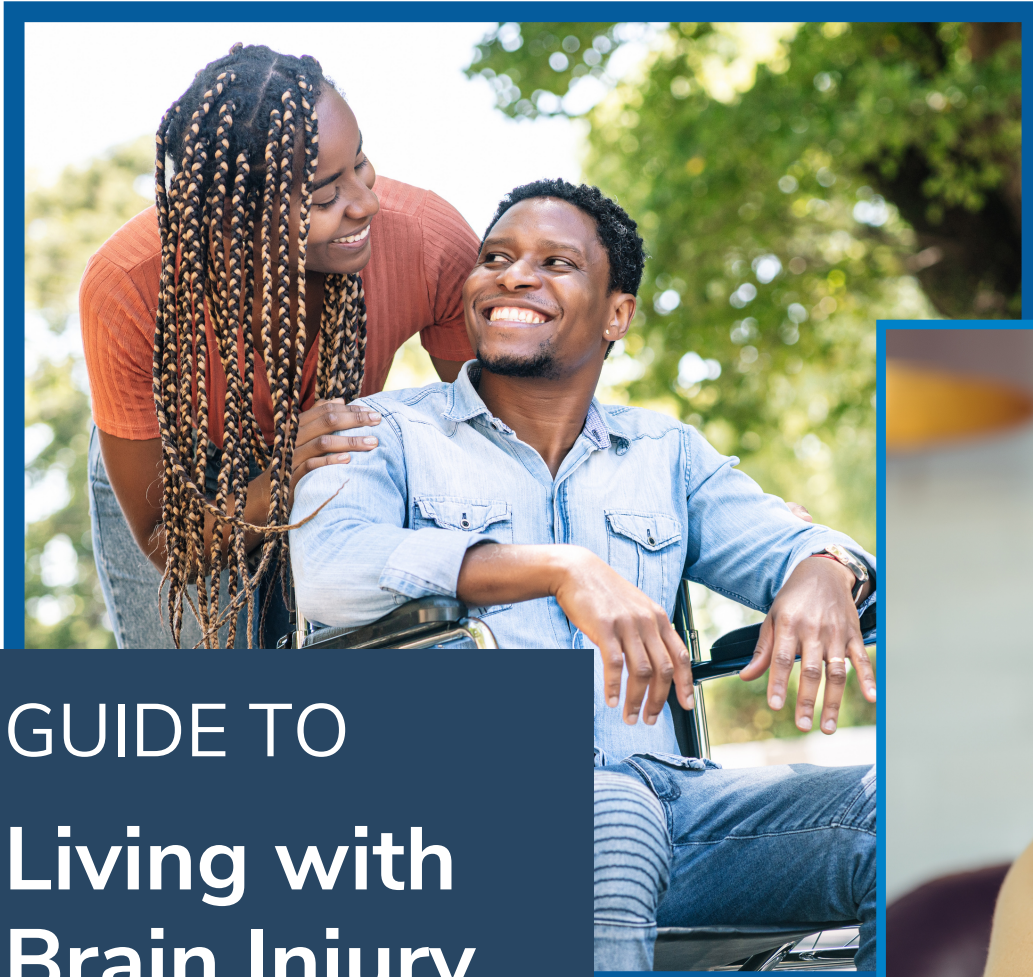


HOPE & HEALING



GUIDE TO Living with Brain Injury



Created by the Brain Injury Association

with support by partners at North Carolina Department of Health & Human Services, Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS).

www.biausa.org

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Statewide Services



Help, Hope, & a Voice for People with Brain Injury

We are statewide nonprofit striving to create an inclusive community for individuals, families, friends, and professionals impacted by brain injury in North Carolina



How We Can Help

With limited resources and an unknown future ahead, it can be overwhelming trying to navigate life after brain injury. The Brain Injury Association of America (BIAA) hopes to be that connection, reduce isolation, and promote quality of life with direction to education, support, awareness, and advocacy.

Testimonial ★★★★★

"Life was full of activity until an auto accident changed everything. Suddenly no job. No interactions with groups and no obvious signs anything was wrong. BIAA has provided guidance to various training, messages, support groups, the website, and educational resources. The Brain Injury Association is considered to be a lifesaver because I fit in with other people that understand and know what I am going through."

→ **Dedicated Guidance to Local Supports**

We offer guidance to different services available related to brain injury, support groups, and other technical assistance.

→ **Better Understand the Impact of Injury**

Get access to handouts, training, toolkits, podcasts, conferences, blogs, learning events, magazines, and more to help better advocate for the services needed to thrive.

→ **Affecting Service Change & Policies**

We engage in efforts of public awareness to help understand and prevent injuries, in addition to active advocacy involvement to help elevate voices impacted by brain injury.



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www.biausa.org



What is a **BRAIN INJURY**

A brain injury, also referred to as an Acquired Brain Injury (ABI), happens when there are disruptions in normal brain functions caused by forces inside and outside of the body. It's basically the umbrella definition and can be further broken down into two categories - determined by how the injury was received.

Non-traumatic Brain Injury

the injury occurs inside the body, there was nothing external that caused it, leading to brain cell death and blood or oxygen disruption.



Poisonings or Substance misuse leading to overdose



Strangulation, choking, drowning, & losing air (Hypoxia or Anoxia)



Strokes, tumors, infections, seizures, & aneurysms

Traumatic Brain Injury (TBI)

injury occurs from jolts or blows to the head outside the body, breaking or movement within the skull causing bruising, swelling, bleeding, or twisting.



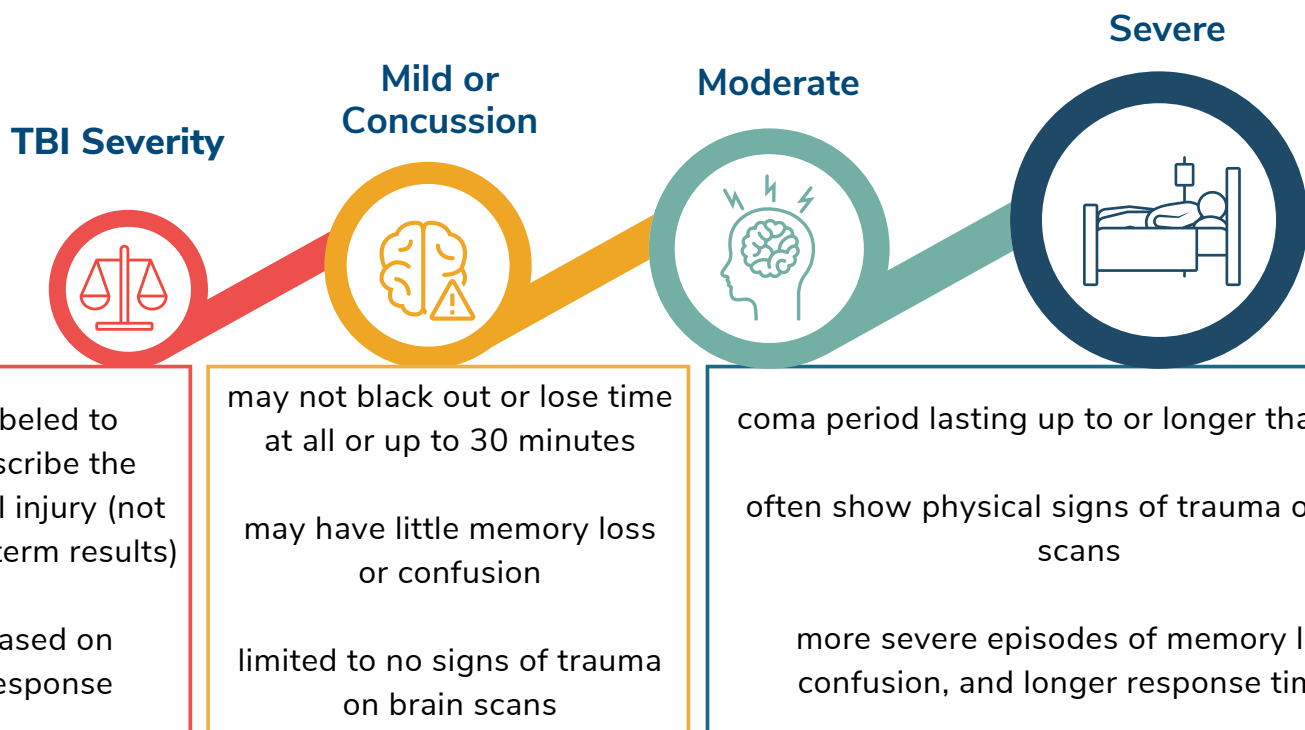
Blasts or falling and hitting the head



Collisions with motorists, pedestrians, or transportation

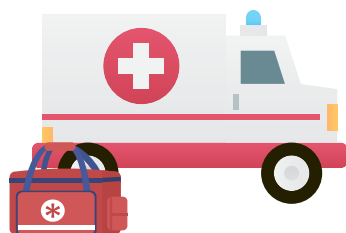


Gunshot, violence, assaults, or abuse



COMMON STAGES OF CARE

EMERGENCY CARE



Often the first interaction with medical care after a brain injury occurs in the emergency department (ED) of a hospital or trauma center. Your loved one may be alert and awake or comatose and unresponsive. Medical professionals may be asking questions to learn more about what happened or decisions related to care. The fast-paced environment can be stressful but the number one goal is your loved one's safety and stability.

