A GUIDE TO
Anoxic/Hypoxic Brain Injury

Roper Rehabilitation
Hospital

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Specific Problems after Brain Injury

Each person's brain injury is unique. There may be some sections in this book that are more relevant to you than others. The information in this book does not replace advice from medical professional

Understanding Anoxic/Hypoxic Brain Injury

Anoxic and hypoxic injuries are a type of **non-traumatic brain injury (NTBI)**, which means that there was no external trauma or physical impact to the brain. They are caused by lack of oxygen to the brain.

What is anoxic brain injury?

Anoxic brain injury is caused by a complete lack of oxygen to the brain. This results in the death of brain cells after approximately four minutes of oxygen deprivation.

What is hypoxic brain injury?

Hypoxic brain injury is caused by reduced oxygen supply to the brain. The restricted flow of oxygen causes the gradual damage or death of brain cells.

Common Causes

Causes of anoxic and hypoxic brain injury include cardiac arrest and other cardiac issues, respiratory failure, choking, overdose, electrocution, and near drowning.

Measuring the Severity of Injury

The effects of hypoxic or anoxic brain injury can range from mild, short-term symptoms to severe, long-term issues. Severity is determined by the amount of time the brain went without oxygen, signs of swelling and damage on brain scans, and the resulting deficits.

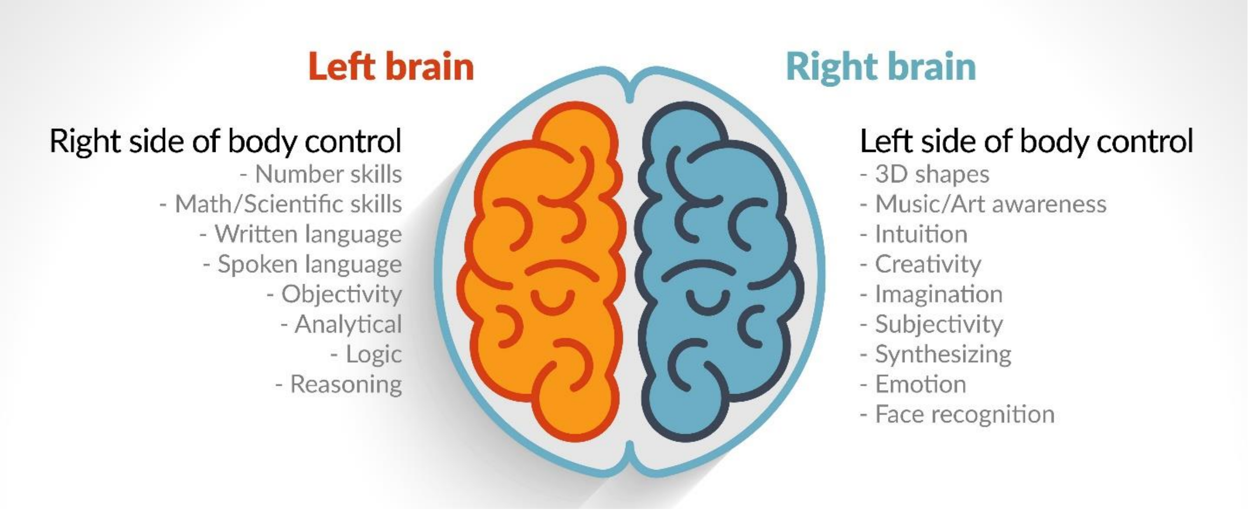
The Brain and Its Functions

There are billions of brain cells that quickly communicate within the brain and to the body to control all human activity.

A brain injury interferes with the way the brain normally works. When nerve cells in the brain are damaged, they can no longer send information in the normal way. This causes changes in the person’s behavior and abilities. Each person’s brain injury is unique depending on which areas of the brain are damaged.

