

# BRAIN INJURY

RESOURCE GUIDE



Brain and Spinal Cord Injury Program Resource Center

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# **BSCIP RESOURCE CENTER & BSCIP**

### BRAIN AND SPINAL CORD INJURY PROGRAM RESOURCE CENTER

### Education, Information & Awareness

The Brain and Spinal Cord Injury Program (BSCIP) Resource Center is a statewide resource center that provides brain and spinal cord injury survivors, their family members, caregivers, friends, and professionals with educational information and resources needed to support them in the community. The center's goal is to help people prevent secondary medical complications, foster independence, and access current resources.

### Information & Referral

The BSCIP Resource Center offers information and referral (I&R) services to individuals with brain or spinal cord injuries and those caring for them. It does not provide direct care but acts as a centralized hub to connect people to available support networks and resources. Services offered include information and guidance, education and awareness, and peer support connections. The Resource Center acts as a vital link between the public and the broader network of services available to people with brain and spinal cord injuries.

# Helpline & Website

The BSCIP Resource Center has a toll-free helpline that is available Monday through Friday 8 a.m. - 4 p.m. The website provides information about brain and spinal cord injuries, resources for families and caregivers, professionals, military, and veterans, and more, Call 1-866-313-2940 for assistance or visit BSCIPResourceCenter to view resources.

### FLORIDA BRAIN AND SPINAL CORD INJURY PROGRAM

The Florida Department of Health Brain and Spinal Cord Injury Program is for eligible adult and pediatric residents of the State of Florida who have sustained moderate-to-severe traumatic brain and/or spinal cord injuries. Funding for the program is primarily sourced from the BSCIP Trust Fund, which is funded by a percentage of civil penalties from moving traffic violations and additional surcharges on motorcycle specialty and temporary tags.

The primary service is case management and care coordination. As a payor of last resort and based upon the availability of funds, the program may provide for the cost of necessary services that will enable an individual to return to an appropriate level of functioning in the community.

Additionally, the program funds educational and preventive initiatives, along with research activities at the University of Florida and the University of Miami. For more information, please visit the Brain and Spinal Cord Injury Program.

### Eligibility

Any resident of the State of Florida who sustains a TBI or SCI and meets the following requirements is eligible for services:

- Has been referred to the BSCIP Central Registry
- Is a legal resident of the State of Florida
- Is medically stable
- Meets the state definition for spinal cord and/or moderate to severe brain injury
- Is reasonably expected to benefit from rehabilitation services based upon the goal of community reintegration

# Central Registry

Anyone can refer a person with a TBI or SCI to the Central Registry. Section 381.76, Florida Statutes, requires that an individual must be a legal Florida resident who has sustained a moderate-to-severe traumatic brain or spinal cord injury that meets the state's definition of such injuries; has been referred to the BSCIP Central Registry; and must be medically stable to be eligible for services. There must also be a reasonable expectation that with the provision of appropriate services and supports, the person can return to a community-based setting, rather than reside in a skilled nursing facility.

To refer a person to the **Central Registry** for BSCIP consideration, call 1-800-342-0778.

# WHAT IS BRAIN INJURY?

Brain injury is a major cause of death and disability in the United States. The human brain has the consistency of gelatin and relies on the skull for protection from the outside world. Even with this protection, the brain can still become injured as the brain moves around in the skull after a blow to the head or body. All brain injuries are serious and can be life altering and no two brain injuries are exactly the same! Recovery often looks identical between different types of brain injury; however, the real differentiation is in how the brain injury occurs.

# Types of Brain Injury

Traumatic Brain Injury (TBI) is a type of acquired brain injury. TBIs are caused by an external force that affects the brain's function and are usually associated with motor vehicle accidents, falls, sports injuries, physical assaults, and gunshot wounds. TBIs are often referred to as invisible injuries because they cannot be seen like a broken limb. Examples of a TBI include:

- Closed Head Injury occurs when the injury is caused by an outside force without any penetration of the skull. With this type of head injury, if the brain swells, it has no place to expand and can cause an increase in intracranial pressure.
- Concussion / Mild Traumatic Brain Injury (mTBI) which is one of the more common traumatic brain injuries. Concussions involve the brain hitting the bony internal walls of the skull which results in changes in the function of the brain.
- Contusion is a bruise (bleeding) on the brain cause by a blow or jolt to the head.
- Coup-Contrecoup Injury is swelling of the brain and is a life-threatening condition that causes fluid to develop on the brain increasing the pressure inside of the skull - more commonly referred to as intracranial pressure (ICP).
- Diffuse Axonal Injury is the shearing of the brain's long connecting nerve fibers (axons) when the brain shifts and rotates inside the bony skull which results in injury to many different parts of the brain.
- Open Head Injury also known as a penetrating head injury involved an open wound to the head from a foreign object (e.g., bullet or bone fragments from a skull fracture) in which the dura mater (outer layer of the meninges) is breached.
- Second Impact Syndrome occurs when an individual sustains a second TBI before the symptoms of the first TBI have healed. The second injury may occur within days to weeks of the first injury and is more likely to cause widespread damage.
- Shaken Baby Syndrome is abusive head and neck trauma from a criminal act in which a baby is forcefully shaken causing the baby's head to move violently back and forth causing the brain to strike the skull resulting in serious and sometimes fatal brain injury.
- **Skull Fracture** is a break in the skull bone. Mild breaks cause few problems and heal over time, severe breaks. or depressed fractures, can lead to complications including bleeding, brain damage, leaking of cerebrospinal fluid, infection and seizures and may require surgical intervention.

Acquired Brain Injury (ABI) is a non-traumatic injury, which is not hereditary, congenital, degenerative, or induced by birth trauma but caused by events after birth such as illness or conditions in the brain. Common causes of ABI include stroke (leading cause), hypoxic or anoxic brain injury due to near drowning, strangulation or aspiration, brain tumor, exposure to neurotoxins such as carbon monoxide or lead, electric shock or lightning strike, and drugs such as cocaine, methamphetamines, opioids, and alcohol.

# Effects of Brain Injury

- Cognitive (Thinking) deficits such as memory problems, difficulty concentrating, slower thought processing and speaking, poor planning and judgment skills, language difficulties, and a lack of problem-solving skills.
- Emotional/Behavioral deficits including verbal and physical outbursts, poor judgement and disinhibition, lethargy, lack of self-awareness, and impulsivity.
- **Sensory deficits** such as problems with hearing, smell, taste, touch, and vision impairments.
- Physical deficits including ambulation, balance, coordination, fine motor skills, strength, endurance, and physical ailments such as headaches and seizures.

# Injury Severity

Mild Brain Injury	Moderate Brain Injury	Severe Brain Injury
Brief, if any, loss of consciousness	Unconsciousness up to 24 hours	Unconsciousness > 24 hours (coma)
Vomiting and dizziness	Signs of brain trauma	No sleep/wake cycle
Lethargy	Contusion or bleeding	Signs of injury on neuroimaging
Memory Loss	Signs of injury on neuroimaging	

### States of Consciousness

- Coma In this state, either the thalamus, the brainstem, or both hemispheres of the brain are damaged. The individual cannot be awakened, is unresponsive to stimuli, does not experience sleep-wake cycles, and often requires ventilatory support to breathe.
- Vegetative State The individual begins to have sleep-wake cycles, may occasionally respond to stimuli and open eyes, but is still unaware.
- Persistent Vegetative State In this state, the individual exhibits no signs of perception, communication, or awareness of self but may be able to breathe on their own, open their eyes, and experience sleep-wake cycles. Doctors consider an individual to be in a persistent vegetative state after 1-year post traumatic brain injury or 3-6 months after a hypoxic/anoxic brain injury.
- Minimally Conscious State Individuals are intermittently aware of their surroundings and may respond to commands although, they are mostly drowsy and unresponsive.
- Brain Death An individual is declared brain dead when all brain functions, including the brain stem cease to function.

# Levels of Recovery

The Rancho Los Amigos Levels of Cognitive Functioning Scale or Rancho Scale, is a medical scale used to assess individuals after a closed head injury, based on cognitive and behavioral patterns as they emerge from a coma.

How long it takes a person to recover depends on:

- 1. The seriousness of the head injury
- 2. How long it took to receive medical help
- 3. The seriousness and complications of other injuries
- 4. The age and health of the person prior to injury
- 5. The involvement of family and friends

The general pattern of recovery looks like this:

Level I No Response - coma and unresponsive to stimuli.

Level II Generalized Response - slow arousal to noises, movement, touch; may respond to simple commands.

Level III Localized response - more responsive to stimuli; moving limb and body.

Level IV Confused-Agitated - agitated response to environment; poor memory and confusion.

Level V Confused-Inappropriate-Non-Agitated - follows simple commands; may act inappropriately.

Level VI Confused-Appropriate - behaviors are appropriate; completes ADLs; speech may be repetitive.

Level VII Automatic-Appropriate - completes daily routines with little or no confusion; poor insight/judgement.

Level VIII Purposeful-Appropriate - improved memory; short-term memory still impaired; socially appropriate.

# TREATMENT PROGRESSION

The treatment journey for brain injury starts with immediate trauma care, progresses through various stages, and culminates in community reintegration. At any stage of this continuum, individuals may enter, exit, or re-enter their treatment.

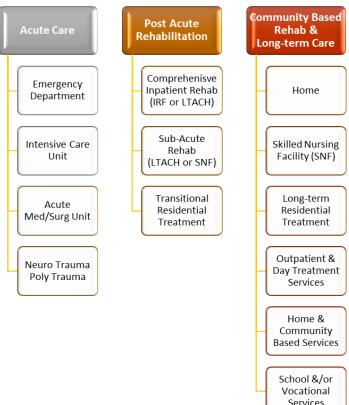
Following a brain injury, an individual may need ongoing or periodic treatment for life. Post-acute rehabilitation aims to optimize achievable physical, cognitive, emotional, psychological, social, and vocational functioning, reduce the risk of long-term complications, and facilitate a smooth transition to further rehabilitation or home life, enabling individuals to resume their optimal lifestyle.

### Acute Care

Acute care rehabilitation is conducted in a dedicated unit within a trauma or rehabilitation hospital, or another inpatient facility. It's a crucial part of the recovery journey, with therapy sessions happening 5 to 7 days a week for a few hours each day. The therapy is centered on helping patients regain the ability to perform daily tasks like dressing, toileting, eating, walking, and talking.

### Subacute Rehabilitation

An individual that has medical needs requiring 24hour skilled nursing care or is not making rapid functional gains may enter a subacute rehabilitation facility such as a skilled nursing facility or nursing home for less intensive therapy over a longer period.



### Post-acute Rehabilitation

This phase of rehabilitation involves more intensive therapy and may take place in a residential rehabilitation or transitional living facility. Treatment focuses on regaining as much independent functioning as possible and relearning and learning compensatory strategies for long-term or permanent disability.

# Day Rehabilitation

Day rehabilitation provides a continuation of recovery for individuals who no longer require 24-hour nursing care. Services are provided 5-days per week and consist of individual and group-based treatments.

# Outpatient Therapy

After discharge from inpatient rehab or for those whose injuries were not severe enough to require hospitalization, outpatient therapy will help to maintain or enhance the recovery process and many include vocational training, physical adaptations in the home, or other daily skills like managing finances.

### PATIENT'S BILL OF RIGHTS & RESPONSIBILITIES

Section 381.026, Florida Statutes, addresses the Patient's Bill of Rights and Responsibilities. Florida law requires that your health care provider or health care facility recognize your rights while you are receiving medical care and that you respect the health care provider's or health care facility's right to expect certain behavior on the part of patients. You may request a copy of the full text of this law from your health care provider or health care facility. For a summary of your rights, visit FloridaHealthFinder.

