

SPINAL CORD INJURY

A Guide for
Caregivers



Shepherd
Center



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Shepherd Center, located in Atlanta, Ga., is a private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury or brain injury. Founded in 1975, Shepherd Center is ranked by *U.S. News & World Report* among the top 10 rehabilitation hospitals in the nation and is a 152-bed facility. For more information, visit Shepherd Center online at shepherd.org.

New 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

Introduction

You will likely get a lot of information about a spinal cord injury in the coming days. Caregivers, well-meaning friends, the Internet, spinal cord injury support groups, families of other patients ... all are good sources of information, but it's a lot to take in. Don't try to learn everything at one time. Rely on your loved one's caregivers to let you know what you need to be concerned about next. You've come to the right place, and your loved one is in the hands of experienced caregivers.

The first few hours, days and weeks following a spinal cord injury are a scary and difficult time for a patient's loved ones. Getting over the shock of the initial injury and learning everything you need to know about what will come next can sometimes be overwhelming. The fact that recovery from spinal cord injury is unpredictable can be very frustrating.

The medical world is sometimes fast-paced, and care happens around the clock. There is a whole new language to learn. Answers may seem hard to come by right now. Understanding all of this and what it means for your loved one will come in time. Right now, you need to do what you can to cope and to take care of yourself, hour by hour and then day by day.

In the pages of this booklet, you'll find information and advice that will help you through these first weeks. You'll also find comments from families of patients who have walked this road before you. More than anything else, what they want you to know is, "It's going to be OK." Whatever level of recovery your loved one makes, you are surrounded by a team of knowledgeable and caring professionals who will help all of you make the changes you'll need to make in order to return to a more normal daily routine.

What you will find in this booklet:

- Spinal Cord Injury 101
- What to Expect
- Taking Care of Yourself
- Resources

Spinal Cord Injury 101

The most important – and sometimes frustrating – thing to know is that every person’s recovery from spinal cord injury is different. Doctors will make educated predictions based on the location, type, and extent of injury, but in the end, each person’s recovery will be different.

Spinal cord injury can affect a person physically as well as emotionally. Some problems we will look for include:

Physical

- Loss of sensation (feeling)
- Loss of movement
- Changes in bowel & bladder control
- Inability to cough
- Inability to breathe properly
- Changes in blood pressure & circulation

Emotional

- Denial
- Depression
- Anxiety
- Grief
- Anger

Some Information About the Spinal Cord

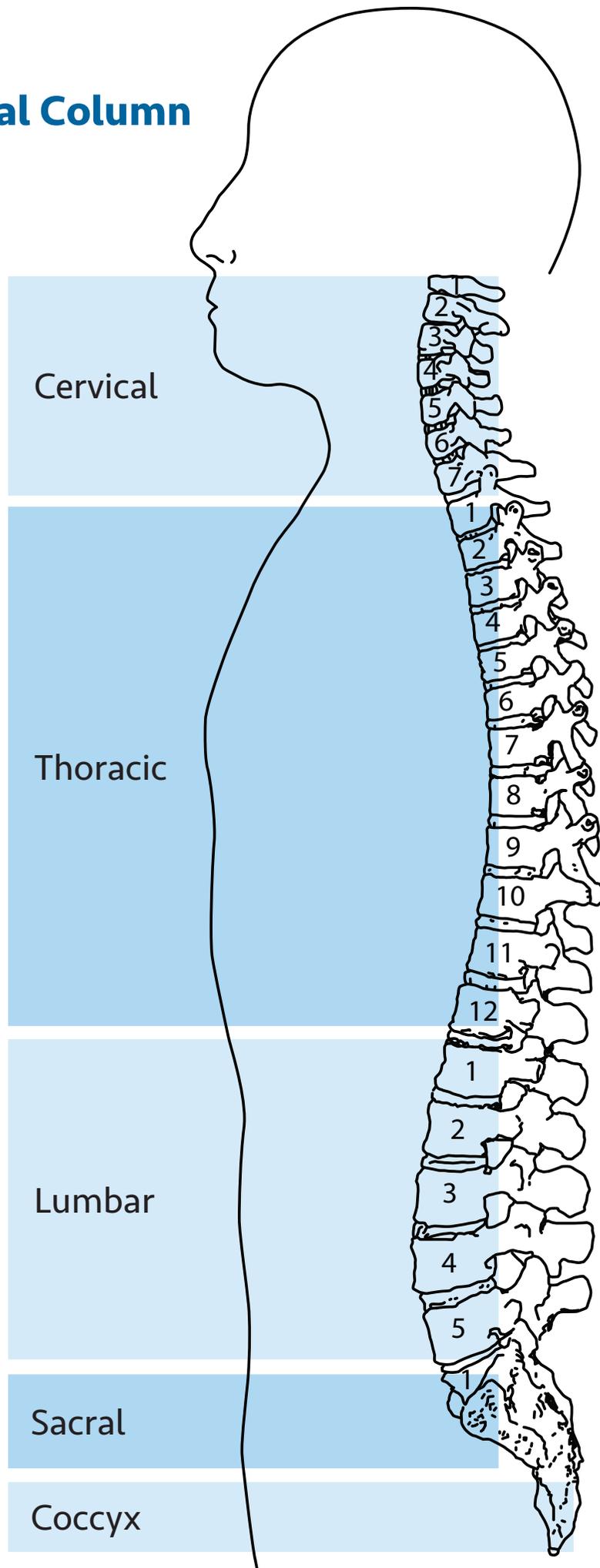
- Your neck and backbones (also called vertebrae) surround and protect your spinal cord. The main job of your spinal cord is to be the communication system between your brain and your body. You can break your neck or back bones and not hurt your spinal cord. If the spinal cord is damaged, you can lose messages about feeling and movement from the damaged point and below. The chart on the next page will show you the relationship between nerves and muscles.
- Damage to the spinal cord can happen in many ways. It can be from loss of blood to the cord from a tumor, a stenosis (narrowing of the bony area where the cord sits) or even a stroke on the cord. Or the damage can be from a motor vehicle collision or a fall where the vertebra is broken, and that can crush, penetrate or pinch the spinal cord.
- The recovery takes place when the bony problems are fixed in surgery (if needed) and the swelling on the cord starts to go down. Sometimes after the swelling goes down you may get more feeling or movement in your body. Remember that it is almost impossible to determine who will have return of feeling or movement.