CRITICAL CARE



Critical care allows for round-the-clock monitoring and prevention. Time spent in the intensive care unit (ICU) can feel overwhelming with new terms and future unknowns. It can be scary seeing your loved one hooked up to medical equipment or testing. Your loved one may be unconscious during this time, but feel free to speak to them encouragingly and avoid saying anything you might not want them to hear if they were more alert.

ACUTE CARE & REHABILITATION



Rehabilitation can occur once your loved one is medically stable and able to participate in therapies to help with resuming daily life (i.e. getting dressed, walking, speaking, eating, and using the bathroom). Be sure to maintain good communication with medical staff, ask questions and learn how to be involved in therapies. Identify people that can help out either at home or in the hospital. Very rarely can a deadline or timeline be put on progress after injury.

HEADED HOME



Transition may look like going home with outpatient therapies or more intensive rehabilitation supports (such as inpatient rehabilitation, skilled nursing facilities (SNFs), or other home-like settings. These resources can allow your loved one to continue rehabilitation depending on care needs.

When choosing care after the hospital, learn from those currently receiving services, explore more than one program, and identify any financial assistance available. Even if it's been a while since you were in the hospital, community supports and rehabilitation are available to improve function or engage.

COMMON TERMS HEARD

Activities of daily living (or ADLs)

eating walking, dressing, bathing, etc.

Anoxia

when blood flow and oxygen to the brain is reduced, resulting in cell death or damage.

Aphasia

loss of speech (understanding or expressing words or thought).

Bilateral

affecting both sides.

Catheter

flexible tube to collect/ monitor pee.

Cerebrospinal fluid (CSF)

nutrient-filled liquid around the brain and spinal cord providing cushion

Coma

prolonged unconsciousness that a person cannot be woken, failing to respond normally to painful stimuli, light, or sound.

Contusion

bruising when torn blood vessels leak blood under the skin.

Coup-Contrecoup

a two-part blow to the head in which bruising occurs at the site of injury (coup) and the site directly opposite (contrecoup) as the brain hits skull.

Craniotomy

skull is opened to relieve pressure.

CT Scan

diagnostic imaging that uses a X-rays and computers to show brain images.

Deep vein thrombosis (DVT)

a blood clot that forms in a vein deep in the body.

Diffuse Axonal Injury (DAI)

tearing of brain tissues resulting in cell death.

Dysautonomia

increased blood pressure with abnormal rapid heart rate, breathing, muscle tone, and body temperature.

Dysphagia

swallowing disorder.

Electroencephalogram (EEG)

records brain's electrical activity using attached electrodes.

Gastrostomy Tube (G-Tube)

tube inserted through a surgical opening into the stomach.

Glasgow Coma Scale (GCS)

severity scale based on response to commands (moving, opening eyes, or answering verbally).

COMMON TERMS HEARD

Hematoma

breaking of brain vessels, leading increased blood and pressure.

Hemorrhage

excess bleeding following damage to blood vessels.

Hydrocephalus

increased pressure as a result of blockage or disruption of fluid flow from the spinal cord and brain.

Incontinence

loss of bowel or bladder control including leaks, intense urge, or not emptying.

Intracranial pressure (ICP)

swelling of the brain after trauma, increasing pressure, and interrupting blood flow or harming brain cells.

Intravenous (IV) line

tube placed in vein to deliver medications and fluids.

Ischemia

severe reduction in the supply of blood to body tissues.

Magnetic resonance imaging (MRI)

diagnostic procedure using magnets and computers to produce detailed brain images.

Nasogastric (NG) Tube

delivers medication and nutrients directly into the stomach.

Neuroplasticity

changing brain pathways with repetition and adapting to surroundings.

Pressure sores

areas of damaged skin caused by staying in one position for too long.

Perseveration

persistence or repetition of a specific movement or word.

Post-Concussion Syndrome (PCS)

persistence or repetition of a specific movement or word.

Post Traumatic Amnesia (PTA)

period of time after the injury when unable to store new information.

Postural Orthostatic Tachycardia Syndrome (POTS)

not enough blood returns to the brain when changing position (i.e. standing), leading to lightheadedness, increased heart rate, nausea, blurry vision, brain fog and fatigue.

Rancho Los Amigos Levels of Cognitive Functioning Scale

clinical tool with ten levels used to rate recovery after injury and rehab readiness.

Seizures

sudden convulsions, a disturbance of senses, or a loss of consciousness caused by disruption in electrical brain activity.

Spasticity

muscles are continuously contracted, causing stiffness or tightness and interfering with normal movement.

Ventilator

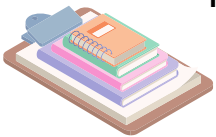
machine to help breathe and receive oxygen with a tube placed through into the airway.



RECOVERY COPING TIPS

Living with brain injury can sometimes feel like one step forward, two steps backward. Stay strong, be patient, and implement some of these tips to help.

KEEP ORGANIZED



Keep a notebook, folder, or binder handy

- Mountains of new information will be given to you all at once partnered with sleep deprivation and high stress. Even if you do not see a need right now, keep it in a safe place for later as a reference.



When it doubt, Write it down

- Write down questions you have as soon as they come up. Also keep track of instructions given by professionals. Write down or video record (with permission) their advice for specific skills, transferring, or other specific assistance given.



Request documentation for any visits, diagnoses, and testing done

- This may be required as eligibility criteria for programs or financial assistance and it may be harder to access the longer time goes by. Keep the information together in your binder or folder.



Gather insurance and funding information

- You may look into seeking insurance, grants, vouchers, disability, or legal advice.



Pay attention and keep a log of symptoms or changes in behavior

- Start to identify any patterns or side effects to certain medications to tell your loved one's doctor or team, as you may see your loved one more than they do.



Free Toolkits

Speak to your therapist for toolkits and resources to help!

RECOVERY COPING TIPS

SEEK SUPPORT



Take breaks and prevent over-stimulation

- Some therapies or certain times during the day may be more tiring. Rotate visitors for smaller groups and keep an eye out for any agitation caused by fatigue or too much going on. Take walks or visit the food court for a breather if needed. Take turns staying with your loved one to give you time for a shower or get some rest. Do not be afraid to ask for a break or alone time to rest your brain during recovery.



Designate a person to keep everyone informed

- Set up a method for sharing information (private Facebook group, e-mail list, website, group text, etc.) with others. Having a system can help prevent having to retell updates over and over again. This might be a good task to delegate to someone else if it seems too overwhelming to take on at this time. Keep a list of the people who reach out or are important to you. You can even use this list to request volunteers or set a schedule for visitors early in rehabilitation or when returning home to keep active.



Don't take this on alone

- You might be constantly going, with the focus on your loved one or your own recovery, then feel hit with a wave of emotions. Ask about a social worker, counselor, or chaplain for someone to talk to. Some places have support groups for education & families to connect with or you can look online for support. You are not alone in this and you don't have to be superhuman. This is something you've never had to experience before and it can take time to adjust.



Create a help list for those asking how they can help

- Determine what everyday tasks might be able helpful to delegate to others. Take note of the people offering to help out, even if you do not see a need right now. Let them know how much you appreciate their support. Often the rehabilitation process is months or years. Let others help, as they can get the benefit of contributing and showing you that they care. Some helpful tasks may include: collecting mail, groceries, laundry, caring for animals/ plants, cleaning/ removing trash, making meals, updating friends, visiting, or carpool/ childcare.

RECOVERY COPING TIPS

THINK AHEAD

Future planning should start early



- Start talking with your case manager or reach out to an advocacy organization early to determine what options are available in your area. Financial factors may affect service placement, but advocating for your or your loved one's needs with the insurance companies may help. Avoid taking denials for face value, check for an appeal process. See if there are medical professionals that can validate the need and submit documentation.



