



BRAIN INJURY

RESOURCE GUIDE



Brain and Spinal Cord Injury Program Resource Center

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BSCIP RESOURCE CENTER & BSCIP

BRAIN & SPINAL CORD INJURY PROGRAM RESOURCE CENTER

MISSION – Education, Information & Awareness

The Brain & Spinal Cord Injury Program (BSCIP) Resource Center, established in January 1994, serves as the statewide clearinghouse of information for individuals who have survived a traumatic brain injury (TBI) and/or spinal cord injury (SCI), their families and friends, health care professionals, support groups, students, and the public.

SERVICES – Information & Education

Information and Referral (I&R) services are provided by trained staff, who have personal experiences with brain and spinal cord injuries, including state and national programs, community resources, support group meetings and activities, recreational opportunities, and upcoming events. Educational in-service trainings regarding best practices for treating patients with brain or spinal cord injuries are conducted with health care professionals and medical and nursing students.

RESOURCES – Helpline & Website

A toll-free helpline is available Monday through Friday from 8 a.m. to 5 p.m. for assistance with information and referral to appropriate resources. The Resource Center website also provides information for brain and spinal cord injury survivors about various types of injuries, resources for family and caregivers, and so much more. 1-866-313-2940, BSCIPResourceCenter.org

FLORIDA BRAIN AND SPINAL CORD INJURY PROGRAM

The Florida Department of Health Brain and Spinal Cord Injury Program is a program 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 services primarily comes from the BSCIP Trust Fund, which is funded by a percentage of civil penalties for moving vehicle violations and surcharges on motorcycle specialty and temporary tags. The program is a payor of last resort and may provide funding for the cost of care for necessary services that will enable an individual to return to an appropriate level of functioning in the community. The primary services are case management and resource facilitation. BSCIP.org

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

REFERRAL

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, and has been referred to the BSCIP Central Registry; the resident 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 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 broken limbs. 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)** 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 caused 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, resulting** 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** include verbal and physical outbursts, poor judgment and disinhibition, lethargy, lack of self-awareness, and impulsivity.
- **Sensory deficits** such as problems with hearing, smell, taste, touch, and vision impairments.
- **Physical deficits** include 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 to 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 before 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 the 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, and poor insight/judgment.

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

TREATMENT PROGRESSION

The treatment progression for brain injury begins with trauma care, moves along the continuum, and ends with community reintegration. Individuals may enter, exit, and re-enter treatment at any point along the continuum.

When an individual sustains a brain injury, they may require treatment continuously or intermittently throughout life. The purpose of post-acute rehabilitation is to maximize attainable levels of physical, cognitive, emotional, psychological, social, and economic usefulness, decrease the likelihood of long-term complications, and clear the path for a safe transition to other forms of rehabilitation or home so individuals can get back to living their best lives.

ACUTE CARE

Acute care rehabilitation takes place in a special unit of the trauma hospital, rehabilitation hospital, or other inpatient settings. As a significant phase of the recovery process, therapy occurs 5-7 days a week for several hours per day. Therapy focuses on regaining the ability to do everyday activities such as dressing, using the bathroom, eating, walking, and speaking.

SUB-ACUTE REHABILITATION

An individual that has medical needs requiring 24-hour 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 independent functioning and relearning and learning compensatory strategies for long-term or permanent disability.

DAY REHABILITATION

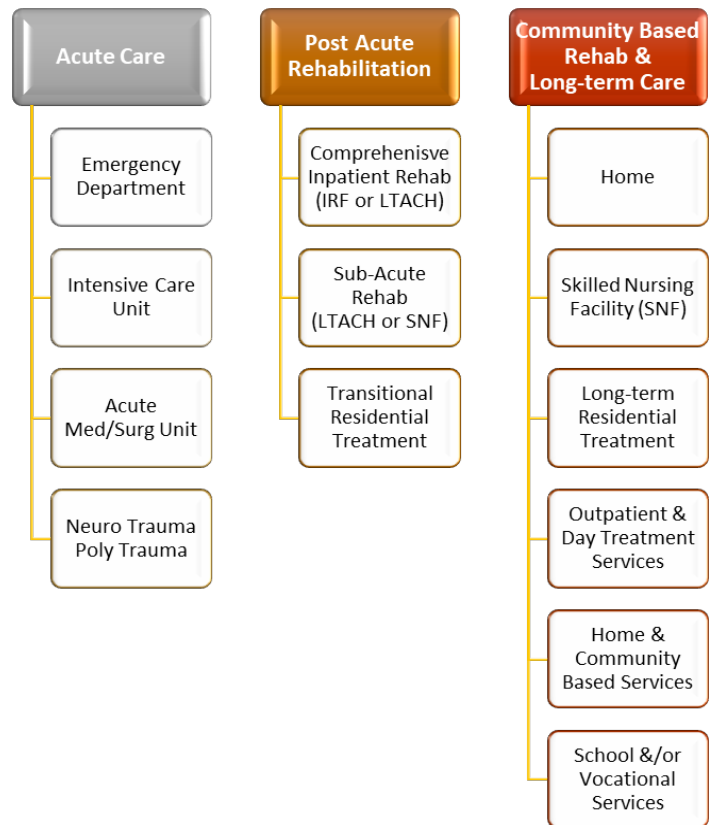
Day rehabilitation provides a continuation of recovery for individuals who no longer require 24-hour nursing care. Services are provided 5-days per week and consist of individual and group-based treatments.