Spinal Cord Level / Spinal Nerve	Spinal Nerve Connected to Muscle	What Can the Muscles Do?
C1 to C3	<ol style="list-style-type: none"> 1. Neck (<i>sternocleido-mastoid</i>) 2. Shoulder (<i>trapezius</i>) 	<ol style="list-style-type: none"> 1. Some neck control 2. Some shoulder shrug
C2 to C4	<ol style="list-style-type: none"> 1. Diaphragm 2. Neck (<i>sternocleido-mastoid</i>) 3. Shoulder (<i>trapezius</i>) 	<ol style="list-style-type: none"> 1. Breathing 2. Some neck control 3. Shrug shoulders
C5	<ol style="list-style-type: none"> 1. Shoulder (<i>deltoid</i>) 2. Arm (<i>biceps</i>) 	<ol style="list-style-type: none"> 1. Good neck control 2. Fair to good shoulder control 3. Arm bends at elbow
C6	<ol style="list-style-type: none"> 1. Wrist extension 2. Forearm extension 	<ol style="list-style-type: none"> 1. Bend wrist up 2. Hold objects using wrist extension
C7	<ol style="list-style-type: none"> 1. All arm (<i>triceps</i>) 2. Some finger extension 	<ol style="list-style-type: none"> 1. Straighten arm at elbow
C8	<ol style="list-style-type: none"> 1. Partial hand 2. Some / back 	<ol style="list-style-type: none"> 1. Arm function is normal and hand/finger movement begins
T1 to T5	<ol style="list-style-type: none"> 1. All hand muscles 2. Upper chest and more back muscles 	<ol style="list-style-type: none"> 1. All arm and hand function is normal 2. Upper body balance is affected
T6 to T12	<ol style="list-style-type: none"> 1. All chest 2. Trunk muscles (<i>depending on level</i>) 3. Abdominal muscles 	<ol style="list-style-type: none"> 1. All upper body 2. Fair to good trunk control (<i>balance</i>) 3. Coughing muscles
L1 to L5	<ol style="list-style-type: none"> 1. All lower back 2. Some leg (<i>quadriceps</i>) 	<ol style="list-style-type: none"> 1. Bend hips 2. Straighten knees (L3) 3. Pull ankle up (L4) 4. Extend toe (L5)
S1 to S5	<ol style="list-style-type: none"> 1. Knee 2. Ankle 3. Bowel control 4. Bladder control 	<ol style="list-style-type: none"> 1. Straighten hip 2. Bend knee 3. Good ankle control 4. Point toe 5. May begin to control bowel/bladder

Use this chart as a general guideline, keeping in mind that everyone is unique. Goals should be set based on the person's own unique abilities and recovery.

Source: The American Spinal Injury Association (ASIA), International Medical Society of Paraplegia. Supported by the American Paraplegia Association.

The Spinal Column



Use this chart as a general guideline, keeping in mind that everyone is unique. Goals should be set based on the person's own unique abilities and recovery.

Source: The American Spinal Injury Association (ASIA), International Medical Society of Paraplegia. Supported by the American Paraplegia Association.

What to Expect in the Intensive Care Unit

Your loved one is most likely in the Intensive Care Unit (ICU) of the hospital, where the nurses and doctors can constantly monitor his or her condition. Entry into the ICU provides the first steps in the recovery process. The first view you have of your loved one may be upsetting.