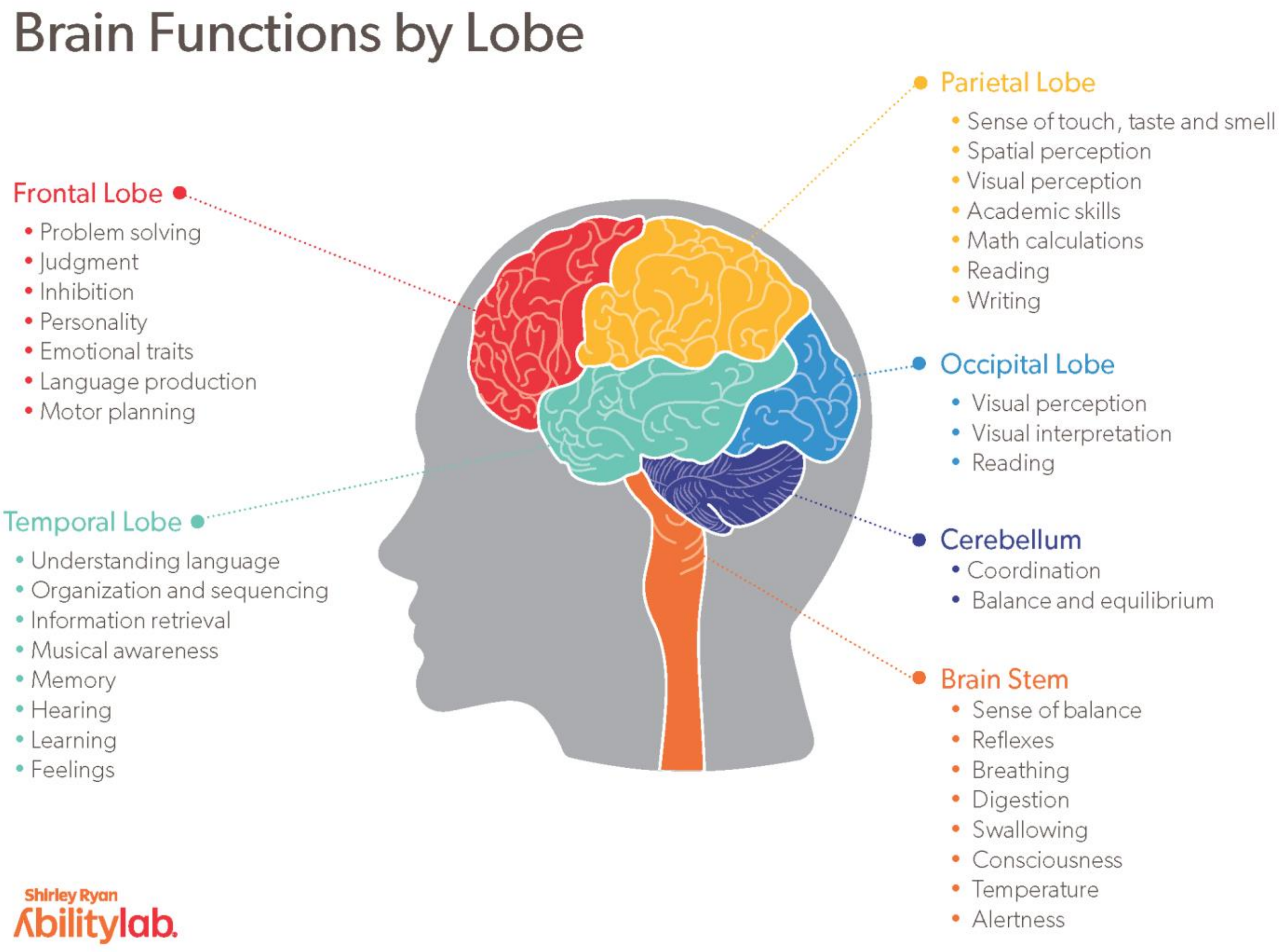
Hemispheres of the Brain

The brain is divided into two halves called hemispheres. The left half controls movement and sensation on the right side of the body, while the right half controls movement and sensation on the left side of the body. Each hemisphere is associated with distinct functions.



Parts of the Brain

The brain is made up of 6 major areas or lobes. Each area is responsible for different functions but they are all interconnected. Anoxic/hypoxic brain injury may produce damage throughout the brain, but there are some areas that are more vulnerable to lack of oxygen than others. The hippocampus (which is important for memory), the parietal lobe, occipital lobe, and cerebellum are particularly sensitive to anoxia.



The Recovery Process

Projecting the recovery for brain injuries is difficult because each case is unique. A full recovery from severe anoxic or hypoxic brain injury is rare, but many patients with mild injury are capable of making a full or partial recovery.

How The Brain Heals

Neuroplasticity (or brain plasticity) is the brain's ability to change over time. Essentially, it's when the brain rewires itself to function differently from how it previously did. This occurs in both healthy brains and brains after injury. Rehabilitation aims to help the brain make new pathways to regain lost functions.

Signals in the brain go from one cell to another forming connections. →

Brain injury damages or kills brain cells which disrupts the connection. →

As the brain is stimulated, cells can form new connections around the injured area

Length of Recovery

Recovery typically happens fastest in the first 6 months after brain injury. You can continue to improve for years, though usually at a slower rate.

Recovery varies greatly from person to person based on factors such as severity of the injury, age, and pre-injury abilities. In more severe injuries, recovery takes longer and a full recovery is less likely. Age is another factor as younger brains have greater potential for neuroplasticity.

Cognitive Problems

Cognition is conscious mental activity such as thinking, remembering, learning, or using language. After a brain injury, it is common to have problems with multiple areas of cognition. Cognitive skills are evaluated and treated by several members of the rehabilitation team including speech-language pathologists, occupational therapists, and neuropsychologists.

Attention

It may be difficult to focus on a task, keep your attention, or attend to more than one thing a time (multi-task). Attention skills are considered a “building block” of higher-level cognition skills so people with attention problems often show signs of other cognitive problems as well.

What can be done to help attention?

- Decrease distractions.
- Focus on one task at a time.
- Begin practicing attention on simple, yet practical activities in quiet room. Gradually make the task harder or work in a noisier environment.
- Take breaks.

Insight

Insight, or self-awareness, is the ability to observe and reflect on your own thoughts and actions. Brain injuries can significantly impair this ability. This leads to a condition called **anosognosia**, where you are not aware of your deficits. Your brain may be telling you that you are able to do something when you’re actually having trouble. This leads to unsafe decision making.

What can be done to help insight?

- Try to listen to the recommendations and advice from family and medical team members, even if you disagree.
- Caregivers should give direct but non-critical feedback.
- Caregivers should avoid arguments. Remember that the survivor is not trying to be “difficult.” If they are not receptive to your feedback, drop the topic for now as long as there is no immediate safety issue.

Executive Functions/ Problem Solving

Executive functions are the brains highest level cognitive skills. They help you solve problems and plan, organize, and execute tasks.

You may have difficulty with one or more steps in the problem-solving process. It may be difficult to recognize a problem, get started on a task, and/or develop a solution. You could get stuck and be unable to consider other solutions. It may be hard to plan and prioritize tasks. If judgement is impaired, you may make quick decisions without thinking about the consequences.

What can be done to help executive functions?