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. For a summary of your rights visit FloridaHealthFinder.gov/reports-guides/patient-bill-rights.aspx or request a copy of the full text from your healthcare provider or healthcare facility.



POST-ACUTE REHABILITATION

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:

REHABILITATION TEAM

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 brain injured individuals, families, insurance carriers, and rehabilitation providers to coordinate goals, develop care plans and delivery, 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) help you become aware of inaccurate or negative thinking so you can view challenging situations more clearly and respond more effectively.

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 diagnoses 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 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 the 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 treatment 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 & FINANCIAL ASSISTANCE

Insurance can be confusing but there are only two types of insurance: Government issued insurance includes policies for government employees, military members and their families, Medicare, and Medicaid. Private insurance is coverage purchased by an individual or an employer. It's important that you understand your policy so you can advocate for coverage. Contact the insurance company and ask to speak to the case manager handling your case; ask if a catastrophic case manager can be assigned and request a copy of your insurance policy and the "Certificate of Coverage" outlining the provisions and benefits. Also, inquire about eligibility for short-term/long-term disability benefits and FMLA. For additional information download, "Navigating the Insurance Maze after Brain Injury" from the Brain Injury Association of America at [BIAUSA.org/wp-content/uploads/Navigating-the-Insurance-Maze.pdf](https://www.biausa.org/wp-content/uploads/Navigating-the-Insurance-Maze.pdf).

INSURANCE

▪ AFFORDABLE CARE ACT

Toll Free: 1-800-318-2596 / TTY 1-855-889-4325

The Affordable Care Act (ACA) created the federal Health Care Marketplace, HealthCare.gov, to simplify the process of finding an affordable, quality health care plan based on your income and personal health needs. Go online to preview health insurance plans and prices or get help applying for health insurance. [HealthCare.gov](https://www.healthcare.gov)

▪ MEDICAID

850-300-4323 / Florida Relay 711 or TTY 1-800-955-8771

Florida Medicaid is the state and federal partnership that shares the cost of health coverage for people with low incomes. To be eligible for Florida Medicaid, you must be a resident of the state of Florida, a U.S. national, citizen, permanent resident, or legal alien, in need of health care/insurance assistance, whose financial situation would be characterized as low income or very low income. Individuals may apply for regular Medicaid coverage and other services, such as food assistance (SNAP) and temporary case assistance online via the Florida Department of Children and Families. [MyFlorida.com/accessflorida](https://www.myflorida.com/accessflorida)

▪ MEDICARE

Toll Free: 1-800-663-4227 / TTY 1-877-486-2048

Medicare is a health insurance program available through the Centers for Medicare & Medicaid Services (CMS). While most recipients are people aged 65 and older, certain younger people with disabilities resulting from a brain injury may also be eligible. It's important to understand what Medicare covers and what it doesn't, such as long-term care. [Medicare.gov](https://www.medicare.gov); [CMS.gov](https://www.cms.gov)

▪ DEPARTMENT OF VETERANS AFFAIRS (VA)

**800-827-1000 VA Benefits Hotline
877-222-8327 Health Care Benefits Hotline**

Veterans may be eligible for programs and services provided by the federal Department of Veterans Affairs (VA), such as: disability benefits, health care, dependent and survivor benefits, home loan guarantees, and education and training. [VA.gov](https://www.va.gov)

▪ WORKERS' COMPENSATION

1-800-342-1741 Employee Assistance Office

Workers' compensation insurance is coverage purchased by the employer or business that provides for job-related employee injuries, with a few exceptions. Under workers' compensation, employees are compensated for work-related injuries regardless of fault, and employers are protected from some injury lawsuits by employees. The Division of Workers' Compensation with the Department of Financial Services (DFS) is a state regulated insurance program that ensures employees receive proper benefits under this coverage, which includes benefits for medical expenses, disability, or death. You may also be eligible to receive some wage replacement benefits if you are unable to return to work or your earnings are lower because of a work-related injury or illness. You must report your injury or illness as soon as possible but no later than 30 days from the date of injury or from when you knew your injury or illness was job-related. Visit the Florida Department of Financial Services or call the Employee Assistance Office for questions about your benefits, denial of benefits, reemployment assistance, or legal representation. [MyFloridaCFO.com/Division/wc](https://www.myfloridaCFO.com/Division/wc)

- **FLORIDA KIDCARE & FLORIDA CHILDREN'S HEALTH INSURANCE PROGRAM (CHIP)**
1-888-540-5437 / TTY 1-800-955-8771

Insurance for children age birth-end of age 18. Based on the age of the child, household size, and family income, each child is automatically matched with their best fit of the four Florida KidCare programs – Medicaid, MediKids, Florida Healthy Kids, or the Children's Medical Services (CMS) Health Plan. Florida KidCare includes free, subsidized, and full-pay options based on family income and household size. Families who do not qualify for free or subsidized coverage may purchase a competitively priced full-pay plan. The CHIP provides health coverage to children and families with incomes too high to qualify for Medicaid but cannot afford private coverage.

