

LIVING WITH PARALYSIS



Restoring Hope:

Preparing for
Rehabilitation
After Spinal
Cord Injury

© 2020

This booklet is a joint production of Shepherd Center and the Christopher & Dana Reeve Foundation.

Cover Photo by Louie Favorite, Courtesy of Shepherd Center

Inside Back Cover Images: Courtesy of the Shepherd Family

First Edition

This guide has been prepared based on scientific and professional literature. It is presented for the purpose of education and information; it should not be construed as medical diagnosis or treatment advice. Please consult a physician or appropriate healthcare provider for questions specific to your situation.

Thanks to our reviewers and contributors from the Shepherd Center (except where otherwise noted):

Pete Anziano
Chet Bhasin, FACHE, MBA, MS
Jennifer Cowhig, MPT, DPT
Sheila Fitzgibbon*
Diane Johnston, MSPT
Sanjay Konakondla, MD**

Jill Koval, Ph.D., ABPP
Bernadette Mauro*
Shari McDowell, PT, DPT
Sarah Morrison, PT, MBA, MHA
Jamie Shepherd, MBA, MHA

Buddy Sledge, BSN, RN, CRRN
Kathy Slonaker, BS, RN, CRRN
Jonathan Slotkin, MD, FANS**
Kati Vines, PT, DPT
Michael Yochelson, MD, MBA
Tammy Young, RN, MSN, CRRN

*from Christopher & Dana Reeve Foundation **from Geisinger Health

LEARN	
About Spinal Cord Injuries.....	2
ORGANIZE	
Information.....	14
CHART A PATH	
To Rehabilitation.....	19
CHOOSE YOUR ROAD	
Comparing Rehabilitation Facilities.....	26
GLOSSARY	37

The call you never want to receive...Your loved one is being transported to a trauma center. In the first few hours after a catastrophic event, patients are admitted to a hospital according to the level of care they require. This typically starts in the emergency department where the patient's condition is assessed. Your loved one may have even been moved to a different hospital to receive the appropriate level of care. This is a challenging time and it is difficult to know what to do.

After finding out your loved one has a spinal cord injury or other type of paralysis, you may not know what questions to ask or what to do. This booklet is designed to help you **LEARN** about spinal cord injuries, **ORGANIZE** information, **CHART** a path, and **CHOOSE** your loved one's road to rehabilitation.

Being familiar with both the typical progression of care and some commonly used terms will help you understand what is happening during these difficult days.



Upon arrival at the hospital after a traumatic injury, onset of disease, or decrease in function, the emergency department staff will evaluate your loved one from head to toe and assess all body systems to identify life threatening conditions and areas of concern. Depending on the number and/or types of injuries, the team will determine how to prioritize and manage your loved one's medical care. It is sometimes necessary to transport patients to another trauma or medical center to meet their needs.

What is a Trauma Center and why are they transporting my loved one there?

A trauma center is a comprehensive medical center capable of providing total care of a patient for any injury. The level of trauma designation varies based on the state.

Level 1 Trauma Centers:

- 24-hour coverage by emergency medicine, general surgeons, orthopedic surgery, neurosurgery, anesthesiology, radiology, internal medicine, plastic surgery, oral and maxillofacial, critical care, cardiac surgery, hemodialysis, microvascular surgery, and pediatric care
- Operates organized teaching and research programs helping to direct new innovations in trauma care
- Meets a minimum requirement of treating severely injured patients

Level 2 Trauma Centers:

- 24-Hour coverage by Emergency Medicine, general surgeons, orthopedic surgery, neurosurgery, anesthesiology, radiology, internal medicine, critical care, plastic surgery, oral and maxillofacial surgery
- Patients needing the care of specialists such as cardiac surgery, hemodialysis, microvascular surgery, and pediatric care, may be referred to a Level 1 Trauma Center.



