Spinal Cord Injury

A spinal cord injury (SCI) is damage to the spinal cord that results in a loss of function. When the spinal cord incurs a trauma (such as a car accident, gunshot, or fall) or disease (such as polio, spina bifida, or Friedreich's ataxia), the damage to the nerves within the bony protection of the spinal canal affects the spinal cord's ability to send and receive messages to coordinate the body's movement and sensation.

Q: What does your spinal cord control?

The spinal cord is the major bundle of nerves that carries impulses to and from the brain to the rest of the body. Similar to the wiring that spreads electricity through your house, the spinal cord and the brain work together to message the body's systems that control sensory
and motor function, and thus your ability to feel and move. The spinal cord also impacts the autonomic nervous system which acts largely unconsciously and regulates bodily functions such as heart rate, digestion, breathing, temperature regulation, bladder and bowel function, and sexual arousal.

**Q: What are the different levels of the spinal cord?**

The spinal cord is organized into segments along its length. Nerves from each segment connect to specific regions of the body. The segments in the neck, or cervical region, referred to as C1 through C7/8*, control signals to the neck, arms, and hands. Those in the thoracic or upper back region (T1 through T12) relay signals to the torso and some parts of the arms. Those in the lumbar or mid-back region just below the ribs (L1 through L5) control signals to the hips and legs. Finally, the sacral segments (S1 through S5) lie just below the lumbar segments in the mid-back and control signals to the groin, toes, and some parts of the legs. In general, the higher the injury on the spinal cord, the more impairments can occur.

**Q: What types of SCI are there?**

SCI occurs when the bony protection surrounding the cord is damaged by way of fractures, dislocation, burst, compression, hyperextension or hyperflexion or when there is a compression or lesion on the cord. There are different types of spinal cord injuries, or syndromes, based on the region of the spinal cord involved. Complete transverse syndrome is a complete severance of the spinal cord. Anterior cord syndrome affects the anterior (front) portion of the spinal cord which controls motor function and the majority of sensation. Central cord syndrome is damage to the middle portion of the spinal cord, often causing increased weakness and numbness in the hands and arms. Brown-Séquard syndrome results from an injury to one side of the spinal cord, causing weakness on the same side, and numbness on the opposite side. This syndrome has the best prognosis and chance for recovery.

**Q: I’m paralyzed, why can I feel pain?**

When the spinal cord is damaged, the signals that inform your brain how your body feels can be misunderstood or amplified in intensity from the area around your injury. This abnormal communication can cause neurogenic pain (also referred to as central neuropathic pain, central pain syndrome or deafferentation pain) at and/or below the level of injury where you have little or no feeling. Musculoskeletal pain can be a secondary pain syndrome caused by the overuse of the remaining functional muscles above or below the level of injury. Referred pain can occur if the pain presents in another part of the body but the source of the pain is below the level of injury. It is important to see a doctor who has experience working with SCI patients to ensure the correct diagnosis and care.

**Q: Are all SCIs the same? Does everyone with the same level of injury have the same function?**
Every SCI is different. Although there are general impairment guidelines outlined in the American Spinal Injury Association (ASIA) Impairment Scale, each individual may have different sensory and motor impairments based on the injury location, severity, duration since injury, and other circumstances. At the same level of injury, there may be variations in the level of orthopedic, functional, and neurological damage.

Q: What is a complete injury vs incomplete injury?

An incomplete injury means that the ability of the spinal cord to convey the brain’s messages is not completely damaged or disrupted. There is some sensory or motor function below the level of injury. In a complete injury, nerve damage obstructs all brain signals resulting in no voluntary motor or conscious sensory function below the injury site. A complete injury may still have intact axons or nerves, but they are not functioning correctly as a result of the trauma.

Q: How come some people can walk and still not feel anything?

Each spinal cord segment serves specific motor and specific sensory regions of the body. When evaluating a spinal cord injury, doctors use the ASIA classification worksheet to independently assess the key muscle and the key sensory points along the spinal cord that are impacted by the injury. Depending on the location and severity of the injury, each damaged segment of the spinal cord may have a varying amount of motor or sensory impairment. For some, an injury may result in severe sensory damage but little or no motor damage or vice versa. If proprioception (perception or awareness of the position and movement of the body) is preserved after injury, the person will be more likely to be able to walk, transfer, etc.