Investigate needs and level of supports needed

- Some people can thrive at home with added services or alternative community options may provide additional safety or supports. Determine what works best for your situation. Get input from the medical team and research supported living options depending on level of care needs (medical, cognitive, behavioral, etc.).



Connect with community programs in your area

- You or your loved one may be used to going to work or school daily, but now feel like they need more time to build up their stamina or skills. Keeping active and busy can help the brain in rehabilitation. Clubhouses, day programs, employment programs, independent living centers, rehabilitation therapies, and support groups can be opportunities for continued skill building. Start with one scheduled activity a week and add from there to avoid overdoing it. Listen to your body and take breaks.



Push for progress, not perfection

- Tasks may be harder than they were before the injury. The brain rebuilds with repetition, determination, and extra cues. Do not be afraid to push yourself or a loved one a little past their comfort zone. However, be cautious to not overwhelm with unrealistic expectations, crowded environments, or moving too fast. Break everything down into their smallest components, slowly building up step-by-step. Over-critiquing yourself or others will only increase helplessness or feeling not good enough. Instead, empower and compliment, while documenting (with photo or video) to celebrate small victories.



Learn More

Visit www.bianc.net for more information, our resource guide, and signing up for our free activity classes.

RECOVERY COPING TIPS

ASK QUESTIONS

Clarify, summarize, and get connected



- You are not expected to be an expert in everything surrounding brain injury. Do not hesitate to clarify what you've heard or ask questions. You're taking in large amounts of information at once, it may help to ask for a summary from the other person, summarize the information back to them, or see if they can follow-up in written format (i.e. text, email, printed paper). Ask for and write down contact information if you have thoughts or questions later. This is true for people you talk with on the phone, as well. Keep a log of who you talk to and when so you can follow-up.

Keep informed during long-term stays



- Identify the time of day for therapies, special events, visiting hours, when the primary doctor visits, and how you will be updated on progress. Ask about scheduling regular meetings to discuss goals, complications, and next steps.

Your voice is meaningful



- Be active in setting goals but make sure they are specific to and driven by the person with the injury. Speak up if you do not understand or have important information to share. Professionals may be experts in their field, but you are the expert on how brain injury impacts yourself or your loved one.

Investigate functions of behaviors, their meaning, and unmet needs



- It is common for people to see negative actions or behaviors at face value. The unfortunate result is disruptive labeling individuals with behavioral "problems" or as uncontrollable. It's more accurate to see communicative behaviors with underlying causes that can be controlled or needing supports to add more structure. What is the person trying to say? How can you connect to the emotions being felt? Are there expectations that need to be clarified to promote future success?



FACTORS AFFECTING REHABILITATION



Connecting to Services

Returning to regular life immediately after brain injury may be difficult, but not impossible to do. Connecting to services early can be helpful.

Health & Getting Diagnosed

- Medical, Emergency, & Diagnostic Supports

Getting Better & More Involved

- Rehabilitation, Mental Health, & Day/Living Supports

Getting Ahead & Having Help

- Home/ Personal Care, Residential/ Daily Management, Assistance & Advocacy Supports

See pages 23-25 for more information

General Health

Factors such as smoking, obesity, and chronic conditions can promote poor health and affect rehabilitation. Exercise, proper nutrition, and sleep are vital after injury.

History

Previous injury may impact the brain's ability to recover. Prevention of falls and difficulty with balance should be addressed early, due to the increased risk for injury.

Severity

Though those with more severe injuries may need additional time for rehabilitation, individuals can regain functioning, even if not at pre-injury levels.

Location

Depending on where the brain is injured, different functions may be more challenging such as vision, movement, processing, pain, language, memory, or alertness.

Support & Coping

Brain injury can affect motivation and hope over time. Be proactive, flexible, and realistic in goal setting while seeking out additional supports for self-care or counseling.



REHABILITATION TEAM

Having a variety of specialists allows for comprehensive rehabilitation after brain injury. The type of professionals involved varies depending on setting and may be involved during or after the hospital/rehabilitation stay.

Case Managers

facilitate service coordination

Chiropractor

assists with spine alignment for movement & relieving pain

Lawyer

can assist in litigation, guardianship, or accessing benefits/trusts

Mental Health Counselor

help seek emotional wellness and healthy coming

Neuropsychiatrists

provide medication management for mental/behavioral health

Neuropsychologists

provide assessment of thinking skills, behavior, and emotions

Neurologists

specialize in medical needs related to the brain (seizures, pain, weakness)

Neuroophthamologists

address needs of vision related to the brain through eye exercises

Occupational Therapists (OTs)

address practical areas of daily living

PM&R Physician

specializes in physical medicine & rehabilitation for the brain

Physical Therapists (PTs)

evaluate and treat the ability to move

Primary Care Physician (PCP)

practices general medicine for routine checkup and non-emergency care

Recreational & Play Therapists

provide activities to improve skills

Rehabilitation Nurses

monitor body systems, health needs, and coordinate with the team

Speech-Language Pathologists (SLPs)

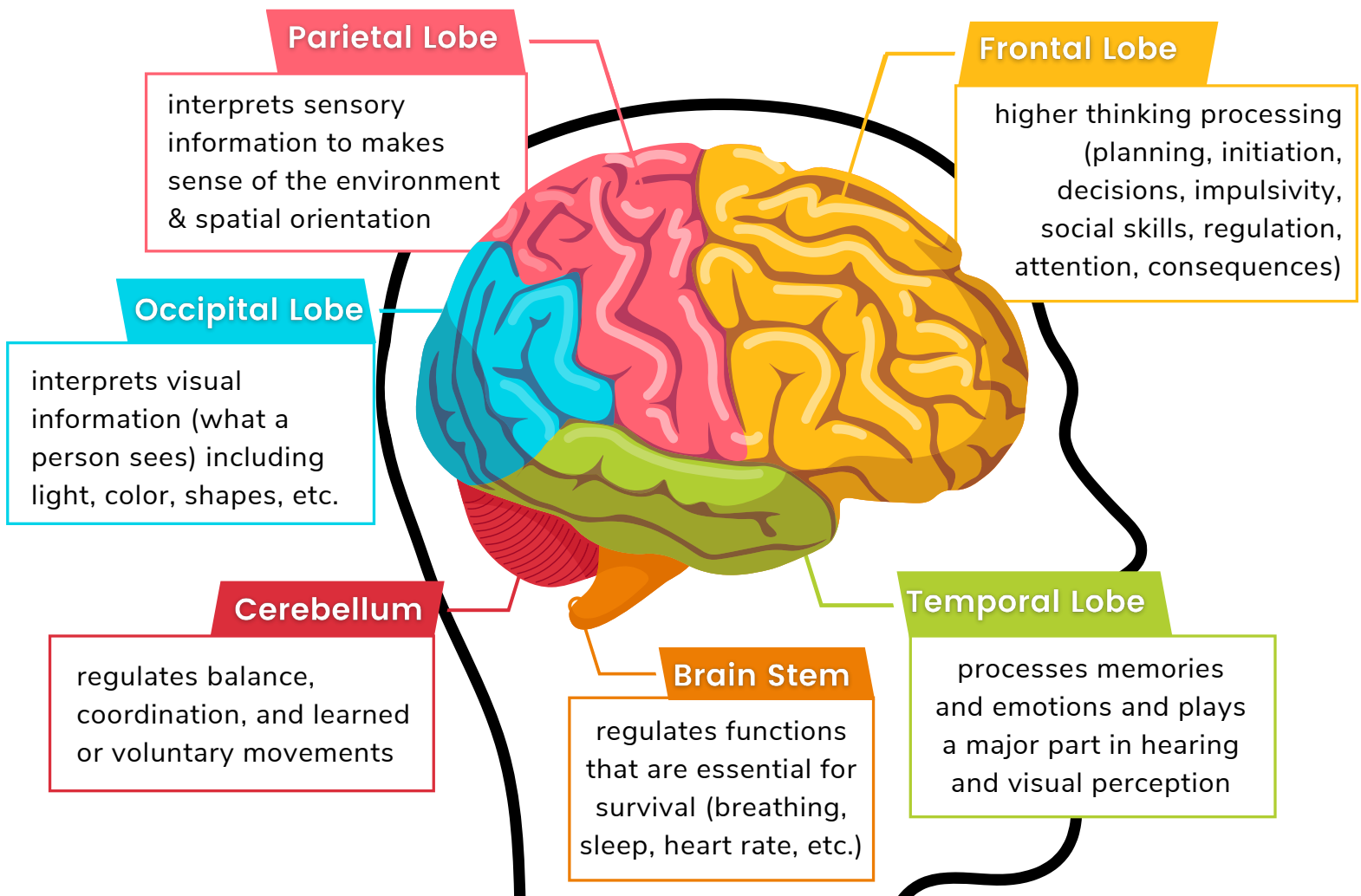
evaluate swallowing, comprehension, and communication skills

Vocational Rehabilitation Counselors

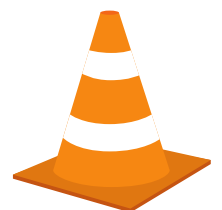
evaluate employment and education opportunities

The Brain & BEHAVIOR

Similar to different departments in a business, different parts of the brain are responsible for different functions. This includes everything from a person's movements, emotions, processing of the sounds and sights around, starting or holding a conversation, or being able to pay attention and remember information.