# POST-ACUTE REHABILITATION TEAM

Because individuals with traumatic brain injury can present with medical, physical, sensory, communicative, cognitive, behavioral, and social problems they require a team of medical and allied health professionals to maximize their potential for recovery. In some cases, they may require a lifetime of care. Based on the severity of your injury, you may need to seek treatment from the following types of rehabilitation providers:

Aquatic Therapist can be an occupational, physical, or recreational therapist who has specialized training to provide therapy in a pool to reduce pain and increase strength, coordination, endurance, and muscle movement.

Audiologist treats hearing disorders that may occur due to brain injury.

Behavioral Optometrist treats visual disturbances resulting from brain injury.

Case Manager / Social Worker works with the brain injured individual, family, insurance carrier and rehabilitation providers to coordinate goals, develop a plan of care, the delivery of and access to rehabilitation services.

Certified Driving Rehabilitation Specialist (CDRS) evaluates the cognitive and/or physical limitations related to safely operating a vehicle.

Clinical Psychologist provides counseling for emotional problems.

Cognitive Behavioral Therapists (CBT) helps you become aware of inaccurate or negative thinking so you can view challenging situations more clearly and respond in a more effective way.

Endocrinologist facilitates the recognition of deficiencies and may prescribe medications and hormone replacement therapy to address endocrine dysfunction because of a TBI.

**Neurologist** specializes in the nervous system and its disorders.

Neurosurgeon cares for all types of brain and spine problems and performs brain surgery as needed.

Neuro-Ophthalmologist diagnosis and treats eye problems connected to a neurological condition.

Neuropsychiatrist is a medical doctor trained in the field of psychiatry who treats behavior and psychological effects of the brain injury from a medical point of view and can prescribe medications.

**Neuropsychologist** is a psychologist who specializes in the functions of the brain, particularly in testing and assessing memory, concentration and problem solving. They can provide cognitive rehabilitation themselves but often they refer to other providers for cognitive behavioral therapy (CBT) which helps individuals learn emotional regulation and healthy coping skills.

**Neurophysiologist** tests electrical functions of the brain, the spinal cord and the nerves in the limbs and muscles.

Occupational Therapist (OT) helps you regain your independence with daily living skills and adapt to any disability including high level thinking skills needed to return to school or work successfully.

Otolaryngologist also known as Ear, Nose, and Throat (ENT) doctors; provide both medical and surgical care and treat for hearing loss, balance disorders (vertigo), ringing ears (tinnitus), voice, speech, eating and swallowing difficulties, and facial trauma.

Pain Management Doctor specializes in the treatment of chronic pain after TBI.

Physiatrist also referred to as physical medical rehabilitation (PMR) doctor, specializes in neurology, physical medicine, and rehabilitation; treatment involves the whole person and addresses the physical, emotional, and social needs.

Physical Therapist (PT) helps to restore movement, mobility, and normal body function by focusing on muscle strength, flexibility, endurance, balance, and coordination.

Recreation Therapist (RT) focuses on activities to improve and enhance self-esteem, social skills, motor skills, coordination, endurance, and cognitive skills and plans community outings where these new skills can be practiced in a social setting.

Speech Language Pathologist (SLP) helps with speech, language, and cognitive issues including attention, memory, organization, reading comprehension, writing skills and strategies to help compensate for deficits related to the brain injury.

Vocational Rehabilitation Counselor (VRC) assists you with successfully returning to school or work.

# INSURANCE

There are essentially two types of insurance: government-issued and private. Government-issued insurance provides coverage for government workers, military members, and their dependents, as well as Medicaid and Medicare recipients. Private insurance is available for individual purchase or through an employer. It's vital to understand your policy. Contact your insurance provider to get a copy of your policy and the "Certificate of Coverage," which outlines your benefits. Check your eligibility for short-term and long-term disability benefits and understand your rights under FMLA. Also, consider requesting a catastrophic case manager for your situation.

The worry about whether health insurance will cover necessary services should not add to the stress of needing medical care. If your insurance company denies coverage, it's important to remember that you have the right to appeal their decision. For a guide on how to begin the appeal process, visit PatientAdvocate.

### **HEALTH CARE MARKEPLACE**

### 1-800-318-2596

The Affordable Care Act (ACA) established the federal Health Care Marketplace, HealthCare.gov, to streamline the process of securing an affordable, high-quality health care plan tailored to your income and health requirements. You can go online to review health insurance plans and prices or receive assistance with the application process. For more information or to apply for insurance, visit HealthCare.

### MEDICAID

### 850-300-4323

Florida Medicaid offers health coverage to low-income individuals. To be eligible for Florida Medicaid, one must be a resident of Florida and possess U.S. nationality, citizenship, permanent residency, or legal alien status, along with a financial status deemed low income or very low income. Applications for regular Medicaid coverage, food assistance (SNAP), and temporary cash assistance are available through the Florida Department of Children and Families' online portal. For more information and to apply for benefits and services, visit MyFLFamilies.

### **MEDICARE**

### 1-800-663-4227

Medicare is a health insurance program provided by the Centers for Medicare & Medicaid Services (CMS). It primarily serves individuals aged 65 and older, but eligibility extends to certain younger individuals with disabilities from a TBI or SCI. Understanding Medicare's coverage, including exclusions like long-term care, is crucial. The program consists of Part A for Hospital Insurance, Part B for Medical Insurance, Part C known as Medicare Advantage—a substitute for Parts A and B, and Part D for Prescription Drug Coverage. For more information, visit CMS.

## DEPARTMENT OF VETERANS AFFAIRS (VA)

### VA Benefits Hotline 1-800-827-1000

The Department of Veterans Affairs (VA) provides a variety of insurance programs tailored to offer financial protection and benefits to veterans, active-duty service members, and their families. These programs encompass life insurance, disability insurance, and mortgage protection, among others. VA's insurance programs aim to deliver financial security and peace of mind, safeguarding service members, veterans, and their families in cases of injury, disability, or death. For more information and to apply for benefits, call the VA Benefits Hotline at 1-800-827-1000 or visit VA.

### WORKERS' COMPENSATION

### Employee Assistance Office 1-800-342-1741

Workers' Compensation is a state-regulated insurance program providing financial and medical benefits to employees with job-related injuries. Its goal is to deliver medical care, wage replacement, and other benefits to injured or ill workers due to their job, thus avoiding the need for litigation. Benefits cover medical expenses, partial wage replacement during recovery, temporary total and partial disability benefits, compensation for permanent impairment, permanent total disability benefits, and death benefits for work-related fatalities. There are strict deadlines for reporting injuries and filing claims, underscoring the importance of prompt reporting. Additionally, it is illegal for employers to retaliate against employees who claim workers' compensation. Learn more at MyFloridaCFO.

### FLORIDA KIDCARE & CHILDREN'S HEALTH INSURANCE PROGRAM

1-888-540-5437

Children's Health Insurance Program (CHIP) is a federal program that provides low-cost health coverage to children and families that earn too much to qualify for Medicaid but cannot afford private insurance. It is part of the Social Security Act and is funded jointly by the federal government and states.

Florida KidCare is the state's implementation of Children's Health Insurance Program (CHIP) and includes Medicaid coverage for children. It provides comprehensive health insurance for children from birth through age 18 and combines several programs: Medicaid for children, MediKids, Health Kids, and Children's Medical Services (CMS), offering different types of coverage based on family income and other factors. Florida KidCare is a tiered coverage system, with families paying premiums based on their income level, and those below certain thresholds receive fully subsidized care through Medicaid. For more information, visit FloridaKidCare.

# FINANCIAL ASSISTANCE

### BRAIN AND SPINAL CORD INJURY PROGRAM

**BSCIP Central Registry 1-800-342-0778** 

The Florida Department of Health Brain and Spinal Cord Injury Program (BSCIP) is a program for eligible adult and pediatric residents of the state who have sustained moderate-to-severe traumatic brain or spinal cord injuries. Funding for services primarily comes from the BSCIP Trust Fund to provide the cost of care for necessary services that will enable them to return to an appropriate level of functioning in the community. The primary services are case management and care coordination. Based upon the availability of funds, additional services may include rehabilitation services, assistive technology, durable medical equipment, and home modifications. For more information, visit FloridaHealth.

### SOCIAL SECURITY

1-800-772-1213

Benefit Eligibility Screening Tool (BEST) is an online tool to help you determine if you qualify for benefits. Based upon your answers to questions, it will list benefits for which you might be eligible and provides information on how to qualify and apply. Visit SSABEST to find the right Social Security benefits for you.

Supplemental Security Income (SSI) is for people who have never worked or who have insufficient work credits. Since Medicaid benefits are tied to SSI, a hospital's social services department will usually have an SSA representative onsite to help establish eligibility for the program.

Social Security Disability Insurance (SSDI) provides benefits to workers who have paid into Social Security and became disabled prior to reaching the age of retirement.

It's best to apply for disability benefits as soon as you become disabled because the approval process is fraught with delays and denials. If you receive a second denial, you should contact a disability attorney who will represent your case at an administrative hearing before a judge. Keep in mind that if the application is approved, payments are retroactive to the date of the original application.

- Complete an online application for benefits at Disability SSA
- Find your local Social Security office at Social Security Office Locator

### CRIME VICTIMS' SERVICES

1-800-226-6667

If you sustained an injury because of a physical crime, you might qualify for benefits. The Bureau of Victim Compensation provides financial aid to victims of violent crimes who have been injured due to the crime and are facing financial difficulties. This compensation can cover medical and funeral costs, professional counseling, lost income, loss of support, disability, expenses for domestic violence relocation, and prescription reimbursements. It is necessary to report the crime to the local law enforcement agency within 120 hours of the incident. Additionally, cooperation with law enforcement, the State Attorney's Office, and the Attorney General's Office is required. You can find applications and help with filling them out on the Attorney General's website or through the Victim/Witness Assistance Program. Visit MyFloridaLegal to apply for compensation.

# LONG-TERM CARE SERVICES & SUPPORTS

Long-term care services and supports assist with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) for individuals who cannot perform these activities on their own due to cognitive, physical, or chronic health conditions. Services are designed to preserve the individual's ability to live in their community or remain employed and can be provided in the home, assisted living, nursing facilities, and integrated settings such as those that provide both health care and supportive services. Long-term care services also include supportive services provided to family members and other unpaid caregivers.

### MEDICAID MANAGED CARE LONG-TERM CARE PROGRAM

The Agency for Health Care Administration (AHCA) administers the Statewide Medicaid Managed Care (SMMC) Long-Term Care Program, sets coverage policy, and gets those eligible for services enrolled in a Long-Term Care (LTC) plan. The Department of Children and Families (DCF) is responsible for determining the financial eligibility for services and the Department of Elder Affairs (DOEA) is responsible for determining medical eligibility and level of care needed. Visit AHCA to view the steps involved in this process.

### AGING AND DISABILITY RESOURCE CENTERS

The Aging and Disability Resource Centers (ADRC) serve as the single point of entry into the long-term supports and services system for older adults and people with disabilities. The core functions of an ADRC are 1) information, referral, and awareness, 2) options counseling, advice, and assistance, 3) streamline eligibility determination for public programs, 4) person-centered transitions, 5) quality assurance and continuous improvement. Visit <u>ElderAffairs</u> or call the **Elder Helpline 1-800-993-5337** to find your local ADRC.

### **ELDERCARE LOCATOR**

The Eldercare Locator serves as a bridge for older adults and their caregivers to access local support, including resources that assist them in remaining in their homes, ensuring the home environment is suitable, managing self-care or caregiver responsibilities, participating in community activities via wellness and senior center programs, obtaining health insurance counseling, and accessing legal and financial assistance, as well as exploring opportunities for training and employment. Call **1-800-677-1116** to speak with an Information Specialist or visit ElderCare for more information.