- Break down complex activities into smaller steps.
- Make a list of what needs to be done in order of importance.
- Use strategies to keep organized like labels, folders, or color coding.
- Work through a problem step-by-step. Define the problem, discuss possible solutions including pros/cons of those solutions, evaluate the success of the solution, and pick another solution if the first one didn’t work.

Memory

Memory is commonly impaired in anoxic/hypoxic injury. Short-term memory is usually affected but long-term memory may be also. There could be disorientation which is unawareness of location, situation, and/or time.

What can be done to help memory?

- Have a set location for things.
- Keep a routine.
- Write things down. You can try memory aids such as calendars, reminders in your smart phone, to-do lists, etc.
- Try strategies of visualization and repetition to retain new information.

Communication Problems

Communication problems can occur after brain injury. This could be difficulty with language, social communication skills, or trouble moving muscles which makes your speech hard to understand. Communication is evaluated and treated by a speech language pathologist.

Language

An injury in the left hemisphere of the brain commonly affects language skills, a condition called **aphasia.** Individuals with aphasia may have difficulty understanding what is said to them, thinking of the words for what they want to say, reading, or writing.

What can be done if I have aphasia?

- Take your time when communicating.
- Ask for repetition if you didn’t understand.
- Trying gestures, pointing, writing, or drawing to get your thoughts across.

What can caregivers do to communicate with someone with aphasia?

- Keep information simple. Don’t say too much at once or talk too fast.
- Be patient. Give them extra time to get their message across.
- Verify that they understood what was said.
- Let one person talk at a time.

Social Communication

Difficulties with social communication after brain injury could include impaired non-verbal communication such as facial expressions, tone of voice, and body language, rambling, or difficulty staying on topic.

Speech

Weakness in the muscles of the mouth and face can make speech slurred, a condition call **dysarthria**. Sometimes there is no weakness but it is hard to coordinate the tongue, lips, and vocal cords to produce sounds correctly, a condition called **apraxia of speech**. Both of these conditions can make your speech difficult to understand.

Changes in Mobility

The brain communicates through the spinal cord and nerves down to the muscles, so brain injury can cause changes in how you are able to move. This can increase the risk of falls. Common changes in mobility include:

- Muscle weakness
- Impaired sensation (difficulty feeling your body parts)
- Decreased balance
- Impaired coordination
- Increased tone (spasticity) or tightness in your muscles
- Apraxia, which is difficulty moving muscles in a desired way even though you have the ability to do so. This includes difficulty with motor planning tasks that require multiple steps, like brushing your teeth.
- Mobility impacted by vision deficits and cognitive changes.

What can be done to help mobility?

- Physical and Occupational Therapy will address mobility. Therapy will help practice skills such as getting in and out of bed, moving around in a wheelchair, walking, getting on and off the toilet, and self-care tasks such as toileting, bathing, and dressing.
- Equipment such as walkers, wheelchairs, and bedside commodes may be used to improve safety.
- Splints or braces may be used to support limbs that are weak or too tight.

Changes in Behavior

Behavior changes, also called personality changes, are common for people with a moderate or severe brain injury. These changes often occur soon after the injury, and behavior may fluctuate over time. Usually the person cannot control these behaviors.

- **Problems Managing Emotions.** Sudden changes in mood could occur. This may be an extreme emotional response or a response that is not appropriate to the situation. This may be crying, laughing, or yelling.
- **Restlessness.** Fidgeting, pacing, or moving in a repetitive way.
- **Problems with Social Behavior.** People with a brain injury may avoid others, interrupt, or say things that do not fit the situation. They may "lose their filter" and say things that are hurtful or inappropriate.
- **Refusing to do things.** Saying "no" to doing something. It may be a place or activity that they previously agreed to.
- **Feeling unmotivated.** Having difficulty engaging in an activity even though they know the benefit of doing it.
- **Agitation.** Agitation is defined as inappropriate or excessive behaviors. It could include excessive talking or movement, aggression, and disinhibition.

What can be done to help behavior?

- During an emotional outburst, the caregiver should remain calm and listen. Don't try to reason or argue with the person while they are upset. Once they are calm, you could discuss what may have caused the behavior.
- When agitated, try distracting the brain with a change in location, change in task, or a comfort item like a favorite snack.
- Watch for patterns such as certain times of days, situations, or people that may trigger unwanted behaviors.
- There are medications that can help improve or stabilize mood. Talk to your doctor.
- Consider counseling for both the survivor and caregivers.

Emotional Problems

The way people experience or express emotions may change after brain injury.

Anxiety

Anxiety may look different from person to person, but most people with anxiety have intense fear and worry. Some people also have physical signs of anxiety such as racing heart, rapid breathing, shaking or sweating. They may feel anxious, stressed, or overwhelmed without knowing why.

Anxiety could occur in situations that did not bother you in the past. You may feel anxious being in a crowd, when being rushed, or when adjusting to sudden changes in plans. Situations that require a lot of attention, fast thinking, or processing a lot of information at the same time could feel overwhelming.

Depression

Some people feel depressed right after their injury, but these feelings may also appear during the later stages of recovery. People with depression may feel sad, irritable, or worthless. They may feel tired much of the time and may experience changes in sleep, appetite, or concentration. Sometimes, people may even have thoughts of death, hurting themselves, or taking their own life. People with these feelings often withdraw from others and lose interest in activities they used to enjoy. Sadness and grief are common after brain injury but if these feelings become overwhelming or interfere with recovery, you may be experiencing depression.

Anger and Irritability

People with brain injury may feel more anger, irritability, and frustration. Family members often describe them as having a "short fuse". Anger can have a big impact on the support that people get from family and friends. It can affect closeness in relationships and lead to further isolation.