FloridaKidCare.org

FINANCIAL ASSISTANCE

- **BRAIN AND SPINAL CORD INJURY PROGRAM**
Central Registry 1-800-342-0778
Central Registry Fax: 850-410-1975

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 and/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 resource facilitation. The case manager and family will work alongside the individual with a brain injury to identify rehabilitation goals and the services necessary to assist with community reintegration. Services Available Include: Acute Care, Post-Acute Rehabilitation Services, Home and Community-Based Services, Assistive Technology and Home Modifications. BSCIPResourceCenter.org

- **SOCIAL SECURITY**
Toll Free: 1-800-772-1213 / TTY 1-800-325-0778

Benefit Eligibility Screening Tool (BEST) is an online tool to help you determine if you qualify for benefits. Based on your answers to questions, it will list benefits for which you might be eligible and provides information on how to qualify and apply. SSABest.Benefits.gov

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 before 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 SSA.gov/applyfordisability
- Find your local Social Security office at Secure.SSA.gov/ICON/main.jsp

- **CRIME VICTIMS' SERVICES**
1-800-226-6667 / TTD 1-800-955-8771

If your injury was the result of a physical crime, you may be eligible for benefits. The Bureau of Victim Compensation offers financial assistance to victims of violent crime who were injured because of the crime and are experiencing financial hardship. Compensation can help pay for medical and funeral expenses, professional counseling, lost wages, loss of support, disability, domestic violence relocation, and reimbursement for prescriptions. You will need to report the crime to your local law enforcement agency within 120 hours of when the incident occurred. You will also need to cooperate with law enforcement, the State Attorney's Office, and the Attorney General's Office. Applications and assistance with completing them are available online through the Attorney General's website or the Victim/Witness Assistance Program. VANext.MyFloridaLegal.com

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 the level of care needed. View the steps involved online. [AHCA.MyFlorida.com/Medicaid/statewide_mc/smmc_ltc.shtml](https://www.AHCA.MyFlorida.com/Medicaid/statewide_mc/smmc_ltc.shtml)

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) streamlining eligibility determination for public programs, 4) person-centered transitions, 5) quality assurance and continuous improvement. To contact your local ADRC, call the Elder Helpline at 1-800-96 ELDER (1-800-993-5337) or visit online. [ElderAffairs.org/resource-directory/aging-and-disability-resource-centers-adrcs](https://www.ElderAffairs.org/resource-directory/aging-and-disability-resource-centers-adrcs)

ELDERCARE LOCATOR

The Eldercare Locator connects older adults and their caregivers to local resources such as the Area Agencies on Aging, Aging and Disability Resource Centers, and others that can help them continue living in their homes, ensure their home meets their needs, take care of themselves or their loved ones, stay actively involved in the community through wellness and senior center programs, access health insurance counseling, legal and financial programs, and even explore training and employment options. 1-800-677-1116; [ElderCare.ACL.gov](https://www.ElderCare.ACL.gov)

AGENCY FOR PERSONS WITH DISABILITIES

It is sometimes difficult to find the best way to support a child with intellectual and developmental disabilities. The Agency for Persons with Disabilities (APD) maintains an extensive resource directory of free and low-cost programs available in the individuals' respective areas. To be eligible for APD services you must be a Florida resident and have one of the following seven developmental disabilities: autism, cerebral palsy, intellectual disabilities (which may result from a TBI in youth under the age of 19), Down syndrome, Prader-Willi syndrome, Phelan McDermid syndrome, or spina bifida or be a child between the age of 3-5 who is at risk of a developmental disability. 1-866-APD-CARES (1-866-273-2273); [APD.MyFlorida.com](https://www.APD.MyFlorida.com)

DEVELOPMENTAL DISABILITIES WAIVER

The Developmental Disabilities Individual Budgeting (iBudget) Waiver provides home and community-based supports and services to eligible individuals with developmental disabilities who are living at home or in a home-like setting and is designed to promote and maintain the health of the individual by providing the medically necessary supports and services to delay or prevent deterioration. For information on how to apply for the iBudget Waiver, contact the Agency for Persons with Disabilities. 1-866-273-2273; [APD.MyFlorida.com/ibudget](https://www.APD.MyFlorida.com/ibudget)

JP-PAS PROGRAM

The James Patrick Personal Attendant Services Program provides a monthly stipend to Florida residents (18 and older) with disabilities who are working and require assistance with at least two activities of daily living, to cover the cost of personal care services. For more information about the program and how to apply, contact the JP-PAS Program Office. 850-575-6004; [FloridaCILS.org/pca-services-program](https://www.FloridaCILS.org/pca-services-program)

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

Start by returning to your daily activities as soon as possible. Creating and maintaining a structured routine will reduce distractions and improve memory. Create a schedule that includes all your appointments using a wall calendar, datebook, or a calendar app on your phone. Don't forget to schedule time each day to complete your ADLs (brushing your teeth, dressing, bathing, and eating). Engaging in these activities regularly will help with your overall recovery. Try an app like Cozi Family Organizer which is a family life organization app that includes a shared calendar, shopping lists, to-do lists, meal planning, and family journal that allows you to stay in sync with your family, available for Apple and Android phones. Cozi.com/calendar

GET MOVING!

Exercise is a vital part of the recovery process as it provides cognitive stimulation, improves balance and flexibility, helps to strengthen muscles, and promotes neuroplasticity. Try to find a local yoga class to help with relaxation, balance, muscle pain, breathing, conditioning, and core strength, and visit LoveYourBrain.com, to read about the benefits of yoga and meditation for TBI. If yoga is not for you, swimming allows individuals to engage in movement exploration in the water without the fear of falling. Dancing aids recovery by improving balance, coordination, memory, and overall wellbeing. Engaging in these activities with others also promotes socialization which promotes better brain function. If a group exercise class is not for you, try taking a walk in your neighborhood to improve balance and decrease spasticity. Neuroplasticity occurs through repetition and consistency. Since the brain likes to be efficient, it will create and strengthen neural pathways for all activities that are practiced regularly.