### JP-PAS PROGRAM

The James Patrick Memorial Work Incentive Personal Attendant Services (JP-PAS) Program is a specialized program in Florida that provides financial assistance to Florida residents (18 and older) with significant and permanent disabilities who are employed and require personal care assistance with at least two activities of daily living, to live independently and maintain their employment. Below are key features of the JP-PAS program:

- Personal Care Assistance: The program helps cover the costs of hiring a personal care attendant (PCA) to assist
  with daily living activities that are necessary for the individual to work. These activities might include tasks like
  dressing, bathing, grooming, eating, or mobility.
- Financial Assistance: The program provides funding that can be used to pay for personal attendant services. The amount of financial assistance varies based on the individual's needs and the availability of program funds.
- Work Incentive: The program is intended to support individuals in staying employed by providing the necessary personal care assistance, thus encouraging greater independence and financial self-sufficiency.
- Program Management: The JP-PAS Program is administered by the Florida Association of Centers for Independent Living (FACIL), and it operates under the oversight of the Florida Department of Health.

The application process typically involves providing proof of employment, a statement of disability, and details about the personal care services needed. For more information call **850-575-6004** or apply for the program at FloridaCILS.

### FLORIDA LONG-TERM CARE OMBUDSMAN PROGRAM

Is a free and confidential program that allows individuals to present grievances and concerns about the quality of life and care of a loved one residing in a facility without fear of retaliation. Call **1-888-831-0404** to speak with a trained volunteer or visit ElderAffairs for more information.

# THE RECOVERY PROCESS

A traumatic brain injury can cause severe physical, cognitive, and behavioral limitations. It is possible to recover from these limitations but until you do, they can present challenges in your daily life. Neuroplasticity is the brain's ability to adapt to change and rewire itself which is particularly important after a traumatic brain injury. Long lasting functional changes in the brain occur when we learn new things or memorize new information. Below are ways to help your brain to adapt and change to these challenges, boost your recovery, and create a meaningful life.

# Managing Your Daily Life

Begin by resuming your daily activities as promptly as possible. Establishing and adhering to a structured routine can minimize distractions and enhance memory. Organize a schedule that encompasses all your appointments, utilizing a wall calendar, planner, or a calendar application on your smartphone. Remember to allocate time each day for your Activities of Daily Living (ADLs), such as brushing your teeth, dressing, bathing, and eating. Regular participation in these activities will aid in your overall recovery. Consider using an app like the Cozi Family Organizer, which is designed for family life management. It features a shared calendar, shopping lists, to-do lists, meal planning, and a family journal, helping you stay coordinated with your family, and is available for both Apple and Android devices.

# Get Moving!

Exercise plays a crucial role in the recovery process by providing cognitive stimulation, enhancing balance and flexibility, strengthening muscles, and fostering neuroplasticity. Consider joining a local yoga class for relaxation, improved balance, alleviation of muscle pain, better breathing, conditioning, and core strength. For insights on the benefits of yoga and meditation for TBI, visit LoveYourBrain. Not into yoga? Swimming offers a safe way to explore movement in water, eliminating the risk of falling. Dancing contributes to recovery by enhancing balance, coordination, memory, and overall well-being. Participating in these activities with others can also enhance socialization, which in turn supports improved brain function. For those who prefer solitary exercise, walking in the neighborhood can help improve balance and reduce spasticity. Neuroplasticity develops through consistent repetition; the brain optimizes efficiency by reinforcing neural pathways associated with regularly practiced activities.

### Eat Well

Incorporating a diet rich in brain-healthy foods can enhance recovery from brain injuries. Brainline recommends adopting dietary habits that include frequent small meals, every three to four hours, composed of elements from the Mediterranean diet. This diet emphasizes proteins from fatty fish such as salmon and mackerel, which are abundant in omega-3 fatty acids, as well as lean meats and eggs. It also suggests consuming healthy fats and oils found in avocados, seeds, and nuts, particularly walnuts, alongside carbohydrates sourced from an array of vegetables, fruits, and grains. To facilitate recovery, avoid gluten, high fructose corn syrup, artificial sweeteners, sugar, and artificial dyes and additives. Establishing a consistent daily eating schedule can also be beneficial, and one practical tip is to incorporate "mealtime" into your daily planner.

# Sleep Well

People with brain injuries often struggle with sleep issues, which can worsen health concerns like depression and fatigue. Improving sleep quality involves regular exercise and a steady sleep routine. Make your bedroom sleep-friendly with quality bedding and light-blocking curtains. Avoid blue light from screens before bedtime to keep your circadian rhythm in check. Keep your bedroom cool, ideally between 60-72 degrees Fahrenheit. If sleep eludes you, try a warm bath, reading, or meditation to relax. Listening to classical music or nature sounds can also soothe you into sleep. Consider special pillow speakers for a peaceful night with calming audio such as the ones reviewed at NoSleeplessNights.

# Adjusting to Your New Normal

A traumatic brain injury is not just a physical ailment; its effects extend well beyond the initial incident and can unfold over time, impacting the brain in unpredictable ways. It's crucial to keep a positive outlook as you navigate life's hurdles and adjust to your changing "new normal." Choosing happiness is key. Venture into new activities, explore what aligns with your interests and what doesn't. You might consider joining a TBI support group, signing up for a class that sparks your curiosity, or starting a new hobby. Be patient with yourself and others, as everyone adjusts to changes and new responsibilities. Recognize and celebrate each small victory; doing so lifts your morale and affirms the progress you've made. Read "Finding My 'New Normal'," a personal story, at BIAUSA.

# RETURNING TO SCHOOL

Traumatic brain injuries come with a lot of uncertainties. The healing process and the persistence of effects are influenced by factors such as the injury's location, post-injury medical and rehabilitation care, and the individual's age. While some people may experience temporary effects, others may face lifelong impairments in memory, attention, coordination, balance, mobility, language, communication, and sensory functions, leading to depression, anxiety, aggression, poor impulse control, and personality shifts. Students aged 15-24 are at a high risk of brain injuries, but any severe injury to a developing brain can disrupt a child's growth, with deficits that may not be immediately noticeable as the pediatric brain continues to develop until the age of 21. According to the American Speech-Language-Hearing Association (ASHA), "TBI in children is a chronic disease process rather than a one-time event, because symptoms may change and unfold over time." It's important to get a thorough evaluation of the student's academic and cognitive abilities to determine what accommodations are necessary.

### **EXCEPTIONAL STUDENT EDUCATION**

Florida Department of Education's Bureau of Exceptional Student Education (ESE) administers programs for student with disabilities and coordinates services throughout the state for students with special needs. Visit FLDOE for more information.

Additional useful websites for parents and teachers are listed below:

- Exceptional Education Eligibility for Students who are Physically Impaired with Traumatic Brain Injury Rule
- Florida Diagnostic and Learning Resources System (FDLRS) serves as a resource for teachers and families, offering support for students with disabilities, including those who have experienced brain injuries.
- Lash & Associates Publishing is a source of information on brain injury, concussion, and PTSD in children and adolescents.
- Brain Injury in Children and Youth: A Manual for Educators by the Colorado Department of Education
- Building Blocks of Brain Development adapted by the Colorado Brain Injury Steering Committee.

### EARLY STEPS

Offers early intervention services to eligible infants and toddlers (birth to 36-months) who are at risk of developmental disabilities or delays with the services provided to children in their communities where they live, learn, and play while families and caregivers receive support to develop the skills and confidence needed to help their children learn and develop. Learn more at FloridaEarlySteps.

### ACCREDITED SCHOOLS ONLINE

Is a student-focused online resource offering information on accredited educational institutions and online programs in the United States. It aims to help students find quality online education programs and make informed decisions regarding their education. The website provides various tools and resources for prospective students, such as School and Program Rankings, Guides and Resources, Accreditation Information, Scholarship and Financial Aid Resources, and Career Resources. Additionally, it features information on "Test-Optional Colleges Not Requiring SAT or ACT Scores." Visit AccreditedSchoolsOnline for more information.

### BRAINLINE

Is an online resource for all things TBI including School & Education with resources and information for returning to school, IPE and Accommodations, Resources for Parents and Educators, College and Higher Education, and Vocational Rehabilitation. Visit Brainline to view these resources and more.

### CENTER FOR PARENT INFORMATION & RESOURCES

This online resource features an extensive section on traumatic brain injury, providing tips for parents and educators on managing TBI in children. It includes online learning modules, a resource library with disability fact sheets, IDEA training materials, guides for parents, details on Individualized Family Service Plans (IFSP) and Individualized Education Programs (IEP), transition planning, webinars, and updates on new resources and forthcoming events. Resources are available in both English and Spanish at ParentCenterHub.

# RETURNING TO WORK

Identifying factors that enable a successful return to work offers benefits for brain injury survivors, employers, and society. For those recovering from brain injuries, resuming work can differ individually, yet it often leads to a sense of achievement, enhanced self-esteem, and an improved quality of life. The Americans with Disabilities Act (ADA) mandates that employers provide reasonable accommodations for all employees with disabilities. Accommodations to consider discussing with your employer include a gradual return to work, reduced hours with frequent breaks, a lighter initial workload or modified job responsibilities, and the use of physical and technological aids. Ready to return to work? Explore the resources below, which are designed to assist you in achieving this significant milestone.

### **VOCATIONAL REHABILITATION**

The Florida Department of Education, Division of Vocational Rehabilitation (VR) is a federal-state program that helps people with disabilities find meaningful careers by assisting them with finding or maintaining employment. To be eligible for services your disability must interfere with your ability to become employed, and you need VR's assistance to find or keep a job. If you receive SSI or SSDI for your disability, you are presumed eligible for services. VR also helps students with disabilities prepare and plan for employment after high school through the Transition Youth program.

### **Examples of Vocational Rehabilitation Services:**

Job Site Assessment and Accommodations Vocational Evaluation and Planning Supported and Customized Employment Career Counseling and Guidance

Job Coaching and Job Placement Assistive Technology and Devices

Medical and Psychological Assessment On-the-Job Training

Training and Education after High School Time-limited Medical and/or Psychological Treatment

Learn more about job programs and services at RehabWorks or apply for services.

### **TICKET TO WORK**

Did you know that there are social security incentives for returning to work (RTW) after a brain injury? If you're receiving SSI, you might also be eligible for the Ticket to Work Program (TTW). This program allows a trial work period to test your ability to work for at least 9-months, expedited reinstatement of SSDI benefits without filing a new application if you become unable to work again within 5-years, and continuation of Medicare coverage for 93-consecutive months after the Ticket to Work program ends. To learn more about the Ticket Program, visit ChooseWork or call 1-866-968-7842.

### CAREER SOURCE FLORIDA

Career Source Florida has 24 local centers throughout the state that offers resources to assist individuals with job searching, career development, and training. Visit CareerSourceFlorida to find your local center.

### FLORIDA ABILITIES WORK

Florida Abilities Work is a resource for both job seekers and employers. The Help Desk provides personalized assistance. answers questions, and offers guidance on navigating the employment process, including how to access disability-related services and accommodations. The program also supports employers who are looking to hire individuals with disabilities by offering resources, information, and advice on creating inclusive workplaces. This includes understanding the benefits of hiring people with disabilities and ensuring compliance with relevant laws and regulations. Visit AbilitiesWork or contact the Abilities Work Help Desk at 1-844-245-3405.

### JOB ACCOMMODATION NETWORK

The Job Accommodation Network (JAN) offers free, expert, and confidential guidance on workplace accommodations and disability employment issues. For help call 1-800-526-7234 or visit AskJAN!

### **GUIDES FOR EMPLOYERS**

The Mayo Clinic, "Understanding Brain Injury, A Guide for Employers" provides an overview of brain injury and strategies employers can implement to support employees with brain injury in the workplace.

