



Spinal Cord Injuries: Information for the Newly Injured

International Edition

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Christopher & Dana Reeve Foundation
Paralysis Resource Center
636 Morris Turnpike, Suite 3A
Short Hills, NJ 07078
1-800-539-7309 (Toll-free)
973-467-8270

www.paralysis.org

Email an Information Specialist: infospecialist@ChristopherReeve.org

Getting Started

Learning that a family member or friend has suffered a spinal cord injury is devastating and overwhelming news. The best way to combat your feelings of helplessness and confusion is to arm yourself with information on what a spinal cord injury is, and what it means in terms of short-term planning and long-range goals.

This New Injury resource is designed to help individuals who are beginning to locate spinal cord injury (SCI) information for an individual who is newly injured. Navigating your way through this new world can be confusing and overwhelming. We have developed a list of the top eight questions to start you on your way.

If you have not done so already, please visit the Reeve Foundation's website at www.paralysis.org. This website provides a wealth of information for the newly injured as well as for those living with SCI for years. You can find valuable links to other organizations as well as information specific to advances in SCI research. The Reeve Foundation offers a free 442-page book called the *Paralysis Resource Guide (PRG)*. To order call 1-800-539-7309 or go to www.ChristopherReeve.org/Guide to view it online.

There is an online community called the Paralysis Community that you can join and post questions in order to gain support from others in the spinal cord injury community whose circumstances are similar to yours. Please see this link for the Paralysis Community: www.ChristopherReeve.org click on "Join the Discussion" in the top right corner, then click on "Discussions".

Staying in touch with loved ones and friends while also managing a healthcare challenge can be difficult. But staying connected is a crucial component to getting, and staying well—for both patients and caregivers. The Reeve Foundation's Paralysis Resource Center understands these obstacles, and we're prepared to help.

You can stay connected with family, friends and colleagues before, during and after hospitalization and rehabilitation through a number of websites. CarePages.org, CaringBridge.org and Lotsahelpinghands.com provide free, private websites that make it easy to communicate with family, friends and colleagues. These sites allow you to post entries on the condition and care of your loved one while they are in the hospital or rehabilitation center via your personal webpage that you set up for your family member. You can also receive messages of encouragement to help sustain you during this difficult transition in your life.

Lotsahelpinghands.com allows you to create your personal community to assist you in your time of need. Some unique options include a calendar to schedule volunteers, meals, rides and visits. In addition, Lotsa Helping Hands allows you to post updates on your family member's recovery.

What is a Spinal Cord Injury?

What is a spinal cord injury? Spinal cord injuries commonly lead to paralysis; they involve damage to the nerves within the bony protection of the spinal canal. The most common cause of spinal cord dysfunction is trauma (including motor vehicle accidents, falls, shallow diving, acts of violence, and sports injuries). Damage can also occur from various diseases acquired at birth or later in life, from tumors, electric shock, and loss of oxygen related to surgical or underwater mishaps. The spinal cord does not have to be severed in order for a loss of function to occur. The spinal cord can be bruised, stretched, or crushed. Since the spinal cord coordinates body movement and sensation, an injured spinal cord loses the ability to send and receive messages from the brain to the body's system that controls sensory, motor, and autonomic function. This packet will take you step by step through layers of understanding a spinal cord injury.

The following information is divided into the top eight questions most frequently asked about spinal cord injuries. Since each injury is different as to its level and severity, the answers and information are provided in general terms to give the framework so that you can have the information you will need to make the best decisions for your loved one.

- The **first** question outlines what occurs following a spinal cord injury or what is suspected to be an SCI.
- The **second** question defines a spinal cord injury at the level of injury to the spinal cord as well as describes the difference between a complete and an incomplete injury.
- The **third** question addresses the secondary conditions associated with a spinal cord injury, that is, how the SCI will affect other organs and systems in the body.
- The **fourth** question addresses how to locate an appropriate rehabilitation facility.
- The **fifth** question describes the clinical trials process.
- The **sixth** question suggests resources for funding of rehabilitation and necessary medical equipment.
- The **seventh** question talks about stem cell research.
- The **eighth** question provides information on depression and adjusting to spinal cord injury.

1. What immediate interventions can I expect?

- Stabilization
- Neuroprotection
- Classifying the Injury
- Surgical Interventions
- Surgical Stabilization
- Spinal Fusion
- Respiratory

Stabilization:

Once a person is injured, the stabilization of the patient's breathing, blood pressure, spinal cord (in most cases with the use of a back board and a cervical neck collar at the

scene of the initial injury) and vital signs along with treatment of other trauma related to the injury are top priority. The patient with a suspected SCI will most likely be brought to or moved to the nearest Level 1 Trauma Center. A Level 1 Trauma Center provides the highest level of surgical care to trauma patients. It has a full range of specialists and equipment available 24 hours a day and admits a minimum required volume of severely injured patients per year.

