



SPINAL CORD INJURY

RESOURCE GUIDE



Brain and Spinal Cord Injury Program Resource Center

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GLOSSARY **22-23**

BSCIP RESOURCE CENTER & BSCIP

BRAIN AND SPINAL CORD INJURY PROGRAM RESOURCE CENTER

Education, Information & Awareness

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

Information & Referral

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

Helpline & Website

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

FLORIDA BRAIN AND SPINAL CORD INJURY PROGRAM

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

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

In addition, the program funds education and prevention activities by supporting organizations, partners with the Florida Association of Centers for Independent Living and the Vocational Rehabilitation and provides funding research at the University of Florida and University of Miami. Visit the [Brain and Spinal Cord Injury Program](#) for more information.

Eligibility

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

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

Central Registry

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

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

WHAT IS A SPINAL CORD INJURY?

According to the World Health Organization (WHO), most spinal cord injuries are due to preventable causes such as traffic crashes, falls or violence. The term 'spinal cord injury' refers to damage to the spinal cord resulting from trauma or from disease or degeneration. The spinal cord is the message relay system between your brain and your body. Injury to your spinal cord can affect more than just your mobility, it can also affect skin sensitivity and autonomic functions such as respiration, bowel/bladder, cardiovascular activities, and sexual functions.

Statistics

The 2024 SCI Data from the National SCI Statistical Center (NSCISC) reports:

- Annually, there are 18,000 new SCI cases, excluding those who die at the scene
- Males comprise 79% of these cases
- 43 is the average age at the time of injury for both men and women
- Vehicle accidents are the predominant cause, accounting for 38%, falls at 30%, acts of violence at 13%, and sports/recreational activities at 9%, while medical and surgical injuries comprise approximately 5% of SCIs
- Incomplete quadriplegia is the most common neurological category, with the rates of complete and incomplete paraplegia being nearly identical

Definition

The State of Florida defines SCI as a lesion to the spinal cord or cauda equina resulting from external trauma with evidence of significant involvement of two of the following: motor deficit, sensory deficit, or bowel/bladder dysfunction.

Types of Spinal Cord Injury

- A complete SCI results in irreversible damage at the injury site, leading to paraplegia or tetraplegia (also known as quadriplegia) below the level of injury; nearly half of all SCIs are complete.
- An incomplete SCI indicates that the spinal cord has only been partially damaged. The extent of remaining movement and sensation can greatly differ, influenced by the injury's location and severity.

Levels of Spinal Cord Injury

- **Cervical injuries (C1-C8)** affect the head and neck region above the shoulders. C1-C4 is the most severe level of SCI and can affect breathing, movement, and speech.
- **Thoracic injuries (T1-T12)** affect trunk and legs (paraplegia), depending on the level of injury, arm and hand function is usually normal.
- **Lumbar injuries (L1-L5)** affect the hips, legs, and lower abdomen and can cause loss of function in these areas and little or no control of the bowel or bladder. Depending on the strength in the legs, a wheelchair or braces may be needed.
- **Sacral injuries (S1-S5)** affect the hips, thighs, buttocks, and pelvic organs. However, individuals with such injuries can typically still walk.

American Spinal Injury Association (ASIA) Impairment Scale

The ASIA scale is a classification system that describes your motor and sensory impairment because of the injury.

First, is the injury complete or incomplete? If it's complete, then there is no feeling or movement below the level of injury. On the ASIA scale, this is rated an **ASIA A-Complete**.

If the injury is incomplete, then there is some feeling and movement below the level of injury. There are four classifications for incomplete injuries:

1. **ASIA B-Incomplete** – Sensory function is preserved, but not motor function.
2. **ASIA C-Incomplete** – Some motor function is preserved, but most muscles are weak against gravity.
3. **ASIA D-Incomplete** – More significant motor function is preserved, with stronger muscles.
4. **ASIA E-Incomplete** – Normal motor and sensory function, but with a history of spinal cord injury.

TREATMENT PROGRESSION

Recovery from spinal cord injuries can be unpredictable, and it is not fully understood why some individuals recover more significantly than others. The extent of recovery largely depends on the injury's severity. While most recovery happens within the first six months, improvement can continue for up to two years. The pace of recovery typically correlates with the injury's level, and complete spinal cord injuries may show signs of healing in just a few days. The initial three months post-injury are usually when the most rapid motor recovery is observed. Nonetheless, regular practice of affected movements and activities can enhance neuroplasticity.

Acute Care

Acute care involves active, short-term treatment for serious or urgent health issues, such as traumatic injuries, sudden illnesses, or the acute phase of a chronic disease. This care usually takes place in hospitals or emergency rooms, focusing primarily on stabilizing you, delivering prompt treatment, and averting further complications. Acute care aims to rapidly manage life-threatening conditions and transition to other types of care upon stabilization. In the case of spinal cord injuries (SCI), acute care concentrates on stabilizing you to prevent additional harm. This may involve spinal immobilization to avoid further injury, admission to an intensive care unit (ICU), diagnostic imaging to determine the injury's severity, surgical procedures, steps to prevent complications like respiratory problems, infections, and blood clots, and managing pain. The objective is to stabilize you, tackle immediate health risks, and lay the groundwork for rehabilitation.

Subacute Rehabilitation

After the initial stabilization in an acute care hospital, patients often move on to subacute rehabilitation. Subacute rehabilitation plays a vital role within the continuum of care as it serves as a bridge between acute medical treatment and comprehensive rehabilitation and provides a structured environment for recovery, allowing you to retain strength and function before entering a more intensive rehabilitation. During this phase, you will receive physical and occupational therapy to improve mobility and independence, helping you to adapt to your new circumstances.

Post-acute Rehabilitation

Post-acute rehabilitation is the next step after subacute care and is usually provided in a dedicated facility. This phase offers a more intensive, comprehensive treatment plan, including several therapy sessions each day, medical oversight, and continuous care. The objective is to assist you in regaining substantial function and autonomy. During this stage, you will receive physical, occupational, speech, swallowing therapies, and psychological support. You will learn skills to manage daily living activities and adapt to any loss of physical abilities. If you are unable to manage the intensity of this therapy, you may be moved to a skilled rehabilitation center as an intermediate step.