The Veterans Employment Toolkit provides a variety of resources for employers, managers, and human resource professionals related to Veteran employment and services.

# CAREGIVING

"My whole life has changed in a flash. I now am the head of the household. [I am] the husband, the mother, the caregiver, the wage earner, the fix em' up handy man, the lawn mower, everything... and the different changes in [my husband's] totally different personality. How do you deal with that?" (Kuipers et. al. 2014)

Brain injuries happen to all people, no matter their age, race, or religion; they do not discriminate, and every injury is unique. Regardless of the severity, brain injuries can have a significant and lasting impact on the lives of the survivors and family members. Roles will change and life as you know it will be impacted!

# Stages of Caregiving

Family member involvement is a key factor in the rehabilitation process. You have a unique advantage because you already know your loved one's personality and habits. By sharing any subtle changes in their behavior with medical providers, you can significantly impact their recovery.

- 1. Golden Hour / Inpatient Hospitalization encompasses the time from when the caregiver learns of the injury to the time that the survivor is discharged from the hospital.
- 2. Initial Reentry / Settling into the Home the survivor has been discharged home and the caregiver must now look after their daily needs.
- 3. Reintegration into Regular Activities this is where it becomes important to restore some normality to the extent it is possible in the lives of the caregiver and survivor.
- 4. Surviving Long-term this is the final stage of the caregiving process; the situation has stabilized and now the caregiver must thing about the long-term ramifications of the injury and the provision of long-term needs for the survivor.

### Stages of Adjustment, Coping and Acceptance

### Stage 1 Shock (1-3 months)

You're shocked at news of the injury, hope for full recovery, and are in denial of severity; you want everything to be the same.

### Stage 2 Recognition (3-9 months)

You begin to recognize the severity and are feeling helpless and frustrated at this time.

### Stage 3 Annoyance (6-24 months)

You're becoming annoyed with the survivor not meeting the recovery expectations because you are expecting full independence and reality is now setting in.

### Stage 4 Realism & Exhaustion (10-24 months)

The situation is real and family members are mentally and physically exhausted, you're reducing time spent with your loved one, and grief may be stronger as bereavement-like emotions occur.

### Stage 5 Mobile Morning (12-24 months)

You experience profound sadness and are mourning loss of your loved one's personality and characteristics, the loss of hopes and dreams you had for loved one.

### Stage 6 Understanding & Adapting (2-3 years)

You're understanding that your loved one may never be the same so you're beginning to accept their condition and you're able to address the needs of the entire family now.

### Stage 1 Denial of Trauma Impact

You're in denial that recovery won't occur, of past abilities or current limitations, avoidance of therapy, refusal of rehabilitation.

### **Stage 2 Grieving Perceived Losses**

Feeling of helplessness and sadness and your directing anger toward others.

### Stage 3 Depression

You're feeling that you have limited control over life, you're experiencing loneliness due to impact of various losses upon life, and you may express depression as anger.

### Stage 4 Guilt

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Feeling the accident is your fault in some way and family blames the person for injury because that can't believe it happened.

### Stage 5 Coping Styles

- > Displacement anger over what has been lost may be displaced to family and friends
- Regression reverting to past methods of gaining gratification
- Intellectualization "could have been worse" or "now I'll be a better person"

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### **ACCEPTANCE**

You've gained a new perspective on living with realities, you are renegotiating old relationships, and redefining new interactions with others.

### ACCEPTANCE COMMITMENT THERAPY (ACT)

Also known as The Psychological Flexibility Model Psychological, psychological flexibility is the core goal of ACT. It involves being aware of one's thoughts and feelings, staying present, and aligning behaviors with personal values and objectives. For caregivers, ACT can improve mental health, coping strategies, self-compassion, and patience. It encourages acknowledging difficult thoughts and emotions, followed by engaging in positive actions to manage their experiences. For more information about ACT or to find a therapist visit ContextualScience.

There are six core processes that ACT practitioners guide you through to help you live a more flexible life:

- 1. Acceptance Willingness to embrace the reality of what is without trying to make it different.
- 2. **Cognitive Defusion** Ability to detach from and observe painful thoughts rather than automatically accepting them as true and becoming controlled by them.
- 3. **Mindfulness** Being fully present in the here-and-now with gentleness, openness, and without judgement.
- 4. **Self-as-Context** Ability to distinguish your identity, worth, and value, from painful thoughts, feelings, and experiences. Awareness that you are larger than any one experience.
- 5. Values Inner knowing of what is most important to you and what you want your life to stand for.
- 6. **Committed Action** –Taking intentional action towards your values.

### ORGANIZATIONS

**Brain Injury Association of America** offers fact sheets and caregiver webinars, as well as assistance with finding an attorney. Visit the Caregiver Information Center at <a href="BIAUSA">BIAUSA</a> for resources.

**Brainline** offers information regarding legal issues as well as resources for caregivers. To view these resources and more, visit <u>Brainline</u>.

**CaringBridge** provides a mobile app that allows you to create a site for yourself and your loved one. Friends and family can also participate. It ensures that everyone in your network stays informed, aligns with your schedule, and offers the ability to post supportive notes. Visit <u>CaringBridge</u> to start your Caring Bridge.

**Center for Neuro Skills** offers information on choosing a provider, living with a brain injury, and a brain injury guide for families through links to articles, websites, and books. View these family resources at <a href="NeuroSkills">NeuroSkills</a>.

**Family Caregiver Alliance** provides information and fact sheets on coping with behaviors post TBI and resources for caregivers as well as the "Hospital Discharge Planning: A Guide for Families and Caregivers". To view these resources, visit Caregiver.

**VA Caregiver Support Program** provides information on caring for someone with a TBI and includes links to additional caregiver resources. Visit <u>CaregiverVA</u> for more information.

**Wiser Women's Institute for a Secure Retirement** offers a booklet, "Financial Steps for Caregivers: What You Need to Know About Protecting Your Money and Retirement" that can be download at <u>WiserWomen</u>.

### MEDICAL BINDER

A medical binder is a useful tool for organizing your family member's medical records. You can download free printable medical forms and find out what to include in the binder by visiting <a href="FamilyCaregiversOnline">FamilyCaregiversOnline</a>. If assembling a medical binder yourself is too time-consuming or taxing, you can purchase a Medical Records Organizer Kit from <a href="OrganizerKits">OrganizerKits</a> for under \$20, which is compatible with any standard 3-ring binder, 1 ½ inches or larger. It is advisable to use a clear-view binder, which allows for the insertion of customizable front and back covers and spine labels.

As a caregiver, self-care is crucial. It's important to educate yourself thoroughly about brain injury. Seeking assistance can lighten the load of caregiving. Don't hesitate to assign tasks; loved ones often wish to assist but may lack direction. Compile a list of helpful tasks or errands and let them select what they're comfortable undertaking. Lastly, concentrate on the capabilities of your loved one rather than their limitations.

# FEDERAL TAX PROVISIONS

Managing a traumatic brain injury (TBI) often comes with significant costs, adding to the emotional and physical strain that can impact your family's quality of life. When Tax Day is nearing, it's crucial to know that some medical and caregiving expenses might qualify for tax deductions and credits.

Need help figuring out your itemized deductions? Use Schedule A (either Form 1040 or 1040-SR).

# Understanding Gross Income

The term 'gross income' can be puzzling. It's your total income before any deductions, usually fully taxable. Yet, some income types can be excluded from your annual taxable income, such as:

- Veterans Administration disability benefits
- Supplemental Security Income
- Certain expenses related to disability

Even with these exclusions, those with a TBI or caregivers for someone with a TBI often encounter financial hurdles. Identifying deductible benefits from your gross income when doing your taxes can reduce your tax liability, freeing up more funds for ongoing TBI care.

# Deductible Medical Expenses

Not all medical costs are covered by insurance. Payments made out-of-pocket for you, your spouse, or dependents can often be deducted. Those with a TBI, or caregivers, should know which expenses are reimbursable. The federal tax code allows deductions for medical costs linked to the long-term care of the chronically ill under a doctor's care. Since a TBI may lead to chronic conditions requiring long-term care, remember that only medical expenses surpassing 7.5% of your adjusted gross income (AGI) are deductible, according to the IRS website. AGI is the total income minus deductions.

# Child & Dependent Care Credit

If you're caring for a dependent with a TBI, you might have extra costs for caregiving. You could be eligible for a dependent care credit, which helps whether you're working or need a caregiver to help while you look for a job. This credit doesn't have age limits for dependents who can't look after themselves, so it could apply even if you're caring for an adult child with a TBI. Remember, the person you're caring for must be listed as a dependent on your tax return. Plus, if your job offers a Dependent Care Flexible Spending Account (FSA), using it for qualified expenses can save you even more.

# Benefits for Caregivers

For dependents who aren't covered by the Child Tax Credit, like an elderly parent, you might get the Credit for Other Dependents, offering up to \$500 per dependent. If your income is on the lower side and you're looking after a qualifying child or relative, the Earned Income Tax Credit could lower what you owe in taxes or even give you a refund. And if you've made changes to your home for medical reasons, like adding ramps or making doorways wider for a dependent, you might be able to deduct those as medical expenses.

# Long-Term Care Insurance

Individuals with TBI often require long-term care insurance due to the lasting impact of their injuries. The IRS permits the deduction of qualified long-term care insurance premiums as medical expenses on an individual basis. These deductible amounts are subject to age-based limits and are adjusted annually for inflation.

# **Qualified Long-Term Care Insurance**

For a policy to be deductible, it must meet IRS criteria for being "qualified." Essentially, it should cover vital services including diagnostic, preventive, therapeutic, curative, treatment, mitigation, and rehabilitative services.

# Important Considerations:

- Eligibility Criteria: Each tax credit and deduction come with its own set of eligibility requirements. It's important to either thoroughly review these criteria or consult with a tax professional to ensure you qualify.
- Record-Keeping: Keep detailed records of all care-related expenses, such as receipts, invoices, and medical documents, to support your claims for deductions or credits.
- Tax Professional Advice: Tax laws can be complex, so it's advisable to get guidance from a tax expert to ensure you're fully benefiting while adhering to all regulations.

# RESOURCES

Now that your loved one is home; you need to accept that you are in for a lifelong commitment. Brain injury is not like a broken limb, which heals over a short period of time. Most of the recovery after a traumatic brain injury occurs in the two years after brain injury; after this, the brain injured individual's future is uncertain. You'll need to find information and resources that can make adjusting to your new normal easier and that process can be overwhelming. Here are some resources to make that process easier.

### CENTERS FOR INDEPENDENT LIVING

The Florida Association of Centers for Independent Living is an advocacy and support organization and represents Centers for Independent Living (CILs), which are community-based nonprofit agencies that empowers people with disabilities to move from dependence to independence. CILs core services include Information and Referral (I&R), Independent Living Skills, Peer Mentoring and Networking, Advocacy, and Transition Services. Visit FloridaCILS for more information.

### FLORIDA HEALTH FINDER

Find and compare health outcomes, licensure information, inspection reports, pricing, and performance measures for Home Health Agencies, Nursing Homes, Assisted Living Facilities, Ambulatory Surgery Centers, Hospitals, and Medicaid Health Plans in Florida and locate facilities at <u>FloridaHealthFinder</u>.

### FLORIDA 2-1-1 NETWORK

Heart of Florida United Way (HFUW) 2-1-1 connects people with the services they need. It is a free, confidential service that connects people with local community-based organizations. The network has information on more than 40,000 different programs and services across the state that can be accessed by phone, email, chat, text or online where you'll be connected to a multilingual specialist in your area. Access the Helpline by dialing **2-1-1** or by texting your zip code to **898-211** or visit HFUW.