During the early days of hospitalization, a variety of medications may be used to control the extent of the damage to the spinal cord, alleviate pain, treat infections, and other issues related to the injury. Patients may be sedated and put into traction to prevent further damage. Some other types of traction techniques are metal bracing attached to weights or a body harness, a halo to prevent the head from moving, or a rigid neck collar.

Neuroprotection:

These therapies, also called neuroprotective therapies, aim to stop or reduce the immediate responses (such as swelling) to the injury that may further spinal cord damage. Methylprednisolone is sometimes used in the first few hours after an injury as it may reduce inflammation and improve recovery. Methylprednisolone is a steroid that is given through an IV, and must be administered within the first eight hours after a spinal cord injury if at all. It may not be appropriate to use it in all cases.

Therapeutic hypothermia (spinal cord cooling) is a medical treatment that lowers the body temperature in order to protect the cells in the body from damage after a traumatic spinal cord injury, stroke or cardiac event. Body temperature can be lowered by invasive and non-invasive methods. Invasive methods use catheters filled with saline that cool a patient's whole body by lowering the temperature of the patient's blood as it leaves the heart.

Non-invasive techniques use water blankets that push cold water through a blanket. These blankets are typically combined with ice packs or cold fans in order to achieve more rapid temperature decline.

According to the American Association of Neurological Surgeons, there is currently no published data that shows that patients who are treated with therapeutic hypothermia for spinal cord injury improve compared to patients who are not treated using this method. The use of local therapeutic hypothermia at the time of surgery appears safe but no criteria for treatment guidelines has been established. Currently, there is not enough evidence available to recommend for or against therapeutic hypothermia with traumatic spinal cord injury.

<http://www.spinesection.org/hypothermia.php>

Classifying the Injury:

Physicians will determine the level and extent of the injury by using x-rays, MRIs, or CT scans. The patient will also undergo a thorough neurological examination by doctors.

This examination looks for evidence of, or lack of, sensation, muscle tone, reflexes of all limbs and the trunk. The level of injury may differ from what is seen on the x-rays or scans because the level of injury is based on function. This will be reflected in the ASIA scale* that will be assigned by the doctors. The ASIA scale is a tool used to classify the spinal cord injury patient into various categories including ASIA A, B, C, D, or E. During an ASIA classification, the physician will be looking at a variety of determinants such as muscle movement, range of motion, and noting whether or not the person can feel light touch or sharp and dull sensations.

*ASIA Scale: American Spinal Injury Association Classification of Spinal Cord Injury
http://www.asia-spinalinjury.org/elearning/ISNCSCI_Exam_Sheet_r4.pdf

Surgical interventions:

Once the patient is medically stable they will meet with a surgeon to make the decision on potential surgical-based interventions. Surgery is recommended for many reasons such as removal of bone fragments, foreign objects, blood clots, herniated disks, fractured vertebrae, spinal tumors or anything that appears to be compressing the spine. Surgery to stabilize the spine helps to prevent future pain or deformity.

Surgical Stabilization:

Stabilization of the spinal cord is a common surgical intervention following a spinal cord injury. This procedure removes bone fragments and restores the alignment of the vertebrae thus reducing compression on the spinal cord. There are two types of stabilization, early stabilization which occurs within the first 72 hours and delayed stabilization that occurs after the body has been medically stabilized.

Spinal Fusion:

If the vertebrae in the spinal column appear unstable, the doctor may perform a spinal fusion. A spinal fusion is done with metal plates, screws, wires and/or rods and sometimes small pieces of bone from other areas of the body (usually the hip or knee) or from a cadaver (bone bank) are used. With the help of the bone grafts, the patient's bones begin growing together which serves to fuse the vertebrae. In cervical injuries the stabilization can be done through the throat (anterior) or through the neck (posterior) or both. Thoracic and lumbar injuries are usually approached through the back.

Respiratory:

The lungs themselves are not usually affected by paralysis but the muscles of the chest, abdomen, and diaphragm may be. If complete paralysis occurs at level C3 or above, the phrenic nerve is no longer stimulated and the diaphragm will not function. Some individuals with lower level injuries may also need ventilator assistance for short periods of time before they can breathe on their own ("be weaned off the ventilator"). Individuals who need ventilator assistance and people injured during water sports may be at risk of pneumonia, lung damage, and other respiratory problems as a result of water entering their lungs at the time of the accident. Successful weaning from a ventilator is impacted by many factors: age, level of injury and time spent on the ventilator. For more detailed information on respiratory management, you can download the clinical practice guideline "Respiratory Management Following Spinal Cord Injury" by the Paralyzed Veterans of

America (www.pva.org). (After you get to their home page, click on Get Support, click on Publications, click on Guidelines and Publications, click on Download CPGs and consumer versions.) This clinical practice guideline also provides info on proper weaning from a ventilator.

People injured at the mid-thoracic level or higher may have trouble taking deep breaths and exhaling forcefully. This can lead to lung congestion and respiratory infections. Ways of preventing respiratory complications include maintaining proper posture, coughing regularly or with assistance, following a healthy diet, drinking plenty of fluids, not smoking or being around smoke, exercising, and getting vaccinated for influenza and pneumonia.

