>• Emotion</li> <li>• Frustration</li> </ul>			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 an anoxic brain injury, 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
- Difficulty with remembering how to do familiar things (like brush one’s teeth or ride a bicycle)

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

## What brain areas are most susceptible to damage from an anoxic brain injury?

The brain is a complex system made up of interconnected pathways. Therefore, while oxygen may have been disrupted to one part of the brain, chances are, deficits may be seen in multiple areas of functioning, including cognitive, physical, and emotional. The extent of the deficits often depends on how long the brain was without oxygen. Brain cells can start to die after only four minutes without oxygen.

There are certain areas of the brain that are more sensitive to a loss of oxygen. These areas include:

- The **hippocampus**, an important structure involved in memory located deep within the temporal lobe
- The **thalamus**, a structure deep within the white matter of the brain, which serves as a major relay station for all sensory inputs except smell. This structure is involved with cognitive, motor, and emotional functions, as well.
- The **basal ganglia**, a collection of nuclei involved in voluntary motor movements
- The **cerebellum**, (as mentioned above), a structure involved in balance, coordinated movements, and cognition

## Possible Medical Complications

Other medical conditions can arise as a secondary effect of an anoxic brain injury. These can include:

- **Seizures** – abnormal electrical impulses within the brain. Individuals who experience seizures after an anoxic brain injury may be put on anticonvulsants.
- **Cardiovascular issues** – related to the heart and blood flow. Sometimes individuals may have trouble regulating their blood pressure or heart rate after an anoxic brain injury.
- **Endocrine and metabolic issues** – related to changes in hormones and other chemicals within the brain.

## 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	Increase alertness, manage fatigue, and improve focus and concentration
Anti-convulsants	Depakote, Lamictal, Dilantin, Keppra	Manage seizures, have a calming effect and minimize agitation

## What to Expect After an Anoxic Brain Injury

Depending on the severity of one's anoxic brain injury, the person may display a variety of symptoms. Initially, the individual will likely be in a coma, during which they are unconscious and unresponsive. Sometimes, individuals will remain in a coma for a long period of time. Other times, individuals may emerge from a coma and be awake, but still remain unresponsive. This is called a persistent vegetative state.

When a person emerges from a coma and begins to gradually recover from their anoxic brain injury, they may display:

### Cognitive Changes

- **Short term memory loss:** This is the most common cognitive symptom and occurs as a result of damage to the thalamus and hippocampus. Individuals may have trouble remembering what they did in the recent past, or what they have to do in the future. Learning new information is a significant challenge, and they will benefit from notes and frequent repetition.
  - > Confabulation may also result, which is the brain's tendency to fill in the missing pieces, sometimes with false information, when it can't remember. This is unintentional and is different from lying.
- **Executive function deficits:** The frontal lobes of the brain control the "executive functions," which include:
  - > Initiating (or starting) activities
  - > Planning
  - > Organizing
  - > Problem-solving
  - > Judgment
  - > Decision-making
  - > Thinking outside the box
  - > Emotion-regulation
  - > Self-awareness – individuals may show poor insight about their challenges
  - > Self-monitoring (ex. not saying something offensive)
  - > Due to challenges with these functions, individuals with anoxic brain injury may occasionally display unsafe or impulsive behaviors.
- **Slowed processing speed:** After an anoxic brain injury, an individual may take longer to understand and/or respond to incoming information. They may seem behind in conversations, or as if they are not paying attention.

These cognitive changes can be frustrating and challenging for both the patient and family members. We also find that persons with these types of 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.



## Physical Changes

- **Visual disturbance:** Individuals may have trouble processing visual information or moving their eyes in a coordinated fashion.
  - > In severe cases, cortical blindness can occur, which is blindness due to damage to the occipital lobes
- **Balance and motor deficits:** Individuals may be unsteady, experience limb weakness, and/or may require assistance with everyday tasks. They may also have trouble coordinating their movements for purposeful activities like walking, talking, or swallowing.
  - > Ataxia is a term that is used to describe uncoordinated movements. Individuals may appear to have jerky or bob-and-weave type movements.
  - > Apraxia is a term that is used to describe difficulty with planning or executing familiar movements, like saying a specific word when asked to repeat it, or using a key.
  - > Spasticity and Tremors: Individuals may experience rigidity, or increased tone in their muscles. This can sometimes lead to spasms. Due to damage to the basal ganglia, tremors may also result.
- **Fatigue and general weakness:** Given the impact to the brain, resulting neurochemical changes, and the body's desire to return to homeostasis (it's natural setpoint), individuals may feel exhausted after an anoxic brain injury. Due to being confined to a hospital bed for a prolonged period, sometimes with poor appetite or an inability to eat solid foods, individuals may also be deconditioned, with reduced strength and endurance.