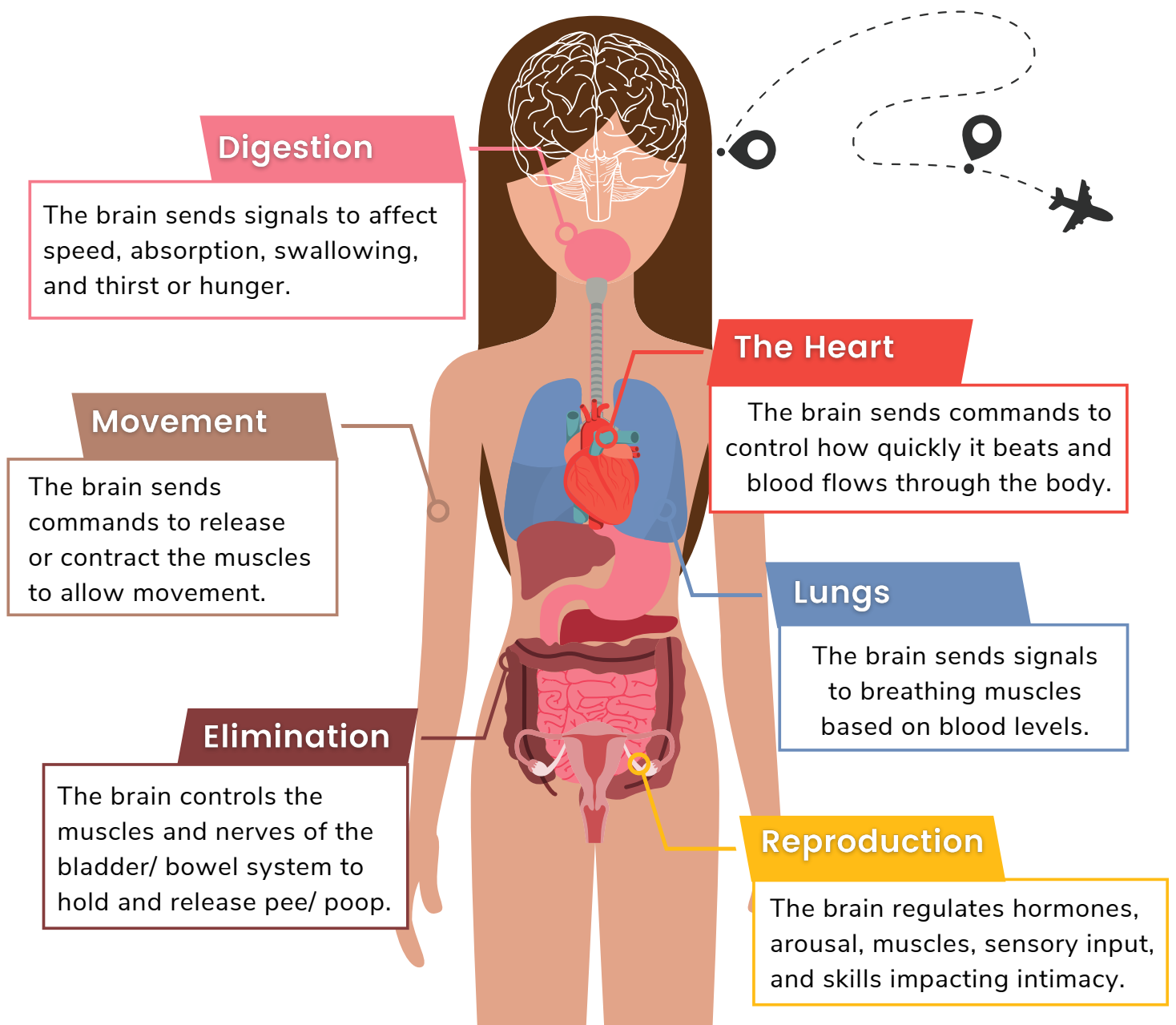
When the brain is injured, tasks may be more challenging than prior to injury, like the brain is a road under construction. The communication brain cells (neurons) may become severed, stretched, or disconnected. The brain's connections end up having "pot holes" or "closed lanes" leading to traffic and a detour. Similarly, people can get frustrated and it takes much longer to accomplish "easy" tasks from before the injury.



The Brain & THE BODY

The brain does not work in isolation. Your nervous system is your body's command center. Starting from your brain, a complex network of electrical signals travel to and from other cells, glands, and muscles all over your body. These nerves receive information from your surroundings, interpret or make sense of it, and control your response or behavior.

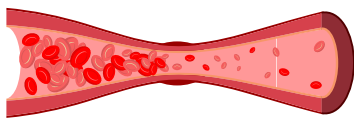
The brain acts as an airport hub, but sending signals instead of planes to different areas. After injury, the disruption of signals is like a grounded plane. Automatic processes (like a direct flight) are now more challenging or people feel less in control of their actions (like requiring a delayed or indirect flight).



The Brain & ENERGY LEVELS

Many people report that their brain injury makes them feel foggy, tired, overwhelmed, and extremely fatigued. That is because it takes a lot of energy for your brain to heal after an injury.

Brain Injury Energy Crisis



Decreased Blood Flow

During an mTBI, Potassium ions exit the neuron, while Calcium ions rush into the cell. When the Calcium enters, it causes the blood vessels to constrict. This results in decreased blood supply to the brain. This diminished cerebral blood flow causes decreased energy within the brain.



Decreased Energy Production

The resulting chemical imbalance after an mTBI can also cause damage to the energy-producing center of the brain cells' mitochondria. This means even less energy is available to your brain.



Increased Energy Demand

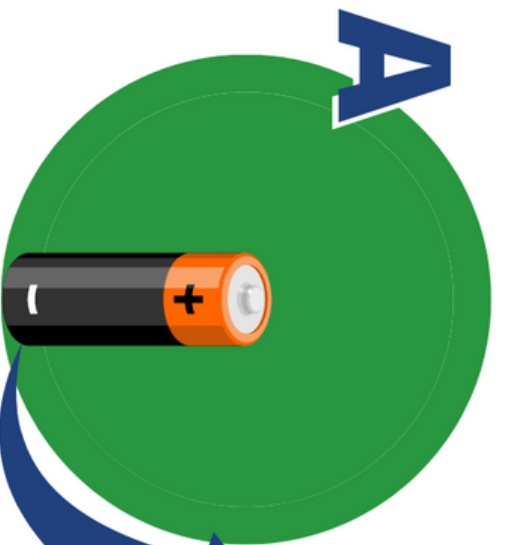
In addition to less available energy for the brain, an injured brain needs more energy than normal to heal. Your brain, eager to repair itself, will prioritize all energy towards recovery which means you have less energy available for daily life, activities, and thinking.

This energy crisis means what used to be normal sensory input in daily life (sounds, bright lights, etc) thinking, problem-solving, and emotional situations, now all feel much more overwhelming and out of control.

To explain this to someone who hasn't experienced a mTBI before, think of it as not sleeping for a full week, having a cold, starting the first day of a new job, and having 40 house guests all at the same time. With so many demands on the brain, everything feels extremely overwhelming.

The 3 Batteries of Energy After a Brain Injury

The goal is to only use your 24 hour battery!



Recharge Time = 24 Hours

Your goal is to only perform tasks that will allow you to wake up the next day with a reasonable amount of energy and mental clarity.

