CHRISTOPHER & DANA REEVE FOUNDATION
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SPINAL CORD INJURY: TOP EIGHT QUESTIONS FOR THE NEWLY INJURED INTERNATIONAL VERSION*

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.

**For those in the US, please see our booklet entitled "Spinal Cord Injury: Top 10 Questions for the Newly Injured"(* https://s3.amazonaws.com/reeve-assets-production/NI-Top-10-Questions-Booklet_-FINAL-6-8-20.pdf*.) which includes U.S. resources such as Medicare, Medicaid, etc.*

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 ten questions to start you on your way.

If you have not done so already, please visit the Reeve Foundation's website at www.ChristopherReeve.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 384-page book called the *Paralysis Resource Guide (PRG)*. To order it, call 1-800-539-7309 or go to www.ChristopherReeve.org/Guide to view it online.

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. 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, Lotsahelpinghands.com 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, 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 systems that control sensory, motor, and autonomic function. This fact sheet will take you step by step through the layers of understanding a spinal cord injury.

The following information is divided into the top ten 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 you a 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 addresses what is promising in 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 (can include cervical discectomy and fusion, corpectomy, facetectomy, laminectomy, spinal cord depression, spinal fusion, or spinal stabilization)
- Respiratory (Ventilation)

Stabilization*:*

Once a person is injured, the stabilization of the patient's breathing, blood pressure, spinal cord 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 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. The steroid drug methylprednisolone appears to reduce the damage to nerve cells if it is given within the first eight hours after injury.* Methylprednisolone is sometimes used in the first few hours after an injury as it may reduce inflammation and improve recovery. It may not be appropriate to use it in all cases.

*NINDS (https://www.ninds.nih.gov/Disorders/All-Disorders/Spinal-Cord-Injury-Information-Page.)

Therapeutic hypothermia (controlled lowering of the body's core temperature) can protect cells from damage following cardiac arrest, stroke, and traumatic brain injury. Therapeutic hypothermia has been shown to reduce the swelling and inflammation that presses on the spinal cord following injury in animal models and in small, limited human studies. It also can reduce damage to susceptible neurons following the primary injury, reduce damage to spinal cord microvasculature, and improve functional outcome. Researchers are studying the safety and effectiveness of different durations of hypothermia following spinal cord injury.
Source: NINDS (https://www.ninds.nih.gov/Disorders/All-Disorders/Spinal-Cord-Injury-Information-Page.)

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. Classifications may be either orthopedic (classified by the bones broken) or neurological. The neurological level of injury is the lowest level along the spine where the nerves are fully functioning. The ASIA impairment scale* is a tool used to classify the spinal cord injury patient into various categories including ASIA A, B, C, D,

or E. (Please see the ASIA link below for the category definitions.) During an ASIA classification, the physician will be looking at a variety of determinants such as muscle movement, range of motion, and noting whether the person can feel light touch or sharp and dull sensations. The classification of the spinal cord injury might not be done until after surgery.

*ASIA Scale: American Spinal Injury Association Classification of Spinal Cord Injury
https://asia-spinalinjury.org/wp-content/uploads/2019/10/ASIA-ISCOS-Worksheet_10.2019_PRINT-Page-1-2.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. Two of the more common surgical interventions are surgical stabilization and spinal fusion. Please see below for their definitions.

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"). Ventilator assistance may be needed because the muscles of the diaphragm are weak down to the T6 level. Individuals who need ventilator assistance and people injured during water sports may be at risk of pneumonia, lung damage, and other respiratory problems (for

people injured during water sports, this is 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). 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* available in print or viewable online(http://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 Types:

Some of the types of injuries are simple fracture, 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, and 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.