Level 3 Trauma Centers:

- 24-hour immediate coverage by emergency medicine and prompt availability of general surgeons and anesthesiologists
- Has transfer agreements developed for patients requiring more comprehensive care to Level 1 or Level 2 Trauma Centers
- Provides back-up care for rural and community hospitals

During the hospital stay, many members of the medical team will interact with you and your loved one. It is important to be able to identify who these individuals are so that you are prepared and can get the help and information you need. There will be one attending physician responsible for coordinating the overall care of the patient. Depending on the hospital, the attending may be a hospitalist so it may rotate during the course of your stay. This physician may bring in additional physicians that are specialists who will be part of your loved one's treatment team. For example, a pulmonologist may be called in



Photo by Louie Favorite, Courtesy of Shepherd Center.

to manage difficulty breathing. Many of the physicians may work with advanced practice providers. Advanced practice providers can be either nurse practitioners (NPs) or physician's assistants (PAs). They are trained to assist the physicians and work under their direct supervision. In addition to the primary team attending physician, specialists, and advanced practice providers, the medical team may include nurses, case managers and therapists. Below are examples of people you may meet.

Physicians:

Emergency Department Physician – responsible for care of patients in the emergency department

Trauma Surgeon – responsible for critical care and surgery for patients who have come in through the emergency department; may become the attending physician

Intensivist – specializes in caring for critically ill patients

Hospitalist – responsible for general medical care of patients in the hospital setting

Resident Physicians – doctors in training across all types of specialties that help with treatment plans

Specialty Physicians & Medical Providers:

Neurosurgeon – specializes in the diagnosis and surgical treatment of disorders of the nervous system

Neurologist – specializes in the diagnosis and treatment of disorders of the nervous system

Orthopedic Surgeon – specializes in the treatment of the bones, joints, ligaments, tendons and muscles

Pulmonologist – specializes in breathing disorders

Cardiologist – specializes in disorders of the heart

Urologist – specializes in disorders of the urinary system (kidneys, bladder)

Nephrologist – specializes in disorders of the kidneys

Gastroenterologist – specializes in the treatment of disorders of the stomach and intestines

Plastic Surgeon – specializes in repair and reconstruction

Maxillofacial Surgeon – specializes in the surgical repair and treatment of facial and jaw injuries

ENT (Ear, Nose & Throat) – specializes in the treatment of injuries of the ears, nose and throat

Psychiatrist – specializes in the medical treatment of psychological issues

Palliative Care – specializes in supportive care including physical, emotional, social and spiritual needs

Nursing Staff

Nurse – responsible for continuous assessment and monitoring of the patient's health status, delivery of medication and coordination of care

Charge Nurse – supervises and supports nursing staff



Photo by Louie Favorite, Courtesy of Shepherd Center.



Photo by Louie Favorite, Courtesy of Shepherd Center.

Certified Nursing Assistant (CNA) or Patient Care Technician (PCT)

– assists with personal care and performs tasks such as taking vital signs (blood pressure, temperature, heartrate) under the direction of the nurse

Unit Secretary or Clerk – administrative assistant for the nursing unit

Respiratory Therapy

Respiratory Therapist – responsible for providing medical treatment for breathing support

Case Management

Case Manager – responsible for assessing, planning and coordinating the care plan and serves as an advocate for facilitating options and services to meet a patient’s needs

Nurse Case Manager – responsible for coordinating plan of care with the health care team, insurance company, and identifying appropriate options for continued care using resources and services in the best way possible

Social Worker or Discharge Planner – responsible for working with agencies and institutions to ensure patients get the appropriate care needed upon discharge from the hospital

Therapy

Physical Therapist – responsible for assessing and treating patients with movement, pain management, and other functional activities

Occupational Therapist – responsible for helping individuals learn or relearn their daily activities necessary to achieve the highest level of independence

Speech-Language Pathologist – responsible for evaluating and treating individuals with speech, language, cognitive, communication and swallowing disorders



Photo by Louie Favorite, Courtesy of Shepherd Center.

REMEMBER!

- Keep a notepad and take notes. Write down who people are, their role, and contact information.
- As you think of questions, write them down so that you have them at hand when the physician visits.
- Be prepared, ask questions, and get the information you need to make good decisions.