- Don't be alarmed by the number of tubes and wires you see hooked up to your loved one's body. They all serve a purpose in delivering medication or monitoring the body functions so that the medical staff can be aware of the slightest change.
- You may see cuts, swelling or bruising, depending on the nature of the injury. This will heal.
- Your family member may or may not be able to feel you touching them. It is ok to still touch them or hold their hands even though they may not feel it; it is comforting to know you are there. You may need to inform them that you are touching them.
- Visiting hours in ICU are limited. The nurses will tell you when you can visit.
- The goal of the ICU stay is to medically stabilize your loved one.
- Once stabilized, your loved one will be transferred to a hospital room.

What You Can Do

Always check with your loved one's caregivers before initiating any activity. The location of their injury on the spinal cord will affect how much they can do for themselves.

- Don't overdo it. Balance time to rest between your visits.
- Limit the number of visitors at one time and maintain a calm tone of voice.
- Remind your loved one of the date, place and situation.
- Encourage deep breathing and coughing.
- Assume he or she can hear you. Be careful not to say anything upsetting within earshot.
- Don't take bad behavior personally; this confusion and agitation is expected.

Be involved with the care giving to your family member. If you are not comfortable doing hands-on activities with your loved one, have the caregiver explain the care they are providing. These activities may include bathing, grooming, feeding, range of motion or skin checks. The more you are involved with their care, the easier your transition to rehabilitation will be.

What to Expect in the Rehab Setting

As your loved one's health status improves, the doctor may recommend transferring into a rehabilitation program. The main goal of rehabilitation is usually to increase a person's strength, learn new ways to do things after an injury and reintegrate back into their lives and community. Not only is this a time for your loved one to learn, but it's a time for you to learn how to help them.

What you should bring to rehab for your loved one:

- Loose comfortable clothing such as elastic waist shorts, sweat pants, T-shirts, socks, underwear (consider boxers) and shoes (buy shoes at least one size larger and make sure they have a rubber sole)
- Toiletry items such as a toothbrush, toothpaste, comb, brush, shampoo, soap and deodorant
- Familiar items such as photos, stuffed toys, comfort items, such as a favorite pillow, blanket or music
- Remember to leave any valuable items at home

Keeping Track of the Details

This journey is a long one and there will be many detours along the way. Once the first few hours or days have passed, you must take breaks from the hospital to sustain yourself for the coming weeks and months. You also need to find a system that works for you in terms of how you organize the questions you have, the information you need to receive, and the people you talk with.

Being a caregiver is not something you may be automatically prepared to do, but these ideas will help:

- **Buy several small notebooks.**
Use one for phone numbers, one for doctor/treatment team information and questions, and one for information about insurance and other financial matters.
- **Choose a spokesperson.**
Family members and friends will want information, and it is exhausting to repeat the daily updates. You can appoint someone to keep notes and provide updates via phone or the Internet to update concerned family and friends.
- **Stay in touch with your case manager, who will assist you along the way with discharge plans.**
- **Use this time to learn about brain injury, but take it slow.**
There is a lot of information, and it can be overwhelming. The library staff at the hospital, the chaplain and your loved one's case manager can help supplement the information you receive from the doctors.
- **Start a journal if it seems like something that would help you deal with your grief.**
Reading it might be helpful to your loved one as he/she recovers.
- **Encourage your loved one to talk to other people who are recovering from a similar injury or illness.**

Taking Care of Yourself

Taking care of yourself may seem time-consuming or even selfish, but your loved one needs you to be rested, well-fed, alert and energetic so that you are up to the task of caregiver. You can:

Here are some things you should do for yourself:

- Save your energy by resting when you can
- Eat healthy meals; skip the vending machines
- Exercise a little each day; go for a walk, stretch your muscles
- Leave the hospital. Your loved one is in good hands
- If you are experiencing any medical problems, such as heart palpitations, muscle aches and pains, headaches or difficulty thinking, sleeping, remembering things or making decisions, call your doctor
- Keep life as normal as possible for your children if you have them, and try to do something special with them once a week
- Ask friends and family to write short notes instead of calling. That way you'll have something to read to your loved one
- Talk about your feelings with family, friends or someone at the hospital (a psychologist, counselor, case manager, chaplain or other staff members can help you)
- Accept offers of help from family and friends; it gives them a way to be a part of the recovery. You might keep a list of things that need to be done (caring for pets and houseplants, picking up the mail, scheduling activities for children, etc.) so that you'll be prepared when someone asks
- Allow yourself to put off "until tomorrow" what doesn't have to be done in one day, but do try to take care of some personal business every day

Resources

Spinal Cord Injury 101

This is a video series developed by Shepherd Center, in partnership with the Brain Injury Association of America, the American Trauma Society and the Christopher and Dana Reeve Foundation. The video can be viewed online at BrainInjury101.org. It is intended to educate patients and families about their new injury and functional expectations for the weeks and months ahead.

SpinalInjury101.org

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

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