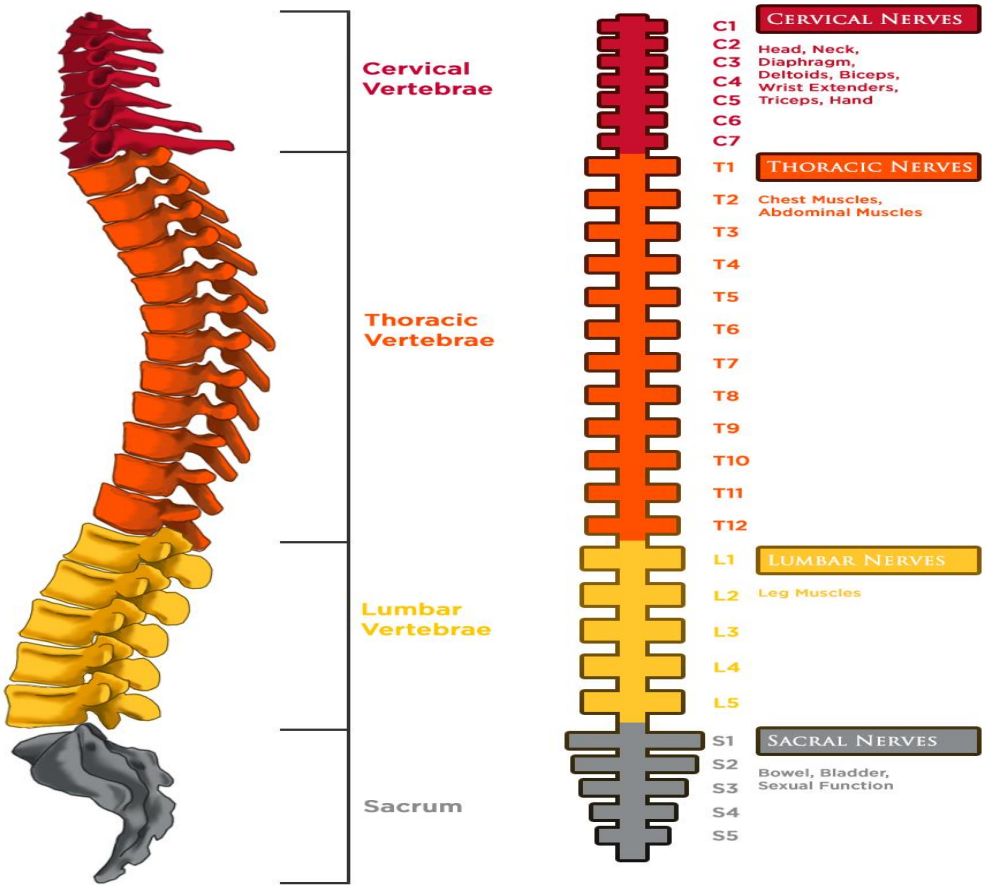

Figure 1:Illustration Credit: Miguel A. Najarro.

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 and 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. Thoracic injuries are almost always complete and it is rare for any function to return with one.

Lumbar Spinal Cord Injury L1 - L5 (Paraplegia)

Lumbar level injuries result in paralysis or weakness of the legs (paraplegia). Loss of physical sensation and bowel, bladder, and sexual dysfunction can occur. Shoulder, arm, 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. 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 Injuries (decubitus ulcers or pressure sores)
- 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* available in print or viewable online (http://www.christopherreeve.org/guide.)

Deep Venous Thrombosis or DVT (blood clots):

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 are a special type of support hose that maintain pressure on the legs. 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, warm 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 use this link: https://christopherreeve.org/cards.

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 medical professionals (especially in the emergency room) 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 the bladder or catheter for fullness or kinks in tubing; the bowel for impaction; the skin for abnormalities such as bruising/burns/ingrown toenails/pressure sores; and broken bones. 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 symptoms 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.

The Reeve Foundation offers a free wallet card on autonomic dyreflexia (http://www.christopherreeve.org/cards) that you can carry around with you and note your baseline blood pressure for emergency room staff.

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 the inability 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 Injuries (decubitus ulcers, pressure sores or pressure ulcers):

Pressure injuries 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 injuries 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 injury. The common areas for pressure sores to develop are any bony area of the body. Pressure injuries 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 pressure injuries 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 five 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.

Unstageable: Can't be determined because the pressure injury is obscured by slough (dead tissue) and eschar (a type of scab).

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

Please see the Reeve Foundation's Pressure Injuries and Skin Management booklet (http://s3.amazonaws.com/reeve-assets-production/Skin-Care-Booklet-FINAL-2017.pdf) for more information.