Day Rehabilitation

Individuals with spinal cord injuries typically require continuous recovery and rehabilitation once they are beyond the need for constant inpatient care. Day rehabilitation programs provide extensive outpatient rehabilitation, which can include 3-5 hours of therapy each day. These interdisciplinary programs are designed to improve independent functioning across various settings, including the home, workplace, school, and community.

Outpatient Rehabilitation

Outpatient rehabilitation, which is less intensive than inpatient rehab, typically begins after discharge from a rehabilitation facility. Its purpose is to build upon the improvements achieved during inpatient rehabilitation. This phase, where the bulk of rehabilitation occurs, often encompasses physical, occupational, and speech therapies, along with psychological counseling. Occasionally, it may also involve vocational training, home adaptations, or assessments for driving and vehicle modifications. You will attend scheduled sessions at a clinic or therapy center while living at home, with the goal of maintaining or enhancing your abilities and functionality.

PATIENT'S BILL OF RIGHTS & RESPONSIBILITIES

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

POST-ACUTE REHABILITATION TEAM

A spinal cord rehabilitation team is made up of a variety of professionals who work together to help you and your family understand the recovery process and how best to support you. The team is often led by a **physiatrist**, a doctor who specializes in neurology, physical medicine, and rehabilitation; treatment involves the whole person and addresses the physical, emotional, and social needs.

Therapists:

- **Physical Therapist (PT)** helps to restore movement, mobility, and normal body function by focusing on muscle strength, flexibility, endurance, balance, and coordination. The physical therapist can also teach family members how to help you with your home exercise program.
- **Occupational Therapist** focuses on increasing your upper body and arm strength and assists with learning new ways to complete your activities of daily living such as eating, bathing, grooming, dressing, cooking, and writing.
- **Speech Language Pathologist (SLP)** helps you relearn how to chew and swallow and how to communicate if your spinal cord injury affected the muscles that control your mouth, throat, and neck.
- **Recreation Therapist (RT)** focuses on activities to help you to return to activities or hobbies you enjoyed in prior to your injury. The RT will help enhance your motor skills, coordination, and endurance, and may plan community outings where these new skills can be practiced in the community.
- **Aquatic Therapist** has specialized training to provide therapy in a pool to reduce pain and increase strength, coordination, endurance, and muscle movement.

Nurses:

- **Rehabilitation Nurse** teaches you self-care and help you restore and maintain function, prevent further complications, and will provide education and support to you and your family.
- **Clinical Nurse Specialist (CNS)** help you achieve and maintain an optimum level of physical and psychosocial well-being.

Mental Health Professionals:

- **Psychologist** develops and applies treatment strategies in counseling to help your adjustment to life after injury.
- **Social Worker** helps you make a smooth transition from hospital to home and everyday life and may provide adjustment counseling and helping you with any supports you may need once you are home.
- **Licensed Counselor** helps both you and your family manage the emotional effects of your injury.

Other Specialists:

- **Registered Dietitian** helps take care of any special dietary needs you may have and teaches you how to prepare a balanced diet.
- **Urologist** manages the conditions related to your urinary tract, such as the bladder and kidneys. Due to the complications often experienced after a SCI, it is important to follow up with your urologist on a regular basis.
- **Catastrophic Case Manager** is essential if you have a **workers' compensation** case. They help you navigate complex health instructions, keep lines of communication open and ongoing between you, your family, medical providers, attorneys, and your employer. They also ensure that you received long-term care if you are unable to return to work.
- **SCI Case Manager** helps you and your family with a variety of needs during inpatient rehabilitation, and after. Their goal is to help you live a fulfilling life that is independent and autonomous. They do this by assessing the needs of you and your family, coordinating services, and identifying and addressing barriers as they prepare you for discharge.
- **Vocational Rehabilitation Counselor (VRC)** assists you with successfully returning to school or work.
- **Certified Driving Rehabilitation Specialist (CDRS)** evaluates physical limitations related to safely operating a vehicle.

The team's interdisciplinary approach is important because it allows each professional to contribute their expertise and work together to achieve better outcomes than a single clinician or group of clinicians working independently.

COMPLICATIONS

A spinal cord injury is a clinical condition that can lead to lifelong disability. Secondary complications, especially long-term complications, increase morbidity and decrease community participation and health-related quality of life. It's important to be aware of chronic complications and learn how to manage them.

For further information on medical complications associated with SCI, consider exploring [Physiopedia](#).

Cardiovascular

- Autonomic Dysreflexia (AD) is a condition characterized by a sudden spike in blood pressure, constituting a medical emergency. It is triggered by an unopposed noxious stimulus to the spinal cord, predominantly in individuals with injuries above the T6 level, and is more prevalent among those with cervical and complete lesions. Symptoms of AD encompass headache, flushing, sweating, and nasal congestion. Commonly, the condition is provoked by bladder distension or bowel impaction. Without prompt treatment, AD may result in severe complications such as stroke, seizures, or death.
- Orthostatic Hypotension (OH) is characterized by a rapid decline in blood pressure when a person stands up too quickly from a lying down position. It frequently occurs with cervical and high thoracic spinal cord lesions. Symptoms include dizziness, lightheadedness, headaches, sweating, weakness, fatigue, and occasionally fainting. While the issue usually resolves swiftly, some individuals may require medication if they persistently experience OH. For further information on medical complications associated with SCI, consider exploring Physiopedia.

Visit [NeuroPT](#) for tips on managing your cardiovascular health.

Osteoporosis & Bone Fractures

Osteoporosis, also known as porous bone, is a condition characterized by decreased bone density, increased fragility, and a higher risk of fractures. For individuals with spinal cord injury (SCI), bone density loss may start as early as six weeks after the injury and typically stabilizes by two years. Contributing factors to osteoporosis include disuse, impaired blood flow regulation, poor nutrition, hormonal changes, metabolic imbalances (like abnormal blood metabolites and acidity), autonomic nervous system dysfunction (marked by inadequate circulation and disrupted gas and nutrient exchange at the bone), and limited mobility. Although there's no cure to completely prevent osteoporosis in non-ambulatory individuals with SCI, adopting a healthy diet, refraining from smoking, limiting alcohol and caffeine intake, and engaging in as much physical activity as possible can help reduce the risk of this condition.