2. Can you help me understand what my injury means?

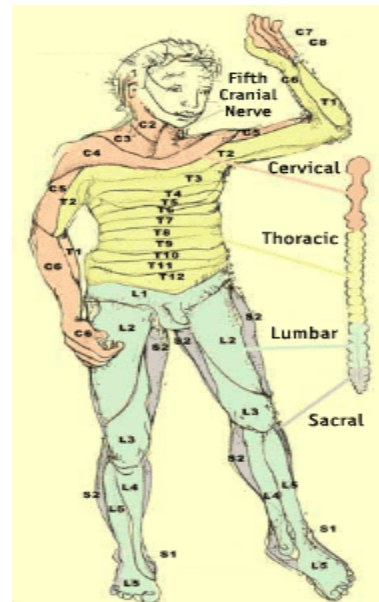
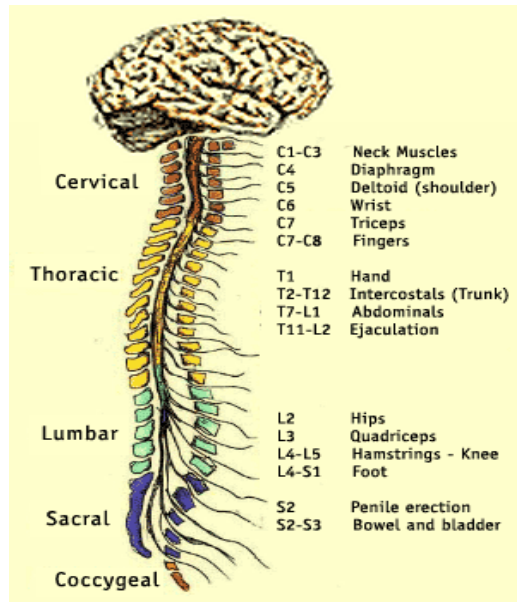
- Injury Styles
- Cervical Spinal Cord Injuries
- Thoracic Spinal Cord Injuries
- Lumbar Spinal Cord Injuries
- Sacral Spinal Cord Injuries
- Complete Versus Incomplete

For more information on spinal cord injury, please refer to Chapter 1 of the Reeve Foundation's free *Paralysis Resource Guide* in print or viewable online at: www.ChristopherReeve.org/Guide

The location of the spinal cord injury dictates the parts of the body that are affected. After a complete examination, the doctor will assign a level of injury. The four regions of the spinal cord are; Cervical, Thoracic, Lumbar, and Sacral. The doctor will also determine if the injury is complete or incomplete. The level of injury and function may change. The initial level of injury may not be the same level upon discharge to rehabilitation. It is **important** to remember that these are general guidelines and that individual outcomes will vary.

Injury Styles:

Some of the types of injury styles are simple fractures, teardrop fracture, dislocation, burst; some mechanisms of injury are compression, hyperextension, hyperflexion; some resultant syndromes (types of clinical presentation) are: cauda equina, conus medularis, central and anterior cord syndrome, Brown-Sequard syndrome. The style of injury is generally dependent on the manner in which the person is injured.



Cervical Spinal Cord Injury C1 – C8 **(Quadriplegia also known as Tetraplegia)**

Cervical level injuries cause paralysis or weakness in both arms and legs (quadriplegia). All regions of the body below the level of injury or top of the back may be affected. Sometimes this type of injury is accompanied by loss of physical sensation, respiratory issues, bowel, bladder, and sexual dysfunction. This area of the spinal cord controls signals to the back of the head, neck and shoulders, arms and hands, and diaphragm. Since the neck region is so flexible it is difficult to stabilize cervical spinal cord injuries. Patients with cervical level injuries may be placed in a brace or stabilizing device.

Thoracic Spinal Cord Injury T1- T12 **(Paraplegia)**

Thoracic level injuries are not as common because of the protection given by the rib cage. Thoracic injuries can cause paralysis or weakness of the legs (paraplegia) along with loss of physical sensation, bowel, bladder, and sexual dysfunction. In most cases, arms and hands are not affected. This area of the spinal cord controls signals to some of the muscles of the back and part of the abdomen. With these types of injuries most patients initially wear a brace on the trunk to provide extra stability.

Lumbar Spinal Cord Injury L1-L5 **(Paraplegia)**

Lumbar level injuries result in paralysis or weakness of the legs (paraplegia). Loss of physical sensation, bowel, bladder, and sexual dysfunction can occur. The shoulders, arms, and hand function are usually unaffected. This area of the spinal cord controls signals to the lower parts of the abdomen and the back, the buttocks, some parts of the external genital organs, and parts of the leg. These injuries often require surgery and external stabilization.