Orthostatic Hypotension (low blood pressure):

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. Physical therapy including muscle stretching, range of motion, electrical stimulation, and other activities can help prevent spasms. If these therapies are not effective, you may want to look into medications used to alleviate spasticity. They include Baclofen, Botox, Valium, Zanaflex, and Dantrium. For more information on spasticity, please see the Reeve Foundation's Managing Spasticity booklet (http://s3.amazonaws.com/reeve-assets-production/Managing-Spasticity_FINAL.pdf.)

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, or 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, anti-epileptic drugs, non-steroidal anti-inflammatory agents, Tylenol and narcotic painkillers. You should work with your doctor to set goals on how long each medication is needed. People need to be aware of the risks of opioids and addiction.

Other helpful interventions are nerve blocks, acupuncture, and 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. For more information on pain management, please see the Reeve Foundation's Pain Management booklet (https://s3.amazonaws.com/reeve-assets-production/Pain-MgmtBooklet-FINAL-4-17-19.pdf.)

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 don't contract as they should and the bladder does not fully empty.

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

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 by 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. For more information on bladder management, please see the Reeve Foundation's Bladder Management booklet. (http://s3.amazonaws.com/reeve-assets-production/2016BladderMgmtToolkit.pdf.)

Bowel Management:
The bowel is affected by the spinal cord injury in a similar way to the bladder. Paralysis often damages the nerves that control the bowel. If the injury is above T12, it can result in upper motor neuron bowel syndrome. The ability to sense a full rectum may also be lost. Lower motor neuron bowel syndrome generally impacts those with a spinal cord injury below T12. In this case, the stool collects in the rectum until it is manually removed. 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 and suppositories. Surgical procedures can be done to facilitate bowel evacuation if less aggressive methods are not successful. For more information on bowel management, please see the Reeve Foundation's Bowel Management booklet (http://s3.amazonaws.com/reeve-assets-production/Bowel-Mgmt-Brochure_FINAL.pdf.)

4. How do I choose a Rehabilitation Center?

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

After stabilization comes acute in-hospital care, then 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 and vice versa?
-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 spinal cord injury?

Listed below are some resources to help you locate an accredited or model spinal cord injury facility:

The Model Systems Knowledge Translation Center
Model Systems Knowledge Translation Center.
is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The 14 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. Model centers are currently located in the following states: Alabama, California, Colorado, Florida, Georgia, Illinois, Massachusetts, New Jersey, New York, Ohio (2), Pennsylvania (2), and Texas.

The Commission on Accreditation of Rehabilitation Facilities (CARF)(http://www.carf.org/) 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. You can call them at 888-281-6531.

Physiatrists are medical doctors who specialize in rehabilitation. Within the field of physiatry, some specialize in spinal cord injury. Please contact the American Academy of Physical Medicine and Rehabilitation (http://www.aapmr.org/) for more info at 312-464-9700.

The Reeve Foundation and Shepherd Center co-produced a booklet on the acute phase of a spinal cord injury. Restoring Hope: Preparing for Rehabilitation After Spinal Cord Injury (https://s3.amazonaws.com/reeve-assets-production/Restoring-Hope-Booklet-FINAL-4-20-20.pdf) covers how to choose a rehabilitation center and includes checklists of questions to ask and what to bring to rehab. Please call 800-539-7309 to receive a free copy.

Pediatric Information:

Listed below are resources available to help you to choose a rehabilitation center for a child who has a spinal cord injury.

Commission on Accreditation of Rehabilitation Facilities (CARF): Find A Provider
http://carf.org/advancedProviderSearch.aspx.
Under "Age Group" you can click on "Children and Adolescents" or "Pediatric Specialty Program."

International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute: Pediatric Rehabilitation
http://www.kennedykrieger.org/patient-care/patient-care-programs/inpatient-programs/pediatric-rehabilitation-unit.
Located in Baltimore, Kennedy Krieger Institute specializes in treating children and young adults with disorders of the brain, spinal cord and musculoskeletal system.

Kosair Charities Center for Pediatric NeuroRecovery at the University of Louisville
https://www.victoryoverparalysis.org/pediatrics-about-us/.)
Kosair offers an outpatient pediatric locomotor therapy program.

