

Understanding SPINAL CORD INJURY

What you should
know about
spinal cord injury
and recovery

Produced by Shepherd Center and KPK*interactive* in collaboration with the American Trauma Society, the National Spinal Cord Injury Association and the Christopher & Dana Reeve Foundation



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Spinal Cord Injury: Basic Facts

Spinal cord injury occurs when there is any disruption in the spinal cord that blocks communication between the brain and the body. After a spinal cord injury, a person's sensory, motor and reflex messages are affected and may not be able to get past the injury in the spinal cord. In general, the higher on the spinal cord the injury occurs, the more alterations in function the person will experience. Injuries are referred to as complete or incomplete, based on whether any movement and sensation occurs at or below the level of injury.

The most important – and sometimes frustrating – thing to know is that each person's recovery from spinal cord injury is different.

CAUSES

Traumatic injuries

Motor vehicle accidents	Sports
Falls	Medical/Surgical
Violence	Diving into shallow water

Spinal cord injuries affect more men than women. The average age for individuals who sustain a spinal cord injury is 43.

Non-traumatic injuries/illnesses

Cancer	Osteoporosis
Multiple sclerosis	Inflammation of the spinal cord
Arthritis	

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EFFECTS

The effects of spinal cord injury may include the following:

Loss of movement

Loss of sensation

Loss of bowel and/or bladder control

Exaggerated reflex actions or spasms

Changes in sexual function, sexual sensitivity and fertility

Pain or intense stinging sensation

Spinal Column Anatomy: The Basics

When a spinal cord injury occurs, sensation and movement may be interrupted, resulting in a temporary or permanent loss of function, paralysis and loss of sensation. Here are some basic anatomy facts:

- The brain is surrounded by the skull.
- The spinal cord is surrounded by rings of bone called vertebrae.
- Both are covered by a protective membrane.
- Together, the vertebrae and the membrane make up the spinal column, or backbone.
- The backbone, which protects the spinal cord, starts at the base of the skull and ends just above the hips.
- The spinal cord is about 18 inches long. It extends from the base of the brain, down the middle of the back, to just below the last rib in the waist area.
- The main job of the spinal cord is to be the communication system between the brain and the body by carrying messages that allow people to move and feel sensation.
- Spinal nerve cells, called neurons, carry messages to and from the spinal cord, via spinal nerves.
- Messages carried by the spinal nerves leave the spinal cord through openings in the vertebrae.
- Spinal nerve roots branch off the spinal cord in pairs, one going to each side of the body.
- Every nerve has a special job for movement and feeling. They tell the muscles in the arms, hands, fingers, legs, toes, chest and other parts of the body how and when to move. They also carry messages back to the brain about sensations, such as pain, temperature and touch.





Levels of Injury

Vertebrae are grouped into sections. The higher the injury on the spinal cord, the more dysfunction can occur.

High-Cervical Nerves (C1 – C4)

- Most severe of the spinal cord injury levels
- Paralysis in arms, hands, trunk and legs
- Patient may not be able to breathe on his or her own, cough, or control bowel or bladder movements.
- Ability to speak is sometimes impaired or reduced.
- When all four limbs and the torso are affected, this is called tetraplegia or quadriplegia.
- Requires complete assistance with activities of daily living, such as eating, dressing, bathing, bowel and bladder care, and getting in or out of bed
- May be able to use powered wheelchairs with special controls to move around on their own
- Will not be able to drive a car on their own
- Requires 24-hour-a-day supervision or personal care

Low-Cervical Nerves (C5 – C7)

- Corresponding nerves control arms and hands.
- A person with this level of injury is usually able to breathe on their own and speak normally.

- **C5 injury**
 - Person can raise his or her arms and bend elbows.
 - Likely to have some or total paralysis of wrists, hands, trunk and legs
 - Can speak and use diaphragm, but coughing will be weakened
 - Will need assistance with most activities of daily living, but once in a power wheelchair, can move from one place to another independently

- **C6 injury**
 - Nerves affect wrist extension.
 - Paralysis in hands, trunk and legs, typically
 - Should be able to bend wrists back
 - Can speak and use diaphragm, but coughing will be weakened
 - Can move in and out of wheelchair and bed with assistive equipment
 - May also be able to drive an adapted vehicle
 - Little or no voluntary control of bowel or bladder, but may be able to manage on their own with special equipment

- **C7 injury**
 - Nerves control elbow extension and some finger extension.
 - Most can straighten their arm and have normal movement of their shoulders.
 - Can do most activities of daily living by themselves, but may need assistance with more difficult tasks
 - May also be able to drive an adapted vehicle
 - Little or no voluntary control of bowel or bladder, but may be able to manage on their own with special equipment

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Thoracic vertebrae are located in the mid-back.