Talk with your doctor about possible medications to help with emotional problems. Consider counseling with a psychologist or licensed therapist.

Overstimulation

Following a brain injury some people find that exposure to normal, everyday stimuli (bright lights, loud noises, or touch), is now uncomfortable, overwhelming, or distressing. This is called **overstimulation** or **sensory overload**. A person who is overstimulated may become irritable, restless, or mentally fatigued.

Signs of Overstimulation:

- Sounds feel louder or startling.
- Background sounds and stimulating environments become overwhelming.
- Fluorescent and bright lights are bothersome or give you headaches.
- Clothing that was comfortable before feels irritating now.
- Large gatherings of people feel overwhelming.

Strategies for Coping with Overstimulation:

- Avoid crowds and busy places.
- Limit the number of visitors at one time.
- Do shopping and errands early in the week and early in the day, when stores are less crowded and quieter.
- Eat out in restaurants when they are quieter, in between regular meal times.
- Ask people to please speak one at a time.
- Try earplugs for noise sensitivity and sunglasses for light sensitivity.
- When feeling overstimulated, take a “brain break”. Try sitting in a quiet and dimly lit room.

Vision Problems

Vision is more than simply what we see. The brain has to process visual information such as size, shape, colors, spatial orientation, and depth perception. Brain injury can interrupt the communication between the eyes and the brain. Common vision problems include:

- **Visual Acuity:** Blurry vision.
- **Eye focusing:** Inability to quickly change focus from near to far objects.
- **Diplopia:** Double vision.
- **Eye movements:** Difficulty following a moving object or losing one's place while reading.
- **Motion sensitivity:** Disruption in the connection between vision system and balance system can make it difficult to process motion properly. This can cause dizziness when traveling, scrolling a digital device, or when in busy environments such as grocery stores, social settings, or sporting events.
- **Visual Field Loss:** The partial or complete loss of peripheral vision. Visual field loss may cause one to bump into objects, be struck by approaching objects, or experience frequent falls.
- **Photophobia:** Sensitivity to light. This may be exacerbated by particular light sources, such as bright sunlight, fluorescent lighting or LCD screens (computer, phone).

What can be done to help vision?

- Professionals including Occupational Therapists, Low Vision Specialists, or Neuro-ophthalmologists can be involved in evaluating and treating vision changes.
- Avoid visual overload by cutting down on clutter and the amount of visual information your brain has to process.
- Equipment such as magnifiers or reading lights may be helpful.
- Take breaks during tasks that rely on vision.
- There are treatments such as corrective eyeglasses, specialized glasses such as prism glasses, and patching. These are prescribed by a optometrist or ophthalmologist.

Medical Problems

Headaches

Headaches may have a variety of causes including a brain change from the injury, tension, stress, or side effects from medication.

Most headaches are not dangerous. You should seek medical attention if the headache is getting worse, there is nausea or vomiting, physical changes along with a headache, or you have increasing sleepiness.

Talk with your doctor about managing headaches. There are over the counter medications or prescription medications for headache. There are lifestyle changes that may be recommended such as avoiding environmental triggers, avoiding caffeine, and getting enough sleep.

Seizures

Seizures could be a secondary complication after brain injury. Most seizures happen in the first several days to weeks. Some may occur for months or years after injury.

During a seizure there is a sudden abnormal electrical disturbance in the brain that results in one or more of the following symptoms:

- Strange movement in your head, body, arms, legs or eyes such as stiffening or shaking
- Unresponsiveness and staring
- Chewing, lip smacking, or fumbling movements
- Sudden tiredness or dizziness
- Strange smell, sound, feeling, taste, or visual images

Symptoms of a seizure happen suddenly and you are unable to control them. Seizures usually last only a few seconds or minutes, but sometimes continue longer. You may have a bladder or bowel accident or bite your tongue or inside of your mouth during the seizure. After the seizure, you may feel drowsy, weak, or confused.

Safety Issues with Seizures

In South Carolina, you cannot drive for 6 months after a seizure. If you are continuing to have seizures, you should always have someone with you when in water (pool, ocean, bath tub) and don't do any climbing (ladders, roof, etc).

What should a caregiver do during a seizure?

- Make sure the person doesn't fall. Hold them steady if in the bed. If standing, get them to the ground safely.
- Watch closely to be able to describe the seizure to a medical professional. Note the length of time the seizure lasted, the day/time it occurred, and symptoms.
- Loosen tight clothing, especially around the neck
- Turn the person and their head so that anything in the mouth doesn't block the throat. Do not put anything in their mouth.
- If this is the first seizure or the seizure doesn't stop after 3 minutes, call 911.

What is a medical emergency after brain injury?

After brain injury, some fluctuations in symptoms and abilities can be normal. Overall, the person with brain injury shouldn't get worse. Sudden changes could be a medical emergency. Call 911 or seek immediate medical attention if you experience any of the following:

- Sudden severe headache, especially with nausea or vomiting
- Clear fluid draining from ears or nose
- Seizure that is new or prolonged
- Sudden decline in physical abilities
- Worsened confusion
- Sudden dizziness or blurred vision

If you have any concerns, it is best to seek medical attention rather than waiting.

Sleep and Fatigue

Sleep

Your brain directs sleep by putting the body to rest. Injury to the brain can lead to changes in sleep. Not sleeping well can increase or worsen depression, anxiety, fatigue, irritability, and overall well-being.