EAT WELL

A proper diet that includes foods that are known to promote healthy brain function can boost brain injury recovery. Brainline.org provides nutritional tips to speed brain injury recovery and suggests eating small meals every 3-4 hours that contain foods commonly found in the Mediterranean diet which includes a combination of proteins found in fatty fish like salmon and mackerel which are a great source of omega-3 fatty acids, lean meats, and eggs; healthy fats and oils like those found in avocados, seeds, and nuts, especially walnuts; and carbohydrates from vegetables, fruits, and grains. It's best to avoid alcohol, caffeine, salt, and sugar as much as possible. Also, try to eat at the same time each day. Here's an idea – add "mealtime" to your daily schedule.

SLEEP WELL

Most people who have brain injuries experience sleep disturbances which can affect both physical and mental health by increasing or worsening depression, anxiety, irritability, and fatigue. How can you improve your sleep? Exercise daily and establish a bedtime routine by going to bed at the same time every night and setting an alarm for the next morning. Create a comfortable bedroom by investing in quality bedding and hanging curtains that block out light. At least 30 minutes before bed, avoid blue light from electronic devices and televisions since it can disrupt your brain's natural sleep-wake cycle. Adjust the temperature between 60 and 72 degrees for optimal sleep. If you don't fall asleep within 30 minutes, get out of bed, and engage in something that will relax you like taking a warm bath, reading a book, or meditating. Classical and instrumental music and nature sounds can help slow the pulse and decrease levels of stress hormones. Using pillow speakers or Bluetooth speakers that fit inside a standard pillow, might provide soothing natural sounds, and help with more restful sleep.

ADJUSTING TO YOUR NEW NORMAL

Traumatic brain injury is not a simple, physical process because its effects extend well beyond the physical injury and can unfold over a long period, affecting the brain in sometimes unpredictable ways. Attitude is important when facing life challenges as your "new normal" evolves. You can make yourself miserable or make yourself happy. Start by trying new things and see what works and what doesn't. Try visiting a TBI support group, take a class in something that interests you, or try a new hobby. Be patient with yourself and others, everyone is adjusting to changes and new responsibilities. Celebrate the small victories as this will not only improve your mood but will reinforce how far you have come.

RETURNING TO SCHOOL

Traumatic brain injuries come with a lot of uncertainties. Factors affecting how a traumatic brain injury heals and what effects linger include the location of the injury, the medical and rehabilitation care after the initial injury, and the age of the individual. For some, the effects may be temporary but for others, the effects can be lifelong and result in temporary or permanent impairments in memory and attention, coordination, balance and mobility, language and communication skills, hearing, vision, touch, smell, and taste, and emotions resulting in depression, anxiety, aggression, poor impulse control, and personality changes. Students ages 15-24 are among the highest risk of sustaining a brain injury however, an injury of any severity to the developing brain may disrupt a child's development and deficits may not be immediately apparent because the pediatric brain (birth-21) is still developing. According to [ASHA.org](https://www.asha.org), "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 students with disabilities and coordinates services throughout the state for students with special needs.

[FLDOE.org/academics/exceptional-student-edu](https://fldoe.org/academics/exceptional-student-edu)

Additional useful websites for parents and teachers are listed below.

- Exceptional Education Eligibility for Students who are Physically Impaired with Traumatic Brain Injury Rule [FLRules.org/gateway/RuleNo.asp?ID=6A-6.030153](https://flrules.org/gateway/RuleNo.asp?ID=6A-6.030153)
- Florida Diagnostic & Learning Resources System (FDLRS) [FDLRS.org](https://fdlrs.org)
- Lash & Associates Publishing [LAPublishing.com](https://lashpublishing.com)
- Special Education Guide [ParentPals.com/gossamer/pages](https://parentpals.com/gossamer/pages)
- For Teachers: Top 10 Classroom Technology Strategies [Info.FLDOE.org/docushare/dsweb/Get/Document-3061/K122005-80a.pdf](https://info.fldoe.org/docushare/dsweb/Get/Document-3061/K122005-80a.pdf)
- Brain Injury in Children and Youth: A Manual for Educators by the Colorado Department of Education [CDE.State.CO.US/cdesped/tbi_manual_braininjury](https://cde.state.co.us/cdesped/tbi_manual_braininjury)

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. [CMS-Kids.com/families/early_steps/early_steps.html](https://cms-kids.com/families/early_steps/early_steps.html)

ACCREDITED SCHOOLS ONLINE

Is an online student-centered community for accredited online education resources that allows you to explore schools by major, state, or degree programs, vocational schools, online K-12 schools, scholarship & financial aid, and resources such as "Colleges That Don't Require the SAT or ACT". Take the free Career Quiz at AccreditedSchoolsOnline.org

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. [Brainline.org/kids-tbi/school-education](https://brainline.org/kids-tbi/school-education)

CENTER FOR PARENT INFORMATION & RESOURCES

This online resource has a great section on traumatic brain injury and offers tips for parents and teachers on dealing with TBI in children. They offer online learning modules, a resource library that includes disability fact sheets, IDEA training materials, parent guides, information on Individualized Family Service Plan (IFSP) and Individualized Education Plan (IEP), transition planning, and webinars, and highlights new resources and upcoming events. Materials are available in English and Spanish. [ParentCenterHub.org/tbi](https://parentcenterhub.org/tbi)

RETURNING TO WORK

There are benefits, for the brain injury survivor, the workplace, and society, to finding factors that facilitate a successful return to work. Returning to work (RTW) will look different for everyone but for brain injury survivors it has been shown to offer a sense of accomplishment, boost self-esteem, and improve the overall quality of life. Under the Americans with Disabilities Act (ADA), employers are required to provide reasonable accommodations to all employees with disabilities. Some accommodations you can discuss with your employer include returning to work gradually, working shorter hours, taking frequent breaks, starting with a lighter workload or adjusting job duties, and physical and technological aides. Are you ready to Return to Work? If so, check out the resources below that can assist you with achieving this goal.