Shriners' Hospital for Children: Pediatric Spinal Cord Injury
(https://www.shrinershospitalsforchildren.org/shc/spinal-cord-injury.)
Click on "Select a Hospital" in the right corner to see the locations that specialize in spinal cord injury.

St. Mary's Kids
(http://www.stmaryskids.org/.)
Located in Bayside, NY, St. Mary's Kids offers a locomotor therapy outpatient program and services to patients ages 12 months through young adult. For further information, contact the Project Coordinator at 718-281-8987.

5. Are there clinical trials I can qualify for?

- Clinical Trials

- Locating a Clinical Trial
- Clinical Trials vs. Human Experiments

For more information on clinical trials, please refer to Chapter 1 of the Reeve Foundation's *Paralysis Resource Guide* available in print or viewable online (http://www.christopherreeve.org/guide.)

Clinical Trials:

Clinical trials are conducted on a wide variety of diseases 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.

ClincalTrials.gov
https://www.clinicaltrials.gov/

CenterWatch
https://www.centerwatch.com/

SCI Trials Finder.net
https://scitrialsfinder.net/home

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. Experimental treatments overseas may have little to no oversight for patient safety. Please read the following report on experimental treatments for spinal cord injury.

International Campaign for Cures of Spinal Cord Injury Paralysis (ICCP): Experimental Treatments for Spinal Cord Injury: What You Should Know If You Are Considering Participation in a Clinical Trial. 2nd version 2012. Full report http://icord.org/wp-content/uploads/2012/09/FINAL-Version-2-Experimental-Treatments-for-SCI-locked.pdf

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, crime victim assistance, and worker's compensation) in addition to your health insurance. Certain credit cards offer some coverage for injuries. If you still need assistance, there are some non-profit organizations that do provide grants or financial assistance 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 financial assistance to individuals as well as those that provide wheelchairs and other equipment.

Fundraising is another option to consider. Help Hope Live (https://helphopelive.org/) formerly called the National Transplant Assistance Fund) assists individuals with managing funds raised through their Catastrophic Injury Program. Because Help Hope Live maintains discretion over the funds you raise, you are less likely to jeopardize your eligibility for asset-based assistance programs. You should check with your state Medicaid office to be sure. Help Hope Live can be reached via phone at 1-800-642-8399.

7. What is promising in research?

- Rehabilitative Therapies Research
- Stem Cell Research

Rehabilitative Therapies Research:

There are now many rehabilitative interventions and therapies in use –some at clinical centers and others at local gyms. What they have in common is that they are activities

or interventions employed for rehabilitative purposes. Some of the more common interventions include:

-**Functional Electrical Stimulation (FES)** is often used in the form of a stationary bicycle.

-**Locomotor or Treadmill Training** involves suspending a person with paralysis over a treadmill with assistance in moving the feet in a walking motion.

-**Neuromuscular Electrical Stimulation (NMES)** in which the central nervous system is stimulated

-**Epidural Stimulation** in which a stimulator is surgically implanted over the dura of the spinal cord

-**Transcutaneous Stimulation** in which electrodes are placed on the skin near the spinal cord to deliver electrical stimulation

Please see the Reeve Foundation's fact sheet "Rehabilitation Interventions and Therapies"(https://s3.amazonaws.com/reeve-assets-production/Rehabilitation-Interventions-and-Therapies-4-19-1.pdf) for a more thorough explanation of the above interventions.

Stem Cells:

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 functional benefit that can be clearly related to the treatment, while risking unknown and potential harm.

Before participating in any clinical trial or research 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.* http://icord.org/wp-content/uploads/2012/09/FINAL-Version-2-Experimental-Treatments-for-SCI-locked.pdf For more information on spinal cord injury research, please refer to Chapter 1 of the Reeve Foundation's free *Paralysis Resource Guide* available in print or viewable online (http://www.christopherreeve.org/guide.)

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

- Adjustment
- Depression

Adjustment to paralysis is a process of changing one's thoughts and feelings 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.