### BRAIN INJURY ADVOCACY ORGANIZATIONS

- Brain Injury Association of America (BIAA) is the foremost national organization advocating for individuals with brain injuries, offering a variety of services, programs, and policy initiatives. They also manage the National Brain Injury Information Center (NBIIC), a helpline that assists with understanding TBI, locating care, and managing the recovery journey. To speak with a Certified Brain Injury Specialist (CBIS), call 1-800-444-6443 or visit BIAUSA.
- Disability Rights Florida (DRF) is the state's designated Protection and Advocacy (P&A) system, tasked with protecting and advancing the right of individuals with disabilities, including those with brain injuries ensuring access to essential services, protection from abuse and discrimination, and promoting independence and community integration. Call 1-800-342-0823 or visit DisabilityRightsFlorida to request assistance.
- Florida Self-Advocacy Central (FSACentral) is a self-advocacy organization for all individuals with disabilities across the state of Florida and is go to source for self-advocacy news and information, resources, education, and events. FSACentral is an arm of the Florida Self-Advocates Network'd, or FLSAND.

### **CONSUMER CENTERED**

- American Stroke Association provides information on prevention, symptoms, and resources for people who
  have had a stroke, their caregivers, and professionals at Stroke.
- Brain&Life Magazine, the official publication of the American Academy of Neurology, offers free resources including tips, research, and inspiring stories to promote brain health. It is published six times a year in English and four times a year en Espanol, and is mailed free to interested individuals in the U.S. To subscribe, visit <a href="main&Life"><u>Brain&Life</u></a> to complete the subscription form. Be sure to visit the website for additional resources.
- Epilepsy Foundation Florida is a chapter of the National Epilepsy Foundation of America and works to implement programs and services for people with epilepsy in Florida. When a person has two or more seizures, they are considered to have epilepsy. Call 1-800-332-1000 or visit <a href="EpilepsyFoundationFL">EpilepsyFoundationFL</a> to learn more.
- Florida Alliance for Assistive Services and Technology, Inc. (FAAST) provides a range of assistive technology services, including device loans, device demonstrations, and equipment exchanges. They offer technology solutions for cognitive assistance, mobility, and communication to support individuals with brain injuries. Visit <u>FAAST</u> for more information on services and products provided.

- Model Systems Knowledge Translation Center (MSKTC) offers a vast array of resources for individuals with traumatic brain injuries and their caregivers, including videos, research-based fact sheets, and tools to improve health outcomes. To view these resources, visit MSKTC.
- National Rehabilitation Information Center (NARIC), a federally funded library for the Department of Education's National Institute on Disability, Independent Living, and Rehabilitation (NIDILRR), is a source of information and referral staffed by Information Specialists to assist people with disabilities, family and friends, and health care professionals find state and federal agencies, national organizations, and local support to help them with their independence. Call to speak to an I&R Specialist at 1-800-346-2742 or visit NARIC for more information.
- Power of Patients is a platform that offers a free, cloud-based virtual therapy dog named Sallie to help TBI patients track symptoms and mood over time. It provides tools to help individuals understand their symptoms and better communicate with their healthcare providers. To learn more, visit PowerofPatients.
- Smart Patients Brain Injury Community is an online community for brain injury patients and their families that provides advise and support. For more information, visit **SmartPatients**.
- The University of Alabama at Birmingham (UAB) In-Home Cognitive Stimulation Guidebook offers activities designed to help support cognitive skills which can be done in the home. The guidebook is available to download digitally or as a pdf at UAB.

### DOMESTIC VIOLENCE

- Florida's Domestic Violence Hotline 1-800-500-1119 offers 24/7 support, information and referrals, access to emergency shelters, and helps with legal protection. Translation services are available.
- National Domestic Violence Hotline 1-800-799-SAFE (7233) is available 24/7 and has interpretation services for 200+ languages and offers crisis intervention, information about domestic violence, and referrals to local programs. If you don't want to call, then text BEGIN to 88788 or visit TheHotLine for resources.

### FUNDING, GRANTS & SCHOLARSHIPS

- Adaptive Driving Alliance (ADA) is a nationwide group of vehicle modification dealers. Their website lists funding sources for automotive adaptive equipment. Call 1-877-853-1402 or visit ADAMobility for additional information.
- AvaCare Medical offers a \$1000 scholarship to a student seeking a college degree in the medical field. All students may apply but preference is given to students who have a physical disability and a GPA of 3.0. For details about the scholarship and how to apply, visit AvaCareMedical or call their helpline at 1-877-813-7799.
- Cerner Charitable Foundation's provides funding for children, age 18 or younger, or 19-21 if they are in a childlike mental state, whose families cannot afford medical care, equipment, vehicle modification, or travel related to care. Visit Cerner Charitable Foundation Medical Grants for details and information on the application process.
- Challenged Athletes Foundation (CAF) Annual Grant Program provides opportunities and support to individuals with permanent physical disabilities in the form of different grants for training, competition, and equipment needs so they can pursue active lifestyles through physical fitness and competitive athletics. Visit ChallengedAthletes for details on when the application process opens and for additional resources.
- Getting Back Up provides qualified individuals with funding for participation in exercise-based recovery programs and the purchase of adaptable products. Their exercise-based recovery programs in Florida include NextStep (Orlando), Center of Recovery and Exercise (Orlando), and BARWIS (Deerfield Beach, Jupiter, and Fort Pierce). Visit GettingBackUp for details and to download the Application for Assistance.
- HelpHOPELive is a national nonprofit that helps individuals and families who have experienced a catastrophic injury afford medically related expenses not covered by insurance through grass-roots fundraising. Learn more at HelpHopeLive.
- High Fives Foundation's Empowerment Fund provides financial assistance for activities and resources that promote rehabilitation and independence to those who suffer a life-changing injury including SCI, TBI, amputation or other mobility-limiting injuries, paid to service providers in specific funding categories: adaptive sports equipment, healing network, medical equipment, programs, living expenses, and emergency care/injury expenses. Visit HighFivesFoundation to view the eligibility criteria.
- United Healthcare Children's Foundation (UHCCF) is a charitable organization that provides medical grants to help children (age 16 or younger) gain access to health-related services not covered, or fully covered, by their family's commercial health insurance plan. View the eligibility requirements and grant exclusions at UHCCF.

Wheelchairs 4 Kids is a nonprofit organization that provides wheelchairs, home and vehicle modifications, and therapeutic and assistive equipment at no charge to the families who have children with physical disabilities through their Let's Roll program. To refer a child call 727-946-0963 and ask for the Programs department or email: <a href="mailto:info@wheelchairs4kids.org">info@wheelchairs4kids.org</a> and include "Child Referral" in the subject line. For more information, visit Wheelchairs4Kids.

### **MILITARY**

- America's VetDogs offers service dogs for veterans with physical disabilities, PTSD, and TBI. Visit <u>VetDogs</u> for eligibility criteria and to apply for a service dog or call 866-282-8047 to speak with Consumer Services.
- Disabled American Veterans (DAG) is a nonprofit charity that provides a lifetime of support at no cost for
  veterans, their families, and survivors with transportation to medical appointments, benefit claims, and connecting
  veterans with meaningful employment. Visit <u>DAV</u> for tools and resources or to contact your nearest DAV Service
  Officer.
- Florida Department of Veterans' Affairs (FDVA) publishes an annual Benefits Guide and provides many other resources to veterans and their families. To download the newest Benefits Guide or get the FDVA App for your phone, visit FloridaVets.
- **Health.mil**, an official website of the Military Health System, offers TBI resources for services members, families, and caregivers. Visit <u>Health.mil</u> to view these resources.
- National Military Family Association (NMFA) is a nonprofit organization that educates military families on their rights, benefits, and services available to them. For more information, visit MilitaryFamily.
- National Resource Directory (NRD) is a resource website that offers resources that supports recovery, rehabilitation, and reintegration of wounded warriors, service members, veterans, family members and caregivers and includes information on employment, homeless assistance, housing, and the military adaptive sports program in addition to other resources. To view these resources, visit NRD.
- VA Caregiver Support Program provides information on caring for someone with a TBI and includes links to additional caregiver resources. For more information, visit <u>CaregiverVA</u>.
- VA Polytrauma System of Care provides specialized TBI care through the VA's Polytrauma System, offering
  rehabilitation services, long-term care, and treatment for veterans with multiple severe injuries, including TBI. For
  more information, visit PolyTraumaVA.
- Veterans Suicide Prevention Hotline provides free, 24/7 access to trained counselor at 1-800-273-TALK (8255).

### YOUTH & PARENTS

- Agency for Persons with Disabilities is a state agency that works with local organizations and private providers
  to support Floridians with developmental disabilities (disabled before the age of 18) so that they may receive
  social, medical, behavioral, residential, and therapeutic services. For more information, visit <u>APDCares</u> or call
  1-866-APD-CARES (273-2273).
- Brainline for Kids offers brain injury information and resources for families and educators at <u>Brainline</u>.
- Children's Hemiplegia and Stroke Association (CHASA) helps children with hemiparesis due to an early brain injury as well as adults who have been living with hemiplegia since childhood. CHASA awards college and vocational scholarships to students who meet the criteria, and their website has some amazing resources for kids and parents at CHASA.
- The Florida Birth-Related Neurological Injury Compensation Association (NICA) provides financial support to families of children who have sustained severe birth-related brain injuries in Florida by covering the costs of medical, therapeutic, and personal care services throughout the child's life. For more information or to file a claim, visit NICA or call 1-800-398-2129.
- The Florida Youth Council, a program of The Family Café, is dedicated to engaging young people and emerging leaders aged 15-30 with disabilities and special health care needs in self-advocacy, peer mentoring, and various activities. These initiatives aim to enhance their quality of life by empowering them to identify, articulate, and devise strategies to tackle the issues most significant to their generation. For more information, visit FloridaYouthCouncil or call 1-888-309-2233.

# **BRAIN INJURY GLOSSARY**

# A

**Activities of Daily Living (ADLs)** – Routine activities of personal hygiene and health such as eating, bathing, dressing, and performing household chores.

**Adaptive Equipment** – a special device which assists in the performance of self-care, work or play/leisure activities or physical exercise.

**Agitation** – Uncontrolled restlessness, upset or excitement in response to internal or external factors.

**Agnosia** – Failure to recognize familiar objects although sensory mechanism is intact. May occur for any sensory modality.

**Agraphia** – Inability to express thoughts in writing.

Alexia – Inability to read.

Alternative Communication – See "augmentative and alternative communication".

Ambulate - To walk.

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

**Aneurysm** – A balloon-like deformity in the wall of a blood vessel. The wall weakens as the balloon grows larger, and may eventually burst, causing a hemorrhage.

**Anomia** – Inability to recall the names of objects. Individuals with this problem often can speak fluently but have to use other words to describe familiar objects.

Anosmia - Loss of the sense of smell.

**Anoxia** – A lack or absence of oxygen. Cells of the brain need oxygen to stay alive. When blood flow to the brain is reduced or when oxygen in the blood is too low, brain cells are damaged.

Anterograde Amnesia – Inability to consolidate information about ongoing events. Difficulty with new learning.

**Anticoagulation** – Process of slowing down normal blood clotting and thus preventing blood clots from forming. Sometimes referred to as "thinning the blood." Common medications utilized to accomplish this are Coumadin and Heparin.

**Anticonvulsant** – Medication used to decrease the possibility of a seizure.

**Aphasia** – Impaired ability to effectively use spoken or written words, or gestural symbols to express ideas and/or impaired ability to understand Aphasia is always due to injury to the brain, most commonly due to stroke but brain injuries resulting in aphasia may also arise form head trauma, brain tumors, or infections.