Visit the [Northwest Regional Spinal Cord Injury System](#) to learn more about osteoporosis and SCI.

Pain Syndromes

- Neuropathic pain, also known as neurogenic pain, can occur above, at, or below the level of injury. It is the result of abnormal communication between damaged nerves and the brain. The brain misinterprets the signals from the nerves, leading to pain sensations like burning, stabbing, or tingling in areas that may lack feeling. This kind of pain is often challenging to manage.
- Nociceptive pain, also known as musculoskeletal pain, can arise from abnormal posture, gait, or overuse of body parts like the arm or shoulder. It may result from injuries, repetitive strain, arthritis, or joint wear and tear, which is commonly linked to prolonged wheelchair use.
- Visceral pain in the abdomen typically stems from damage, irritation, or distension of internal organs and is frequently characterized as cramping or a dull ache. This kind of pain can be caused by various conditions such as constipation, appendicitis, kidney stones, or ulcers. Visceral pain differs from Referred pain which is a discomfort experienced in a part of the body separate from the source, like shoulder pain that occurs due to gallbladder disease.

Visit the [Model Systems Knowledge Translation Center \(MSKTC\)](#) for managing pain after SCI.

Pressure Ulcers

Pressure Ulcers (PUs) are potentially life-threatening conditions that can lead to further functional disability and serious infections, even though they are largely preventable. They are defined as localized injuries to the skin and/or underlying tissue, typically occurring over bony areas where body pressure and tissue distortion are greatest. The treatment of pressure ulcers is complex and may result in repeated hospitalizations, numerous surgeries, and various complications.

There are four levels of injury classification:

Category I: Intact skin with non-blanchable erythema.

Category II: Partial thickness loss of dermis with shallow open ulcer and red/pink wound bed.

Category III: Full thickness tissue loss, subcutaneous fat visible but no bone, tendon or muscle exposed.

Category IV: Full thickness tissue loss with exposed bone, tendon, or muscle.

Visit [MSKTC](#) for information on skincare and pressure sores.

Respiratory

Respiratory complications vary with the severity of a SCI and the extent of motor function loss. Impaired respiratory muscle control can weaken the lungs, reduce lung capacity, and lead to increased congestion. The risks and complications escalate with complete injuries or tetraplegia. Ventilatory failure is frequent in injuries at the C1-5 level, where individuals often cannot breathe unaided. Atelectasis, a collapse of a lobe, lung, or even both lungs, and pneumonia are also prevalent in those with tetraplegia. While pleural effusion, pneumothorax, and hemothorax are rarer, all injury levels carry a risk for pulmonary embolism, a major cause of death in the first-year post-injury. Pneumonia remains the primary cause of mortality among individuals with SCI, irrespective of injury level or duration since the injury.

Learn more about respiratory health at [ChristopherReeve](#).

Spasticity

Spasticity is a condition marked by ongoing muscle contractions, unexpected movements, and a lack of muscle control. It affects approximately 65-75% of individuals with spinal cord injuries (SCI), particularly more prevalent in cervical injuries compared to thoracic and lumbar ones. Severe spasticity can lead to heightened functional limitations, contractures, ulcers, postural issues, pain, and significant disability for many affected individuals.

Visit [MSKTC](#) for information on managing spasticity.

Urinary & Bowel

Genitourinary and gastrointestinal function post SCI is one of the most important complications.

- Bladder dysfunction, also known as neurogenic bladder, results from SCI and varies depending on the level of injury. It can manifest as either an overactive or flaccid bladder, with the former leading to frequent urination in small amounts and the latter resulting in potential leakage due to the bladder's inability to contract. Poor bladder function may cause kidney failure. Management techniques include intermittent and indwelling catheterization, such as Foley or suprapubic catheters. Hyperreflexic bladder, often resulting from injuries above the sacral level, has a reduced capacity, while areflexic bladder, typically due to sacral level injuries, becomes overstretched and accommodates larger urine volumes.

Visit [MSKTC](#) for bladder management options.

- Neurogenic bowel, also known as bowel dysfunction, impacts the body's ability to store and eliminate waste, significantly affecting social life and quality of life. Reflexic bowel, often a consequence of cervical or thoracic spinal injury, leads to involuntary bowel movements due to a build-up of stool in the rectum. Areflexic bowel, resulting from damage to the lower spinal cord or its nerve branches, diminishes the reflexive control of the anal sphincter, preventing the sensation of the need to evacuate and the rectum's ability to empty. Management of this condition includes digital evacuation.

Visit [MSKTC](#) for managing bowel function.

INSURANCE

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

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

HEALTH CARE MARKEPLACE

1-800-318-2596

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

MEDICAID

850-300-4323

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

MEDICARE

1-800-663-4227

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

DEPARTMENT OF VETERANS AFFAIRS (VA)

VA Benefits Hotline 1-800-827-1000

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

WORKERS' COMPENSATION

Employee Assistance Office 1-800-342-1741

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

FLORIDA KIDCARE & CHILDREN'S HEALTH INSURANCE PROGRAM

1-888-540-5437

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

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

FINANCIAL ASSISTANCE

BRAIN AND SPINAL CORD INJURY PROGRAM

BSCIP Central Registry 1-800-342-0778

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

SOCIAL SECURITY

1-800-772-1213

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

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

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

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

- Complete an online application for benefits at [Disability SSA](#)
- Find your local Social Security office at [Social Security Office Locator](#)

CRIME VICTIMS' SERVICES

1-800-226-6667

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

LONG-TERM CARE SERVICES & SUPPORTS

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

MEDICAID MANAGED CARE LONG-TERM CARE PROGRAM

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

AGING AND DISABILITY RESOURCE CENTERS

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

ELDERCARE LOCATOR

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

JP-PAS PROGRAM

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

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

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

FLORIDA LONG-TERM CARE OMBUDSMAN PROGRAM

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

THE RECOVERY JOURNEY

While reversing SCI damage continues to be challenging, beyond the conventional methods of physical therapy, occupational therapy, and sometimes speech therapy, a range of advanced and complementary treatments can also support the recovery journey and improve the outcomes for individuals with SCI. Here are some popular treatments

Regenerative Medicine

- **Stem Cell Therapy:** Current research is exploring the use of stem cells to repair damaged spinal cord tissue. These cells hold the potential to regenerate nerve cells and improve functional recovery.
- **Neurotrophic Factors:** These proteins aid in the growth and survival of neurons. Certain treatments apply these factors to encourage nerve repair.