MSKTC: Adjusting to Life After Spinal Cord Injury Info Sheet
https://msktc.org/lib/docs/Factsheets/SCI_Adjusting_To_Life_After.pdf

University of Washington's Depression and Spinal Cord Injury pamphlet (http://sci.washington.edu/info/pamphlets/depression_sci.asp.) For more information on adjustment and depression, please refer to Chapter 2 of the Reeve Foundation's free

Paralysis Resource Guide available in print or viewable online (http://www.christopherreeve.org/guide.) The Reeve Foundation also has a free booklet "Women's Mental Health After Paralysis" (https://s3.amazonaws.com/reeve-assets-production/Womens-Mental-Health-After-Paralysis-Booklet-Final-Master-4-8-2020.pdf) which covers depression, adjustment to injury, and other types of mental health issues. The Reeve Foundation offers a peer mentoring program so that people living with paralysis can speak to or meet with someone who has already navigated a new injury. Please see www.ChristopherReeve.org/peer to obtain a peer mentor. Caregiver to caregiver mentoring is also offered.
If after going through this information you have additional questions, please contact the Reeve Foundation Paralysis Resource Center's Information Specialist team at 1-800-539-7309 (toll-free) or 973-379-2690 if you are calling internationally.

Resources:

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

Christopher & Dana Reeve Foundation's patient education booklets including spasticity, bowel and bladder management, skin and pressure injury management, sexual and reproductive health, women's mental health after paralysis, and pain management.
https://www.christopherreeve.org/about-us/publications
Christopher & Dana Reeve Foundation's fact sheets on clinical trials, grants for individuals, depression, rehabilitation, Spinal Cord Tutorial 101, along with many other topics and state-based information.
https://www.christopherreeve.org/factsheets

ClinicalTrials.gov: Learn About Clinical Trials
https://clinicaltrials.gov/ct2/about-studies/learn

Epstein, Lita. The Complete Idiot's Guide to Social Security and Medicare. New York: Alpha, 2010. Third edition.

Henry J. Kaiser Family Foundation
www.KFF.org

ICORD (International Collaboration on Repair Discoveries) Experimental Treatments for SCI: What You Should Know If You Are Considering Participation in a Clinical Trial--summary
http://icord.org/wp-content/uploads/2012/08/Experimental_treatment_for_SCI-6pg.pdf

ICORD (International Collaboration on Repair Discoveries) Experimental Treatments for SCI: What You Should Know If You Are Considering Participation in a Clinical Trial —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/

Kirshblum, Steven and Vernon W. Lin. Spinal Cord Medicine. Demos Medical, 2018. Third edition.

Maddox, Sam. Paralysis Resource Guide.
Short Hills, NJ:
Christopher and Dana Reeve Foundation, 2017. 4th edition.
Call 1-800-539-7309 for a free copy. Also available in Spanish. First two chapters available in various other languages electronically.
For online version: https://www.christopherreeve.org/guide

Mayo Clinic: SCI Coping and Support
https://www.mayoclinic.org/diseases-conditions/spinal-cord-injury/diagnosis-treatment/drc-20377895

Model Systems Knowledge Translation Center (MSKTC)
https://msktc.org/

MSKTC: Adjusting to Life After Spinal Cord Injury Info Sheet
https://msktc.org/lib/docs/Factsheets/SCI_Adjusting_To_Life_After.pdf

National Institute of Neurological Disorders and Stroke (NINDS): Spinal Cord Injury Information Page
https://www.ninds.nih.gov/Disorders/All-Disorders/Spinal-Cord-Injury-Information-Page

National Pressure Injury Advisory Panel
https://npiap.com/default.aspx

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

Social Security Administration: Disability Programs
https://www.ssa.gov/disability/

Social Security Administration: Red Book
https://www.ssa.gov/redbook/
The Red Book serves as a general reference source about the employment-related provisions of the Social Security Disability Insurance and the Supplemental Security Income Programs for educators, advocates, rehabilitation professionals, and counselors who serve people with disabilities.

Spinal Cord Injury: Hope Through Research.
https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Spinal-Cord-Injury-Hope-Through-Research
Bethesda: National Institute of Neurological Disorders, 2014.

US Dept. of Health and Human Services' Centers for Medicare & Medicaid Services:
https://www.cms.gov/

University of Washington pamphlet: Depression and SCI pamphlet
http://sci.washington.edu/info/pamphlets/depression_sci.asp

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