Traumatic spinal cord injuries occur due to damage of any of the supporting elements of the spine, whereas non-traumatic causes of spinal cord injury are due to a disease process. Depending on the diagnosis and extent of injury or illness, different medical procedures may be required.

Procedures and treatments commonly used to diagnose and treat spinal cord injury are aimed at reducing swelling in and around the spinal cord, improving blood flow to the spinal cord and aiding the immune response. Procedures such as a lumbar puncture, IVIG, plasmapheresis and steroids may be recommended.

If there is any instability or risk of instability of the spine, the physician may order a brace to be used to protect the spinal cord and keep the bones aligned. A brace may be provided before, after or instead of surgery. A brace for the spine may be used for the neck (cervical collar), upper or lower back (TLSO) or in combination. The brace is typically secured with straps to ensure proper fit and stability. The amount of time the brace will be utilized is dependent on the person's healing. In some cases, a halo vest may be recommended to stabilize the neck, rather than a neck brace.

Spinal surgery may be recommended to protect the spinal cord and nerves, realign the vertebrae and/or stabilize the spine by securing the bones with rods and screws.

Common surgeries include
(see glossary to learn more about these terms):

- Cervical Discectomy and Fusion
- Corpectomy
- Facetectomy
- Laminectomy
- Spinal Cord Decompression
- Spinal Fusion
- Spinal Stabilization



Understanding Spinal Cord Injury: Basic Facts

Spinal cord injury (SCI) occurs when there is any damage to the spinal cord, blocking communication between the brain and the body. Damage to the spinal cord can occur due to injuries or illnesses. After a spinal cord injury, a person's ability to feel and move, including reflexes, can be affected.

Causes of SCI

Traumatic (injuries)

- Motor vehicle accident
- Acts of violence (such as from guns or knives)
- Sports and recreational activities (such as diving)
- Falls
- Medical or surgical complication

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

In many cases, injuries to the spinal cord happen because of the force of the trauma on the spine. These forces can cause strain and damage the structures that support the spine. These forces can happen alone or in combination.

- Flexion injuries occur due to the spine bending too far forward.
- Extension injuries occur due to the spine bending too far backward.
- Compression injuries occur due to pressing down on the spine top to bottom, these commonly result in a burst fracture.
- Distraction injuries occur due to over stretching.
- Rotation injuries occur due to too much turning or twisting.
- Dislocations or translation injuries occur when there is separation of joints and movement of one vertebra over the other.
- Transection injuries occur due to the spinal cord being cut, such as in knife injuries.

Non-traumatic (illnesses)

- Tumors
- Spinal Cord Stroke
- Guillain-Barre Syndrome
- Transverse Myelitis
- Multiple Sclerosis
- Congenital disorders
- Inflammation of the spinal cord
- Osteoporosis
- Stenosis
- Arthritis
- Infection

Effects of SCI

May include:

- Loss of movement
- Loss of sensation (feeling)
- Loss of bowel and/or bladder control
- Pain or intense burning/stinging sensation
- Changes in breathing, heartrate, blood pressure, temperature control and skin integrity
- Changes in reflexes
- Muscle spasms
- Changes in sexual function, sexual sensitivity and fertility

Spinal Column Anatomy: The Basics

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



Levels of Injury

Vertebrae are grouped into sections. Damage to the spinal cord can take place in any of these sections. The higher the injury on the spinal cord, the more impairments can occur.

Tetraplegia (Quadriplegia) - Occurs in cervical (neck) injuries - affecting the neck, arms, trunk and legs

Paraplegia - Occurs in thoracic (trunk), lumbar and sacral (low back) injuries - affecting the trunk and legs

The impact on function may vary greatly between individuals, levels of injuries and secondary complications. Below are possible outcomes based on the level of injury.