- Anomic Aphasia affects one's word finding abilities. It is the persistent inability to supply the words for what one wants to talk about, particularly the significant nouns and verbs. As a result, their speech while fluent in grammatical form and output is full of circumlocutions and expressions of frustration. Their understanding of speech and reading is unaffected however, difficulty finding words is as evident in writing as in speech.
- Broca's Aphasia (non-fluent aphasia) speech output is severely reduced and limited to short utterances of less than four words. Vocabulary is limited and the formation of sounds is often laborious and clumsy hence, 'non fluent aphasia' because of the halting and effortful quality of speech. Individuals with this form of aphasia may understand speech well and be able to read, but they will be limited in writing.
- Global Aphasia is the most severe form of aphasia. Individuals with this type of aphasia produce few
  recognizable words and understand little or no spoken language. They can neither read nor write. With greater
  damage to the brain, severe and lasting disability may result.

- Mixed Non-fluent Aphasia characterized by sparse and effortful speech, resembling severe Broca's aphasia; however, unlike individuals with Broca's aphasia, they remain limited in their comprehension of speech and do not read or write beyond an elementary level.
- Wernicke's Aphasia (fluent aphasia or receptive aphasia) is a form of aphasia in which the individual's ability to grasp the meaning of spoken works is chiefly impaired, while the ease of producing connected speech is not affected much; speech is far from normal. Sentences do not hang together, and irrelevant words intrude, sometimes to the point of jargon, in severe cases. Ready and writing are also severely impaired for individuals with this type of aphasia.

Apoptosis – Cell death that occurs naturally as part of the normal development, maintenance, and renewal of tissues within an organism.

Apraxia - Inability to carry out a complex or skilled movement, not due to paralysis, sensory changes, or deficiencies in understanding.

Arachnoid Membrane – One of the three membranes that cover the brain; located between the pia mater and the dura. Collectively, these three membranes form the meninges.

Arousal – A primitive state of alertness (change from a state of sleep to one of being awake) managed by the reticular activating system (extending form the medulla to the thalamus in the core of the brain stem) activating the cortex. Cognition is not possible without some degree of arousal.

Articulation - The process by which sounds, syllables, and words are formed when your tongue, jaw, teeth, lips, and palate alter the air stream coming from the vocal cords. When an individual cannot produce or distort sounds, it draws attention away from the speaker's message.

Aspiration – The entry of food or liquid into the lungs because of swallowing difficulty. Can cause a lung infection or pneumonia.

Assistive Device - Equipment used to help with a task such as a walker, cane, reacher, etc.

**Astereognosia** – Inability to recognize the form of objects by touch without visual input.

Ataxia – A lack of muscle control or coordination of voluntary movements. Caused by lesion of the cerebellum or basal ganglia. Can interfere with a person's ability to walk, talk, eat, and to perform other self-care tasks.

**Atrophy** – A wasting away or decrease in size of a cell, tissue, organ, or part of the body caused by lack of nourishment, inactivity, or loss of nerve supply.

Attention Span – The ability to focus on a given task or set of stimuli or the ability to ignore distractions and mentally focus on the task at hand.

Audiologist – One who evaluates hearing defects and who aids in the rehabilitation of such defects.

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

Automatic Speech – Words said without much thinking on the part of the speaker. These may include songs, numbers. and social communication; or can be items previously learned through memorization. Spontaneous swearing by individuals who did not do so before their injury is another example.

**Awareness** – Understanding the problems resulting from a brain injury.

# B

**Balance** – The ability to keep your body centered over your feet; determined by many factors including your physical strength, coordination, senses, and cognitive ability. Maintaining balance while sitting and standing is important for all daily activities, including self-care, walking, and driving.

**Behavior** – The total collection of actions and reactions exhibited by a person.

**Behavior Disorders** – Patterns of behavior preventing participation in active rehabilitation, including destructive behavior to self and others.

Bilateral – Pertaining to both right and left sides.

**Biofeedback** – A process in which information not ordinarily perceived (such as heart rate, skin temperature or electrical activity of muscles) is recorded from a person and then relayed back instantaneously as a signal so that the individual becomes aware of any alteration in the recorded activity.

**Brain Death** – An irreversible cessation of measurable brain function.

**Brain Injury** – An injury that affects how the brain works.

- Acquired Brain Injury the implication of this term is that the individual experienced normal growth and development from conception to birth, until sustaining an insult to the brain at some later time which resulted in impairment of brain function.
- Closed Brain Injury occurs when the head accelerates and then rapidly decelerates or collides with another object (for example the windshield of a car) and brain tissue is damaged without fracture of the skull, not by the presence of a foreign object within the brain, but by violent smashing, stretching and twisting of brain tissue. Closed brain injuries typically cause diffuse tissue damage that result in disabilities which are generalized and highly variable.
- Mild Brain Injury (Concussion) a traumatic brain injury that affects brain function. Effects are usually temporary and may include headaches and problems with concentration, memory, balance, and coordination. Some concussions may result in a brief loss of consciousness, but most do not. Falls are the most common cause of concussions but contact sports-related concussions are also common. Most people usually recovery fully after a concussion.
- Moderate Brain Injury a Glasgow Coma Scale score of 9 to 12 during the first 24 hours post injury.
- Penetrating Brain Injury Occurs when an object (for example a bullet or an ice pick) fractures the skull, enters
  the brain, and rips the soft brain tissue in its path. Penetrating injuries tend to damage relatively localized areas of
  the brain which result in discrete and predictable disabilities.
- Severe Brain Injury severe injury is one that produces at least 6 hours of coma or Glasgow Coma Scale of 8 or less within the first 24 hours.
- Traumatic Brain Injury damage to living brain tissue caused by an external mechanical force. It is usually characterized by a period of altered consciousness (amnesia or coma) that can be very brief (minutes) or very long (months/indefinitely). The specific disabling condition(s) may be orthopedic, visual, aural, neurologic, perceptive/cognitive, or mental/emotional in nature. The term does not include brain injuries that are caused by insufficient blood supply, toxic substances, malignancy, disease-producing organisms, congenital disorders, birth trauma or degenerative processes.

**Brain Plasticity** – The ability of intact brain cells to take over functions of damaged cells; plasticity diminishes with maturation.

**Brain Scan** – An imaging technique in which a radioactive dye is injected into the blood stream and pictures of the brain are taken to detect tumors, hemorrhages, blood clots, abscesses, or abnormal anatomy.

**Brainstem** – The life support entity of the nervous system, the structure that connects the body of the brain to the spinal cord. Responsible for respiration, heart rate and blood pressure, swallowing, motor production of speech, hearing, and consciousness.

# C

**Catheter** – A flexible tube inserted in the bladder for the purpose of draining urine. There are several kinds (Foley catheter, condom catheter, and straight catheter).

**Cerebellum** – The portion of the brain (located at the back) which helps coordinate movement. Damage may result in ataxia.

**Cerebral Spinal Fluid (CSF)** – A clear fluid produced in and for the support of the brain and spinal cord that provides a medium in which the brain floats and assists in constant purification of the brain by removing waste.

**Chronic** – Long duration or frequent recurrence.

**Chronic Traumatic Encephalopathy (CTE)** – A progressive neurology disorder associated with a variety of symptoms, including cognition and communication problems, motor disorders, poor impulse control, depression, confusion, and irritably.

**Circumlocution** – A strategy used by individuals with brain injury where they "talk around" the name of the object, person or place that are attempting to identify.

**Clonus** – Involuntary and rhythmic jerks (muscle contractions and relaxations) caused by a permanent lesion in descending motor neurons.

**Cognition** – The intellectual skillset of knowing, perceiving, understanding, reasoning, problem solving and remembering.

**Cognitive Impairment** – Difficulty with one or more of the basic functions of the brain: perception, memory, attentional abilities, and reasoning skills.

**Cognitive Rehabilitation** – Therapy programs which aid individuals in the management of specific problems in perception, memory, thinking, and problem solving. Skills are practiced and strategies are taught to help improve function and/or compensate for remaining deficits.

**Coma** – A state of deep unconsciousness in which the individual does not interact with the environment. Could result from trauma or induced by medication to promote healing.

**Communicative Disorder** – Impairment in the ability to comprehend, detect, or apply language and speech to engage in discourse effective with others. The impairment may be observed in disorders of language, hearing, and/or speech process.

**Community Integration / Reintegration** – A process that enhances an individual's ability to return home form a hospital or rehabilitation center by minimizing disruptions and facilitating access to community-based programs and existing resources.

**Comprehension** – Understanding spoken, written, or gestural communication.

Compressive Cranial Neuropathies – Degeneration of nerves in the brain caused by pressure on those nerves.

**Computed Tomography (CT)** – A scan that creates a series of cross-sectional X-rays of the head and brain; also called computerized axial tomography or CAT scan.

**Computerized Axial Tomography** – A series of X-rays taken at different levels of the brain that allows the direct visualization of the skull and intracranial structures. A scan is often taken soon after the injury to help decide if surgery is needed and may be repeated later to see how the brain is recovering.

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

**Concrete Thinking** – A style of thinking in which the individual sees each situation as unique and is unable to generalize from the similarities between situations. Language and perceptions are interpreted literally so that a proverb such as "a stitch in time saves nine" cannot be readily grasped.

**Confabulation** – Subconscious fabrication of facts or events, emerging from confusion to fill in gaps in memory. It is not lying; the individual really believes the confabulated event occurred.

**Confusion** – The inability to make sense of the environment, a disorientation to time, place, and circumstance. Confusion may be reflected in confused language, agitation, and inaccurate memories.

**Continent** – The ability to control urination and bowel movements.

**Contracture** – Lack of full range of motion in a joint due to spasticity, abnormal shortening of tissues, insufficient movement, or orthopedic problem.

Contralateral - Opposite side.

**Contusion, Brain** – A bruise. The result of a blow to the head which bruises the brain.

**Convergence** – Movement of two eyeballs inward to focus on an object moved closer. The nearer the object, the greater is the degree of convergence necessary to maintain single vision.

Cortical Blindness – Loss of vision resulting from a lesion of the primary visual areas of the occipital lobe.

**Contrecoup** – Bruising of the brain tissue on the side opposite where the blow was struck.

**Contusion** – Area of swollen brain tissue mixed with blood released from broken blood vessels.

**Cortex** – The upper quarter of brain matter, often referred to as gray matter. It's responsible for sensation, movement, communication, and intellectual function. It's also vulnerable in the event of a TBI due to its location on the top surface of the brain.

**Coup-Contra Coup** – Two locations of injury resulting from the acceleration/deceleration movement of the brain within the skull. The coup is the initial impact site where contra coup is the opposite side of the head.

**Cranioplasty** – Replacement of the bone flap (cranial plate) removed during a craniotomy.

**Craniotomy** – Removal of part of the skull to perform an operation on the brain. The cranial plate or bone flap (the part of the skull removed) may not be replaced immediately to allow for swelling to recede.



**Decubitus Ulcer** – Any break in the skin caused by prolonged pressure over a bony prominence. Severity ranges from Stage 1 through Stage IV, with Stage III and Stage IV presenting potential serious complications that may even require surgery. Common areas most prone to breakdown are buttocks or backside, hips, shoulder blades, heels, ankles, and elbows. Also called bedsores and pressure ulcers.

**Deep Vein Thrombosis (DVT)** – A blood clot in a vein, located deep from the skin, most seen in the calf or thigh. Veins lying just beneath the skin are called superficial veins.

**Depressed Skull Fracture** – A break in the cranial bone (or "crushed" portion of skull) with depression of the bone in toward the brain.

**Diffuse Axonal Injury (DAI)** – A shearing injury of large nerve fibers (axons covered with myelin) in many areas of the brain. It appears to be one of the two primary lesions of brain injury, the other being stretching or shearing of blood vessels from the same forces, producing hemorrhage. See Shearing.