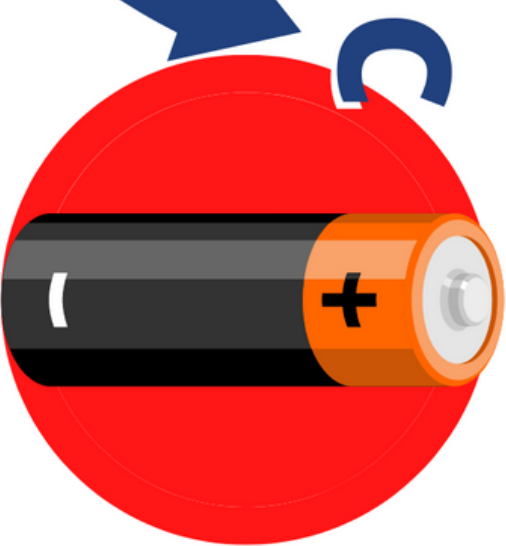
Only using energy from battery A will allow your brain sufficient energy for healing.



Recharge Time = 2-3 Days

Battery B is a protective battery for you. It allows you to push through when you can't avoid it.

If you have to use this battery, allow yourself 2-3 days of limited activity to recover.



Recharge Time = Up to 2 Weeks

This battery should only be used in extreme circumstances. When you use battery C you will feel like you have had a major setback in your recovery.

In the extreme circumstance where you have to dip into battery C, allow yourself up to two weeks of extra rest to recover.



Elliot, C. (2015) *The Ghost Inside My Brain: How a Concussion Stole My Life and How the New Science of Brain Plasticity Helped Me Get It Back*

The Brain & GETTING BETTER

The brain is able to adapt and change due to experience and repetition, making rehabilitation possible. Though we wish this were an instant process, it often takes months or years of developing strategies to help compensate or adapt for changes in the way we function after brain injury.

Repetition is a way for the brain to identify what is and is not important that needs to be remembered. Because of how the brain functions, the more we repeat something, the stronger the path in which information or thoughts travel is, and the easier a thought or task can be. Eventually this becomes automatic.

Every time you think a thought, it is like walking across the lawn. If you walk across it once, it makes no permanent impact. But if you repeat the thought, it creates a path. If you continue to think the thought over and over even more, it's like pouring a sidewalk. If you continue further to think that thought, it's like paving the road in your mind determining attitudes, values and behavior.



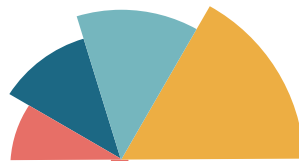
Interval Learning

Repeating something 10 times over the course of the week produces better results. Research shows that it takes about 30 days of repetition for our brain to rewire itself and begin to give us a new capacity.



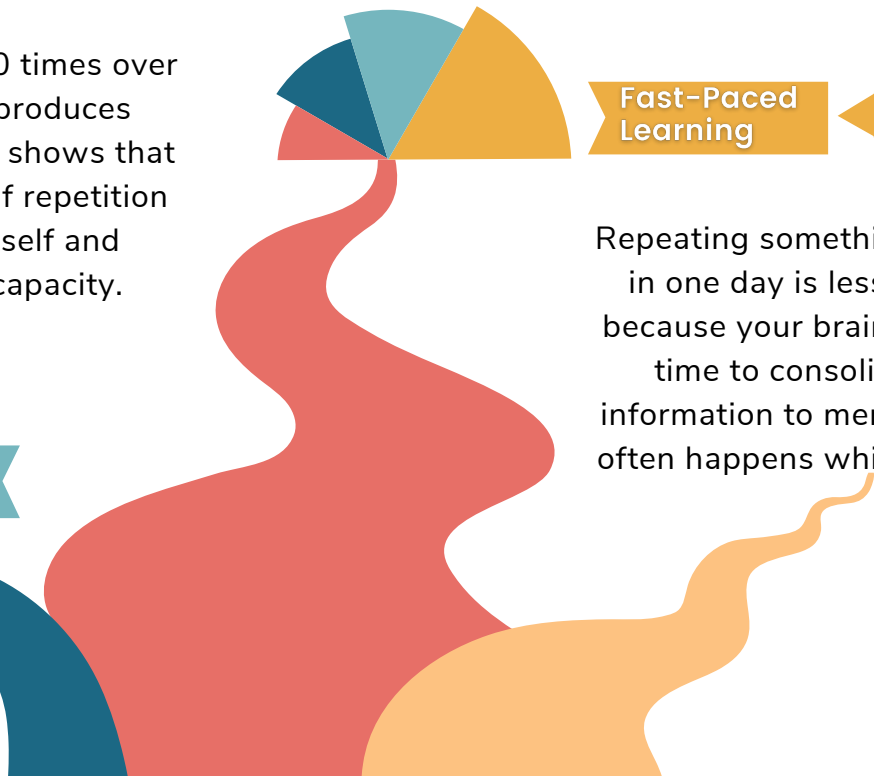
One-time Learning

Performing a task once won't create lasting change toward your goals and it's less likely to stick in your memory.



Fast-Paced Learning

Repeating something 20 times in one day is less effective because your brain still needs time to consolidate the information to memory, which often happens while we sleep.

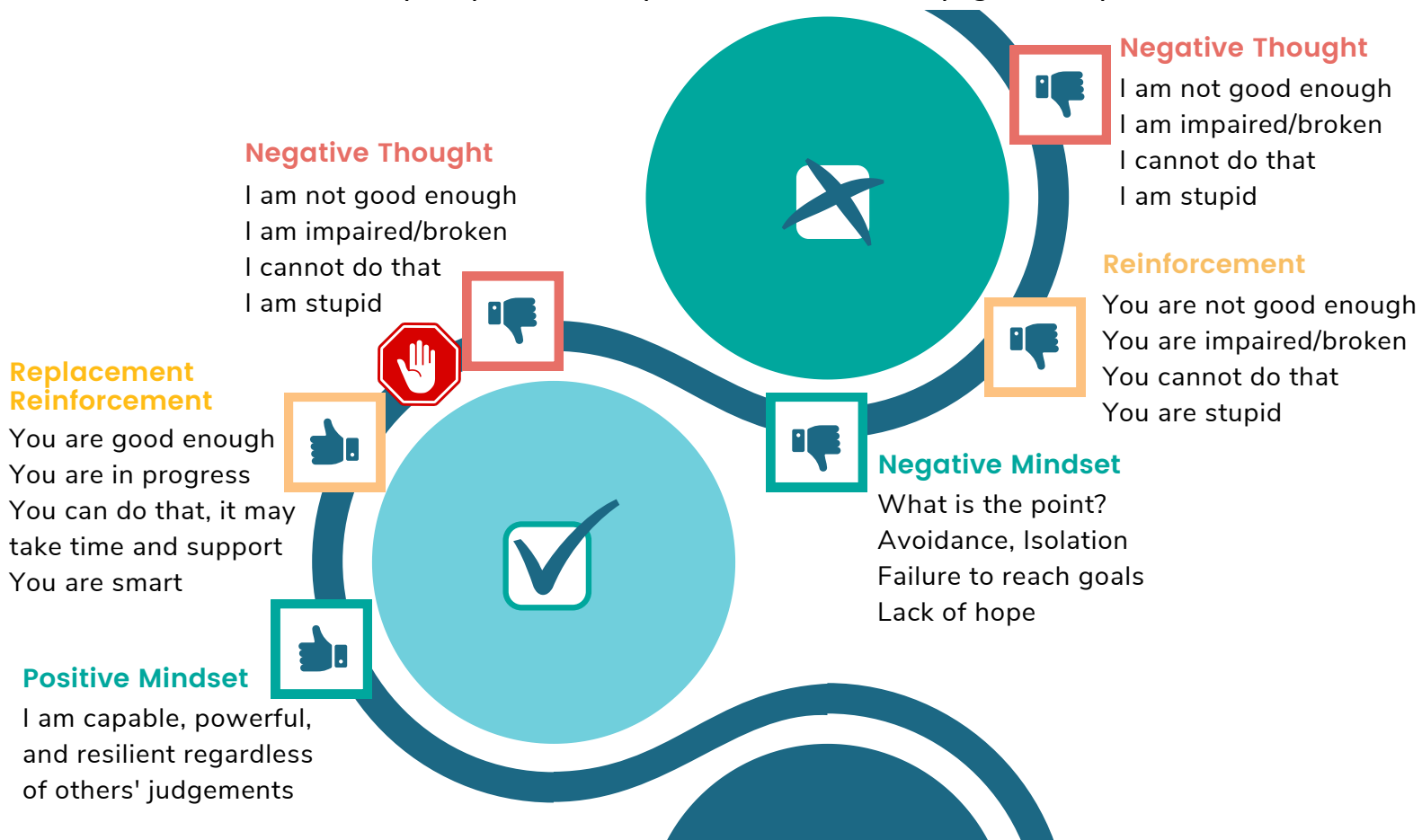


The Brain & MINDSET

Medical professionals may try to put a tangible number on progress or full recovery, saying that improvement occurs up to a certain point but then plateaus, staying at a consistently "impaired" state. Actually, current research shows that progress is possible in the years after brain injury and people can work or develop strategies to counteract the weaker skill areas.