High-Cervical Nerves (C1-4)

- Paralysis in neck, arms, hands, trunk and legs
- Patient may not be able to breathe on his or her own, cough, or control bowel or bladder movements.
- Ability to speak is sometimes impaired or reduced.
- Requires complete assistance with activities of daily living, such as eating, dressing, bathing, bowel and bladder care, and getting in or out of bed
- May be able to use powered wheelchairs with special controls to move around on their own
- Will not be able to drive a car on their own
- Requires 24-hour-a-day supervision or personal care

Low-Cervical Nerves (C5 - C8)

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

C5 injury

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



C6 injury

- Paralysis in hands, trunk and legs typically
- Able to bend wrists back
- Can speak and use diaphragm, but coughing will be weakened
- Can move in and out of wheelchair and bed with assistive equipment
- May also be able to drive an adapted vehicle
- May be able to manage their bowel or bladder with special equipment

C7-8 injury

- Nerves at this level control straightening the elbow and some finger movement.
- Most individuals can straighten their arm and have normal movement of their shoulders.
- Can do most activities of daily living by themselves, but may need assistance with more difficult tasks
- May also be able to drive an adapted vehicle
- May be able to manage their bowel or bladder with special equipment



Photo by Phil Skinner, Courtesy of Shepherd Center.

Access to these devices and emerging technologies may be important to your loved one and should be considered when choosing a rehabilitation facility.

Emerging Technologies

There are devices and technology currently available or being developed to assist a person with paralysis. Some devices may be available purely for research, while others are used for strength training while in rehabilitation or for limited use at home and in the community.



Photo by Louie Favorite, Courtesy of Shepherd Center.

Thoracic Nerves (T1 - T5)

- Corresponding nerves affect muscles, upper chest, mid-back and abdominal muscles.
- Arm and hand function is usually not affected.
- Injuries usually affect the trunk and legs (also known as paraplegia).
- Most likely use a manual wheelchair
- Can learn to drive a modified car
- May be able to manage their bowel or bladder with special equipment

Thoracic Nerves (T6 - T12)

- Nerves affect muscles of the trunk (abdominal and back muscles) depending on the level of injury.
- Usually results in paraplegia
- Normal upper-body movement
- Fair to moderate ability to control and balance trunk while in the seated position
- Should be able to cough productively (if abdominal muscles are intact)
- May be able to manage their bowel or bladder with special equipment
- May use a manual wheelchair
- Can learn to drive a modified car
- Some individuals can stand in a standing frame, while others may walk with adapted devices.

Lumbar Nerves (L1 - L5)

- Injuries generally result in some loss of function in the hips and legs.
- May be able to manage their bowel or bladder on own
- Depending on strength in the legs, may need a wheelchair and may also walk with assistive devices and special equipment

Sacral Nerves (S1 - S5)

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



Severity of Injury

A spinal cord injury may be described by the physician in terms of the bones that were broken or by the neurological level of injury.

When a spinal cord injury is due to broken bones along the spine, an orthopedic level of injury is determined by CT scan to identify the specific vertebrae that are broken.

The neurological level of injury is the lowest level along the spine where the nerves are fully functioning. The neurological level of injury is determined by the ASIA (or ISNCSCI) exam. The ASIA exam is used to define and describe the extent and severity of an individual's spinal cord injury and help determine future rehabilitation and recovery needs. It is ideally completed within 72 hours after the initial injury and periodically in rehabilitation. The ASIA Impairment Scale (AIS Grade) is based on how much sensation can be felt at multiple points on the body as well as the strength of specific muscles.

All AIS grades have the potential to improve over time.

ASIA Impairment Scale (AIS)

Complete Injury:

AIS A Lack of muscle contraction and ability to feel more than three levels below the neurological level of injury (including the anal area)

Incomplete Injuries:

AIS B Some ability to feel below the level of the injury (including anal sensation)

AIS C Some muscles work below the level of injury, but more than half are weak.

AIS D Majority of the muscles below the level of injury are strong enough to move against gravity.

AIS E All neurologic function has returned.

After a spinal cord injury, there are secondary complications that can occur due to the impact on the nervous system that controls different areas of the body.

- Complications can occur in the digestive system as digestion takes longer and the ability to have a bowel movement is directly impacted by the spinal cord injury. Therefore, obtaining proper nutrition and having a regular bowel movement is essential to reduce the risk of other conditions.
- Since the ability to feel has been impacted, the skin is at a high risk for developing skin sores or pressure injuries. Frequent checks of the skin, weight shifts and turning while in bed are necessary to reduce this risk of injury.