Q: Can SCI be cured?

While many doctors and scientists have made amazing advancements in SCI research, no definitive cure has been proven yet. Ongoing clinical research to test promising surgical and drug therapies is progressing rapidly, with many more potential therapeutics in the research pipeline. Drug, gene therapy, surgical, and cell based treatments are being examined as ways to both minimize injury progression and improve nerve cell regenerative ability in chronic SCI. Neuromodulation therapies (i.e. epidural and transcutaneous stimulation), stem cell therapies, drug, and biologic interventions are being explored to maximize the output of spared connections after injury and recover function. It is likely that a meaningful cure will vary by individual, and will likely include a combination of medication, biologic interventions, and rehabilitation.

Q: Does anyone fully recover?

Some types of injuries or disease lend themselves to a more complete recovery than others, often depending on the severity of the trauma. After the initial swelling of the spinal cord...
decreases, most people show some functional improvement. The sooner muscles start working again, the better the chances are of additional recovery. Some improvement often means more improvement is possible. Generally, the longer there is no improvement, the lower the odds it will start to happen on its own. With some injuries, especially incomplete injuries, a person may recover function 18 months or even years after the injury. Although some paralysis due to viral and/or bacterial infections can be reversed, only a small fraction of individuals sustaining a spinal cord injury recover all function.

Q: How do you maintain or optimize good health after SCI?

Overall health and lifestyle habits can have a big impact on minimizing secondary conditions and improving quality of life. Good diet, healthy weight and regular physical activity can reduce pain and stress while improving your strength, mood and general health. Participating in fun and meaningful activities can help you feel more in control of your life. For people living with paralysis, normal blood flow can be compromised, and skin can be damaged by prolonged pressure. Make it a point to release pressure regularly by moving or being adjusted.

Q: What does upper motor neuron and lower motor neuron mean?

Extending from the base of the brain, down the middle of the back, to about the waist, the spinal cord is about 18 inches long. Neuron cells that carry electrical impulses are the basic functional and structural units of the nervous system. Upper motor neurons lie within the spinal cord and carry the messages back and forth from the brain to the spinal nerves along the spinal tract. Lower motor neurons branch out from the spinal cord to the other parts of the body. Individuals with upper motor neuron preservation maintain their reflexive response while those with lower motor neuron response have minimal preservation of reflexive response. Reflexive responses have an impact on bowel and bladder control as well as sexual functioning.

*There is no C8 vertebra—C8 refers to the nerve root between C7 and T1 vertebrae.

Sources: American Spinal Injury Association, FlintRehab.com, Paralyzed Veterans of America, Shepherd Center, Travis Roy Foundation, University of Southern California.

Resources for Spinal Cord Injury

American Academy of Neurology: Monitoring the Spinal Cord During Surgery
This fact sheet describes spinal cord monitoring procedures and how they may help prevent paralysis related to surgery.

American Academy of Neurology: Intraoperative Spinal Monitoring with Somatosensory and Transcranial Electrical Motor Evoked Potentials
This fact sheet presents a summary of the evidence that intraoperative spinal monitoring with somatosensory and transcranial electrical motor evoked potentials reduce the risk of adverse neurologic outcomes during surgery.

American Association of Neurological Surgeons: Spinal Cord Injury
This page has general information on spinal cord injury, including the number of people in the U.S. with SCI, types and levels, treatment, prevention, safety tips, and mortality.

American Spinal Injury Association (ASIA)
2209 Dickens Rd.
Richmond, VA 23230-2005
Phone: 804-565-6396
E-mail: ASIA.office@asia-spinalinjury.org
ASIA’s mission is to promote and establish standards of excellence for all aspects of health care of individuals with SCI; to educate members, other healthcare professionals, patients and their families as well as the public on all aspects of spinal cord injury and its consequences; to foster research; and to facilitate communication among members and other physicians, allied health care professionals, researchers and consumers.

ASIA: International Standards for Neurological Classification Diagram

BackBones
PO Box 7334
Prospect Heights, IL 60070
Email: info@backbonesonline.com
A non-profit organization that provides peer support in person and by phone as well as web support to people with spinal cord injuries.