**Diplopia** – Seeing two images of a single object; double vision.

**Disinhibition** – Inability to suppress (inhibit) impulsive behavior and emotions.

**Disoriented** – Confused as to person, place, time and/or circumstance.

**Distractibility** – Inability to screen internal and external stimuli resulting in difficulty focusing/concentrating on a task.

**Dura Mater** – The outermost layer the of the meninges that surround and protect the brain and spinal cord (pia, arachnoid, and dura, from the inside to outside).

**Dysarthria** – Difficulty with speech due to muscle weakness or coordination due to brain injury; may result in slurred or imprecise articulation.

**Dysphagia** – A swallowing disorder due to neurological damage but may be due to mechanical problems like the placement of a tracheostomy tube. Swallowing can also be impaired due to motor function or decreased sensation of the mouth and throat. An individual with dysphagia is at risk of aspiration.

Е

**Echolalia** – Imitation of sounds or words without comprehension. This is a normal stage of language development in infants but is abnormal in adults.

Edema – Swelling due to collection of fluid.

Electroencephalogram (EEG) – A procedure used to assess electrical activity in the brain, often used to detect seizures.

**Electromyogram** (EMG) – A test that converts electrical activity in the skeletal muscles into images to facilitate a diagnosis of neuromuscular disorders.

**Embolism** – A clot or foreign body that blocks an artery.

**Emotional Lability** – Uncontrollable laughing, crying, or cursing at inappropriate times, often more than the individual's genuine emotional state.

**Endotracheal Tube** – A tube that serves as an artificial airway and is inserted through the individual's mouth or nose into the air passages to help breathing. To do this it must also pass through the patient's vocal cords. The individual will be unable to speak if the endotracheal tube is in place. It is this tube that connects the respirator to the individual.

**Epidural Hematoma** – Bleeding into the area between the skull and the dura.

**Episodic Memory** – Memory for ongoing events in a person's life. More easily impaired than semantic memory.

**Evoked Potential** – Registration of the electrical responses of active brain cells in response to specific stimulus applied to the visual, auditory, or other sensory receptors of the body, detected by electrodes placed on the surface of the head at various places.

**Executive Function** – Frontal brain function; ability to plan, initiate, execute and revise and task.



Flaccid – Lacking normal muscle tone; limp.

**Flexion** – Bending a joint (i.e., bending at the elbow).

**Frontal Lobe** – Front part of the brain; involved in planning, organizing, problem solving, selective attention, personality, and a variety of "higher cognitive functions."

Frustration Tolerance – The ability to persist in completing a task despite apparent difficulty.

**Functional** – Skills or tasks applicable in daily living tasks such as preparing meals, showering, paying bills, and balancing a checkbook. Functional may also refer to a level of skill, while not perfect, is adequate for the completion of a task.

# G

**Gainful Employment** – Employment in the competitive labor market where the employee receives steady work, payment from the employer and that allows for self-sufficiency.

**Gait** – Walking pattern.

Gait Training – Instruction in walking, with or without equipment; also called "ambulation training".

**Gastrostomy (GI Tube/PEG Tube)** – A surgically implanted feeding tube in the stomach. Used to introduce non-oral liquids, foods, or medications when the individual is unable to take substances by mouth. Also referred to as a PEG Tube.

**Glasgow Coma Scale (GCS)** – A standard system used to assess the degree of brain impairment and to identify the seriousness of injury in relation to outcome. The system involves three determinants: eye opening, verbal responses and motor response all of which are evaluated independently according to a numerical value that indicates the level of consciousness and degree of dysfunction. Scores run from a high of 15 to a low of 3.

- Mild brain injury GCS 13 to 15.
- Moderate brain injury GCS 9 to 12
- Severe brain injury CGS 8 or less



**Handicap** – Describes a condition or barrier imposed by society, the environment, or by one's own self that limits or prevents the fulfillment of a role that is normal, depending on age, sex and social and cultural factors, for the individual. Handicap can be used when citing laws and situations but should not be used to describe a disability. Not a synonym for disability.

Head Injury - Injury to the head and/or brain, including lacerations and contusions of the head, scalp, or forehead.

**Hematoma** – A localized collection of blood due to bleeding of a ruptured blood vessel.

- **Epidural (EDH)** usually caused when a skull fracture tears an underlying artery or blood vessel, resulting in a buildup of blood between the dura mater and the skull.
- **Subdural (SDH)** bleeding that fills the brain area rapidly, compressing the brain tissue. Most often the result of a severe head injury and among the deadliest of all head injuries.
- Intracerebral (ICH) a collection of blood within the brain tissue or underneath the skull, pressing on the brain.

**Hemianopsia** – A problem of visual perception where half of the visual field is either disorganized or missing altogether.

Hemiparesis – Weakness of one side of the body.

**Hemiplegia** – Paralysis of one side of the body because of injury to neurons carrying signals to muscles from the motor areas of the brain.

Hemorrhage – Profuse internal or external bleeding from a ruptured blood vessel or copious blood loss.

Subarachnoid (SAH) – bleeding in the space that surrounds the brain. Most often occurs when a weak area in a
blood vessel (aneurysm) on the surface of the brain bursts and leaks. The blood builds up around the brain and
inside the skull increasing pressure on the brain.

**Hemorrhagic Stroke** – A stroke caused by bleeding out of one of the major arteries leading to the brain.

**Hydrocephalus** – Enlargement of fluid-filled cavities in the brain, not due to brain atrophy.

**Hypermetabolism** – A condition in which the body produces too much heat.

**Hypothyroidism** – Decreased production of thyroid hormone leading to low metabolic rate, weight gain, chronic drowsiness, and/or fluid accumulation and retention in connective tissues.

**Hypoxia** – Insufficient oxygen reaching the tissues of the body.

Impulse Control – Refers to the individual's ability to withhold inappropriate verbal or motor responses while completing a task. Individuals who act or speak without first considering the consequences are viewed as having poor impulse control.

Impulsive - Acting before thinking. A problem of judgment often associated with executive dysfunction and frontal brain damage.

**Incontinence** – Inability to control bowel and bladder functions.

Independent Living - Community-based to maximize an individual's ability to be empowered and self-directed; allows an individual to live in one's own home with maximum personal control over how services are delivered, combined with the opportunity to work as appropriate.

**Inhibition** – Stopping abnormal movement or behavior.

**Initiation** – Ability to begin an activity.

**Initiative** – Ability to assess and initiate things independently.

Intake and Output (I and O) - Measurement of the amount of fluid taken in and eliminated during a 24-hour period.

Intracerebral Hematoma – Bleeding withing the brain caused by damage to a major blood vessel.

Intracranial Pressure - The pressure within the craniospinal compartment, a closed system that comprises a fixed volume of neural tissue, blood, and cerebrospinal fluid (CSF).

Intracranial Pressure Monitor (ICP) - A device inserted into the skull to monitor the amount of pressure exerted on the brain by swelling after a brain injury.

**Ischemia** – A severe reduction in the supply of blood to body tissues.



**Jargon** – Spoken language that has normal rate and rhythm but is full of nonsense words.

Job Analysis – The process of gathering and analyzing information about the content and the human requirements of jobs, as well as the context in which jobs are performed.

Judgment - Process of forming an opinion, based upon an evaluation of the situation at hand in comparison with personal values, preferences, and insights regarding expected consequences. The ability to make appropriate decisions.



**Kinesthesia** – Sensory awareness of body parts as the move in space.

**Lability** – State of having notable shifts in emotional state (uncontrolled laughing or crying).

**Levels of Assistance** – Degree of physical or cognitive facilitation required to perform a task; graded by levels:

- **Independent** able to being and complete task safely without physical assist or direction.
- **Supervised** requires only verbal cues or supervision for safety and thoroughness.
- **Modified Independent** may need use of an assistive device to complete the task.
- Contact Guard requires hand on help for guiding.
- **Minimal Assistance** 0-25% physical assistance required to complete task.
- **Moderate Assistance** 25-50% physical assistance required.
- **Maximal Assistance** 50-75% physical assistance required.
- **Dependent** 75-100% physical assistance required.

Locked-in Syndrome – A condition in which the individual is aware and awake but cannot move or communicate, other than moving their eyes, due to complete paralysis of the body resulting from interruption of motor pathways usually by infarction. Individuals can receive and understand sensory stimuli and communication may be possible by code using blinking, or movement of the jaw or eyes.

# M

Magnetic Resonance Imaging (MRI) - Imaging of the body using magnetic field and radio waves used to determine damage to soft tissues (brain and muscle) due to greater clarity and resolution vs x-rays.

**Malingering** – To pretend inability to avoid duty or work.

**Memory** – The ability to retain and recall information.

- **Immediate Memory** memory of information a few seconds after presentation.
- **Short-Term Memory (working memory)** memory of information up to 24-hours after presentation.
- Long-Term Memory (remote memory) memory of personal information from the past, including information learned prior to injury.

Meningitis – Inflammation of the three membranes (dura mater, pia mater, and arachnoid) covering the brain and spinal cord, collectively known as the meninges.

Mental Competence – The quality or state of being competent; having adequate mental abilities; legally qualified or adequate to manage one's personal affairs. An individual found by a court to be mentally incompetent has a guardian appointed to make personal and/or economic decisions on their behalf.

Motor Control - Regulation (carried out by the nervous system) of the timing and amount of contraction of muscles to provide smooth and coordinated movement. Factors that affect control include strength, coordination, sensation, and the ability to plan purposeful movement.

**Motor Planning** – Action formulated in the mind before attempting to perform.

Muscle Tone – The amount of tension (or resistance to movement) in muscles. When nerve fibers in the brain or spinal cord are damaged, the balance between facilitation and inhibition of muscle tone is disturbed. The tone of some muscles may become increased, and they resist being stretched – a condition called hypertonicity or spasticity.

# N

**Nasogastric Feeding Tube (NG Tube)** – A feeding tube inserted through the nose, down the back of the throat through the esophagus that provides nutrition, hydration, and medication.

**Neuroexcitation** – Electrical activation of cells in the brain; is part of the normal functioning of the brain or can also be the result of abnormal activity related to an injury.

**Neurogenic Bowel/Bladder** – Difficulty with bowel and bladder function due to nerve damage.

**Neuropsychologist** – A psychologist who specializes in evaluating brain/behavioral relationships, planning training programs to help the survivor of brain injury return to normal functioning and recommending alternative cognitive and behavioral strategies to minimize the effect of brain injury.

**Neurotransmitters** – Are chemical messengers in the body that transmit signals from nerve cells to target cells. The brain needs neurotransmitters to regular many necessary functions, including heart rate, breathing, sleep cycles, and muscle movement.

Non-ambulatory - Unable to walk.

**Nothing by Mouth (NPO)** - This means no food or liquids for a set period, usually in preparation for certain tests, or when a person cannot safely swallow.

**Nystagmus** – Involuntary horizontal, vertical, or rotary movement of the eyeballs.



**Occipital Lobe** – Region in the back of the brain which processes visual information. Damage to this lobe can cause visual deficits.

**Orientation** – A sense of what is going on around you. This includes knowing the day, date, month and year; knowing things about yourself; knowing where you are and how to get around; and knowing what happened to you; along with the ability to use this information appropriately in a functional setting.

**Orthopedics** – The study and treatment of the skeletal system, its joints, muscles, and associated structures.

**Orthotics** – Braces or splints.

**OT** – Occupational Therapist; Occupational Therapy. Occupational therapy is the therapeutic use of self-care, work and play activities to increase independent function, enhance development and prevent disability; may include the adaptation of a task or the environment to achieve maximum independence and to enhance the quality of life. The term occupation, as used in occupational therapy, refers to any activity engaged in for evaluating, specifying, and treating problems interfering with functional performance.