- Breathing requires coordination of muscles from the neck, chest and stomach. After a spinal cord injury, the person is at risk for developing pneumonia as the ability to draw in a larger breath and cough to clear secretions has been impacted. Some individuals will require mechanical ventilation (breathing machine), oxygen and/or frequent procedures to clear the airway. One way to reduce the risk of pneumonia is maintaining healthy oral care, reducing the occurrence of bacteria that may enter the airway and lungs.

Remember: Risks of complications are greatest for bowels, skin and breathing.

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

How to be an Effective Advocate

Advocacy is speaking on behalf or in support of your loved one receiving proper care and rehabilitation.

- Be strong, firm and calm.
- Be courteous.
- Follow the chain of command.
- Be present, get involved in care “I’ll help you... Show me how to...”.
- Keep a log of activities and information from care providers to promote communication between care providers and family.
- Engage with the patient and encourage patient involvement.



Photo by Louie Favorite, Courtesy of Shepherd Center.

- Gather as much information as possible. This will help you to be the best advocate for your loved one.
- Resource for Advocates: Call the Reeve Foundation at (800) 539-7309 for a free copy of their [Become a Self-Advocate](#) brochure.

Helpful Questions to Ask:

- **How severe is my loved one's spinal cord injury?**
 - What is the neurological level of injury?
 - What is the AIS Grade?
 - What does this mean for recovery?
- **What is the plan of treatment and how will it help my loved one?**
- **What kind of complications can arise from a spinal cord injury?**
 - How can I help prevent them in my loved one?
 - What is being done to prevent skin sores?
 - What is being done to prevent pneumonia?
 - How are they having a bowel movement?
- **If on a ventilator, how long will they be on the ventilator?**
 - How does my loved one come off the ventilator (wean)?
 - Is my loved one a candidate for diaphragmatic pacing system (DPS)?
- **What are the next steps?**
 - When will I know my loved one is ready for the next step?
- **What other injuries occurred in addition to the spinal cord injury?**

Caregivers: Taking care of you



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

Everyone will grieve the injury and resulting life changes, such as loss of physical function, decreased independence and alteration of family roles. Grieving is healthy and a process that takes time, but no one can predict how long it can last. For some people,

it never ends, but improves over time. The goal of grieving is not acceptance; everyone wants life to go back to the way it was before injury. Grieving is a path leading to adjustment and adaptation. Rehabilitation provides a map for learning ways to adjust, adapt and even thrive!

- Speak up and ask lots of questions.
- Make a list of your questions and concerns.
- Tell the hospital staff, family and friends about your feelings and fears.
- Get your rest. If visitors energize you and your loved one, let them come, but pace yourself in terms of the numbers and lengths of the visits.
- Take turns at the hospital with other family members, so that you get a break and get some rest.
- Take advantage of every training or education class offered. Try, even when you don't feel up to it.
- Talk to peer supporters, counselors or psychologists. They can provide insight and guidance during this challenging time.
- Remember your loved one is still learning too. They've never done this before either. Try to be patient with both yourself and your loved one.
- Check out the [Resources](#) near the end of the booklet for other ideas, suggestions and support.

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

- Encourage family and friends to be around, but make sure the number is not too overwhelming for the healing process.
- Allow yourself and your loved one time to rest between visits.
- Try to take turns at the trauma care center so you can get some rest.
- If your loved one is asleep or sedated, assume that your loved one can hear you.
- Keep an open mind during every step of the process and never give up hope.
- Take advantage of all training opportunities.
- Talk about your feelings and concerns with supportive friends, family and spiritual leaders you trust.
- Meet with other people with both new and old spinal cord injuries (peer supporters) and other families who are sharing a similar experience.
- Take care of yourself in the best manner possible (eat, hydrate, exercise, sleep, stress management).
- Talk openly with your loved one. Don't feel like you need to hide your feelings and concerns.