Brain and Spinal Cord Injuries
201 South Orange Ave., Suite 1500
Orlando FL 32801
Phone: 855-979-4407 (Toll-free)
This site was created and sponsored by the Newsome Law Firm as a knowledge-base for brain injury and spinal cord injury survivors to help answer questions involving a wide spectrum of issues: health, rehabilitation, hope for recovery, current research, financial, legal, and more. The site includes blogs, in-depth articles, links to resources, and commentary on developments in research and recovery. There is also a video library with basic information that survivors need to
know about and videos of other brain injury and spinal cord injury survivors and their families talking about lessons they have learned and telling their personal stories about hope and coping.

Christopher & Dana Reeve Foundation Paralysis Resource Center (PRC)
636 Morris Turnpike, Suite 3A
Short Hills, NJ 07078
Toll-free: 800-539-7309
The PRC offers a wealth of information. There is a section specifically for the newly spinal cord injured (https://www.christopherreeve.org/living-with-paralysis/newly-paralyzed) as well as for those living with SCI (https://www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/spinal-cord-injury). You can find valuable links to other organizations as well as information specific to advances in SCI research. Please also ask for a free copy of our Paralysis Resource Guide book. A team of Information Specialists responds to paralysis-related questions, please call them. All services and materials are free to the public.

Cleveland FES Center
10701 East Boulevard
Cleveland, OH 44106
Phone: 216-231-3257
The FES Center is a consortium of three Cleveland-based institutions founded to introduce FES into clinical practice. FES, or functional electrical stimulation, is the application of electrical currents to either generate or suppress activity in the nervous system. It can produce and control the movement of otherwise paralyzed limbs. The Center’s information specialists can provide fact sheets, references, and background on FES and its other applications.

Craig Hospital: Spinal Cord Injury Nurse Advice Line
Phone: 303-789-8508, 800-247-0257 (Toll-free)
The Nurse Advice Line provides a dedicated nurse to answer non-emergent calls from people with SCI, caregivers, and health care professionals. The service is open Monday through Friday from 9 am to 4 pm MST. They also provide Spanish speaking assistance.

Craig Hospital: Spinal Cord Injury (SCI) Resources

Craig Hospital: Incomplete Spinal Cord Injuries: Down the Road
Craig Hospital: Incomplete Spinal Cord Injuries: The Early Days
Craig Hospital: Diabetes & Spinal Cord Injury: Prevention and Treatment

Determined to Heal
8112 River Falls Dr.
Potomac, MD 20854
Phone: 703-795-5711
E-mail: determined2heal@aol.com
The Determined2heal Foundation offers educational and health related information relevant to
persons with spinal cord injuries, their families, and others of interest. The Foundation was created by Josh Basile, injured at C5, to help others with new spinal cord injuries.

**Facing Disability: For Families Facing Spinal Cord Injury**
Hill Foundation
737 N. Michigan Avenue, Suite 1560
Chicago, IL 60611
Phone: 312-284-2525
E-mail: info@facingdisability.com
Facing Disability is designed to provide Internet-based information and support for people with spinal cord injuries and the members of their families. The site has over 1,000 videos drawn from personal interviews with people who live with spinal cord injuries and their caregivers and families as well as experts in the field. It also offers a peer counseling service.

**Flint Rehab.com: The Aftermath of C8 Spinal Cord Injury: Outcomes and Recovery**

**Florida Spinal Cord Injury Resource Center**
c/o Tampa General Rehabilitation Center
6 Tampa General Circle - Room R212
Tampa, FL 33606
Phone: 813-844-4711, 866-313-2940 (Toll-free)
A resource information clearinghouse that provides ready access to the most recent magazines, books, videos and reference materials related to SCI. It also provides listings of Florida’s designated SCI treatment centers, independent living centers and support groups. The center serves spinal cord injured individuals, their families, support groups and rehabilitation professionals. They list some pediatric resources and materials, which can be downloaded. Many of their information sheets are excellent and the information is the same regardless of where you live.