Learned helplessness can lead to not speaking one's thoughts, not trusting capabilities, and not acknowledging how a person feels. Over time, the person may stop trying, feeling trapped by their circumstances. Not only does this mindset undermine strengths and creative capacity, but it also creates prolonged exposure of negative thought pathways staying active within the brain.

After brain injury, this looks like dependence on others, isolation, fear of failure, no motivation toward goals, and continual stress. It is important to identify when these negative comments occur (by oneself or others), stop them, and replace them with more positive (and likely more true) thoughts. They may feel like lies to start, but a kinder perspective on yourself can develop gradually.



COMMON CHANGES

Brain injury affects people differently, with some days being worse than others. One of the more challenging aspects of brain injury is that many of the challenges cannot be seen by the naked eye (how a person thinks, feels, or why they act the way they do). There is not one "look" to brain injury. This can make it difficult for family and friends to understand how brain injury impacts a person. Some symptoms can present as something entirely different. For example, trouble with sleeping could show up as agitation, headaches, trouble with speech or vision. It may help to look deeper for specific causes to address.

HOW YOU MOVE

- affected movement and coordination
- spasticity or jerking movements
- pain or stiffness
- paralysis or weakness
- lethargy or slowness
- balance & dizziness

YOUR SENSES

- changes in vision, hearing, smell, taste and overstimulation
- change in sexual function
- headaches
- seizures
- sleep disruption and fatigue



EXPRESSING IDEAS

- social skills (verbal and non-verbal communication)
- gestures, and body language
- talking & using facial muscles
- emotional affect, tone, and volume
- comprehension
- reading & writing
- finding words
- having "no filter" or appropriateness of responses
- empathy & projecting

HOW YOU FEEL

- regulating emotions or actions
- self-awareness
- quick irritability or anger
- unrelated laughter or crying
- personality changes
 - traits, interests, drives, values, self-concept, abilities, and emotional patterns
- disrupted mental health (depression, anxiety, etc.)

HOW YOU THINK

- recalling, paying attention, and learning new information
- processing speed
- orientation (time, place)
- sequencing, flexibility or switching between ideas/tasks
- problem solving, planning & organization
- making decisions, initiation & motivation
- mental fatigue
- safety awareness & impulsivity

ABI Symptom Checklist

Identifying your symptoms and monitoring those symptoms is the first step in taking control after an ABI. Circle all of the symptoms that you experience.

PHYSICAL SYMPTOMS:

- ★ • headaches
- ★ • nausea or vomiting
- ★ • fatigue or drowsiness
- ★ • balance problems/unsteady gait
 - initial feeling of being dazed or confused
- dizziness
- dizziness when looking up/down
- dizziness when rolling in bed
- difficulty talking
- motion sickness
- difficulty sleeping
- sexual dysfunction/changes

Cognitive Symptoms:

- ★ • brain feels foggy and tired
- difficulty knowing how to start a task
- difficulty with problem-solving
- difficulty multitasking
- difficulty planning your day
- difficulty remembering
- difficulty with decision-making
- difficulty with time management
- memory problems
- difficulty concentrating

COMMUNICATION PROBLEMS:

- ★ • difficulty understanding conversations
- difficulty speaking or writing
- inability to organize thoughts & ideas
- difficulty understanding written words
- anxiety with conversations
- difficulty following stories

VISUAL SYMPTOMS:

- ★ • eye fatigue/difficulty with eye tracking
- ★ • feel overwhelmed with lots of visual input (riding in a car, grocery store, etc)
 - lights feel too bright (especially fluorescent lights)
- difficulty scanning to find items
- difficulty with reading- words may "jump" on a page
- difficulty with depth perception
- feel overwhelmed when using the computer

AUDITORY SYMPTOMS:

- ★ • sounds are overwhelming
- hear everything and unable to focus on the important sounds
- hard to follow conversations
- unable to tune out background noise
- family gatherings, church, ball games, and crowded places are overstimulating
- shut down/become flooded when people talk too loudly
- everything sounds extremely loud
- ringing in the ears (tinnitus)

EMOTIONAL SYMPTOMS:

- ★ • overwhelmed/anxiety/heart racing
- mood changes/mood swings
- depression
- social avoidance
- lack of empathy for others
- irritability

★ Starred items are the most common symptoms and are the ideal symptoms to track for monitoring/management (next page)



COMMON STRATEGIES

Reduce the amount of information

Treat your brain like a funnel - less is more when it comes to your surroundings (distractions, lights, noise, movement). Wearing hats, sunglasses, or earplugs may help with overstimulation.

One instruction, question, or task at a time

Break down directives or activities step by step - multitasking or switching back and forth too often can lead to fatigue or overload.

Written & verbal cues when possible

Don't rely on just told information - write it down in a planner, notes on your phone, notebook, voice note, post-it, checklist, or add a calendar event with an alert.

Breaks are helpful for the brain

Avoid feeling exhausted by resting throughout the day, from screen time, standing, or mental focus - set up alarms to cue breaks or use timers to help get started.

Often is better, routines help

Keep important items in view and create a similar schedule every day/week to help with memory - chunk your time to stay active (ex. consistent sleep and set times, 1 hour of therapy, 1 hour social time, 1 hour games, 30 minutes work/chores etc.).

Ask to summarize, repeat, or rephrase

Be patient with yourself and others, it might take you longer to process information - advocate for supports or adjustments needed - when talking with others, repeat what you heard back to them to make sure you understood correctly.

Take your time, go slowly

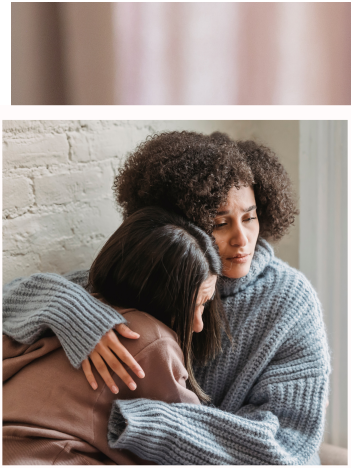
Scale back and build up your tolerance to activity (i.e. add 30 more minutes each day), break things down into smaller steps, and focus on your breath when you get overwhelmed.

Simple & organized information is best for attention

Keep important items in designated places (out of sight, out of mind), use labels, bins, pictures, or color code to make them easier to find.



Remember
ROWBOATS
Visit
www.bianc.net
for more.



REACTIONS & COPING



Each person is different in how they respond to the stress, trauma, and impact of brain injury. You may find it easy to shift into problem-solving mode, neglecting sleep, food, and one's own health. However, the brain needs rest and food to function, take in information, recall memories, and control emotions. Taking care of yourself during this time will allow you to do more or care for your loved one longer. Some common reactions after injury may be:

Panic & Worry

You may find yourself breathing rapidly, having trouble eating or sleeping, or crying uncontrollably at times. Try centering using 4-7-8 Breathing: 1) Inhale through your nose to a mental count of four. 2) Hold your breath for a count of seven. 3) Exhale through your mouth to a count of eight. Repeat 3-4 times.

Anger & Frustration

You may get agitated at things that are out of your control. Expressing your anger outwardly toward others (i.e. staff, your loved one, or family members) may end up alienating people who care. Find ways to let out your anger: writing, taking breaks, art, exercise, using comforting objects or stress balls, and relaxation.

Grief & Isolation

You may experience deep sadness for previous skills, roles, and lifestyle. Feeling grief is a complex process that is not time specific or predictable. Avoid getting trapped in the 'what might have been', were it not for the injury. Seek new roles. Get to know your loved ones, relationship, and yourself without expectation or judgement.

Hope

Keeping up hope can feel impossible when you are being told what you or your loved one may not be able to do. No one can know the future or a person's full potential. Be patient with yourself, your loved one, professionals, and staff. Regularly name 5 things you are grateful for and are hopeful for to counter negative thoughts.

LIVING WELL WITH E'S



Whether a person is experiencing a mild, severe, or non-traumatic brain injury keeping up a healthy lifestyle becomes even more essential than before. The brain requires specific nutrients, good sleep, and regular engagement to function normally. With an injury these needs are even more essential to build new pathways and combat the new challenges that make every living more difficult. Expect some days to feel like a step or two backwards. Listen to your body when it needs to rest or you feel pain. It may take time, but creating healthy habits with help get you toward your goals faster.