Common sleep disorders include:

- **Insomnia:** difficulty falling asleep or staying asleep. Insomnia can worsen other problems from brain injury including cognitive and behavior difficulties.
- **Excessive Daytime Sleepiness:** extreme drowsiness.
- **Delayed Sleep Phase Syndrome:** mixed up sleep patterns.
- **Narcolepsy:** Falling asleep suddenly and uncontrollably during the day.
- **Physical and Chemical Changes:** The “internal clock” in the brain controls when people sleep and wake every day. The brain may not be able to tell the body to fall asleep or wake up.

What can be done to help sleep?

- Set an alarm to wake up at the same time every day.
- Try to get outdoors for sunlight during the daytime.
- Exercise (in a safe way) each day. People with brain injury who exercise regularly report fewer sleep problems.
- Limit daytime naps if not sleeping well at night.
- Avoid caffeine, alcohol, nicotine, and sugar in the hours leading up to bedtime.
- Talk to your doctor about supplements or prescription medications that can help sleep.

Fatigue

Fatigue is a feeling of exhaustion, tiredness, or lack of energy. After brain injury, fatigue often occurs more quickly and frequently. When you are fatigued, you are less able to think clearly or do physical activities.

There are different types of fatigue you may experience.

- **Physical Fatigue** can come from muscle weakness. Your body is working harder to do things. Physical fatigue may get worse in the evening and is better after a good night's sleep. Often, it will lessen as strength improves and you become more active.
- **Psychological Fatigue** is associated with depression, anxiety, and other psychological conditions. This type of fatigue gets worse with stress. Sleep may not help.
- **Mental Fatigue** comes from the extra effort it takes to think after your brain injury. Many common tasks take much more concentration than they did before.

What can be done to decrease fatigue?

- Identify what triggers your fatigue then incorporate rest breaks during those situations.
- Resume activities gradually. Start with familiar, simple tasks then increase complexity.
- Get more sleep and rest.
- Manage your time. Do things that require the most physical and mental effort earlier in the day. Avoid scheduling too many things in the same day.
- Exercise daily. Over time, exercise and being more active helps lessen physical & mental fatigue and builds stamina.
- Avoid alcohol and marijuana. They make fatigue worse.

Wellness and Prevention

Wellness

There are things you can do to support your physical health and recovery.

- **Eat well.** Choose healthy items such as lean protein, whole grains, fruits, and vegetables. Ensure you're getting enough calories to fuel your healing. After brain injury, your appetite may change, or it may be difficult to remember what and when you ate. Try writing down your meals to monitor intake. Talk with a dietitian for information on diet and supplements.
- **Stay active.** Get exercise in a safe way. Ask your physical therapist for some safe exercises or ways to modify your previous exercise routine.
- **Avoid alcohol and drugs.** Alcohol and drugs can have a toxic effective on the brain. This will limit the brain's ability to recover and get better. Drugs and alcohol impair judgment and can also affect coordination and balance, making people more likely to injure themselves or others.
- **Get adequate rest.** Our bodies need sleep to function well and facilitate healing. Not getting enough sleep may affect our memory, thinking, energy level, and mood.
- **Maintain your mental health.** Engage in activities that reduce stress and support your mental well-being. See a counselor, join a support group, and engage with friends. Try stress relief techniques such as walking, writing in a journal, practicing medication, or enrolling in a yoga class.

Prevention

Brain injuries have a "cumulative effect" on the brain. This means that a second injury would have a bigger impact on your brain. It is important to do everything you can to prevent another brain injury.

- **Prevent falls.** After brain injury, changes in balance and mobility can increase your fall risk. Remove trip hazards from your home and always follow safety recommendations. This includes using wheelchair, walker, or having assistance as recommended by your therapists.
- **Wear a seatbelt.**
- **Use a helmet**. If you return to activities such as bike riding, motorcycles, or skiing, always wear a helmet.
- **Avoid contact activities.** Don't engage in activities that have a high chance of causing a blow to the head.

Sexuality after Brain Injury

Changes in sexual functioning are common after brain injury. Some sexual problems are directly related to damage in the brain. Others are related to cognitive changes, problems with movement, shifts in relationships, or even medication side effects.

The following sexual changes can happen:

- **Decreased Desire:** Less interest in sex
- **Increased Desire:** Increased interest in sex. Some people have difficulty controlling their sexual behavior. They may make sexual advances in inappropriate situations or make inappropriate sexual comments.
- **Decreased Arousal:** Difficulty becoming sexually aroused. This means they may be interested in sex but their bodies do not respond. Men may have difficulty getting or keeping an erection. Women may have decreased vaginal lubrication.
- **Reproductive Changes:** Women may experience irregular menstrual cycles. Periods may not occur for weeks or months after injury. There may be difficulty getting pregnant. Men may have decreased sperm production.

What can be done to improve sexual functioning?

- Talk openly with your doctor or other rehab professionals about the problem. Some people may feel embarrassed talking openly about sexual issues. Keep in mind that sexuality is a normal part of human functioning and this can be addressed just like any other medical problem.
- Get a comprehensive medical exam. This could include checking hormone levels and asking about the role medications may play in sexual functioning.
- Considering starting sex therapy. A sex therapist is an expert who helps people to overcome sexual problems and improve functioning.
- When having sex, position yourself so that you can move without being in pain or becoming off balance. This may mean trying different positions.
- Plan sexual activities for time of day when you are less tired. Try minimizing distractions during sexual activity.
- There are sexual aids developed to help people with disability. Try searching online.

After brain injury, it remains important to protect yourself from unplanned pregnancy and sexually transmitted diseases.