**Gaylord Hospital’s Spinal Cord Injury Toolkit**
The New England SCI Toolkit (NESCIT) is a collaborative effort between facilities providing spinal cord injury (SCI) rehabilitation in New England. This collaboration ensures patients throughout New England and beyond are receiving the same coordinated standard of care wherever they receive rehabilitation. Further, this toolkit will aid in building capacity at facilities that may not treat patients with SCI often enough to have developed expertise. The toolkit focuses on the following areas: patient/family caregiver education, AD, skin care, bladder and bowel management, sexual health and fertility, and spasticity.

**Jefferson University Hospital/Magee Rehabilitation: Spinal Cord Injury Patient-Family Teaching Manual**
This manual is designed to provide information on the many aspects of spinal cord injury and dysfunction to patients and family members.

**Makoa: Spinal Cord Injury and Disease Resources**
This page has links to resources for information, treatment and rehabilitation, research, online discussions, newsletters and magazines, articles and pamphlets, fact sheets, books, and more.
Johns Hopkins Medicine Health Library: Acute Spinal Cord Injury

Mayo Clinic: Spinal Cord Injury

MedicineNet.com: Spinal Cord Injury
This page has general information on the spinal cord and spinal cord injuries, including treatments, rehabilitation and research.

MedlinePlus: Spinal Cord Injuries
This page has links to general information on spinal cord injuries, including treatments, prevention, rehabilitation and recovery, coping and research.

MSKTC: Understanding Spinal Cord Injury
MSKTC is a national center that works to put research into practice to serve the needs of people with traumatic brain injuries, spinal cord injuries, and burn injuries.

National Rehabilitation Information Center (NARIC)
8400 Corporate Drive, Suite 500
Landover, MD 20785
TTY: 301-459-5984
Toll-free: 800-346-2742
Email: naricinfo@heitechservices.com
NARIC’s site has over 75,000 resources collected and organized according to topic, including organizations, agencies, Internet resources, reports, and research projects. The Center provides a computerized listing of commercially available products for rehabilitation and independent living. In addition, they will provide a computerized listing of rehabilitation literature and materials.

National Institute of Neurological Disorders and Stroke: Spinal Cord Injury Information Page
This page has general information on spinal cord injury, including treatment, prognosis, research, and links to other organizations and publications.

National Institute of Neurological Disorders and Stroke: Spinal Cord Injury – Hope Through Research
This page has general information on the spinal cord and spinal cord injury, including anatomy, immediate treatments, effects on the rest of the body, the benefits of rehabilitation, and research. Hope Through Research can be ordered as a booklet:

National Spinal Cord Injury Statistical Center (NSCISC) at the University of Alabama-Birmingham provides statistics on the incidence of spinal cord injury as well as the lifetime costs of a spinal cord injury. It has created a Life Expectancy Tool for individuals with SCI, clinicians, practitioners, and caregivers. The tool provides an estimate as to the life expectancy of a person with a spinal cord injury who is at least two years post-injury, has access to good-quality health
care, is not on a ventilator, and has not regained all normal feeling and movement. The Life Expectancy Tool was developed from data collected and research conducted by the NIDILRR-funded Spinal Cord Injury Model System Centers.

**NeuroTech Network**
P.O. Box 27386  
Tampa, FL 33623  
Phone: 727-321-0150  
E-mail: info@neurotechnetwork.org  
Neurotech Network of The Society to Increase Mobility is a non-profit organization focusing on education about and access to neurotechnology devices, therapies and treatments for persons with neurological and psychiatric disorders or impairments. Neurotechnology is the application of medical electronics to improving and restoring the function of the human nervous system. They provide a directory of neurotech devices by condition including SCI:  
https://neurotechnetwork.org/directory-home/spinal-cord-injury/

**New England Regional Spinal Cord Injury Center (Boston University): The SCI Guide**  
The SCI Guide was created to give the SCI community a place to go to get trusted, peer-reviewed information. The site brings together the best websites on SCI as rated by a team of people with SCI on things like quality of information and user-friendliness.

**Paralyzed Veterans of America (PVA)**
National Headquarters  
801 18th Street NW  
Washington, DC 20006-3517  
Phone: 800-424-8200 (Toll-free), 800-795-4327 (TTY)  
Health Care Hotline: 800-232-1782 (Toll-free)  
E-mail: info@pva.org  
PVA is a federally chartered national veterans’ service organization. In addition to a strong national presence in the areas of legislation, advocacy, research and education, they have chapter and service offices located throughout the United States. PVA has many excellent publications available in areas of interest to people with spinal cord injury. PVA also publishes two nationally distributed magazines, Paraplegia News and Sports ’n Spokes. Please see their [PVA Guidelines for Consumers](#)—scroll down to Expected Outcomes by level of injury.