Electrical Stimulation

- **Epidural Stimulation:** This technique implants a device to provide electrical stimulation to the spinal cord, aiding in the restoration of voluntary movement and autonomic functions such as bladder control.
- **Functional Electrical Stimulation (FES):** FES employs electrical currents to activate nerves and muscles, aiding in the recovery of movement in paralyzed muscles.

Exoskeletons

- **Robotic Rehabilitation Devices:** Utilized in physical therapy, these devices support movement and walking. Exoskeletons enable patients to stand and walk, benefiting circulation, bone density, and mental health.

Virtual Reality (VR) & Neuroplasticity Training

- **VR Therapy:** VR creates immersive environments that prompt patients to engage in exercises and tasks, stimulating neural pathways and fostering neuroplasticity.
- **Brain-Computer Interfaces (BCIs):** BCIs enable patients to control devices such as computers or robotic limbs using their thoughts, aiding in the retraining of the brain to regain lost functions.

Hyperbaric Oxygen Therapy (HBOT)

- **HBOT** involves inhaling pure oxygen in a pressurized room, potentially enhancing the body's healing process by increasing oxygen delivery to damaged tissues.

Nutritional Support

- **Anti-inflammatory Diets:** Consuming foods high in antioxidants and with anti-inflammatory properties may mitigate secondary injuries post-SCI by reducing inflammation.
- **Supplements:** Omega-3 fatty acids and vitamin D, among other supplements, are commonly suggested to promote nerve health and aid in recovery.

Psychological Support & Mental Health

- **Cognitive Behavioral Therapy (CBT):** It's vital to address the emotional and psychological repercussions of SCI for comprehensive recovery. CBT and other psychotherapeutic approaches can be advantageous.
- **Mindfulness and Meditation:** These techniques can assist in managing pain, stress, and anxiety, thus enhancing life quality for those with SCI.

Complementary & Alternative Medicine

- **Acupuncture:** Acupuncture may offer pain relief and improved blood flow for some.
- **Massage Therapy:** Massage may help lessen muscle spasticity, boost circulation, and provide emotional comfort.

Activity-Based Therapy

- **Locomotor Training:** This intensive therapy aims to retrain the spinal cord to recall walking through repetitive, task-oriented movements.
- **Aquatic Therapy:** Water's buoyancy can facilitate movement, simplifying exercises that may be challenging on land.

Peer Support & Community Integration

- **Support Groups:** Interacting with fellow SCI survivors can offer emotional backing, practical tips, and encouragement.
- **Community Programs:** Initiatives aimed at reintegrating individuals into society, such as job training and leisure activities, are crucial for sustained recovery.

ADVANCES IN SCI TREATMENT

Significant advances have been made in optimizing the management of patients with SCI. Early surgical decompression, adequate bony decompression and expansile duraplasty are surgical strategies that may improve neurological and functional outcomes in patients with SCI. There have also been several advances in the treatment of SCI and paralysis with emerging treatments focusing on nerve cell regeneration and the enhancement of existing nerve functions, including:

Mesenchymal Stem Cells

A recent study by the Mayo Clinic, published in "Nature Communications," demonstrated that stem cells derived from the patients' own fat tissue are safe and have the potential to improve sensory and motor functions in those with SCI. The phase 1 clinical trial involved 10 participants, with seven showing improvements on the ASIA Impairment Scale, including better sensation and increased muscle strength. This research highlights the potential of autologous stem cell therapy as a groundbreaking approach for SCI treatment, calling for more research to confirm its effectiveness. Watch: [Dr. Mohamad Bydon discusses improvements in research study](#).

Wrap Around Implants

A team from the University of Cambridge developed a flexible device that wraps around the spinal cord to record nerve signals between the brain and spinal cord. The device can record 360-degree information, which could provide a more complete picture of spinal cord activity. In tests on animals and human cadavers, the device was able to stimulate limb movement and bypass complete spinal cord injuries. Visit [Cambridge](#) to read more about the research.

Arc-Ex Therapy

ONWARD Medical's Up-LIFT trial published results in Nature Medicine in May 2024 that showed their non-invasive ARC-EX Therapy may help people with chronic tetraplegia. The trial was conducted at 14 SCI centers in the US, Canada, and Europe. Read more about ARC-Ex Therapy at [ClinicalTrialsArena](#).

Wireless Implantable Device

Another NIH-funded team has developed a wireless device that monitors bladder filling in real time and sends data to a smartphone. Read more about this implantable device at [NIH](#).

Johns Hopkins Implantable and Wearable Technology

In 2021, the Defense Advanced Research Projects Agency (DARPA) awarded Johns Hopkins a \$13.48 million grant to foster innovations in treating spinal cord injuries (SCI) and paralysis. Johns Hopkins is at the forefront with cutting-edge implantable and wearable technology aimed at mitigating secondary injuries and enhancing the health of muscles, heart, and bladder. The suite of technology includes a versatile implant, a spinal stimulator, and a fluid management device, all integrated with wireless sensors that monitor blood pressure, bladder volume, and muscle activity. This technology focuses on meticulous patient monitoring and real-time data utilization to advance healthcare quality, aiming to bring these tools to clinical trials with FDA approval within the next five years. Visit [HopkinsMedicine](#) for more information about this technology.

Red Light Therapy

According to the study, red light therapy, particularly low-level laser therapy (LLLT), has shown potential in aiding recovery and mitigating damage associated with SCI. The therapy works by enhancing cellular repair and reducing inflammation through the activation of mitochondrial functions. In animal models, this approach has led to improved motor function and better overall recovery. This study suggests that red light therapy could be a beneficial tool in managing SCI, but more research is needed, including human trials. Read more about red light therapy at [MedicalXpress](#).