Thoracic Nerves (T1 – T5)

- Corresponding nerves affect muscles, upper chest, mid-back and abdominal muscles.
- Arm and hand function is usually normal.
- Injuries usually affect the trunk and legs (also known as paraplegia).
- Most likely use a manual wheelchair
- Can learn to drive a modified car

Thoracic Nerves (T6 – T12)

- Nerves affect muscles of the trunk (abdominal and back muscles) depending on the level of injury.
- Usually results in paraplegia
- Normal upper-body movement
- Fair to good ability to control and balance trunk while in the seated position
- Should be able to cough productively (if abdominal muscles are intact)
- Little or no voluntary control of bowel or bladder but can manage on their own with special equipment
- Most likely use a manual wheelchair
- Can learn to drive a modified car
- Some can stand in a standing frame, while others may walk with adapted devices or robotics as appropriate.



Lumbar Nerves (L1 – L5)

- Injuries generally result in some loss of function in the hips and legs.
- Little or no voluntary control of bowel or bladder, but can manage on their own with special equipment
- Depending on strength in the legs, may need a wheelchair and may also walk with assistive devices and special equipment

Sacral Nerves (S1 – S5)

- Injuries generally result in some loss of function in the hips and legs.
- Little or no voluntary control of bowel or bladder, but can manage on their own with special equipment
- Most likely will be able to walk



ASIA/ISCoS Exam and Grade

This is a system of tests used to define and describe the extent and severity of an individual's spinal cord injury and help determine future rehabilitation and recovery needs. It is ideally completed within 72 hours after the initial injury. The grade is based on how much sensation he or she can feel at multiple points on the body, as well as tests of motor function.

*ASIA/ISNCSCI Exam Chart (ASIA Impairment Scale)	
Grade A	Lack of motor and sensory function more than three levels below the level of injury (including the anal area)
Grade B	Some sensation below the level of the injury (including anal sensation)
Grade C	Some muscle movement is spared below the level of injury, but 50 percent of the muscles below the level of injury cannot move against gravity.
Grade D	Most (more than 50 percent) of the muscles that are spared below the level of injury are strong enough to move against gravity.
Grade E	All neurologic function has returned.

Glossary of Terms You May Hear

Arteriovenous malformation – Misconnection between the arteries and the veins

ASIA/ISNCSCI Exam and Grading System – System to describe spinal cord injury and help determine future rehabilitation and recovery needs. It is based on a person's ability to feel sensation at multiple points on the body and also tests motor function. Ideally, it's first given within 72 hours after the initial injury.

Autonomic Dysreflexia – Potentially life-threatening condition caused by painful stimuli below the level of injury that the body cannot respond to because of non-functioning nerve cells (especially in people with complete tetraplegia). Symptoms include painful headache due to a sudden increase in blood pressure, slowed heart rate, increased or abnormal sweating, red blotches on the skin and restlessness. It's important to be alert for causes, such as an overfull bladder, impacted stool, infected pressure ulcers or even ingrown toenails.

CT Scan (Computerized Tomography) – Provides doctors with more detailed information about spinal cord or brain damage than X-rays can show

Healthcare advocate – A person who works directly for the patient or family for a fee, helping with paperwork, billing and management of post-trauma care

Hemorrhage – Internal or external bleeding caused by damage to a blood vessel

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.

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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.

Occupational therapist – Skilled in helping individuals learn, or relearn, the day-to-day activities they need to achieve maximum independence

Paraplegia – Paralysis, or loss of motion. It typically affects the trunk and both legs, but not the arms. This is usually a result of injuries at the thoracic and lumbar levels.