Sacral Spinal Cord Injury S1 – S5 (Paraplegia)

Sacral level injuries primarily cause loss of bowel and bladder function as well as sexual dysfunction. These types of injuries can cause weakness or paralysis of the hips and legs. This area of the spinal cord controls signals to the thighs and lower parts of the legs, the feet, and most external genital organs.

Complete and Incomplete:

An incomplete injury means that the ability of the spinal cord to convey messages to or from the brain is not completely lost. A complete injury is indicated by a total lack of sensory and motor function below the level of injury, especially in the rectal area. But the absence of motor and sensory function below the injury site does not necessarily mean that there are no remaining intact axons or nerves crossing the injury site, just that they do not function appropriately following the injury.

3. How might my health be impacted?

- Blood Clots (deep venous thrombosis or DVT)
- Autonomic Dysreflexia
- Pneumonia
- Skin Care/Pressure Sores (decubitus ulcers or pressure ulcers)
- Low Blood Pressure (hypotension)
- Spasticity
- Pain
- Bladder/Urinary Tract Infections
- Bowel Management

The above conditions are sometimes known as secondary conditions because they follow or are caused by the spinal cord injury. Please note that having a spinal cord injury does not mean that you will automatically get any or all of these conditions. For more information on secondary conditions, please refer to Chapter 2 of the Reeve Foundation's free *Paralysis Resource Guide* in print or viewable online at:

www.ChristopherReeve.org/Guide

Blood clots (deep venous thrombosis or DVT):

Blood clots can be common in the first few months after a spinal cord injury and throughout the entire span of your injury when illnesses occur. Walking and leg movement promotes blood circulation and prevents blood clots from forming. However, when legs lack the ability to have movement or walk, the risk of blood clots increases. Excessive bed rest may also raise your risk. One way to prevent clots is the use of circulation stockings which is a special type of support hose that maintain pressure on the leg. Sequential compression devices are used as well. These machines use bags of air to put pressure on the legs. Blood thinners may be used in some cases. Some individuals may have filters placed in their femoral artery. These filters stop the blood clots from reaching the lungs, heart and brain. Warning signs of blood clots in legs are swelling,

redness, bluish or whitish discoloration of skin, warmth to the touch, and pain. You can be proactive and examine your extremities daily for signs of a possible clot.

For a free wallet card on DVT from the Reeve Foundation, please go to www.ChristopherReeve.org/dvt

Autonomic Dysreflexia:

Autonomic Dysreflexia is your body's abnormal response to a problem below your level of injury. Autonomic dysreflexia (AD) is a condition that usually occurs with injuries at T6 level and above. It is an over-activity of the autonomic nervous system causing an abrupt and dangerous rise in blood pressure. Autonomic dysreflexia is triggered from an irritating, painful, or uncomfortable stimuli below the level of injury. Symptoms may include severe headache, goose bumps, sweating above level of injury, nasal congestion, hypertension (blood pressure significantly above the patient's baseline pressure), slow pulse (less than 60 beats per minute), flushed face, and clammy skin. It is important that individuals with spinal cord injury learn to recognize their symptoms so they can start treatment.

Since some individuals in the medical field may be unaware of autonomic dysreflexia, individuals at risk of AD should carry information or a card about this condition in case of a medical emergency. This is to ensure prompt and appropriate treatment of AD.

Treatment:

Identify and remove the stimulus causing the discomfort. Check bladder or catheter for fullness or kinks in tubing; check the bowel for impaction, the skin for abnormalities such as bruising/burns/ingrown toenails/pressure sores and broken bone. Check clothing for tightness and be aware of extreme hot and cold temperatures. In women, menstrual cramps or ovarian cysts may also be the cause. There are prescription medicines that can help in lowering blood pressure during an AD event. Work with your doctor to learn your signs and to develop a treatment plan. Autonomic dysreflexia is a medical emergency that needs to be treated at the first signs of an episode to prevent further complications that can result from hypertension such as stroke or other cardiovascular complications.

Prevention:

Autonomic dysreflexia is preventable and manageable when you learn and recognize your individual triggers. Some ways to prevent an episode of AD are to relieve pressure while lying in bed or sitting in a wheelchair. Other means of prevention are using sunscreen, monitoring your water intake and air temperature, avoiding tight-fitting clothing, maintaining a proper bowel/bladder program, and keeping catheters clean.

For a free wallet card on AD from the Reeve Foundation, please go to www.ChristopherReeve.org/adcard

Pneumonia:

With cervical and mid-thoracic level injuries, pneumonia is a possible complication due to secretions building up in the lungs as a result of not being able to inhale and exhale forcefully or cough effectively. Bacteria can then build up and infect the lungs. Pneumonia commonly occurs as a result of water related injuries because water gets into the lungs and particles of debris can be aspirated. The symptoms of pneumonia are shortness of breath, pale skin, fever, and increased chest congestion. It is important to be aggressive with pulmonary-based infections and seek medical treatment. The best way to prevent pneumonia is to be consistent with clearing secretions to maintain good respiratory health.

