Understanding SPINAL CORD INJURY
What you should know about spinal cord injury and recovery

Produced by Shepherd Center and KPInteractive 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 damage to 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 damage in the spinal cord. In general, the higher on the spinal cord the injury occurs, the more dysfunction 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**

<table>
<thead>
<tr>
<th>Motor vehicle accidents</th>
<th>Football</th>
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<tr>
<td>Falls</td>
<td>Gymnastics</td>
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<tr>
<td>Violence</td>
<td>Diving into shallow water</td>
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Spinal cord injuries affect more men than women. The majority of people who sustain a spinal cord injury are young adults between the ages of 16 and 30 because of riskier behaviors.

**Non-traumatic injuries/illnesses**

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Osteoporosis</th>
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<tbody>
<tr>
<td>Multiple sclerosis</td>
<td>Inflammation of the spinal cord</td>
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<tr>
<td>Arthritis</td>
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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
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 are affected, this is called tetraplegia or quadriplegia.
- Requires complete assistance with activities of daily living, such as eating, dressing, bathing, 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 personal care
Low-Cervical Nerves (C5 – C8)

- Corresponding nerves control arms and hands.
- A person with this level of injury may be 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 breathing 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 breathing 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.

**C8 injury**
- Nerves control some hand movement.
- Should be able to grasp and release objects.
- 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
- Can stand in a standing frame, while others may walk with braces

**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 braces.
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 braces.

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 a patient’s spinal cord injury and help determine future rehabilitation and recovery needs. It is ideally completed within 72 hours after the initial injury. The patient’s 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/ISCoS Exam Chart (ASIA Impairment Scale)*

<table>
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<tr>
<th>Grade</th>
<th>Description</th>
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<tr>
<td>Grade A</td>
<td>Complete lack of motor and sensory function below the level of injury (including the anal area)</td>
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<tr>
<td>Grade B</td>
<td>Some sensation below the level of the injury (including anal sensation)</td>
</tr>
<tr>
<td>Grade C</td>
<td>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.</td>
</tr>
<tr>
<td>Grade D</td>
<td>Most (more than 50 percent) of the muscles that are spared below the level of injury are strong enough to move against gravity.</td>
</tr>
<tr>
<td>Grade E</td>
<td>All neurologic function has returned.</td>
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Glossary of Terms You May Hear

**Arteriovenous malformation** – Misconnection between the arteries and the veins

**ASIA/ISCoS Exam and Grading System** – System to describe spinal cord injury and help determine future rehabilitation and recovery needs. It is based on a patient’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.

**Complete injury** – No function or sensation below the level of the injury

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

**Incomplete injury** – Some sensory or motor function below the primary level of the injury

**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.

**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** – Treats disabilities that result from motor and sensory impairments

**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 and legs.

**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.

**Vocational therapist** – 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?
Expected Emotions and Helpful Coping Tips

Emotional stages you will probably experience are: first, denial and disbelief; second, sadness, anger and bargaining; and third and most important, acceptance.

It’s natural and important to grieve the loss of the way things were before the injury. It’s also necessary to set new goals and find a way to move forward with your life.

As you begin to accept the consequences of what has happened, you can start to plan how to make the best of the challenge you’re facing.

Your relationships with family and friends will be tested, you may feel overwhelmed or try to go on like nothing has changed. Everyone copes with these feelings in different ways. With time and support, you’ll begin to adjust to the challenge of spinal cord injury and understand your “new normal.” As you go through this process, be sure to:

- Empower yourself with as much knowledge as you can.
- Check out local and state support groups, as well as nationally recognized spinal cord injury organizations, such as the National Spinal Cord Injury Association, The American Trauma Society and the Christopher & Dana Reeve Foundation.
- Be wary of random internet surfing of topics related to spinal cord injury.
- Rely on Websites from reputable organizations that have already consolidated information and offer helpful tools and checklists.
Important Tips for the Days and Weeks After the Injury or Diagnosis

- Limit visits and the number of visitors at any given time.
- 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.
- Have everyone who visits maintain a soft and calm tone of voice.
- 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 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.

**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.

**INQUIRE**

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

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*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 Web Sites

**The American Trauma Society**  
Dedicated to the prevention of trauma and improvement of trauma care  
www.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  
www.paralysis.org | 800-539-7309

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

**Disabled Sports USA**  
A network of community-based chapters offering sports rehabilitation programs to anyone with a permanent disability  
www.dsusa.org/chapter.html | information@dsusa.org

**National Spinal Cord Injury Association**  
Leading the way in maximizing the quality of life and opportunities for people with spinal cord injuries and diseases since 1948  
www.spinalcord.org | 800-962-9629

**NTAF**  
NTAF helps families address financial hardships arising from uninsured medical expenses related to catastrophic spinal cord or brain injury. Established in 1983 by medical professionals, NTAF 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.  
www.ntafund.org | 800-642-8399
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
www.dol.gov/odep | 866-487-2365

Spinal Cord Injury Information Network
The UAB-SCIMS works to maintain and improve a cost-effective, comprehensive service delivery system for people who incur a spinal cord injury. A Model System facility must demonstrate outstanding care to individuals with spinal cord injury, from the emergency medical services to acute care in the hospital to rehabilitation.
www.spinalcord.uab.edu | 205-934-3450

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
www.americanheart.org | 800-242-8721

American Stroke Association
Works to build healthier lives, free of cardiovascular diseases and stroke
www.strokeassociation.org | 888-478-7653

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
www.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
www.braintrauma.org | 212-772-0608
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**

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<th>Title</th>
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<td>Introduction and About This Video</td>
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<tr>
<td>2</td>
<td>The Anatomy of the Spinal Cord and How it Works</td>
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<td>3</td>
<td>Understanding Spinal Cord Injury, its Causes, Effects and Classifications</td>
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<td>5</td>
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<tr>
<td>6</td>
<td>Practical Advice for Coping with Spinal Cord Injury</td>
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Visit [SpinalInjury101.org](http://SpinalInjury101.org) to learn more about this video series.