Physiatrist – Doctor specializing in physical medicine and rehabilitation

Physical therapist – Skilled in helping people improve movement strategies and control pain in the presence of weakness, paralysis or sensory impairment

Recreational therapist (or therapeutic recreation specialist) – Helps patients discover the wide range of recreational options they may be able to participate in and trains them to do so

Rehabilitation nurse – Nurse with special training in rehabilitative and restorative medicine

Tetraplegia (also quadriplegia) – Paralysis from approximately the neck down. It results from injury to the spinal cord in the neck and is associated with total or partial loss of function in both arms, torso and legs.

Sensory Index Score (SIS) – Part of ASIA/ISNCSCI 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.

Vocational specialist – Helps people assess their job skills/readiness and return-to-work options

Questions Families Should Ask Their Trauma Care Medical Team

How severe is my loved one's spinal cord injury?

Which neurological level of injury does my loved one have?

What is my loved one's ASIA/ISCoS score? What does this mean for his or her future recovery?

How will the treatment you are doing right now help me/my loved one?

What secondary symptoms do I need to be aware of in people with spinal cord injury?

What kind of complications can arise from a spinal cord injury?
How can I help prevent them in my loved one?

What are the next steps? When will I know my loved one is ready for the next step?

What is the goal of rehabilitation therapy?

What level of independence can he/she look forward to having in life?

How can I learn to take care of my loved one at home?

What should I be looking for in a rehabilitation center?

What other injuries occurred in addition to the spinal cord injury?

How to Cope with Spinal Cord Injury

Spinal cord injury is devastating and life changing for both the injured person and their family. There is no “right” way to feel after an injury. Having a range of feelings, such as disbelief, anger, sadness, depression and jealousy is normal. No two people – even spouses, partners or family members – experience their feelings in the same way.

Everyone who is impaired will grieve the injury and resulting life changes, such as physical function, independence and family roles. Grieving is healthy and a process that takes time, but no one can predict how long it can last. For some people, it never ends, but improves over time. The goal of grieving is not acceptance: Everyone prefers that life would go back to the way it was before the injury. Grieving is a path leading to adjustment and adaptation. Rehabilitation provides a map for learning ways to adjust, adapt and even thrive!

Here are some important tips for the days and weeks following injury:

- Speak up and ask lots of questions.
- Tell the hospital staff, family and friends about your feelings and fears.
- Get your rest. If visitors energize you, let them come, but pace yourself in terms of the numbers and lengths of the visits.
- Take advantage of every therapeutic activity. Try, even when you don't feel up to it. Even sitting in your wheelchair is therapy.
- Get to know other patients so you don't feel as lonely.
- Talk to peer supporters. They've been where you are and are living proof of how your life has lots of possibilities.
- Remember how your family/friends are learning, too. They've never done this before either. Try to be patient with them.
- Check out **facingdisability.com** to get ideas, suggestions and support.
- Talk to your mental health professional.

Important Tips for the Days and Weeks After the Injury or Diagnosis

- Encourage family and friends to be around, but make sure the number is not too overwhelming for your healing process.
- Allow yourself and your loved one time to rest between visits.
- Try to take turns at the trauma care center so you can get some rest.
- If your loved one has medications to help them sleep or are sedated, assume that your loved one can hear you and be careful of everything that is said within earshot.
- Keep an open mind during every step of the process and never give up hope.
- Take advantage of all therapeutic opportunities.
- Talk about your feelings and concerns with supportive friends, family and spiritual leaders you trust.
- Meet with other people and families with both new and old spinal cord injuries.
- Take care of yourself in the best manner possible.

Steps to Negotiate the Insurance Maze

OBTAIN

Obtain a copy of the full (not abbreviated or summarized)

EXPLANATION OF INSURANCE BENEFITS. Read your policy carefully and thoroughly, including fine print, definitions, exclusions, etc., to learn the extent of covered services.

CONTACT

Find out if you have been assigned a **CASE MANAGER** and contact that individual; if not, request that you be assigned to a case manager, social worker or benefits advisor. To be your loved one's best advocate, you should educate the case manager about his/her spinal cord injury and particular needs to preserve the integrity of their body and health. Understand that the length of the hospital stay is driven by medical necessity to be in a rehabilitation setting.

DETERMINE

Determine the **REHABILITATION BENEFITS.** Inquire about the number of allowed days of coverage for inpatient acute and sub-acute rehabilitation, outpatient and home health rehabilitation; ask whether there is an annual maximum number of days and a lifetime maximum number of days. Understand that the length of the hospital stay is driven by medical necessity to be in a rehabilitation setting. Even if a total number of days are allowed, they may not be approved if there is not evidence to support that the patient needs to stay in a rehabilitation facility.