**Paraplegia** – Paralysis of the legs (from the waist down).

Parietal Lobe – One of the two parietal lobes of the brain located behind the frontal lobe at the top of the brain.

- **Right Parietal Lobe** Damage to this area can cause visuo-spatial deficits (e.g., the patient may have difficulty finding their way around new, or even familiar, places).
- Left Parietal Lobe Damage to this area may disrupt a patient's ability to understand spoken and/or written language.

**Perception** – Awareness, recognition, and meaningful interpretation of that which is seen, felt, or heard.

**Perseveration** – The inappropriate persistence of a response in a current task which may have been appropriate for a former task. Perseverations may be verbal or motoric.

**Phonation** – The production of sound by means of vocal cord vibration.

**PT** – Physical Therapy; Physical Therapist.

Physiatrist – A physician who specializes in physical medicine and rehabilitation and is an expert in enhancing and restoring functional ability in and quality of life to individuals with physical or cognitive impairments. The physiatrist follows the patient closely throughout treatment and oversees the patient's rehabilitation program.

**Plateau** – A temporary or permanent leveling off in the recovery process.

PO - To be taken by mouth (as with medication).

Post-Concussion Syndrome (PCS) – Occurs when concussion symptoms last beyond the expected recovery period after the initial injury. The usual recovery period is weeks to months. Most PCS symptoms fall into four categories: Cognitive, Sleep, Mood/Behavioral, and Physical.

Post-Traumatic Amnesia (PTA) – The time after a period of unconsciousness when the individual is conscious and awake but is behaving or talking in a bizarre or uncharacteristic manner. The individual may be disoriented and unable to remember events that occur after the injury. They may also have difficulty retaining new information or creating new memories which can affect daily activities. May also be called Anterograde Amnesia.

Post-Traumatic Epilepsy – Recurrent seizures occurring more than 1-week after a traumatic brain injury.

**Pre-Morbid Condition** – Characteristics present before the disease or injury occurred.

**Problem-Solving Skill** – The ability to define a problem, determine the cause of the problem, identify, prioritize, and select alternatives for a solution, and then implement the solution. Memory loss might affect problem solving ability because of a difficulty remembering how a similar problem has been resolved in the past. Impulsivity might also affect decision-making because decisions are made quickly without thinking them through.

**Prognosis** – The prospect as to recovery from a disease or injury as indicated by the nature and symptoms of the case.

**Prone** – Lying on one's stomach.

**Proprioception** – The sensory awareness of the position of body parts with or without movement. Combination of kinesthesia and position sense.

PRN - Pro Re Nata - as needed. Often refers to medication that can be taken as needed.

**Prone** – Lying on stomach.

**Prosody Dysfunction** – Problems with inflections or intonations of speech.

Prosthesis - Artificial limb.

**Proximal** – Next to, or nearest, the point of attachment.

**Proximal Instability** – Weakness of muscles of the trunk, shoulder girdle or hip girdle which causes poor posture. abnormal movement of the arms or legs and the inability to hold one's head up. Strength of muscles of the hands or legs may be normal.

Ptosis – Drooping of a body part, such as the upper eyelid, from paralysis, or drooping of visceral organs from weakness of the abdominal muscles.

**Purposeful Movement** – Motor activity with an apparent goal.



Quad Cane - 4-legged cane.



Rancho Los Amigos Levels of Cognitive Functioning – A scale of cognitive functioning used to describe specific cognitive and behavioral characteristics associated with brain injury.

Range of Motion (ROM) – Refers to movement of a joint (important to prevent contractures).

- Range of Motion, Active the muscles around the joint do the work to move it.
- Range of Motion, Passive movement of a joint by means other than contraction of the muscles around that joint (e.g., someone else moves the joint).

**Recreation Therapist** – Develops a program to assist individuals with disabilities plan and manage their leisure activities.

Rehabilitation – A comprehensive program to reduce and/or overcome deficits following an injury or illness to assist the individual in attaining the optimal level of mental and physical ability.

Rehabilitation Counselor - Helps people with physical, mental, developmental, or emotional disabilities live independently. See also Vocational Rehabilitation Counselor.

Rehabilitation Facility – A facility operated for the primary purpose of assisting in the rehabilitation of disabled individuals by providing comprehensive medical evaluations and services, psychological and social services, or vocational evaluation and training.

Respite Care – A means of taking over the care of a patient temporarily (a few hours up to a few days) to provide a period of relief for the primary caregiver.

Residential Services – 24-hour dependent care and treatment services provided in a residential environment outside the home (e.g., assisted living facilities or group homes)

Retrograde Amnesia – Inability to recall events that occurred prior to the accident; may be a specific span of time or type of information.



**Scotoma** – Area of blindness of varying size anywhere within the visual fields.

Secondary Condition - People with disabling conditions are often at risk of developing secondary conditions that can result in further deterioration in health status, functional capacity, and quality of life. Secondary conditions are causally related to a primary disabling condition and include, among others, contractures, physical deconditioning, mental depression, cardiopulmonary conditions, and decubitus ulcers.

**Seizure** – An uncontrolled discharge of nerve cells which may spread to other cells nearby or throughout the entire brain. It usually lasts only few minutes. It may be associated with loss of consciousness, loss of bowel and bladder control and tremors. May also cause aggression or other behavioral change.

**Selective Attention** – Ability to focus on the most important aspect of a situation without becoming distracted.

**Sensorimotor** – All aspects of movement and sensation and the interaction of the two.

Sensory Integration – The brain's ability to take in information from senses, organize it, and respond to it during experiences of daily life. The three primary sensory systems are the tactile system (our ability to touch something and comprehend it, including the sense of pain and temperature), the vestibular system (located in the inner ear and involved in eye-hand coordination balance and coordination) and the proprioceptive system (involved in determining spatial relationships with our body and the world around us).

**Sequelae** – An after effect of a disease or injury.

**Sequencing** – Performing a task or expressing a thought in an orderly and meaningful manner.

**Shearing** – A tearing of nerve fibers in the brain, especially along the outer surface of the cortex, resulting from the brain rubbing along the coarse inner surface of the skull in a rotational or acceleration/deceleration injuries. See Diffuse Axonal Injury.

**Shunt** – A surgically-placed tube running from the ventricles which deposits fluid into either the abdominal cavity, heart, or large veins of the neck. A procedure to draw off excessive fluid in the brain.

**Spasm** – An involuntary and abnormal muscular contraction; also, a sudden violent and temporary effort or emotion.

**Spasticity** – An involuntary increase in muscle tone (tension) that occurs following injury to the brain or spinal cord, causing the muscles to resist being moved. Characteristics may include increase in deep tendon reflexes, resistance to passive stretch, clasp knife phenomenon, and clonus.

**Speech Language Pathologist (SLP)** – Assess, diagnoses, and treats communication and swallowing disorders in children and adults.

**Speech Language Pathology Services** – A continuum of services including prevention, identification, diagnosis, consultation, and treatment of individuals regarding speech, language, oral and pharyngeal sensorimotor function.

**Spontaneous Movement** – A reaction resulting from a natural impulse without obvious planning or premeditation.

**ST** – Speech-Language Therapy.

**Strabismus**, **External** – Outward turning of the eye which may be due to a lesion of the oculomotor nerve (III) causing paralysis of the medial rectus muscle.

**Strabismus, Internal** – Inward turning of the eye which may be due to a lesion of the abducens nerve (VI) causing paralysis of the lateral rectus muscle.

Supine - Lying on one's back.

**Supported Independent Living Programs** – Provides normalized community living opportunities by offering support to assist the resident in maximizing and/or maintaining independence and self-direction. Support and supervision are provided as needed, 24/7.



Tactile Defensiveness – Over sensitivity to touch; withdrawing, crying, yelling, or hitting when one is touched.

**Tangentiality** – A disturbance in the thought process where an individual tends to move from one topic to another often losing the main point.

**Telegraphic Speech** – Speech which sounds like a telegram. Only the main words of a sentence (nouns, verbs) are present; the small words (ifs, ands, buts) are missing. This type of speech often gets the message across.

**Temperament** – Personal traits consisting of the individual's characteristic mode or inclination of emotional response.

**Temporal Lobes** – There are two temporal lobes, one on each side of the brain located at about the level of the ears. These lobes allow a person to tell one smell from another and one sound from another. They also help in sorting new information and are believed to be responsible for short-term memory.

- Right Lobe Mainly involved in visual memory (e.g., memory for picture and faces).
- Left Lobe Mainly involved in verbal memory (e.g., memory for words and names).

**Thrombosis/Thrombus** – Formation of a blood clot at the site of an injury.

**Tracheostomy** – Temporary surgical opening at the front of the throat providing access to the trachea (windpipe) to assist in breathing.



Urinary Tract Infection (UTI) - Voiding disorders are very common after traumatic brain injury. Incontinence and urinary retention can cause UTIs, development of skin ulcers, formation of stones and renal failure. Most of the voiding issues in brain injured individuals is due to neurogenic bladder although they can also occur due to use of medications with anticholinergic effect or clogged catheters.



Vasospasm – The narrowing of the arteries caused by a persistent contraction of the blood vessels, which is known as vasoconstriction. Vasospasms can affect any are of the body including the brain (cerebral vasospasm) and the coronary artery (coronary artery vasospasm).

Vegetative State (VS) - Is a chronic or long-term condition that differs from a coma. It is a state in which an individual is awake but has not regained awareness. They may open their eyes, have sleep-wake cycles, and basic reflexes (blinking eyes when startled or withdrawing hand when squeezed) but completely lack cognitive function. The chances of regaining awareness diminish considerably as the time spent in the vegetative state increases.

Persistent Vegetative State (PVS) – An individual is classified as in a PVS after four weeks in a vegetative state following numerous neurological testings. After a year, the chances that an individual in a PVS will regain consciousness are very low and most individuals who do recover consciousness experience significant disability. The longer an individual is in a PVS, the more severe the resulting disabilities are likely to be. Rehabilitation can contribute to recovery, but many individuals never progress to the point of being able to take care of themselves.

Ventilator – Machine that performs breathing function for an individual who is unable to breath on their own.

Ventricles, Brain - Four natural cavities in the brain which are filled with cerebrospinal fluid. The outline of one or more of these cavities may change when a space-occupying lesion (hemorrhage, tumor) has developed in a lobe of the brain.

Ventriculostomy – Surgical procedure to drain cerebrospinal fluid from the brain by creating an opening in one of the small cavities called ventricles.

Verbal Apraxia - Impaired control of proper sequencing of muscles used in speech (tongue, lips, jaw muscles, vocal cords). These muscles are not weak, but their control is defective. Speech is labored and characterized by sound reversals, additions, and word approximations.

**Verbal Fluency** – The ability to produce words.

Vestibular – Pertaining to the vestibular system in the middle ear and the brain which senses movements of the head. Disorders of the vestibular system can lead to dizziness, poor regulation of postural muscle tone and inability to detect quick movements of the head.

**Visual Tracking** – Visually tracking an object as it moves through space.

Visual Field Defect - Inability to see objects located in a specific region of the field of view ordinarily received by each eye. Often the blind region includes everything in the right half or left half of the visual field.

Visual Perception – The ability to recognize and discriminate between visual stimuli and to interpret these stimuli through association with earlier experiences. For example, to separate a figure from a background, to synthesize the contents of a picture and to interpret the invariability of an object which is seen from different directions.

Vocational Evaluation – A comprehensive process that systematically utilizes work, real or stimulated, as the focal point for assessment and vocational exploration, the purpose of which is to assist individuals in vocational development. Vocational evaluation incorporates medical, psychological, social, vocational, educational, cultural, and economic data in the attainment of the goals of the evaluation process.

Vocational Rehabilitation Counselor - Helps people with disabilities find and maintain meaningful employment and enhance their independence.