RETURNING TO WORK OR SCHOOL

Most people with spinal cord injuries want to return to work or school yet need support, training, and vocational services to be successful. Under the **Americans with Disabilities Act (ADA)**, employers and schools are required to provide reasonable accommodations to all people with disabilities. Some accommodations you can discuss with your employer or school administrator include returning to work or school gradually, working shorter hours or attending school part-time, taking online classes, taking frequent breaks, and using physical and technological aides. If you're ready to return to work or school, here are some resources 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. 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

Learn more about job programs and services at [RehabWorks](#) or apply for services.

TICKET TO WORK

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

CAREER SOURCE FLORIDA

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

FLORIDA ABILITIES WORK

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

JOB ACCOMMODATION NETWORK

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

INTERVIEW TIPS FOR EMPLOYERS

The United Spinal Association Pathways to Employment offers tips for employers interviewing people with disabilities. Visit [UnitedSpinal](#) to view or download the document.

CAREGIVING

A spinal cord injury can drastically alter a person's life in an instant, requiring them to relearn basic tasks. Those who don't regain full independence rely on support to manage their condition and daily activities. This assistance, often from family or loved ones, is vital for their quality of life and social involvement.

Stages of Caregiving

Caregiving for SCI individuals involves two stages: Acute and Lifelong.

The Acute Stage – a.k.a The Initial Adjustment Stage

This stage occurs immediately after the injury and involves significant emotion and practical adjustments:

1. **Emotional Support** – Caregivers often deal with shock and emotional distress, both for themselves and the injured individual.
2. **Learning New Skills** – Caregivers need to quickly learn how to assist with daily activities such as bathing, dressing, and mobility.
3. **Medical Management** – Understanding and managing medical needs, including medication, wound care, and recognizing signs of complications.

The Lifelong Stage

This stage focuses on maintaining and improving the quality of life over the long term:

1. **Ongoing Physical Care** – Continued assistance with daily activities and physical therapy to maintain mobility and prevent complications.
2. **Emotional and Social Support** – Encouraging social engagement and providing emotional support to help the individual adapt to their new lifestyle.
3. **Resource Management** – Coordinating with healthcare providers, managing finances, and accessing community resources and support groups.

These stages underscore the dynamic and enduring nature of caregiving, demanding flexibility, and ongoing education.

ORGANIZATIONS

AARP offers general “Family Caregiver Resources in Florida”. Call the AARP toll-free caregiving resource line at 1-877-333-5885, for Spanish speakers call 1-888-971-2013 or visit [AARP](#).

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

The Christopher & Dana Reeve Foundation offers caregiver support, information and resources at [ChristopherReeve](#).

Family Caregiver Alliance offers the “Hospital Discharge Planning: A Guide for Families and Caregivers” that can be downloaded or ordered at [Caregiver](#).

SpinalCord offers a list of essential resources every caregiver should have. Download the Beginner's Guide to Caregiving and explore additional resources at [SpinalCord](#).

Wiser Women's Institute for a Secure Retirement offers a booklet, “Financial Steps for Caregivers: What You Need to Know About Protecting Your Money and Retirement” that can be download at [WiserWomen](#).

The [VA Caregiver Support Program's Comprehensive Assistance for Family Caregivers](#) (CAFCP) provides support and resources to family members or friends who care for veterans with serious injuries or illnesses.

MEDICAL BINDER

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

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

FEDERAL TAX PROVISIONS

Managing a spinal cord injury (SCI) often comes with significant costs, adding to the emotional and physical strain that can impact your family's quality of life. When Tax Day is nearing, it's crucial to know that some medical and caregiving expenses might qualify for tax deductions and credits. Need help figuring out your itemized deductions?

Use [Schedule A](#) (either Form 1040 or 1040-SR).

Understanding Gross Income (AGI)

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

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

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

Deductible Medical Expenses

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

Dependent Care Credit

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

Benefits for Caregivers

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

Long-Term Care Insurance

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

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

Important Considerations:

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

RESOURCES

When a person with a spinal cord injury returns home and prepares for community integration, several essential resources are vital for a smooth transition and fostering independence. Together, these resources help create a supportive, safe, and empowering environment for reintegrating into home life and the community. Here are some key resources to facilitate this process.

CENTERS FOR INDEPENDENT LIVING

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

FLORIDA HEALTH FINDER

Find and compare health outcomes, licensure information, inspection reports, pricing, and performance measures for Home Health Agencies, Nursing Homes, Assisted Living Facilities, Ambulatory Surgery Centers, Hospitals, and Medicaid Health Plans in Florida and locate facilities at [FloridaHealthFinder](#).

FLORIDA 2-1-1 NETWORK

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

SCI ADVOCACY ORGANIZATIONS

- **United Spinal Association** improves the quality of life of people with SCI/D through education, peer support, advocacy, support groups, consulting services, employment assistance, and a network of regional chapters. Membership is free and open to people with SCIs or disorders, family members, care providers and professionals, and interested individuals (aged 18 and older). For more information contact their Resource Center at **1-800-962-9629** or visit [UnitedSpinal](#).
- **Disability Rights Florida (DRF)** is a federally mandated Protection & Advocacy (P&A) system, is part of the National Disability Rights Network (NDRN). Its mission is to protect the rights of people with disabilities, ensuring they have access to necessary support and services. As the leading legal advocacy service for individuals with disabilities in the U.S., the P&A/CAP Network is dedicated to upholding their rights. Contact DRF at **1-800-342-0823** or visit [DisabilityRightsFlorida](#).
- **Florida Self-Advocacy Central (FSACentral)** is a self-advocacy organization for all individuals with disabilities across the state of Florida and is go to source for self-advocacy news and information, resources, education, and events. [FSACentral](#) is an arm of the Florida Self-Advocates Network'd, or [FLSAND](#).