## Emotional Changes

Behavior or how one acts or conducts oneself, can change dramatically after an anoxic brain injury. 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 long-lasting. Personality can also affect a patient's predisposition to feel certain emotions. After this type of 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, disinterested, or irritable
- Anxiety - feeling nervous, agitated, jittery, or expressing frequent worries
- 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 or irritable more quickly than usual and without much provocation
- Impulsivity- acting 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

## What is the prognosis for an anoxic brain injury?

Recovery from an anoxic brain injury depends on several factors, and the course of recovery can take months, and in many cases, years. It can help to think of recovery as a marathon, rather than a sprint. Some of the factors that may influence prognosis include:

- **Duration of the anoxic event:** Brain cells can die after only four minutes without oxygen. The longer an individual is without oxygen, the more cell death that occurs, which can impact functioning to a greater degree.
- **Age at injury:** Younger individuals (early to mid 20s and younger) are thought to fare better after an anoxic brain injury, but individuals of all ages can benefit from rehabilitation.
- **Duration of coma:** Generally, the longer someone is in a coma (naturally, not medically induced), the worse their prognosis. An individual who is in a coma for weeks or months, has a worse prognosis than an individual who has been in a coma for hours or days.
- **Brain imaging:** Individuals with significant damage noted on CT and MRI scans may have a longer, potentially more complicated course of recovery.
- **Pupillary reaction:** Individuals who show dilated or fixed pupils without response to light likely have brainstem damage, which is a poor prognostic sign.
- **Electroencephalograms (EEG) and Evoked Potentials:** An EEG can be done to determine the extent of activity within the brain. Continued activity on an EEG is a positive sign. Evoked Potentials (EPs) shows how the brain responds to external stimuli. The absence of EPs is associated with a worse outcome.

Complete recovery, meaning the patient returns to 100% of the level of functioning and independence they had before their anoxic brain injury, is often unrealistic. It is very difficult for rehabilitation professionals to predict how well a person will recover after an anoxic brain injury because the brain is so complex. Recovery depends on many factors, such as:

- Severity and areas of the brain impacted
- Pre-injury condition
- Personality
- Lifestyle
- Family dynamics
- Relationships

## What treatments are there for anoxic brain injuries?

Specific treatments for anoxic brain injuries are limited. The main goal is to resume adequate oxygen flow to the brain. This may require mechanical ventilation to secure the airway, fluids, blood products, or medications to support heart rate and blood pressure. Medications for seizure prevention may also be given. In some cases, in the intensive care unit, medically induced cooling called therapeutic hypothermia, is used to assist with reducing the oxygen needs of the brain, which is thought to have a protective effect.

Once an individual achieves medical stability, neurorehabilitation is an important consideration after anoxic brain injury. Your neurorehabilitation will be led by a Physical Medicine and Rehabilitation (PM&R) doctor. You may work with several different types of clinicians, including a Nurse, Case Manager, Physical Therapist, Occupational Therapist, Speech Therapist, Therapeutic Recreational Specialist, Neuropsychologist or Rehabilitation Psychologist, or Dietitian. Recovery from an anoxic

brain injury 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.

Recovery from an anoxic brain injury is a process and the focus should be on the journey of recovery – not just the final outcome.

## **Safety after an Anoxic Brain Injury**

Many changes that occur with brain injury can cause safety risks to the individual and others at times. Some patients with anoxic brain injury lack awareness or understanding of how their brain is different. After an anoxic brain injury, 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 anoxic brain injury 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.

## **WakeMed Rehabilitation Services for Anoxic Brain Injuries**

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.

## **Anoxic Brain Injuries in Children and Adolescents**

Just like adults, outcomes after an anoxic brain injury 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. 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 an anoxic brain injury who has mastered tying her shoes before the injury may easily recover that skill. But learning a new skill after suffering from an anoxic brain injury 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.