INQUIRE

Inquire about rehabilitation in a **SPINAL CORD INJURY-ACCREDITED REHABILITATION FACILITY**, including both in-state and out-of-state facilities.

VOICE

Contact your insurance representative for **ISSUES AND/OR CONCERNS** that relate to your health insurance and whenever you have been denied a service that you believe to be covered.

DOCUMENT

Remember to always document/record **ALL CONVERSATIONS** with your insurance company: Include the date of the call, the reason for the call, the person with whom you spoke and the outcome of the call.

EDUCATE

Educate your **INSURANCE REPRESENTATIVE** to be an advocate for your loved one's health care needs. Teach this person the risk factors for the secondary complications of spinal cord injury, necessary measures to preserve the health and integrity of your body and importance of immediate access to insurance and health care professionals.

CONTACT

If your injury occurred while on the job and you have qualified for **WORKERS' COMPENSATION**, talk to your Workers' Compensation case manager about what options for care are available to you following your trauma care treatment.

Adapted from What You Should Know About Health Insurance: Guidelines for Persons with Spinal Cord Injury (National Spinal Cord Injury Association)

Helpful Resources, and Credible Organizations and Websites

The American Trauma Society

Dedicated to the prevention of trauma and improvement of trauma care
amtrauma.org | 800-556-7890

Christopher & Dana Reeve Paralysis Resource Center

Promoting the health and wellbeing of people living with spinal cord injury, mobility impairment and paralysis by providing comprehensive information, resources and referral services
paralysis.org | 800-225-0292

Disabled Sports USA

A network of community-based chapters offering sports rehabilitation programs to anyone with a permanent disability
disabledsportsusa.org/chapters/ | info@dsusa.org

Family Voices

Aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities
familyvoices.org | 888-835-5669

Help Hope Live

Help Hope Live helps families address financial hardships arising from uninsured medical expenses related to catastrophic spinal cord or brain injury. Established in 1983 by medical professionals, Help Hope Live is a 501(c)(3) nonprofit organization that provides expert fundraising guidance to patients, families and communities nationwide, while offering fiscal accountability for funds raised.
helphopelive.org | 800-642-8399

Model Systems Knowledge Translation Center

The Model Systems Knowledge Translation Center (MSKTC) summarizes research, identifies health information needs, and develops information resources to support the Model Systems programs in meeting the needs of individuals with traumatic brain injury, spinal cord injury and burn injury.
msktc.org | 202-403-5600

Office of Disability Employment Policy

Federal government agency within the U.S. Department of Labor helping ensure that people with disabilities have equal employment opportunities
dol.gov/odep | 866-4-USA-DOL

United Spinal Association

Leading the way in maximizing the quality of life and opportunities for people with spinal cord injuries and diseases since 1948
unitedspinal.org | 718-803-3782

If your loved one has a **dual diagnosis** of both brain and spinal cord injury, you may want to access these organizations:

American Heart Association

Works to build healthier lives, free of cardiovascular diseases and stroke
heart.org | 800-242-8721

American Stroke Association

Works to build healthier lives, free of cardiovascular diseases and stroke
stroke.org | 800-242-8721

Brain Injury Association of America

Dedicated to increasing access to quality health care and raising awareness and understanding of brain injury through advocacy, education and research
biausa.org | 800-444-6443

Brain Trauma Foundation

Dedicated to improving the outcome of traumatic brain injury (TBI) patients worldwide by developing best practices guidelines, conducting clinical research, and educating medical professionals and consumers
braintrauma.org | 800-934-6866

This booklet is a companion to the DVD **Understanding Spinal Cord Injury**. Together, these tools can help you understand and navigate this challenging time in your life.

DVD Chapters

- 1 Introduction and About This Video
- 2 The Anatomy of the Spinal Cord and How it Works
- 3 Understanding Spinal Cord Injury, its Causes, Effects and Classifications
- 4 Tests, Surgery, Post-Op Devices, Secondary Complications and Prevention Techniques
- 5 Levels of Injury Explained
- 6 Practical Advice for Coping with Spinal Cord Injury

Visit [SpinalInjury101.org](https://www.SpinalInjury101.org) to learn more about this video series.