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. RehabWorks.org

VR also helps students with disabilities prepare and plan for employment after high school through the **Transition Youth** program.

Examples of Vocational Rehabilitation Services:

Vocational Evaluation and Planning

Career Counseling and Guidance

Job Coaching and Job Placement

On-the-Job Training

Training and Education after High School

Job Site Assessment and Accommodations

Supported and Customized Employment

Assistive Technology and Devices

Medical and Psychological Assessment

Time-limited Medical and/or Psychological Treatment

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. SSA.gov/work

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.com/career-services/your-local-team, to find your local center.

FLORIDA ABILITIES WORK

Employ Florida website serves as the hub for the state's workforce services focusing on job openings, job candidates, and helping employers who are looking to hire qualified job seekers with disabilities. EmployFlorida.com/vosnet/Default.aspx

JOB ACCOMMODATION NETWORK

The Job Accommodation Network (JAN) offers useful articles on dealing with employment after brain injury. AskJAN.org/disabilities/Brain-Injury.cfm

GUIDE FOR EMPLOYERS

The Mayo Clinic Guide, "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. MCForms.Mayo.edu/mc1200-mc1299/mc1298.pdf

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 handyman, the lawnmower, 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 engagement has been recognized as an influential factor in the rehabilitation continuum. You already have a unique advantage in that you are already familiar with your loved one’s personality and habits, and you can alert the medical providers to any nuances in behavior, this will drastically influence the recovery process. (Kuipers et. al. 2014)

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 think 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 the news of the injury, hope for full recovery, and are in denial of the 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 the loss of your loved one’s personality and characteristics, the loss of hopes and dreams you had for your 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

Feelings 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 the impact of various losses upon life, and you may express depression as anger.

Stage 4 Guilt

Feeling the accident is your fault in some way and the family blames the person for the injury because they 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”

ACCEPTANCE

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

CAREGIVER RESOURCES

Acceptance Commitment Therapy (ACT) a.k.a **The Psychological Flexibility Model**. Mindfulness and positive psychology have gained substantial momentum and applicability in ameliorating caregivers’ distress, grief, loss, depression, and anxiety (Brown et al., 2015; see Klonoff, 2014, for a review; Williams et al., 2014). ATC applies mindfulness and acceptance processes, and commitment and behavior change processes. to encourage people to embrace their thoughts and feelings rather than fighting or feeling guilty for them. “ACT” is a good abbreviation because this therapy is about taking effective action. For more information about ACT or to find a therapist visit ContextualScience.org.

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 judgment.
 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 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.
- **Brain Injury Association of America, BIAUSA.org**, offers fact sheets and caregiver webinars, as well as assistance with finding an attorney. You may download their “Guide for Families and Caregivers” at BIAUSA.org/wp-content/uploads/Guide-for-Families-and-Caregivers.pdf
 - **Brainline** offers information regarding legal issues as well as resources for caregivers. Brainline.org/topic/legal-issues; Brainline.org/caregivers
 - **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. NeuroSkills.com/patients-and-families/family-resources
 - **Family Caregiver Alliance** provides information and fact sheets on coping with behaviors post TBI and a comprehensive “Brain Injury Handbook” and resources for caregivers. Caregiver.org/resource/traumatic-brain-injury; Caregiver.org/caregiver-resources
 - **Mayo Clinic Guide** “Understanding Brain Injury, A Guide for the Family” is available at NBIA.CA/pdfs/understanding-brain-injury.pdf
 - **VA Caregiver Support Program** provides information on caring for someone with a TBI and includes links to additional caregiver resources. Caregiver.VA.gov/tips_by_diagnosis/tbi.asp

As a caregiver, it’s important to take care of yourself. Learn as much as you can about brain injury. Asking for help will ease the burden of being a caregiver. Don’t be afraid to delegate responsibilities; family and friends often want to help but don’t know what to do. Make a list of tasks or errands that would be helpful and allow them to choose what they feel they can take on. Finally, focus on your loved one’s abilities instead of focusing on their limitations.

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. 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.

BSCIP RESOURCE CENTER

The Brain and Spinal Cord Injury Program Resource Center is the statewide clearinghouse for traumatic brain injury (TBI) and spinal cord injury (SCI) information, resources for survivors, their families and friends, health care professionals, and support groups, the media, and the public. The resource center also recruits, trains, and certifies peer mentors with existing brain and spinal cord injuries to mentor newly injured individuals. The goal of the resource center is to increase knowledge of TBI and SCI related resources, help prevent secondary medical complications resulting from a lack of knowledge, and foster independence through self-knowledge. 1-866-313-2940; BSCIPResourceCenter.org

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 empower 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. FloridaCILS.org

THE FAMILY CAFÉ

The Family Café serves as a source of disability information through the Annual Family Café event every June that brings Floridians with disabilities together for three days of information, training, and networking. The event includes an exhibit hall, special events, and guest speakers. Registration for the annual event starts in February each year. 850-224-4670 or 1-888-309-CAFÉ (2233); FamilyCafe.net

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. FloridaHealthFinder.gov

FLORIDA 2-1-1 NETWORK

Heart of Florida United Way 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. You can access the Helpline by calling 2-1-1 or by texting your zip code to 898-211. HFUW.org/gethelp; 211.org