Relationships after Brain Injury

After brain injury, relationships with family members and significant others will likely change. Everyone's situation is unique but there are some common problems that family member's face such as less time for yourself, financial difficulties, changes in relationship roles, problems with communication, and lack of support from other family members and friends. As a caregiver to someone with brain injury, it is common to feel overwhelmed, sad, anxious, angry, guilty and/or frustrated.

Coping Tips for Caregivers

- **Accept that you cannot do this alone.** Do not feel guilty enlisting the help of friends and family! Ask for assistance and take offers of help. Most people are glad to help but are not sure what you need. Assign specific tasks to those helping.
- **Educate yourself.** Learn about your loved one's condition from reliable sources. Knowledge can be empowering.
- **Allow yourself to grieve.** It takes time to accept the loss of your former relationship and lifestyle. It's ok to feel sad, angry, and frustrated. Remember that time will also bring about new goals and dreams for you and your loved one.
- **Try to reduce stress.** Seeing a professional counselor is strongly encouraged for managing stress, processing what you've been through, and adjusting to a new role as caregiver. Try stress relief techniques such as walking, writing in a journal, practicing medication, or enrolling in a yoga class.
- **Take care of yourself.** Make sure you are getting some rest, eating healthy foods, and engaging in some physical activity. Healthy habits can impact your mood. If you aren't taking care of yourself, it becomes even more difficult to care for your loved one.
- **Stay social.** Try to interact with people. It may feel overwhelming to schedule a visit with friends or a social outing but you will likely be glad you did it.
- **Find a caregiver support group.** Being around others who are going through similar experiences provides an outlet for sharing ideas, venting frustrations and supporting each other through hardships.
- **Take things one day at a time.** There are many uncertainties in the recovery process. Try to focus on the accomplishments of each day rather than the "what ifs" of the future.

Driving after Brain Injury

Because we drive so often, it is easy to forget that driving is the most dangerous activity completed in our everyday lives. A brain injury can affect the skills needed to drive safely including vision, concentration, reaction time, memory functioning, and hand-eye coordination. Even mild cognitive changes increase risks while driving. Discuss return to driving with your doctor, therapists and family members. A formal driving evaluation to determine readiness to drive is strongly encouraged.

Driving Evaluations

A driving evaluation is a crucial step in determining a person's ability to drive after brain injury. While there is no standardized assessment for driving, a typical evaluation has two parts:

- **Preliminary evaluation:** An evaluation of cognitive skills, a review of road rules, assessment of vision and depth perception, reaction time, and physical mobility for getting in/out and operating a vehicle. Recommendations for adaptive equipment can be made.
- **On-the-Road Evaluation:** A test of the actual operation of the vehicle in the presence of the evaluator. This helps assess safe driving skills in various traffic environments.

A driving evaluation is typically completed by an Occupational Therapist who has done additional training to be come a Certified Driving Rehabilitation Specialist.

- In the Charleston area, contact:
  Roper Driving Solutions
  3510 Hwy 17 North, Ste 140, Mount Pleasant, SC 29466
  843-606-7605
- Find a driving specialist in your area by going to aded.net and then selecting "Find a Provider".

Legal Considerations

In the state of SC, a brain injury is not reported to the DMV and your license remains valid. If you have a seizure, it is illegal to drive for 6 months after the most recent seizure. Documented clearance to drive from a medical professional is recommended to protect you in the event of an accident.

Returning to Work

The cognitive, physical, and emotional changes after brain injury may make returning to work difficult. This doesn't necessarily mean that you cannot work, but you may require adaptations or a different role. Alternatively, you may find that return to work is not feasible and you need to consider other options. Talk with your doctor, therapists, family, and/or employer when making decisions about work.

Returning to a Previous Job

It is usually better to return to a job that you know well rather than to learn a new job. Familiarity of the role, colleagues, and the workspace can be helpful. You do not have to disclose or give details of your brain injury to your employer, but you might find it useful to do so. Under the Americans with Disabilities Act (ADA), employers have a legal duty to make reasonable accommodations for a disabled employee.

Some things to consider and discuss with your employer:

- Return to work gradually. Consider shortened hours, less days per week, or working from home.
- Return with less workload or scheduled rest breaks.
- Take up a different role.
- Sensory accommodations such as different lighting or noise cancelling headphones
- Change of office space to reduce distractions
- Organization tools such as labels, binders, or timers
- Request clear and written directives for job tasks and due dates
- Disability training on brain injury for the rest of your work team
- Ask for regular meetings with your employer to discuss your performance, whether the adaptations are helping, or whether you need further support to be arranged.

Alternatives to Returning to Work

For some brain injury survivors, return to their previous job is not possible. There are some alternatives to consider.

- **Volunteer work** can be a good way to get out in the community and engage in something meaningful.
- **Accessing disability and social security benefits.** Benefits can be received through disability insurance (SSDI) or supplemental security income (SSI). It can take several weeks or months to process the claims and receive the benefits, so it is important to apply early. Benefits don't typically begin until 6 months after injury. A social worker/case manager may be able to assist you with these claims. Learn more and apply at ssa.gov/benefits.

Vocational Rehabilitation

Vocational Rehabilitation (VR) is a nationwide agency that helps individuals with disabilities achieve and maintain competitive employment. They offer services including a comprehensive evaluation, disability benefits counseling, job training and placement, and assessment for assistive technology.