CONSUMER CENTERED

- **BestColleges.com's [College Guide for Students with Disabilities](#)** provides valuable resources and information tailored to help students with disabilities, including those with spinal cord injuries (SCI) by providing information on: accessibility resources, financial aid options, academic support services, campus life information, legal rights and protection, and personal stories and advice.
- **Christopher & Dana Reeve Foundation** provides a comprehensive range of services, communities, and programs for individuals with spinal cord injuries and their families. These include FAQs, connections to current research studies, a peer and family support program, an SCI blog, local events, and resources. Learn more at [ChristopherReeve](#).
- **Client Assistance Program (CAP)** is administered by Disability Rights Florida and offers free and confidential support to individuals with disabilities and their families. It addresses concerns related to rehabilitation and independent living, while also providing guidance on the services and benefits available under the *Rehabilitation Act of 1973* and Title I of the ADA. For assistance and to explore the full range of services, reach out to Disability Rights Florida. To apply for the CAP, contact Disability Rights Florida at **1-800-342-0823**.

- **Florida Alliance for Assistive Services and Technology (FAAST)** provides a range of assistive technology services, including device loans, device demonstrations, and equipment exchanges. They offer technology solutions for cognitive assistance, mobility, and communication to support individuals with brain injuries. Visit [FAAST](#) for more information on services and products provided.
- **Florida Independent Living Council (FILC)** is a nonprofit organization that promotes independent living for people with disabilities in Florida. FILC works to ensure that individuals with disabilities, including those with SCI, have access to the resources, services, and support they need to live independently and fully participate in their communities. They also advocate for improved accessibility in housing, transportation, education, and employment for people with disabilities. Visit [FloridaSILC](#) for more information or call **850-488-5624**.
- [Florida Property Tax Benefits for Totally & Permanently Disabled Persons](#) provides property tax relief for residents with spinal cord injuries (SCI). For more information, visit the [Florida Department of Revenue](#).
- **Miami Project to Cure Paralysis**, a Center of Excellence at the University of Miami Miller School of Medicine, is a leading research program focused on traumatic spinal cord and brain injuries, as well as other neurological disorders. Its mission is to find a cure for paralysis and enhance quality of life. For enrollment in a research program, reach out to The Miami Project Education Office at **305-243-7108** or visit [TheMiamiProject](#).
- **New Mobility Magazine**, published by United Spinal, features comprehensive information on equipment, an annual Consumer Guide, and a wide range of articles on topics related to spinal cord injuries. Visit [NewMobility](#) for details.
- **Southeastern Spinal Cord Injury Model System (SCIMS) at the University of Miami** is one of the national SCIMS centers funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) that focuses on research, treatment, and community integration for people with SCI. Services include clinical care and advocacy for improving outcomes for individuals with SCI. Visit [MedMiami](#) to learn more.
- **Spinal Cord Injury Information Pages** offers a complimentary and informative resource for individuals living with a spinal cord injury and caregiver resources. Visit [SCI-INFO-PAGES](#) for more information.
- **United Spinal Association's** local chapters in Florida provide education, legal support, employment assistance, and peer mentorship. Join UnitedSpinal for free at [UnitedSpinal](#). Family members and friends may also join for free. United Spinal Association also has an online [Disability Products & Services](#) guide that allows you to search by type or location. You can also contact the United Spinal Association's Resource Center at **1-800-962-9629**.

DOMESTIC VIOLENCE

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

SCI EDUCATION

- **CareCure Community** offers more than 70 forums featuring the latest updates on SCI and related issues, providing a platform for users to interact, share images, post comments, and consult with spinal cord injury nurses. It also hosts specialized forums for women, veterans, and individuals with conditions such as TBI, MS, and various disabilities. Stay informed with [CareCure](#).
- **facingdisability.org** offers video interviews with family members who address real-life questions, insights from medical experts on spinal cord injury topics, a wealth of resources, medical information, and an informative blog at [facingdisability.com](#).
- **Model Systems Knowledge Translation Center (MSKTC)** offers resources for individuals with spinal cord injuries (SCI) and their caregivers, featuring patient-centered fact sheets, slideshows, videos, and research reviews. To view these resources, visit [MSKTC](#).
- **University of Alabama Spinal Cord Injury Model System (UAB-SCIMS) Information Network** offers insights into research, health, and quality of life for individuals with spinal cord injuries (SCI) and their caregivers. For more information, visit [UAB](#).