BRAIN INJURY ADVOCACY ORGANIZATIONS

- **The Arc of the United States**, TheARC.org, is the largest national community-based organization advocating for services and support for individuals with intellectual and developmental disabilities (I/DD) to support full inclusion in their community. With state and local chapters, they can provide residential, educational, and vocational services, person-centered financial planning, recreational activities, and many other supports in the community. To locate your local chapter, visit **The Arc of Florida**. ARCFlorida.org
- **Brain Injury Association of America's (BIAA)** website contains information for consumers and professionals concerning brain injury consequences, resources, and prevention. The non-profit organization also has chapters and offices in every state to assist individuals with information and referrals (I&R). BIAUSA.org

- **Florida Self-Advocacy Central (FSACentral)** is a self-advocacy organization for all individuals with disabilities across the state of Florida and is a go to source for self-advocacy news and information, resources, education, events, and a blog. FSACentral is an arm of the Florida Self-Advocates Network or FLSAND.org; FSACentral.org
- **National Association of State Health Injury Administrators (NASHIA)** efforts are aimed at assisting the state government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families and provides information on brain injury and juvenile justice systems/corrections, state special education definitions and resource materials at NASHIA.org
- **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; NARIC.com

BRAIN INJURY RESEARCH INSTITUTIONS & PRODUCTS

- **Brain Trauma Foundation (BTF)** works to improve the lives of TBI individuals worldwide and offers a variety of information on critical care guidelines, treatment options, and the latest research on TBI. BrainTrauma.org
- **The Center on Brain Injury Research and Training (CBIRT)** is a center under the Department of Psychology at the University of Oregon that focuses on intervention to improve outcomes related to education, employability, and quality of life for individuals with brain injury and their website provides brain injury education resources at CBIRT.org
- **Centers for Disease Control and Prevention (CDC)** provides basic information, data, statistics, reports, fact sheets, etc. on TBI and concussion. Their HEADS UP Initiative provides tools to help educators, coaches, providers, and parents recognize, respond to, and minimize concussion and brain injury risks. CDC.gov/TraumaticBrainInjury; CDC.gov/headsup
- **Centre for Neuro Skills (CNS)** is the website for monthly updates on brain injury news and general resources to help you understand brain injury, commonly used medication after TBI, and a glossary of TBI terms and definitions. You can also sign up to receive free the *Inside View* quarterly E-Magazine and/or their monthly E-Newsletter. NeuroSkills.com
- **Independent Living Research Utilization (ILRU)** is a national center for providing research, education, and consultation in the areas of independent living, home and community-based services, and the Americans with Disabilities Act (ADA). ILRU provides training and technical assistance for Centers for Independent Living (CILs) and other programs. CILs are consumer-controlled, community-based, cross-disability, non-residential, private nonprofit agencies that provide a range of services to consumers and the community. ILRU.org
- **Model Systems Knowledge Translation Center** is a national center that works with researchers that translate health information into easy-to-understand fact sheets, videos, and slideshows for people living with brain injuries and their caregivers. MSKTC.org/tbi
- **National Institute of Neurological Disorders and Stroke (NINDS)**, part of the NIH, supports and conducts research on issues related to neurological conditions, including brain injury. They also offer information on a variety of neurological issues and provide free publications on TBI. Ninds.nih.gov/Disorders/All-Disorders/Traumatic-Brain-Injury-Information-Page
- **National Resource Center for Traumatic Brain Injury (NRCTBI)**, TBI.VCU.edu, developed by the Medical College of Virginia and Virginia Commonwealth University, provides relevant, practical information for professionals, individuals with TBI, and family members and is affiliated with the Virginia Commonwealth Traumatic Brain Injury Model System. TBIMS.VCU.edu
- **Ohio Valley Center for Brain Injury Prevention and Rehabilitation** is one of the TBI Model Systems research centers in the country. The website contains various TBI topics, tip sheets, and special content for community service providers called Ask an Expert About TBI. WexnerMedical.OSU.edu/neurological-institute/departments-and-centers/research-centers/ohio-valley-center-for-brain-injury-prevention-and-rehabilitation

- **The University of Alabama at Birmingham (UAB) Home Stimulation Program** created by the University of Alabama Traumatic Brain Injury Model System, offers activities designed to help support cognitive skills which can be done in the home. The guidebook is available digitally or as a pdf. UAB.edu/medicine/tbi/uab-tbi-information-network/uab-tbims-home-based-cognitive-stimulation-activities

CONSUMER CENTERED

- **American Stroke Association** provides information on prevention, symptoms, and resources for people who have had a stroke, their caregivers, and professionals. Stroke.org
- **Brainline** is a website about brain injury and PTSD that offers information for survivors, caregivers, professionals, and veterans. Read personal stories and blogs or access their online resource directory. Brainline.org
- **Brain Injury Resource Center (BIRC)** is a clearinghouse for brain injury services, resources, and supports operated by professionals and advocates who provide educational programs, advising, counseling, life skills training, and case management assistance. Call a free consultation or sliding scale care coordination of services. 206-621-8558; HeadInjury.com
- **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. 1-800-332-1000, EpilepsyFoundationFL.org
- **Olmstead Rights** provides links to government agencies and disability rights organizations that can assist with disability advocacy, home health and nursing aide services, home care, Medicaid, and accessing other community resources for individuals with disabilities residing in Florida. OlmsteadRights.org/self-helptools
- **Smart Patients Brain Injury Community** is an online community for brain injury patients and their families that provides advice and support. SmartPatients.com/communities/brain-injury