**SCI Info Pages**  
This site is a free and informative resource for those living with a spinal cord injury or other disabling injuries or diseases of the spine. It is meant to be a "best of the web" site for SCI health and caregiver information.

**Shepherd Center: Spinal Cord Injury Information**

**Spinal Cord Injury Information Network (SCIIN)**  
The Spinal Cord Injury Information Network, sponsored by the University of Alabama at Birmingham Spinal Cord Injury Model System, provides a comprehensive and organized source
of SCI information and resources from recognized centers, organizations, researchers and educators.

**SCIIN: Secondary Conditions of Spinal Cord Injury Health Education Video Series**
This series includes 11 videos on functional goals, life with SCI, sexuality and sexual function, bowel management, bladder management, pressure sores, pain management, spastic hypertonia, respiratory management, cardiovascular health, and bone health. Each video can be streamed online or downloaded.

**SCIIN: Understanding Spinal Cord Injury & Functional Goals (Basic)**
This InfoSheet provides a brief summary of the changes that take place after a spinal cord injury. It tells how the spinal cord works and what some of the realistic expectations are for what a person should eventually be able to do following a spinal cord injury. Included is a chart of functional goals for specific levels of injury as well as additional information resources.

This InfoSheet provides a brief summary of the anatomy and physiology of the spinal cord as well as additional information resources.

**Spinal Cord Injury Rehabilitation Evidence (SCIRE)**
The SCIRE Project
Janice Eng PhD BSc (PT/OT)
Department of Physical Therapy
Friedman Building
212-2177 Wesbrook Mall
University of British Columbia
Vancouver, BC
Canada V6T 1Z3
Phone: 604-714-4105
The SCIRE project is a Canadian research collaboration between scientists, clinicians and consumers on best rehabilitation practices following SCI.

**Spinalis Tips**
Has tips from the people with spinal cord injuries on adapting your environment, self-care, travel, and wheelchair life among others. Spinalistips is run by Spinalis Foundation. Info also available in Swedish.

**Travis Roy Foundation: SCI Levels and Classification**

**United Spinal Association**
120-34 Queens Blvd #320
Kew Gardens, NY 11415
Phone: 718-803-3782
Toll-free: 800-404-2898
Resource Center helpline: 800-962-9629 (Toll-free)
United Spinal is dedicated to helping people living with spinal cord injury and disease. The organization provides information, peer support and advocacy that empower individuals to achieve their highest potential in all facets of life. Its NSCIA Resource Center provides information and resources to meet the needs of individuals with SCI/D; their families and friends; the medical and scientific community; service and business professionals; the media; students; government; elected officials; and the public.

**Unite 2 Fight Paralysis**
528 Hennepin Ave., Suite 705
Minneapolis, MN 55403
Phone: 888-564-2228
E-mail: unite@u2fp.org
Unite 2 Fight concentrates on advocacy, education and support for research. They provide an annual Working 2 Walk Science & Advocacy Symposium in a different location each year.

**University of Southern California: Spinal Cord Injury**

**Resources for Spinal Cord Injury—Choosing a Rehab Center**

**CARF International (Commission on Accreditation of Rehabilitation Facilities)**
6951 East Southpoint Road
Tucson, AZ 85756-9407
Phone: 520-325-1044, 888-281-6531 (Toll-free voice/TTY)
E-mail: medical@carf.org for medical rehabilitation
CARF is an independent, not-for-profit accrediting body promoting quality, value, and optimal outcomes of services through a consultative accreditation process that centers on enhancing the lives of the persons receiving services. CARF establishes customer-focused standards to help providers measure and improve the quality, value, and outcomes of their services. CARF has accredited more than 3,500 organizations in the United States, Canada, and Sweden in the areas of Adult Day Services, Assisted Living, Behavioral Health, Employment and Community Services, and Medical Rehabilitation. CARF develops and maintains practical and relevant standards of quality for such programs.