FUNDING, GRANTS & SCHOLARSHIPS

- **180 Medical Scholarship** is open to full-time college students living with specific medical conditions, including SCI, spina bifida, transverse myelitis, neurogenic bladder, or an ostomy. The application process begins every January. For the most current details and application information, visit [180Medical](#).
- **Adaptive Driving Alliance (ADA)** is a nationwide group of vehicle modification dealers. Their website lists funding sources for automotive adaptive equipment. Call **1-877-853-1402** or visit [ADAMobility](#) for additional information.
- **AvaCare Medical** offers a \$1000 scholarship to a student seeking a college degree in the medical field. All students may apply but preference is given to students who have a physical disability and a GPA of 3.0. For details about the scholarship and how to apply, visit [AvaCareMedical](#) or call their helpline at **1-877-813-7799**.
- **Cerner Charitable Foundation's** provides funding for children, age 18 or younger, or 19-21 if they are in a child-like mental state, whose families cannot afford medical care, equipment, vehicle modification, or travel related to care. Visit [Cerner Charitable Foundation Medical Grants](#) for details and information on the application process.
- **Challenged Athletes Foundation (CAF) Annual Grant Program** provides opportunities and support to individuals with permanent physical disabilities in the form of different grants for training, competition, and equipment needs so they can pursue active lifestyles through physical fitness and competitive athletics. Visit [ChallengedAthletes](#) for details on when the application process opens and for additional resources.
- **Getting Back Up** provides qualified individuals with funding for participation in exercise-based recovery programs and the purchase of adaptable products. Their exercise-based recovery programs in Florida include NextStep (Orlando), Center of Recovery and Exercise (Orlando), and BARWIS (Deerfield Beach, Jupiter, and Fort Pierce). Visit [GettingBackUp](#) for details and to download the Application for Assistance.
- **Gridiron Heroes Spinal Cord Injury Foundation** provides immediate and long-term resources and support to individuals sustaining a catastrophic SCI through activities associated with high school football including providing medical equipment and supplies not covered by Medicaid or insurance. To apply, visit [GridIronHeroes](#).
- **HelpHOPELive** is a national nonprofit that helps individuals and families who have experienced a catastrophic injury afford medically related expenses not covered by insurance through grass-roots fundraising. Learn more at [HelpHopeLive](#).
- **High Fives Foundation's Empowerment Fund** provides resources and inspiration to those who suffer a life-changing injury including SCI, TBI, amputation or other mobility-limiting injuries that occurred in an individual's lifetime by providing grant funding, paid to service providers in specific funding categories: adaptive sports equipment, healing network, medical equipment, programs, living expenses, and emergency care/injury expenses. Visit [HighFivesFoundation](#) to view the eligibility criteria.
- **Joseph Groh Foundation** provides financial assistance for those connected to the contracting HVAC industry who are living with life altering disabilities. To apply for assistance, visit [JosephGrohFoundation](#).
- **Kelly Brush Foundation (KBF)** provides grants for adaptive sports equipment and scholarships for individuals seeking to get active post SCI injury. KBF also hosts several camps throughout the year for people with SCI. Learn more and apply for a grant or scholarship at [KellyBrushFoundation](#).
- **MW Fund** provides financial assistance to individuals who want to attend specialized SCI rehabilitation centers and other exercise-based rehabilitation programs not covered by insurance. For more information on the MW Fund and how the grant program works, visit [MWFund](#).
- **New Perspective Foundation** assists family and friends of individuals in Florida, Georgia, or Ohio who are currently hospitalized due to a SCI, with airfare, gasoline, and/or lodging expenses so they can be with their loved one. Apply online at [NewPerspective](#).
- **Project 34** offers financial grants to alleviate the strain associated with rehabilitation, home modifications, and ongoing therapy sessions to support SCI survivors. Apply online at [ProjectThirtyFour](#).
- **SCORE (Spinal Cord Opportunities for Rehabilitation Endowment)** provides grants, to people paralyzed while participating in sports or recreational activities, to cover out-of-pocket costs for items or services that will improve the recipients quality of life such as home modifications, adaptive sports equipment, and vehicle adaptations. Get the details at [ScoreFund](#).
- **United Healthcare Children's Foundation (UHCCF)** is a charitable organization that provides medical grants to help children (age 16 or younger) gain access to health-related services not covered, or fully covered, by their family's commercial health insurance plan. View the eligibility requirements and grant exclusions at [UHCCF](#).

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

HEALTH/FITNESS, SPORTS & RECREATION

- **Florida Adaptive Sports**, a community outreach program of AGED, Inc., is a community-focused social sports club that brings individuals together for fun, exercise, and team competition. It's a place where developing chair skills and control not only boosts physical abilities but also confidence, translating these benefits into everyday life. Even those who may not typically use a chair find value in the physical activity and unique exercise opportunities. To find a program, visit FloridaAdaptiveSports.
- **National Center on Health, Physical Activity and Disability (NCHPAD) Connect** is a safe, free, and personalized online portal to tailored resources and wellness programs for individuals with physical disabilities. Connect with a NCHPAD Expert Inclusion Specialist (EIS) for personalized support, tailored resources, and continuous guidance at NCHPAD.
- **National Sports Center for the Disabled** is based in Winter Park and Denver, Colorado and provides information about summer and winter sports and recreation for children and adults with disabilities. Make a reservation to participate in adaptive sports programs in year-round adventures in Colorado that are designed for all disabilities and diagnosis at all ages. See what they have to offer at NSCD.
- **SportsAbility Alliance** (formerly Florida Disabled Outdoor Association – FDOA) offers various accessible, inclusive recreation and active leisure programs. Call **850-201-2944** or visit SportsAbility for more information on programs offered and resources. Also check out the [iFind Recreation Directory](http://iFindRecreationDirectory) for events going on in your county.
- **VA Adaptive Sports & Arts** offers individuals with spinal cord injuries opportunities to engage in sports—such as wheelchair basketball, hand cycling, swimming, and archery—as well as creative activities like painting, photography, writing, and music. Additionally, the **VA National Veterans Sports Programs & Special Events Office** provides a monthly training allowance for veterans with disabilities training in Paralympic sports or competing with the national Olympic team. For more information, visit [VA Adaptive Sports and Arts](http://VAAdaptiveSportsandArts).

MILITARY

- **America's VetDogs** offers service dogs for veterans with physical disabilities, PTSD, and TBI. Visit VetDogs for eligibility criteria and to apply for a service dog or call **866-282-8047** to speak with Consumer Services.
- **Disabled American Veterans (DAV)** 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 for tools and resources or to contact your nearest DAV Service Officer.
- **Florida Department of Veterans' Affairs (FDVA)** publishes an annual Benefits Guide and provides many other resources to veterans and their families. To download the newest Benefits Guide or get the FDVA App for your phone, visit FloridaVets.
- **Health.mil**, an official website of the Military Health System, provides resources for service members with SCI which includes rehabilitation services, support programs and more. Visit Health.mil to view these resources.
- **National Military Family Association (NMFA)** is a nonprofit organization that educates military families on their rights, benefits, and services available to them. For more information, visit MilitaryFamily.
- **National Resource Directory (NRD)** is a resource website that offers resources that supports recovery, rehabilitation, and reintegration of wounded warriors, service members, veterans, family members and caregivers and includes information on employment, homeless assistance, housing, and the military adaptive sports program in addition to other resources. To view these resources, visit NRD.
- **VA Spinal Cord Injuries and Disorders System of Care** is a comprehensive framework designed to provide specialized life-time care for veterans with spinal cord injuries and related disorders. To learn more of view all locations, visit SCI/D.
- **Reeve Foundation Military & Veterans Program (MVP)** provides support and programs to help servicemen and women connect with military services, programs, and benefits. For more information, visit ChristopherReeve.