Engage Regularly

- Try new things and challenge yourself.
- Meet up with friends regularly or keep in touch digitally. Find groups, activities, or locations in the community.
- Make chores and regular activity therapy opportunities.
- Connect outside of yourself by reading or listening to a book/ podcast, reflect through journal or blog writing, and create with art, craft, woodworking, etc.

Encourage Quality Sleep

- Sleep well by going to bed and getting up at the same time every day, with limited to no lengthy naps.
- Keep your bedroom quiet, dark, at a comfortable temperature, and avoid watching TV, scrolling on your phone, or working on your computer while in bed.
- Relaxation techniques, light stretching, calm noise, or meditation prior to bedtime may help quiet rambling minds or tense muscles.



Exercise & Stay Active

- Helps improve strength, movement, thought processing, memory, mood, self-esteem, and blood flow to the brain to promote healing.
- Check with your doctor before participating in any exercise program including aerobic, strength, balance, or flexibility training.

Eat a balanced, healthy diet

- Choose whole grains for more energy, healthy fats (i.e. olive oil, omega-3) found in fish, seeds, and nuts to help with memory, and darker-colored fruits/ vegetables (such as spinach, kale, blueberries and strawberries) filled with antioxidants.
- Reduce salt, sugar, caffeine, alcohol, & drugs.
- Speak to your doctor before taking supplements to prevent interactions.

Ensure Routine Appointments

- Keep up to date on appointments (therapies, annual physical, eye, & hearing exams).
- Note changes in symptoms or side effects of medications (write down when they occur).
- Talk to medical professionals about falls or other safety risks to address.



FEELING HEARD

Self-advocacy relies on the ability to speak up and make decisions for yourself. It involves taking responsibility for your own health, needs, and rights. Many kind people want to help, but do not know how. You may take on a role of educating and helping others understand brain injury. Having a brain injury does not mean that your thoughts, needs, or ideas are not worthy. Your brain injury may slow down or prevent doing certain things, but far more limitations exist by systemic discrimination and negative attitudes about disability.



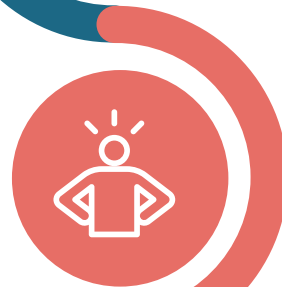
Knowing your needs/ rights, & being self-aware

What supports do you need? What are your goals? What value can you provide? Self-assess regularly to understand areas of needed help. Avoid blaming misfortune on others or your injury. Turn focusing on your weaknesses around to overcome barriers and identify solutions. What services or therapies are available?



Practicing assertiveness

Be polite, honest, stick to the facts, and speak to your experience. If needed, stay calm by taking a deep breath. Stop to see the other person's perspective, as others may be dealing with barriers themselves. Give people time to respond or try a different method of contacting them (phone, email, etc.). Set a recurring reminder to remember to follow up.



Developing confidence

Start small and use your strongest skills to advocate. Take short practice trips to locations, meetings, or activities to understand what to expect, watch or go through a process. Write down a log of conversations had (collect contact information, dates, etc.) and questions or talking points ahead of time if you get nervous or have trouble speaking. Do not allow others to speak over or ignore you. Encourage others to let you do more or take the lead.



Avoiding self-limited beliefs

Do not be afraid to seek the same opportunities as people without disabilities. Even if you need extra supports, you have the right to live in an accessible home and community, receive an education, and gain employment opportunities paying at least minimum wage. Just as you should treat others, you have the right to be treated with kindness and respect by friends, loved ones, and strangers alike.



CONNECTING TO SERVICES

There is life and support after brain injury - you don't have to take this on alone. There are different services you can access depending on your need. Some may be time-limited supports, reduced over time as functioning improves, and others may be long-term.



Health & Getting Diagnosed

	Medical & Diagnostic Supports	Emergency Supports
What to Expect	Focus on different specialties of physical and medical care • Often fast-paced & symptoms-focused (headaches/pain, seizures, weakness, dizziness, vision, etc.)	Focus on medical stability and reduce other complications • bleeding, swelling, bruising, penetrating, broken bones • treatment depends on injury severity
Special Considerations	Mild injuries or multiple concussions may not be easily seen on brain scans despite existing symptoms	Available in behavioral or mental health crisis to help with stabilization (psychosis, suicidality, severe mood swings, etc.)
Examples	• Primary Care Physician (PCP) • Federally Qualified Health Center (FQHC) • Neurologist and Physiatrist • Functional Neurologist • Neuro-psychologist • Neuro-Ophthalmologist	• Emergency Medical Services (EMS) • Emergency Department (ED) & Urgent Care • Concussion Clinics • Intensive Care Unit (ICU) • Acute Hospital or Medical Center • Behavioral Health or Crisis Clinic

CONNECTING TO SERVICES



Getting Better & More Involved

What to Expect

Special Considerations

Examples

Rehabilitation Supports	Mental Health Supports	Day & Living Supports
Includes evaluation, assessment, and exercises to improve function (modality of rehab differs) • movement, speech, daily living skills, cognition, etc.	Focus on emotion, feeling, & adjustment related to distress of mental health • different specializations, remote options, and certifications	Group-based, outside of the home • useful for social skills, life-skills, meaningful activity, self-esteem, and productivity
Inpatient, outpatient, or home options • insurance and funding may be a significant limit	Peer-groups or support groups may be an informal space to help people feel like they are not alone	Provide support related to job or education preparation, interviewing, and maintaining
• Physical & Occupational Therapy • Speech & Cognitive Therapies • Music & Art Therapies • Recreation & Animal-Assisted Therapies • Aquatic & Vestibular Therapy	• Counselors & Social Workers • Support or Peer-Led Group • Assertive Community Treatment (ACT) • Substance Use Specialist • Neuro-Psychiatrist & Pharmacist	• Adult Day Programs & Clubhouses • Community Rehabilitation Programs (CRPs) • Recreation, Allied Health, or Interest Groups • Vocational Rehabilitation (VR) • Job Coaching & Supported Employment

CONNECTING TO SERVICES



Getting Ahead & Having Help

	Home & Personal Care Supports	Residential & Daily Management Supports	Assistance & Advocacy Supports
What to Expect	Support & supervision with participation in daily living - eating, bathing, positioning, dressing - recreation, transportation - groceries, chores, laundry, cleaning	Living supports for acquiring and retaining life skills for independence striving to avoid improper placement that does not focus of growth and rehabilitation	Helpful connection to and access to appropriate services - Special Needs Trusts, ABLE Accounts - Guardian of the Person vs. Estate - TBI Medicaid Waiver
Special Considerations	Respite vouchers and options are available for short-time relief to both carers and individuals with brain injury	Different levels of care available depending on insurance as well as medical, cognitive, and behavioral support needs	If calling 911 for support, request a Crisis Intervention Team (CIT) Officer trained about disability
Examples	- Non-medical Companion Care - Respite Care - Medical Home Health	- Supported Apartments - Group Homes - Alternative Family Living (AFL) - Assisted/Supported Living - Skilled Nursing Facilities (SNFs) - Neuro-behavioral Health Units	- Guardianship & Lawyers - Case or Care Management - State & Medicaid Services - Local Management Entities & Tailored Plans

Statewide Resources

MI Department of Health & Human Services

MI DHHS supports for people with, or at risk of, mental illness, developmental disabilities and substance abuse problems.

- [Adult Behavioral Health & Developmental Disability](#)
Mental Health Contact Phone: 1-888-733-7753

MI BRIDGES (Medicaid)

assistance for [MI Medicaid](#) eligibility and other government assisted programs available in each county.

- MI Bridges Phone: 1-800-642-3195
- <https://newmibridges.michigan.gov/>

Michigan Rehabilitation Services (MRS)

can help you prepare for and find work. They can help you get the training or other services that you need to return to work.

- Phone: 517-241-5324
- MRS-CustomerAssistance@michigan.gov

Brain Injury Association of Michigan (BIAMI)

provides resources for brain injury in the State of Michigan including support groups and specialized providers in your community.

- Phone: 800-444-6443
www.biami.org

Disability Rights MI

self-advocacy, litigation, policy, and disability rights education.

- Website: www.drmich.org/

MI Developmental Disabilities Council

partner with organizations to provide services for people with disabilities

- www.michigan.gov/mdhhs/keep-mi-healthy/mentalhealth/developmentaldisability

MI Statewide Independent Living Council

support a network of regional Centers for Independent Living (CILs).