To locate an accredited rehabilitation facility near you contact CARF. They have information on rehab facilities accredited in spinal cord injury, brain injury, and pain management. The CARF website has a provider search tool at [http://carf.org/advancedProviderSearch.aspx](http://carf.org/advancedProviderSearch.aspx) where you can look for rehab programs by location (18 countries). You can also narrow the focus by program type, program focus (including Brain Injury Spinal Cord System of Care), and/or age group or special population served.

**Model Systems Knowledge Translation Center (MSKTC)**
MSKTC is a national center that works to put research into practice to serve the needs of people with traumatic brain injuries, spinal cord injuries, and burn injuries. The site lists contact
information for the 14 model SCI centers in the U.S. The 14 model centers are currently located in the following states: Alabama, California, Colorado, Florida, Georgia, Illinois, Massachusetts, New Jersey, New York, Ohio (2), Pennsylvania (2), and Texas.

Choosing a High-Quality Medical Rehabilitation Program: An NRH Field Guide for People with Disabilities. National Rehabilitation Hospital, Medstar Research Institute, 2004. For copies call 866-380-4344 (Toll-free). This guide addresses what medical rehabilitation is, insurance coverage, and how to choose a medical rehabilitation program.

For more on choosing a rehab center, please see the Reeve Foundation fact sheets and its booklet Restoring Hope: Preparing for Rehabilitation After a Spinal Cord Injury, co-produced with the Shepherd Center.

Online Discussion Forums

Care Cure Community
The online home of neuroscientist Wise Young, Ph.D., M.D., Professor II and Director at the W. M. Keck Center for Collaborative Neuroscience at Rutgers University. This site offers lively Internet forums with news and comment on spinal cord injury care, caregiving, cure, funding, active living, pain treatment, sexuality, biomedical research, clinical trials and more.

Reeve Connect (the Reeve Foundation’s online community)
Is an online community and social networking website from the Christopher & Dana Reeve Foundation Paralysis Resource Center. The Paralysis Community is a place for dialogue about spinal cord injury or disease, and about all issues related to paralysis. Members of The Paralysis Community will be able to connect with other members who have spinal cord injuries and/or paralysis or care for those who do. You may participate in discussion groups, post personal profiles with an optional photo, invite members to be friends, and build your own online support network.

Please ask for the Reeve Foundation’s list of SCI chat rooms if you would like the names of additional online forums, chat rooms and e-mail discussion groups.

Print Magazines—Consumer

New Mobility
United Spinal Association
120-34 Queens Blvd #320
Kew Gardens, NY 11415
Phone: 800-404-2898 ext. 7203 (Toll-free)
This monthly magazine encourages the integration of active-lifestyle wheelchair users into mainstream society and covers topics such as travel and relationships.
**PN: Paraplegia News**
PVA Publications  
2111 East Highland Avenue, Suite 180  
Phoenix, AZ 85016-4702  
Phone: 602-224-0500, 888-888-2201 (Toll-free)  
*PN (formerly Paraplegia News)* is a monthly magazine that provides practical news and information to wheelchair users, family members, and medical professionals.

**Spinal Column**
*Spinal Column* is a quarterly magazine from the Shepherd Center in Atlanta, Georgia, that features patient profiles, medical and treatment news, upcoming events, research features, volunteer and donor recognition and more.

**Videos**

**Christopher & Dana Reeve Foundation’s YouTube Channel**
provides an archive of past webinars and videos

**Spinal Cord Injury Information Network: Secondary Conditions of Spinal Cord Injury Health Education Video Series**
The 26-minute video “Understanding Spinal Cord Impairments and Functional Goals” offers a basic understanding of the normal function of the spinal cord and the impact of impairment at different types and levels of injury. In addition, functional goals are addressed for levels of impairment.

The information contained in this message is presented for the purpose of educating and informing you about paralysis and its effects. Nothing contained in this message should be construed nor is intended to be used for medical diagnosis or treatment. It should not be used in place of the advice of your physician or other qualified health care provider. Should you have any health care related questions, please call or see your physician or other qualified health care provider promptly. Always consult with your physician or other qualified health care provider before embarking on a new treatment, diet or fitness program. You should never disregard medical advice or delay in seeking it because of something you have read in this message.

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