Getting Started with VR

Contact your local VR office and schedule an appointment with a counselor.
Your counselor will work with you to complete your application. They will request information from your current care providers is reviewed to determine if you are eligible for services. Your counselor will then help you identify your job-related strengths and abilities and outline the steps needed to obtain or maintain employment. Every individual receives a customized plan designed to help them enter or re-enter the workforce.
Learn more at scvrd.net

Returning to School

When a student returns to the more challenging thinking and social activities of school, effects of brain injury may become more obvious. Knowing about services and accommodations that a student is entitled to is important. There are some major differences between high school and college. Good communication between the student, school, family and rehabilitation professionals is key.

Return to High School

- Contact school personnel as soon as possible after the injury.
- Determine if an **Individualized Education Plan (IEP)** is needed. An IEP is a formal plan that details the special education services and supports a school will provide to meet the unique needs of a student with a disability. IEPs are covered by law under the Individuals with Disabilities Education Act (IDEA). They're created for eligible kids who attend public school. A brain injury is an eligible diagnosis for an IEP. The process begins with an evaluation that shows a student's strengths and challenges. The results are used to create a program of services and supports to meet the student's needs. Parents are involved in the IEP process.
- Determine if a **504 Plan** is needed. This is a formal plan for how a school will remove barriers so a student with a disability can learn alongside peers in general education. It does not include specially designed instruction. It will include specific accommodations such as preferential seating, extra time for tests, or assistive technology. A student who doesn't qualify for an IEP may still get a 504 plan. A 504 plan is also covered by law under IDEA for students who attend public school.

Return to College

- Colleges have to offer equal access under the Rehabilitation Act of 1974, but they do not have to provide written plans and special education services like in high school. A college student may be eligible for accommodations but they must be reasonable and not compromise the academic integrity of the class. Examples of accommodations include extended time on exams, permission to audio record lectures, and copies of notes from a classmate. Students must reach out and request accommodations. Family members cannot initiate this on the student's behalf. Also, the college is not permitted to communicate with family without the student's permission.
- Most colleges have a disability services office that you should contact.
- Consider your class schedule such as spacing out classes for rest breaks or taking less course hours.

Support Groups

Support groups can be an important part of brain injury recovery. Whether you're a survivor or caregiver, it is helpful to know you're not alone. Support groups can provide education about brain injury and community resources, a place to socialize, and a safe space to share struggles and accomplishments.

Find a listing of all support groups in SC on Brain Injury Association of South Carolina's (BIASC) website: https://www.biaofsc.com/support-groups

Local to Charleston

Trident Head Injury Support Group is for BI survivors and caregivers.
They meet monthly in-person. Learn more at thisg.net or email thisgsc@gmail.com

For Young Adults

BrainStorm is specifically for young adults (ages 16-29) impacted by brain injury. It is open to brain injury survivors, or those who have a loved one impacted by brain injury. This group meets monthly via Zoom. For more information or to join, contact BIASC program coordinator at coordinator@biaofsc.com

For Caregivers

Neuro Caregiver Support Group is for caregivers of brain injury and stroke survivors. This group meets monthly via Zoom and has quarterly in-person social gatherings. For more information or to join, contact michelle.moore@rsfh.com or call 843-720-8378.

Community Resources

After discharge from the hospital, getting connected to community resources can help with support and quality of life.

able
SOUTH CAROLINA

AbleSC is a disability-led organization. They offer independent living services, peer support, emergency preparedness, employment programs, transportation programs and more. Learn more at able-sc.org

AccessAbility
A BRIDGE TO INDEPENDENCE

Access Ability provides independent living services including peer mentoring, employment advising, daily living skills training, young adult leadership, emergency disaster preparedness and more. Learn more at abilitysc.org

Adaptive Expeditions
Outdoor Adventures & Paralympic Dreams!

Adaptive Expeditions offers sport and recreation programs to individuals with disabilities. Activities include adaptive paddlesports, wheelchair tennis and pickleball, cycling and hand-cycling, water safety & swimming, and natural history tours. Learn more at adaptiveexpeditions.org

BRAIN INJURY ASSOCIATION
OF SOUTH CAROLINA

Brain Injury Association of SC (BIASC) is dedicated to supporting brain injury survivors. They provide support groups, a helpline, and training through conferences and courses. They also have advocacy and education efforts across the state. Learn more at biaofsc.org

brainline

Brainline.org is a website that offers reliable information on brain injury for veterans, civilians, and caregivers. Check it out at brainline.org

NExT Wellness

The MUSC Neurological Exercise and Training (NeXT) Wellness Center is a safe, accessible, and free gym for individuals managing a neurological condition and their caregivers. Learn more at chp.musc.edu/research/centers/next-center

Charleston Area Therapeutic Riding (CATR) empowers children and adults with disabilities to enjoy more active and fulfilling lives through therapeutic horsemanship. Learn more at catr-program.org

Charleston County Parks is committed to inclusion in their programs and facilities. They offer programs and events that promote physical fitness, mental wellness, and provide social opportunities. Parks are handicap accessible. Learn more at ccprc.com

Coastal Adaptive Sports is dedicated to facilitating sports opportunities and scheduling recreation activities to enhance the lives of individuals and families who have disabilities. They offer basketball, cycling, surfing, and other sports. Learn more at coastaladaptivesports.org

Disability Rights SC helps people with disabilities understand and defend their rights. They provide services including client assistance, training, abuse & neglect investigation, legal assistance, and advocacy for change. Learn more at disabilityrightssc.org

Love Your Brain Foundation offers mindfulness, meditation, and yoga for brain injury survivors and caregivers. Most of their content is available online through on-demand and live virtual classes. They also offer in person retreats. Learn more at loveyourbrain.org

SC Thrive helps individuals navigate the complex system of available benefits including food security and healthcare benefits. Learn more at scthrive.org

Vocational Rehabilitation (VR) is an agency that assists individuals with disabilities achieve and maintain competitive employment. They offer services including a comprehensive evaluation, disability benefits counseling, job training and placement, and assistive technology assessments. Learn more at scvrd.net

Getting Assistance

There are state and federal agencies that may provide aid on a short or long-term basis. It can be confusing to determine what assistance you qualify for. You are encouraged to work with a social worker or case manager.