- Website: <https://www.misilc.org/>

BELIEVE Stroke Recovery Foundation

provide stroke & brain injury survivors with financial and resource assistance.

- Website: believesrf.org

NAMI NC (National Alliance on Mental Illness)

support, education and advocacy for people living with mental illnesses.

- Website: www.nami.org

Suicide Prevention

- **Suicide & Crisis Lifeline:**
- **Call or text: 988**
- Website: 988lifeline.org



Medical Binder

Information is power when it comes to your health! Having a medical binder is a handy way to keep your health information organized and in one place. This can eliminate stress over finding medical history, insurance information, or other details needed to keep you in good health. It is also a great communication tool for you, your loved ones, and your care team.

When using this medical binder, fill it out to the best of your ability. If you need to, have a loved one help you with this information. Always carry it with you to medical appointments for easy reference and add your visit summaries into this binder after the medical appointment tracking log page.

Something as simple as this medical binder can give you back so much time and streamline your medical care! We hope that you use this binder and it empowers you to live your best life!



Are you ready to live your best life?

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Our Mission

AT **GALAXY BRAIN AND THERAPY CENTER**,
WE EMPLOY AN ALL INCLUSIVE APPROACH TO TREAT THE
MIND AND BODY THROUGH CLIENT FOCUSED PROGRAMS TO
EMPOWER OUR CLIENTS TO **LIVE THEIR BEST LIVES**.

Core Values

OUR TEAM MEMBERS ARE DEVOTED TO **BUILDING TRUSTING
RELATIONSHIPS TO EMPOWER POSITIVE CHANGE** IN THE
LIVES OF OUR CLIENTS AND THEIR FAMILIES. THIS ALLOWS
THOSE WE SERVE TO **MOVE FORWARD** IN LIFE AND FIND
WAYS TO PARTICIPATE IN **AND GIVE BACK** TO THEIR
COMMUNITIES.



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My Information

Name: _____ Date of Birth: _____

Address: _____

City: _____ State: _____ Zip: _____

Drug Allergies:

Drug: _____ Reaction: _____

Drug: _____ Reaction: _____

Drug: _____ Reaction: _____

Drug: _____ Reaction: _____

Emergency Contact:

Name: _____ Phone: _____

Relationship: _____



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My Care Team

Provider: _____

Phone Number: _____

Speciality: _____

Fax/Email: _____

Provider: _____

Phone Number: _____

Speciality: _____

Fax/Email: _____

Provider: _____

Phone Number: _____

Speciality: _____

Fax/Email: _____

Provider: _____

Phone Number: _____

Speciality: _____

Fax/Email: _____

Provider: _____

Phone Number: _____

Speciality: _____

Fax/Email: _____

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Phone Number: _____

Speciality: _____

Fax/Email: _____

Provider: _____

Phone Number: _____

Speciality: _____

Fax/Email: _____



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My Insurance Information

(include copies of your insurance cards if possible)

Health Insurance: _____

Phone Number: _____

Policy #: _____ Group #: _____

Auto Insurance: _____

Adjustor & Phone Number: _____

Claim #: _____ Date of Loss: _____

Dental Insurance: _____

Phone Number: _____

Policy #: _____ Group #: _____

Vision Insurance: _____

Phone Number: _____

Policy #: _____ Group #: _____



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Medical Appointment

Doctor or Clinic:	Notes:
Date & Time:	
Reason for visit with timeline of symptoms:	
New problems since last visit (recent illness, sleep issues, energy level problems, changes in pain, attention span difficulty, mood issues):	
Questions for the doctor:	Future actions related to this appointment:
Goals of the appointment:	
Requests for doctor (med refill, handicap sticker, work/school note):	



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Medical Questions/Topics

Treatment update since the last visit:	Mood, anxiety, depression?
Medication changes since last visit:	Issues with concentration/memory?
Upcoming medical appointments:	Sensory issues? (sight, sound, smells)
Recent illnesses:	Light headed, dizzy, vision issues?
Falls since last visit:	Bowel, bladder issues?
Energy level:	Social issues? Trouble going out in public?
Weight gain or loss? Appetite?	Pain location(s) and severity on 1-10 scale:
Trouble falling asleep? Trouble staying asleep? Naps?	-What makes your pain better? -What makes your pain worse?

Navigating Sensory Overload:

Tips for Making Daily Life More Manageable

In today's fast-paced and often overwhelming world, sensory overload can be a constant challenge. The bustling noise of a restaurant, the harsh glare of lights in a doctor's office, or the cacophony of voices at the DMV can make even the simplest tasks feel impossible. While working with a trained therapist is always a valuable option for managing sensory challenges, there are steps you can take to modify these situations and make daily life more manageable.

Identifying Your Sensory Challenges

The first step in addressing sensory overload is recognizing the specific challenges that affect you. Do loud noises, bright lights, or sudden surprises overwhelm your senses? Identifying these triggers is crucial for finding effective solutions. By pinpointing your sensitivities, you can take proactive steps to create a more accommodating environment.

Consider the following scenarios:

- **Loud Noises:** If you find yourself getting overwhelmed in places with loud music or constant chatter, it's essential to acknowledge this as a sensory challenge.
- **Bright Lights:** Sensitivity to bright or harsh lighting can also be a significant issue, especially in medical settings or workplaces with fluorescent lights.
- **Crowded Spaces:** Overstimulation in crowded spaces, such as waiting rooms, can lead to anxiety and discomfort.

Once you've identified your challenges, you can start exploring situational solutions that empower you to manage these sensory triggers.

Making Sensory-Friendly Accommodations

Here are some strategies to consider when dealing with sensory overload:

- **Choose Your Seating Wisely:** When dining at a restaurant or attending an event, opt for a seat in a quieter area. Request a corner table with your back to the wall, which can provide a sense of safety and reduce sensory distractions.
- **Adjust Lighting:** In places with harsh lighting, such as doctor's offices or workplaces, don't hesitate to ask if the lights can be dimmed or if window shades can be drawn. Creating a softer lighting environment can make a significant difference.
- **Use Noise-Canceling Headphones:** Noise-canceling headphones can be a valuable tool for blocking out unwanted sounds in busy or noisy settings. They can help create a quieter, more comfortable space within the chaos.

By identifying your unique challenges and implementing these practical strategies, you can regain control over your environment and reduce sensory overload.



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Self-Advocacy: Empowering Yourself and Others

One powerful way to address sensory overload is through self-advocacy. The following page provides a valuable self-advocacy tool that can help you identify your challenges and communicate your needs effectively. This tool is not only for your benefit but also for educating your friends, family, employers, and businesses on how they can assist you in navigating sensory challenges.

It's important to remember that people generally want to help, but they may not fully understand your sensory sensitivities or how to assist you effectively. By sharing your needs and preferences, you can empower those around you to create more inclusive and accommodating environments.



To learn more about self-advocacy, listen to the Brainthropology podcast on self-advocacy!

www.brainthropology.com



*"Be courageous, and move forward in
your day with hope, joy, and purpose."*



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Live your best life!

To Whom It May Concern,

I do not normally disclose this personal information however, it has become necessary for me to inform you so that I can be productive and efficient with everything that I do. I have a brain injury and some of the deficits that I may experience are:

- o Headaches
- o Nausea
- o Balance Problems
- o Visual Issues
- o Dizziness
- o Sensitivity to Lights
- o Sensitivity to Sound
- o Mentally Foggy
- o Difficulty Concentrating
- o Difficulty Remembering
- o Difficulty Multitasking
- o Difficulty Making Decisions
- o Difficulty Following Directions
- o Difficulty Prioritizing
- o Difficulty Word Finding
- o Irritability
- o Sadness
- o Anxiety
- o Drowsiness

So that I can be successful with everything I do, I need to be able to do the following:

- o Dim the lights
- o Decrease noise in the room
- o Make lists/have information written
- o Take frequent breaks
- o Provide me with one task at a time
- o Reduce distractions in the environment
- o Have spoken information presented slowly with pauses
- o Wear a hat
- o Take a walk
- o Be seated on the outer edge
- o Use a hand fan
- o Limit environmental scents
- o Provide increased time to process information
- o Provide me with limited choices to help with decisions
- o Provide large print

If you have any questions, please contact Galaxy Brain and Therapy Center at 734-627-8001 or e-mail them at info@galaxybraincenter.com to learn more about brain injury and accommodations that can improve my abilities.

Thank you,



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