Skin Care/Pressure Sores (decubitus ulcers or pressure ulcers):

Pressure sores can have many different names but they all refer to a serious and potentially dangerous condition. The healing process can take a long time and it is important to be aware of the warning signs. Pressure sores develop when certain areas on the body are under prolonged pressure which creates a decrease in blood flow to the area. If the pressure is relieved, skin can improve; but if the pressure persists it can potentially turn into a pressure sore. The common areas for pressure sores to develop are any bony area of the body. Skin ulcers may be prevented by changing body position every two hours, wearing loose, comfortable clothing, keeping skin moisture free, and by using proper seating and positioning. Sometimes, skin ulcers occur as a result of a trivial trauma (scrape occurring during a transfer, minor cut from not wearing shoes). No skin injury is to be ignored in the setting of paralysis!

There are four stages of pressure sores.

Stage 1: Skin is not broken but it is red and color does not fade 30 minutes after pressure is removed. Stay off the affected area and maintain proper hygiene.

Stage 2: The top layer of skin (the epidermis) is broken. The sore is shallow but open and drainage may be present. Follow Stage 1 procedures and cleanse the wound with water or saline solution and dry the wound site, then apply a transparent or hydrocolloid dressing.

Stage 3: The skin has broken down further into the second layer of skin (the dermis) and subcutaneous fat tissue. Consult a doctor for treatment.

Stage 4: The skin has broken down to bone and muscle and will need medical attention and surgery as this condition may be life threatening.

Signs the sore is healing include a shrinking in size and the formation of pinkish skin around the edges. Once the sore is completely healed, you can apply pressure for limited time intervals, (about 15 minutes) and build up time gradually.

Low blood pressure (hypotension):

Blood pressure after injury may suddenly drop when changing from a flat position to an upright position. Some ways to prevent blood pressure from dropping are to wrap your legs with support bandages or elastic stockings or place an elastic belt around your abdomen. Moving to an upright position slowly can help, as well. Symptoms of low blood pressure can be lightheadedness, dizziness, and/or faintness. Low blood pressure most commonly occurs in people with quadriplegia. Persons with injuries below T8 are

not usually at risk for low blood pressure. Medications may be prescribed to keep blood pressure stable.

Spasticity:

Following a spinal cord injury, some patients may suffer from an increased amount of stiffness, muscle jerks and involuntary spasms in some muscle groups below injury level. This is called spasticity and it results from loss of inhibition of reflex muscle activity associated with central nervous system (brain and/or spinal cord) injury. If spasticity becomes a significant health issue for many people with a spinal cord injury, there are drugs used to alleviate spasticity. They include Baclofen, Botox, Valium, Zanaflex, and Dantrium. Physical therapy including muscle stretching, range of motion, electrical stimulation, and other activities can also help prevent spasms.

Pain:

In most cases, pain is a part of the recovery process post spinal cord injury and can be related to the actual trauma and treated with pain medicine. However, pain may persist and turn into chronic pain or nerve pain (also called neuropathic pain). This type of pain is not caused by a direct painful stimulus; it stems from “jumbled” transmission of sensory signals from below injury level through the injured cord. Neuropathic pain might be felt as a burning, stinging, tingling sensation. These sensations may be sporadic or they may be a chronic issue. If chronic, the goal of treatment is to moderate the pain and improve quality of life. Commonly used drugs are antidepressants and anti-epileptic drugs, non-steroidal anti-inflammatory agents, Tylenol and narcotic painkillers. Other helpful interventions are nerve blocks, acupuncture, biofeedback, as well as psychological approaches. The goal of pain management is to decrease pain while allowing people to continue functioning with their lives. Other secondary conditions of paralysis, such as spasticity and autonomic dysreflexia, may be caused or triggered by pain.

Bladder/Urinary Tract Infections:

After paralysis, the bladder’s normal system of control may be affected. Two of the most common ways the bladder is affected post injury are either spastic bladder (high tone) or flaccid bladder (low tone). Spastic bladder occurs when the bladder fills and a reflex automatically triggers the bladder to empty. This is common in injuries above T12. Flaccid bladder occurs when the reflexes of the bladder are either sluggish or absent.

The most common methods of bladder management are intermittent catheterization, indwelling catheter (thru urethra), supra pubic catheter (catheter surgically placed thru the abdomen into the bladder) and/or an external condom catheter.

Urinary tract infections (UTIs) can occur when the bladder is not completely emptied, or when bacteria from the catheter get into the bladder. Some symptoms of UTIs are fever, chills, nausea, headache, spasms, and autonomic dysreflexia. The best way to minimize UTIs is maintaining a proper bladder management routine, drinking the proper amount of liquids, and using sterile equipment. Treatment for a UTI is usually oral antibiotics. In

severe cases with a fever, the infection can affect the kidneys and may require injectable antibiotics.