YOUTH & PARENTS

- **BACKBONES Youth Program** is designed for teenagers (ages 15-18) with spinal cord injuries and diseases (SCI/D) to develop self-advocacy skills and explore important topics relevant to youth with disabilities. Topics include college preparation, employment, recreation and travel, dating, advocacy, disability identity, and more! This engaging virtual program meets weekly from June through August, offering a fun opportunity to connect with peers who have SCI/D and learn from leaders and professionals in the disability community. For more information about this program, visit [BACKBONES](#) or contact Amanda Russel, Program Coordinator at arussel@backbonesonline.com.
- **facingdisability.com** provides guidance on discussing spinal cord injuries with children and teenagers, finding therapists to assist in building positive self-esteem, managing traumatic stress, and addressing PTSD. It also offers resources for parents to support their children through these challenges. For resources, visit facingdisability.com.
- **Reeve Foundation's Youth and Family Resources** focuses on providing tools, information, and community connections for young people with paralysis and their families. For more information, visit [ChristopherReeve](#).
- **Sportsability Alliance RecConnect** offers community-based recreation and active leisure for people of all ages with spinal cord injuries. Get involved with adaptive sports, the arts, engage with support groups or clubs, or take advantage of volunteer opportunities. To learn more, visit [Sportsability Alliance](#).
- **United Spinal Association** offers resources, support, and information tailored for youth and their families dealing with SCI. They also have a virtual support group, **Empowering Parental Caregivers** that meets every other Tuesday, 7 pm – 8 pm ET. Register for the event online at [UnitedSpinal](#) or email Lindsey Elliott at lelliott@unitedspinal.org with any questions or to learn more.

SCI GLOSSARY

Spinal cord injury survivors often encounter terms and definitions that are crucial to understanding their condition, treatment options, and prognosis. Understanding these terms can help survivors and their caregivers navigate the challenges of SCI more effectively and communicate with healthcare providers.

Here are some of the most important SCI definitions that survivors should be familiar with:

ASIA/ISCoS Exam and Grading System

A method used to assess spinal cord injuries and guide decisions on subsequent rehabilitation and recovery. It evaluates a patient's sensory perception across various body points and motor function capabilities. The assessment is optimally conducted within the first 72 hours following the injury.

Atrophy

Loss of bulk in a muscle, nerve, or organ from less than normal usage or from previous damage.

Autonomic Dysreflexia

A serious condition that occurs in people with SCI at or above the T6 level and can be life-threatening, often triggered by painful stimuli below the level of spinal injury. This occurs due to the malfunctioning of nerve cells, particularly in individuals with complete tetraplegia. Symptoms may include severe headache from a rapid rise in blood pressure, a decrease in heart rate, excessive or unusual sweating, skin blotches, and agitation. Awareness of potential triggers, such as bladder distension, bowel impaction, infected sores, or ingrown toenails, is crucial for prevention and management.

Brown-Sequard Syndrome

A rare type of incomplete SCI where one side of the spinal cord is damaged. This results in loss of motor function and proprioception (sense of body position) on the same side of the injury and loss of pain and temperature sensation on the opposite side.

Central Cord Syndrome

An incomplete SCI where there is greater weakness in the arms than the legs, often caused by trauma to the cervical region.

Complete injury

This means there is a total loss of sensation and muscle function below the level of the injury. No motor or sensory function is preserved in the sacral segments (S4-S5).

CT Scan (Computerized Tomography)

Provides doctors with more detailed information about spinal cord or brain damage than X-rays can show.

Decubitus

A skin sore caused by unrelieved pressure.

Deep Vein Thrombosis (DBT)

A blood clot that forms in a deep vein, often in the legs, which can lead to serious complications such as a pulmonary embolism. People with SCI have an increased risk due to limited mobility.

Functional Electrical Stimulation

Application of low-voltage currents to enhance the function of paralyzed muscles.

Functional Independence Measure (FIM)

A scale used to assess a person's level of independence in performing daily activities. It measures physical and cognitive functions and helps to set rehabilitation goals.

Incomplete injury

Some sensory or movement is retained below the level of injury. There may be varying degrees of function remaining.

Hemiparesis

Weakness on one side of the body.

Hemiplegia

Paralysis on one side of the body.

Hemorrhage

Internal or external bleeding caused by damage to a blood vessel.

Level of Injury

Refers to the point on the spinal cord where the injury occurred. For example, an injury at the C6 level affects parts of the body below the sixth cervical vertebra. The higher the injury, the more extensive the paralysis.

Motor Function

Ability to control muscles voluntarily and their resultant use.

Motor Index Score (MIS)

A portion of ASIA/ISCoS exam that determines muscle strength of 10 different muscles on both sides of the body.

MRI (Magnetic Resonance Imaging)

Uses a strong magnetic field and radio waves to produce computer-generated images. It can help identify blood clots, swelling or skull fractures that may be compressing the brain and/or the spinal cord.

Myelography

A test using injected dye to help the doctor visualize your loved one's spinal nerves more clearly. After the dye is injected into the spinal canal, X-rays and CT scans of the vertebrae can reveal herniated disks or other problems.

Neuroplasticity

The ability of the nervous system to adapt and reorganize itself, even after an injury. It plays a key role in rehabilitation and recovery for SCI survivors.

Ostomy

An opening in the body to drain the bladder (cystostomy), remove solid waste (colostomy or ileostomy) or allow passage of air (tracheostomy).

Paraplegia

Paralysis, or loss of motion affecting the lower half of the body, including both legs and, sometimes, parts of the trunk. It results from damage to the thoracic, lumbar, or sacral regions of the spinal cord.

Tetraplegia (also quadriplegia)

Paralysis affecting all four limbs (both arms and legs) and the trunk. It typically results from an injury to the cervical (neck) spinal cord.

Sensory Index Score (SIS)

Part of ASIA/ISCoS exam that measures patient's response to light touch and a pinprick in 28 points on each side of the body to determine what the patient can feel. Together, the SIS and MIS determine the patient's level and severity of injury.

Spasticity

A condition in which muscles become stiff or experience involuntary spasms due to the disruption of communication between the brain and spinal cord. This is common after SCI and can affect mobility and comfort.

Spinal Shock

A temporary condition after SCI where reflexes, motor, and sensory functions are absent below the level of injury. This can last days or weeks and gradually resolves as swelling around the spinal cord decreases.