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, the extent of 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. The Neuropsychologist and Speech Therapist may also complete cognitive evaluations to determine what areas the child or adolescent struggles with most and may make recommendations to the child’s school related to accommodations that may optimize the child’s ability to participate and learn in school.

## Impact on Family Members

Anoxic brain injuries can affect the patient’s entire family. Many family members and friends struggle emotionally during the early stages of recovery. 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. Others have also found it helpful to seek their own counseling to manage the emotions related to a catastrophic event like this.
- **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** – You may 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:** You can reduce the risk of further medical complications, like an infection, by washing your hands before you touch or visit your loved one. Avoid 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 brain injury 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 anoxic brain injuries and the impact on the person and the family. Ask your treatment team if you have any questions.
- **Use cues:** Once your loved one is out of the acute stages of recovery, they may need reminders, or cues, to stay on track, be on time, or use compensatory strategies that they learned in therapy to assist with memory and other cognitive functions.

## **Anoxic Brain Injury Resources**

### **Books That May Help**

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

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

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

By Lee and Bob Woodruff

Many of these books are geared towards traumatic brain injuries but will still have relevant information. If you would like more info regarding resources, talk with the Case Manager.

### **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

[www.bianc.net](http://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](http://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](mailto:norman.case.soaringeagle@gmail.com) and  
Brooke Hinnant: [brookewhinnant@gmail.com](mailto: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](mailto:cgettle@communitypartnerships.org)  
Note: this group has a Brain Injury Family/Caregiver Group that meets at the same time.

## Resources for Seniors

Maintains a list of caregiver and other specific support groups. Call for more information.  
919-872-7933

### TapNet

Support group for families/caregivers of individuals with aphasia.  
919-800-8047  
[www.aphasiaproject.org](http://www.aphasiaproject.org)

## National Support and Education Organizations

### Anoxic Brain Injury Advocates

Information and resources related to anoxic brain injuries.  
[www.anoxicbrain.com](http://www.anoxicbrain.com)

### Model System Knowledge Translation Center

Learn about new research findings and TBI education. The information is specific to TBI but is often relevant to anoxic brain injury.  
[www.msktc.org/tbi/factsheets](http://www.msktc.org/tbi/factsheets)

### National Information Center for Children and Youth with Disabilities

Information for parents on federal laws for special education, including rights and responsibilities of parents. Many pamphlets are free.  
[www.nichcy.org](http://www.nichcy.org)

### Brain Injury Resource Guide

Articles and information on brain as well as products relating to brain injury. Includes an online bookstore. Organized by Center for Neuro Skills.  
[www.neuroskills.com](http://www.neuroskills.com)

## 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:

<b>SPC</b>	Single Point Cane
<b>SW</b>	Standard Walker
<b>RW</b>	Rolling Walker
<b>PRW</b>	Platform Rolling Walker
<b>HW</b>	Hemi-Walker
<b>W/C</b>	Wheelchair
<b>SB</b>	Slide Board
<b>BSC</b>	Bedside Commode

<b>DABSC</b>	Drop Arm Bedside Commode
<b>SC</b>	Shower Chair
<b>TTB</b>	Tub Transfer Bench
<b>RSC</b>	Rolling Shower Chair

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

<b>AFO</b>	Ankle Foot Orthotic
<b>PRAFO</b>	Pressure Relief Foot Orthosis
<b>TLSO</b>	Thoracolumbosacral Orthosis
<b>D or Dep</b>	Dependent

**Extremities (Arms and Legs)**

<b>L</b>	Left
<b>R</b>	Right
<b>B</b>	Bilateral (both)
<b>UE</b>	Upper Extremity
<b>LE</b>	Lower Extremity

**Levels of Assistance**

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

**Amnesia:** Loss of memory. You may also hear an individual described as amnesic, which means they have significant challenges with remembering information.

**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).

**Anoxic Brain Injury:** An injury to the brain that occurs due to a complete loss of oxygen.

**Anticonvulsant:** Medication used to decrease the possibility of seizures.

**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, reminder, 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 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.

**Overstimulation:** An overload of sensory input (ex. lights, sounds, commotion) that causes mental or cognitive fatigue.

**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.

## Notes



[www.wakemed.org](http://www.wakemed.org)

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