Bowel Management:

The bowel is affected by the spinal cord injury in a similar way with the bladder. Paralysis often damages the nerves that control the bowel. If the injury is above T12, there is resultant spastic bowel. The ability to sense a full rectum may also be lost. Flaccid bowel is common below T12 injuries and results in an inability to have a bowel movement. Flaccid bowel means that there is damage to the defecation reflex causing the anal sphincter to relax. The best way to prevent bowel issues is to follow a schedule since bowel issues can lead to other issues such as autonomic dysreflexia. Bowel programs typically require 30-60 minutes and should be done at least every other day. There are many different options available for bowel management, including digital stimulation, suppositories, laxatives and enemas. Surgical procedures can be done to facilitate bowel evacuation if less aggressive methods are not successful.

4. How do I choose a Rehabilitation Center?

- Rehabilitation
- Model Centers
- CARF
- Choosing a Rehabilitation Center
- Pediatric Rehabilitation
- Physiatrists

For more information on rehabilitation, please refer to Chapter 3 of the Reeve Foundation's free *Paralysis Resource Guide* in print or viewable online at: www.ChristopherReeve.org/Guide

After stabilization, the person with a spinal cord injury needs to go to a specialized hospital called a rehabilitation center. It is very important to locate the most appropriate rehabilitation center in order to receive the appropriate spinal cord specific care and facilitate maximum recovery. There are several resources available to help you choose the most beneficial center. Some of the most important questions to ask when choosing a rehabilitation center are:

- Does the facility have experience with the particular diagnosis or condition?
- How many patients with the specific diagnosis or condition does the facility see per year?
- How far is the patient willing to travel or be away from family?
- Does the facility have cutting edge therapies?
- Is the facility age appropriate?
- What is the staff to patient ratio?
- Is the facility accredited – that is, does it meet professional standards of care for your specific needs?

To locate an accredited facility, there are a few websites sites that can help make process easier.

<https://www.nscisc.uab.edu/sci-model-systems.aspx>

<http://www.msctc.org/sci/model-system-centers>

Model SCI Centers across the United States work together to demonstrate improved care, maintain a national database, participate in independent and collaborative research, and provide continuing education relating to spinal cord injury. Projects are currently located in the following states: Alabama, California, Colorado, Florida, Georgia, Illinois, Kentucky, Massachusetts, Michigan, New Jersey, Pennsylvania, and Washington.

The Commission on Accreditation of Rehabilitation Facilities (CARF) is another resource for locating accredited rehabilitation facilities. CARF accreditation means the facility has passed an in-depth review of its services. You can request a provider in your region by emailing or calling CARF. Please know that there is a difference between a general CARF accreditation and one specific to spinal cord injury. Ask for a list of spinal cord injury accredited centers.

Commission on Accreditation of Rehabilitation Facilities (CARF):

<http://www.carf.org/>

Phone: 888-281-6531

Listed below are resources available to help you to choose a rehabilitation center for a child.

Shriners' Hospital for Children: Spinal Cord Injury

<http://www.shrinershospitalsforchildren.org/en/care/spinal-cord-injury>

Click on "Select a Hospital" in the right corner to see the locations that specialize in spinal cord injury.

Pediatric Brain and Spinal Cord Injury Program

<http://pedibrain.org/>

International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute

www.spinalcordrecovery.org

<http://www.kennedykrieger.org/patient-care/patient-care-programs/inpatient-programs/pediatric-rehabilitation-unit>

Commission on Accreditation of Rehabilitation Facilities (CARF)

<http://carf.org/advancedProviderSearch.aspx>

Under Age Group you can click on "Children and Adolescents" or "Pediatric Specialty Program"

Physiatrists are medical doctors who specialize in rehabilitation. Within the field of physiatry, some doctors specialize in spinal cord injury. Please contact the American Academy of Physical Medicine and Rehabilitation for more info at 847-737-6000 or visit their website at <http://www.aapmr.org>.

5. Are there clinical trials I can quality for?

- Clinical trials
- Locating a clinical trial
- Clinical trial vs. human experiments

For more information on clinical trials please refer to Chapter 1 of the Reeve Foundation's free *Paralysis Resource Guide* in print or viewable online at: www.ChristopherReeve.org/Guide

Clinical trials

Clinical trials are conducted on a wide variety of disease and conditions including topics related to spinal cord injury. There are three distinct phases in clinical trials that may lead to the FDA approval of a drug or therapy.

Phase I clinical trials are directly built upon basic and animal research and their primary goal is to test the safety of a therapy for a particular disease or condition and to estimate possible usefulness in a small group (usually under 100) of human subjects.

Phase II clinical trials usually involve many subjects (usually a few hundred people) at several different research centers and are used to test safety and efficacy of a medication or surgical procedure on a broader scale, to test different dosing for medications or to perfect techniques for surgery, and to determine the best methodology for the larger Phase III clinical trial to come.

Phase III clinical trials often involve many centers and may include a few thousand subjects. These trials usually have several groups of subjects who receive different interventions (different doses of drugs or types of treatments) which are then compared for effectiveness against each other or against no intervention (placebo).