CONTINUING EDUCATION & TECHNOLOGY

- **Florida Alliance for Assistive Services and Technology, Inc. (FAAST)** is a nonprofit organization for people with disabilities who need assistive technology to increase, maintain, or improve their functional capabilities. Services include training, information and assistance, device demonstrations, short-term device loans, device reuse, and reutilization, and low-interest financial loans to purchase assistive technology devices. FAAST.org
- **Lash & Associates Publishing, Inc.** offers information and resources on TBI, concussion, blast injury, and PTSD and publishes tip cards, books, workbooks, guides, brain injury kits, and software. LAPublishing.com
- The **Michigan Dept. of Community Health Web-Based Brain Injury Training for Professionals** offers free training that consists of 4 modules, each being approximately 30 minutes long and can be used to earn CBIS CEUs. MITBITraining.org

DOMESTIC VIOLENCE

- **Brain Injury Association of America:** “Understanding Domestic Violence as a Cause of TBI” BIAUSA.org/public-affairs/media/domestic-violence-as-a-cause-of-tbi and DOJ.State.OR.us/wp-content/uploads/2017/08/traumatic_brain_injury_and_domestic_violence.pdf
- **Florida Department of Children** MyFLFamilies.com/service-programs/domestic-violence
 - Domestic Violence Hotline **1-800-500-1119** / Florida Relay **711**
 - Find a Local Shelter MyFLFamilies.com/service-programs/domestic-violence/map.shtml
 - National Domestic Violence Hotline TheHotline.org
- **National Resource Center on Domestic Violence’s (NRCDV)** project is an online resource library that is focused on violence against women and other forms of gender-based violence. VAWNet.org
 - “Traumatic Brain Injury and Domestic Violence: Understanding the Intersections” VAWNet.org/sc/traumatic-brain-injury-and-domestic-violence-understanding-intersections
 - “TBI and Children” VAWNet.org/sc/tbi-and-children
 - Children and Youth Services Review: “Developmental effects of exposure to Intimate Partner Violence in early childhood: A review of the literature” ChildWitnessToViolence.org/uploads/2/5/7/9/257929/developmental_effects_of_exposure_to_intimate_partner_violence_in_early_childhood.pdf

MILITARY

- **Bob Woodruff Foundation** ensures that veterans, service members, and their families have access to the highest level of support and resources they deserve, for as long as they need it, so they are thriving long after they return home. BobWoodruffFoundation.org
- **Brainline** is a website funded through the Defense and Veterans Brain Injury Center and offers civilians, service members, families, and professionals' information and resources regarding life after brain injury. Brainline.org
- **Computer/Electronic Accommodations Program (CAP) and Wounded Service Member Initiative (WSM)**, the program provides assistive technology (AT) and reasonable accommodations to people with disabilities and wounded Service members. CAP.mil/Solutions/Index.aspx
- **Disability Benefits for Wounded Warriors through the Social Security Administration is where** military service members can receive expedited processing of disability claims from Social Security. Benefits available through Social Security are different than those from the Department of Veterans Affairs and require a separate application. SSA.gov/pubs/EN-05-10030.pdf
- **Disabled American Veterans (DAV)**, DAV.org, 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 DAV.org/veterans/resources for tools and resources or contact your nearest DAV Service Officer at DAV.org/veterans/find-your-local-office.
- **Employ Florida Vets** is the online source for veterans' employment and employer recruitment information. Veteran.EmployFlorida.com
- **Florida Veterans' Benefits Guide** is an annual publication, produced by the Florida Veterans Foundation, for information on federal and state benefits in a concise, easy-to-read online format. FloridaVets.org
- **Military OneSource** is a 24/7 toll-free information and referral phone service available to active duty, Reserve, and National Guard military members and their families; and to deployed civilians and their families. 1-800-342-9647; MilitaryOneSource.mil
- **My Healthy Vet** is an online personal health record for veterans, active service duty service members, their dependents, and caregivers. MyHealth.VA.gov/mhv-portal-web/home
- **National Military Family Association (NMFA)** is a nonprofit organization that educates military families on their rights, benefits, and services available to them. MilitaryFamily.org
- **National Resource Directory (NRD)** is a resource website, developed by the Defense Health Agency's Recovery Coordination Program, that supports the 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. NRD.gov
- **Traumatic Brain Injury Center of Excellence (TBICoE)** The TBICoE (formerly DVBiC) promotes traumatic brain injury (TBI) care from point of injury to reintegration and supports, trains, and monitors service members, veterans, family members, and providers who have been or care for those who are affected by traumatic brain injury and provides TBI clinical tools. The site has fact sheets, caregiver guides, and other patient resources. <https://health.mil/Military-Health-Topics/Centers-of-Excellence/Traumatic-Brain-Injury-Center-of-Excellence/Patient-and-Family-Resources>
- **U.S. Department of Veterans Affairs** allows you to browse resources and support regarding VA benefits and services, provides instructions for using VA.gov tools, and other helpful articles which you can browse by topic. VA.gov/resources
- **VA Caregiver Support Program** provides information on caring for someone with a TBI and includes links to additional caregiver resources. Caregiver.VA.gov/tips_by_diagnosis/tbi.asp
- **Veterans Employment Toolkit** provides a variety of national resources, compiled by the VA, for employers, managers, and human resource professionals. VA.gov/vetsinworkplace/docs/em_fullversionResources.asp
- **Veterans Suicide Prevention Hotline** founded through the Veterans' Health Administration (VHA) provides free, 24/7 access to a trained counselor. 1-800-273-TALK (8255).