Additionally, there can be a lot of "red tape" when dealing with a government agency. To facilitate the process, become a good record keeper. Create a log of all appointments and the results. Document phone calls with the name of the person called and the results. Keep a copy of medical records and don't give away your original copies.

Social Security Administration

Information regarding Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) can be obtained directly from the Social Security Administration Office. When applying to Social Security, a person is often turned down the first time. On reapplication, however, they may meet the criteria for a program. It can take several weeks or months to process the claims and receive the benefits, so it is important to apply early. Learn more and apply at ssa.gov/benefits.

Other State/Federal Agencies

Other resources maintained by state or federal agencies may provide aid depending upon your specific need. A partial list includes:

- **Medicaid** is a joint federal and state program that gives health coverage to some people with limited income and resources. Visit medicaid.gov
- **Medicare** is federal health insurance for anyone 65 or older and some people under 65 with certain disabilities. Visit medicare.gov
- **The SC Department of Disabilities and Special Needs (DDSN), Head and Spinal Cord Injury Division (HASCI)** offers information, referrals, and service coordination to directly assist an individual in accessing all appropriate public and private resources. Visit ddsn.sc.gov or call (888) 376-4636.

- **Community Long Term Care** helps individuals who want to live at home, need assistance with their care, and are financially eligible for Medicaid. For info, visit scdhhs.gov or call (888) 549-0820.
- **Supplemental Nutrition Assistance Program (SNAP)** provides nutrition assistance (food stamps) to some individuals who are unemployed, disabled, or low-income. Visit dss.sc.gov/assistance-programs/snap/

Planning for the Future

It is important to consider financial and legal matters for the future after brain injury. It is easy to get caught up in the day-to-day activities and not consider the long-term plans.

Care Options

Depending on the severity of the injury, care options can range from in-home care to long-term care facilities. In-home care allows the individual to stay in a familiar environment but requires significant support from family members or hired caregivers. Long term care facilities such as nursing homes provide professional care but may lack specific expertise in brain injury.

Financial Planning

Situations such as inability to return to work or need for long-term care can have significant financial implications. Explore financial options such as health insurance, long-term care insurance, Medicaid, or other government programs.

Legal Considerations

Consider if you need to establish legal documents so that the brain injury survivor's wishes are respected and that there is a clear plan for decision-making if they are unable to make decisions themselves.

- **Living Will** is a legal document that states how you want to be treated if you are unable to make your own medical decisions
- **Power of attorney (POA)** is a legal document that gives someone the power to make decisions on your behalf, such as legal, medical, or financial matters. POA is used if an individual can identify who they would like to make decisions.
- **Guardianship** is a legal process utilized when a person can no longer make decisions about their person, property, or finances. A court chooses who will act as guardian. Guardianship is more involved than POAs, with more legal fees and time required. In some cases, guardianship is divided among different individuals; one may be responsible for money and property and another responsible for the care of the person with the brain injury.

Life Care Plan

A life care plan is a comprehensive document that outlines the future medical and supportive care needs of an individual with chronic illness. It is created by a professional known as a life care planner. The plan identifies the person's ongoing care requirements and quantifies the costs of necessary medical items and services throughout their lifetime. Life care plans are often created if there are legal settlements to ensure that individuals receive the care and financial support they need.

Regular Monitoring and Reevaluation

Brain injury is a chronic condition and the needs of a person with brain injury may change over time. Regular medical check-ups and reevaluations are essential to adjust the plan of care as needed. Ask if medications are still required or what new resources may be available.

Advocacy

It can be important to learn how to be an effective advocate for your rights and resources after brain injury. Here are some suggested steps to advocacy.

- **Learn the basics**. Every brain injury is unique and impacts the individual in a specific way. The more knowledge you can gain, the better you can advocate for yourself.

- **Find the appropriate medical providers.** There is no one doctor, therapist, or facility that is right for everyone. You may need to see multiple different professionals, from doctors to therapists to counselors, to determine how best to move forward. *Try to find a provider who knows brain injury.*

- **Don’t be afraid to ask for a second opinion.** If you see a provider who does not understand your symptoms, you will want to seek a second opinion. You can reassess the situation if you find that you are getting consistent feedback from multiple sources.

- **Know your rights.** The Americans with Disabilities Act (ADA) guarantees legal protections for individuals with disabilities. Learn more at www.ada.gov. Sometimes it is useful to reach out to a disability attorney. They can help with situations such as establishing fault after sustaining an injury or assist in applying for disability benefits. The Brain Injury Association of America (BIAA) offers a list of preferred attorneys who have been vetted for this purpose: https://www.biausa.org/professionals/preferred-attorneys

- **Set boundaries.** Do not hesitate to speak up for what you need. Communicate boundaries with family and friends such as desire for reduced social activity, increased time to complete tasks, fewer questions, etc. Your psychological well-being and emotional health are important priorities.

- **Seek help.** Brain injury associations offer referrals to resources, medical providers, and attorneys that specialize in many of the services above. Support groups can be a great way to learn about resources and get help from those in similar situations.

Roper Rehabilitation
Hospital

Brain Injury Program Coordinator

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Please contact us if you have questions or need support, even after discharge from rehab.

ASPIRE to Excellence®
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