Human participation occurs in all three phases. If you are considering joining a clinical trial, the research staff will give you informed consent documents that include the details about the study. All clinical trials have guidelines about who can get into the program. Guidelines are based on such factors as age, type of disease, medical history, and current medical condition. Before you join a clinical trial, you must qualify for the study.

Locating a clinical trial

The websites listed below can be used to find clinical trials. Physicians involved in the care of your family member may be consulted as well.

ClinicalTrials.gov
www.ClinicalTrials.gov

CenterWatch (617) 948-5100
www.centerwatch.com

Clinical trials vs. human experiments?

The difference between clinical trials and human experiments is that human experiments or treatments have in most cases not been medically proven and/or peer reviewed making it difficult to determine the benefits or the patient outcomes. Clinical trials have a specific protocol to be followed and are looking for specific results. Human experiments can pose a danger because they are not reviewed and monitored by an Institutional Review Board (IRB) for safety, ethics, and usefulness. In the United States, the Food and Drug Administration requires an IRB for all clinical trials.

6. How can I locate Funding for Rehabilitation and Equipment?

Depending upon the cause and the nature of the injury, you should seek out various insurance policies that may cover medical emergencies (homeowners, auto, and Worker's compensation) in addition to your health insurance. If you still need assistance, there are some non-profit organizations that do provide grants for individuals. However, funding levels and guidelines do vary from organization to organization. Please call the Reeve Foundation at 800-539-7309 for more information on organizations that provide grants to individuals as well as those that provide wheelchairs and other equipment.

Fundraising is another option to consider, HelpHopeLive (formerly called the National Transplant Assistance Fund) assists individuals with raising funds through their Catastrophic Injury Program.

HelpHopeLive's Catastrophic Injury Program:

<http://www.helphopelive.org/services/catastrophic-injury-patients/>
1-800-642-8399

7. Can stem cell and spinal cord injury research help me?

- The here and now
- The future
- Spinal cord injury
- Will participation in stem cell therapies keep a person out of future trials?

For more information on stem cells and spinal cord injury research, please refer to Chapter 1 of the Reeve Foundation's free *Paralysis Resource Guide* in print or viewable online at: www.ChristopherReeve.org/Guide

We think about the usefulness of stem cells in two ways: the here and now and the future. In the here and now, stem cells are a powerful tool for scientists to use as they explore the underlying causes and mechanisms of injury and disease. The cells can be studied in a healthy state and then after the onset of injury or disease. Human embryonic stem cells can help reveal how organisms, including human beings, develop, which will in turn

enable scientists to better understand how the body might repair itself after injury and disease. Stem cells can also be used to screen and test drugs.

In the future, innovative stem cell therapies will likely be developed that will effectively treat disorders such as spinal cord injury and diseases like diabetes, heart disease and Parkinson's.

In spinal cord injury, an already complicated situation becomes more so. Any stem cell strategies will have to be set within the framework of the most current, cutting-edge research in the field. The spinal cord is very complex and the role of stem cells in repair and regeneration can only be investigated within the context of what is known about the normal and injured cord.

The ability of different stem cell populations to repair different aspects of the pathology in SCI will have to be investigated. There may be no single population of stem cells that is universally 'good' from a therapeutic perspective. Accordingly, the multiple pathologies of SCI may mean that it will be necessary to choose a single target at a time for intervention, for example, remyelination, neuroprotection, or support of regeneration.

Participation in a stem cell trial or any clinical trial may prevent you from being eligible for future trials. There are potential risks for undergoing a treatment that has not been validated and approved by an appropriate national regulatory agency. An individual who receives an unapproved treatment is unlikely to achieve a function benefit that can be clearly related to the treatment, while risking unknown and potential harm.

Before participating in any clinical trial it is important to read the ICCP's booklet: **Experimental Treatments for Spinal Cord Injury: What You Should Know If You Are Considering Participation in a Clinical Trial*, the link is below and you can also call the PRC for a copy at 1-800-539-7309.

<http://icord.org/wp-content/uploads/2012/09/FINAL-Version-2-Experimental-Treatments-for-SCI-locked.pdf>

8. How do I adjust to my spinal cord injury? Is depression common after an injury?

- Adjustment
- Depression

For more information on adjustment and depression please refer to Chapter 2 of the Reeve Foundation's free *Paralysis Resource Guide* in print or viewable online at:

www.ChristopherReeve.org/Guide

Adjustment to paralysis is a process of changing one's thoughts and feeling and is not immediate and takes time. The goal of adjusting is to rebuild one's identity and to find a new balance in relationships. The stages of adjustment can include grieving, taking control, talking about your disability, taking care of yourself, and looking ahead.

Depression is a serious medical disorder that affects your thoughts, feelings, physical health and behaviors as well as other aspects of your life. Depression can cause physical and psychological symptoms. It can worsen pain, make sleep difficult, cause loss of energy, take away your enjoyment of life and make it difficult for you to take good care of your health. Other symptoms include oversleeping, change in weight, loss of interest or pleasure, and/or negative thoughts. If left untreated, depression may last as long as 6 to 12 months or even longer. Depression is common in the spinal cord injury population--affecting about 1 in 5 people.