REHABILITATION

- **Academy of Cognitive Therapy (ACT)** is a non-profit organization dedicated to cognitive therapy and ensuring that cognitive therapists have appropriate training. The ACT Web site provides information about cognitive therapy and includes a function to find a certified cognitive therapist in your area. AcademyOfCT.org
- **American Academy of Physical Medicine and Rehabilitation (AAPM&R)** provides information about conditions and treatments, as well as ways to find local rehabilitation services. AAPMR.org
- **Commission on Accreditation of Rehabilitation Facilities (CARF)**, CARF.org, is an independent, nonprofit annual accreditor of health and human services. To search for a brain injury program visit: CARF.org/ProviderSearch/Advanced-search-for-brain-injury-stroke-or-spinal-cord-rehabilitation-programs

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. APD.MyFlorida.com
- **Brainline for Kids** offers information for families and educators. Brainline.org/children-tbi
- **Center for Parent Information and Resources** has a great section on traumatic brain injury and offers tips for parents and teachers on dealing with TBI in children. They have a resource library that includes disability fact sheets, IDEA training materials, parent guides, information on Individualized Family Service Plan (IFSP) and Individualized Education Plan (IEP), transition planning, and webinars. ParentCenterHub.org/tbi
- **Children's Hemiplegia and Stroke Association (CHASA)** helps children with hemiparesis (weakness to one side of the body) 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. CHASA.org
- **Colorado Kids Brain Injury Resource Network** has some amazing information and resources for parents and educators at COKidsWithBrainInjury.com. Check out the "Building Blocks of Brain Development" at COKidsWithBrainInjury.com/educators-and-professionals/brain-injury-matrix-guide and the companion for educators, "Brain Injury in Children and Youth: A Manual for Educators" at CDE.State.CO.US/cdesped/tbi_manual_braininjury that defines and fully illustrates each building block, provides a detailed explanation of how each building block may be affected in the school setting, and a list of accommodations, strategies, and interventions for each building block.
- **The Florida Youth Council** is a program of The Family Café and focuses on getting youth and emerging leaders aged 15-30 with disabilities and special health care needs involved in self-advocacy, peer mentoring, and other activities that will improve their quality of life by deciding, presenting, and developing strategies to address issues that are most important to their generation. FloridaYouthCouncil.org
- **LEARNet** created by the Brain Injury Association of New York State, is a website geared toward children, parents, and teachers to help children with brain injuries navigate the classroom. Information and strategies are not only useful for children but also for adults at home, in the community, and at work. ProjectLEARNet.org
- **The M.O.R.G.A.N Project (Making Opportunities Reality Granting Assistance Nationwide)** provides support and resources for children with special health care needs, especially for students with limited mobility and sensory issues. Families are serviced locally in Florida (Melbourne) and nationwide through a host of quality-of-life programs. 321-506-2707; TheMORGANProject.org

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 that 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 the 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.

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 must 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 from 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 words 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. Reading 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, 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 from 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 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 is determined by many factors including your physical strength, coordination, senses, and cognitive ability. Maintaining balance while sitting and standing are 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** – this term implies 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 results in disabilities that 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 recover 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 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 bloodstream 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, blood pressure, swallowing, motor production of speech, hearing, and consciousness.

C

Catheter – A flexible tube inserted in the bladder to drain 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 irritability.

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 that 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 effectively 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 from 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 can 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.

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 believes the confabulated event occurred.

Confusion – The inability to make sense of the environment, disorientation to time, place, and circumstance. Confusion may be reflected in confusing 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 a 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 operate 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.

D

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 the 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 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 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.

E

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 to breathe. 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 a 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.

F

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 the 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, and 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 relating to outcome. The system involves three determinants: eye opening, verbal responses, and motor responses 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

H

Handicap – Describes a condition or barrier imposed by society, the environment, or by one’s 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.

I

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 is 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 within 24 hours.

Intracerebral Hematoma – Bleeding within 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.

J

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.

K

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

L

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 begin and complete tasks safely without physical assistance or direction.
- **Supervised** – requires only verbal cues or supervision for safety and thoroughness.
- **Modified Independent** – may need the 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 tasks.
- **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 a 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 the 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 – These 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.

O

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.

P

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 visuospatial 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 that may have been appropriate for a former task. Perseverations may be verbal or motoric.

Phonation – The production of sound using 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 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 bizarrely or uncharacteristically. 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 its cause, identify, prioritize, and select alternative solutions, and then implement the solutions found. Memory loss might affect problem solving ability because of 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 of 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 the 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. The strength of muscles of the hands or legs may be normal.

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

Purposeful Movement – Motor activity with an apparent goal.

Q

Quad Cane – 4-legged cane.

R

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 the 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 – the 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 to 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 before the accident; maybe a specific period or type of information.

S

Scotoma – Area of varying blindness 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 that may spread to other cells nearby or throughout the entire brain. It usually lasts only a 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 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 the excess 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 an 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.

T

Tactile Defensiveness – Oversensitivity 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 that 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 pictures 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.

U

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 are due to neurogenic bladder although they can also occur due to the use of medications with anticholinergic effects or clogged catheters.

V

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

Vegetative State (VS) – This 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 testing. 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 breathe 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, synthesize the contents of a picture, and interpret the invariability of an object which is seen from different directions.

Vocational Evaluation – A comprehensive process that systematically utilizes work, real or simulated, 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 careers and enhance their independence.