If you are concerned that you may be suffering from depression, please speak with your physician. You can also download a free copy of *Depression: What You Should Know, A Guide for People with Spinal Cord Injury* at: <http://www.pva.org>

University of Alabama at Birmingham's Adjustment to Spinal Cord Injury
<http://www.uab.edu/medicine/sci/daily-living/adjustment>

Depression and Spinal Cord Injury
http://sci.washington.edu/info/pamphlets/depression_sci.asp

If after going through this information you have additional questions, please contact the Paralysis Resource Center's Information Specialist team at 1-800-539-7309 (toll-free) or 973-467-8270 if you are calling internationally.

Resources:

Apparelyzed: What is a Spinal Cord Injury?
http://www.apparelyzed.com/spinal_cord_injury.html

American Spinal Injury Association (ASIA)
<http://www.asia-spinalinjury.org/>

Autonomic Dysreflexia: What You Should Know. Washington, DC: Paralyzed Veterans of America, 2006. Consortium for Spinal Cord Medicine Clinical Practice Guidelines series. www.pva.org click on Publications

CareCure
<http://sci.rutgers.edu/>

Christopher & Dana Reeve Foundation's Paralysis Resource Center
<http://www.paralysis.org/>

Christopher & Dana Reeve Foundation's Paralysis Resource Guide online at www.ChristopherReeve.org/Guide

Christopher & Dana Reeve Foundation's Fact sheets on clinical trials, grants for individuals, depression, rehabilitation, Spinal Cord Tutorial 101, and spasticity booklet. http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.5041181/k.C489/Fact_Sheets_A_to_Z.htm

ClinicalTrials.gov: Understanding Clinical Trials
<http://www.clinicaltrials.gov/ct2/info/understand>

Epstein, Lita. The Complete Idiot's Guide to Social Security and Medicare. New York: Alpha, 2006. Second edition.

Henry J. Kaiser Family Foundation: www.KFF.org

ICORD (International Collaboration On Repair Discoveries) Clinical Trials Experimental Treatments for SCI: What You Should Know--summary
http://icord.org/wp-content/uploads/2012/08/Experimental_treatment_for_SCI-6pg.pdf

ICORD (International Collaboration on Repair Discoveries) Clinical Trials Experimental Treatments for SCI: What You Should Know—full document
<http://icord.org/wp-content/uploads/2012/09/FINAL-Version-2-Experimental-Treatments-for-SCI-locked.pdf>

International Ventilator Users Network: <http://www.ventusers.org/>

Maddox, Sam. Paralysis Resource Guide. Short Hills, NJ: Christopher and Dana Reeve Foundation, 2013. Third edition. Call 1-800-539-7309 for a free copy.
For online version: www.ChristopherReeve.org/Guide

Mayo Clinic: SCI Coping and Support
<http://www.mayoclinic.com/health/spinal-cord-injury/DS00460/DSECTION=coping-and-support>

MSKTC: <http://www.msktc.org/>

MedicineNet: <http://www.medicinenet.com/script/main/hp.asp>

Miami Project: Hypothermia in SCI
<http://www.themiamiproject.org/Page.aspx?pid=476>

NINDS: Spinal Cord Injury Information Page
<http://www.ninds.nih.gov/disorders/sci/sci.htm>

Palmer, Sarah, et al. Spinal Cord Injury: A Guide for Living. Baltimore: Johns Hopkins Press, 2008. Second edition, Chapter 1 Into the Wilderness.

Palmer, Sarah, et al. Spinal Cord Injury: A Guide for Living. Baltimore: Johns Hopkins Press, 2000.

Social Security Administration: Disability Programs

<http://www.ssa.gov/disability/>

Spinal Cord Injury: Hope Through Research. Bethesda: National Institute of Neurological Disorders, 2003.

Spinal Injury Network: Pressure Sore Stages

<http://www.spinal-injury.net/pressure-sore-stages-sci.htm>

SpineSection.org's Hypothermia and Human Spinal Cord Injury: Position Statement and Evidence Based Recommendations from the AANS/CNS Joint Section on Disorders of the Spine and the AANS/CNS Joint Section on Trauma. Nov. 2007

<http://www.spinesection.org/hypothermia.php>

US Dept. of Human Services' Centers for Medicare & Medicaid Services:

www.cms.gov

University of Alabama at Birmingham's Adjustment to Spinal Cord Injury

<http://www.uab.edu/medicine/sci/daily-living/adjustment>

University of Kansas: Stem Cell Research 101

http://www.kumc.edu/Documents/stemcell/stemcell_101.pdf

University of Washington pamphlet: Depression and SCI

http://sci.washington.edu/info/pamphlets/depression_sci.asp

Zejdlik, Cynthia Perry. Management of Spinal Cord Injury. Boston: Jones and Bartlett, 1992. Second edition.

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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