In the days and weeks following diagnosis, it is important to familiarize yourself with the health care team, gather information and resources to become an advocate, be an active member of your loved one's care and become educated about the next steps. Be prepared, ask questions, and get the information you need to make good decisions.

TIP: Use a highlighter to mark what you need to do.

To Do:

Keep a Notebook

- Tape an envelope in front to hold business cards.
- Document dates and activities.
- Keep track of who is providing care, what their role is, and any information given (including phone numbers).
- Create a list of questions – write down answers, record the conversation or have a scribe.
- Document/record ALL CONVERSATIONS with insurance company: Include date, reason for the call, the person with whom you spoke and outcome of the call.

Collect Personal Documents

- ID (driver's license, passport, birth certificate)
- Insurance cards
- Social Security card
- Advance directives
- Marriage certificate
- Custodial papers
- Power of attorney (financial and medical)

Contact Insurance Company

- Ask for the assigned case manager and contact that individual.
 - If one hasn't been assigned, request a nurse case manager, social worker or benefits advisor.
 - To be your loved one's best advocate, educate the case manager about his/her spinal cord injury and particular needs to preserve the integrity of their body and health.

- Obtain a full copy (not abbreviated or summarized) of your loved one's explanation of insurance benefits.
 - Read your policy carefully, including fine print, definitions, and exclusions to learn the extent of covered services.
- Determine the rehabilitation benefits.
 - Ask about the number of rehab days allowed (inpatient acute rehabilitation, sub-acute rehabilitation, outpatient and home health rehabilitation).
 - Ask whether there is an annual maximum number of days and a lifetime maximum number of days.

The length of stay in an inpatient rehabilitation facility is driven by the medical necessity to be in the rehabilitation setting. Even if a total number of days are allowed, they may not be approved if there is no evidence to support that your loved one needs to stay in the particular rehabilitation facility.

- Inquire about rehabilitation in a spinal cord injury rehabilitation facility, including both in-state and out-of-state facilities.
 - Inquire about the In-network vs Out-of-network facilities.
- Ask about exclusions.

Making a Case for an Exception - If the facility you prefer is out-of-network for your insurance, you may need to request an exception. Try describing why the current facility or recommended facility cannot provide the care your loved one's needs, but the preferred facility **can**. For example, compare the facility-based outcomes, age and peer groups (pediatric program accredited), number of patients served with the same diagnosis, services and specialty programs (such as vocational rehabilitation to return to work or school; recreation therapy for community reintegration, or dual diagnosis), low admission to skilled nursing facility after discharge. These points may help justify the exception you are seeking.



Photo by Louie Favorite, Courtesy of Shepherd Center

- Contact the insurance representative for issues and/or concerns that relate to the patient's health insurance and whenever they have been denied a service that you believe to be covered.
- Educate the insurance representative so they can be a better advocate for your loved one's health care needs.
 - Teach this person the risk factors for the secondary complications of spinal cord injury, necessary measures to preserve the health and integrity of your loved one's body and importance of immediate access to insurance and health care professionals.
- If the injury occurred while on the job and your loved one may be qualified for workers' compensation. Talk to your workers' compensation case manager about what options for care are available following trauma care treatment.
- Ask about getting approval for transportation.
 - Ask who makes transportation arrangements.
 - Considerations for air versus ground transportation are based on medical necessity or level of care along with considering the distance, time and risk for complications during transport.
 - Advocate to enlist the attending physician or surgeon to speak with the medical director of insurance company for a peer to peer discussion.
- Ask about starting an application for disability benefits.



Photo by Louie Favorite, Courtesy of Shepherd Center

Contact Employer

- Make HR (human resources) a part of the team; reach out within 24 hours or as soon as possible.
- Inquire about short-term and long-term benefits.

Contact School/University Registrar Office

Contact Attorney

- Inquire about your legal rights for choosing a rehab center.

Identify Your Support System

- Family members
- Friends and neighbors
- Community members/ organizations
- Church members
- Employer or school friends/ colleagues
- Peer supporters

Create List of Ideas for Needs

- Walking dogs, caring for animals
- Making meals
- Providing rides for children
- Shopping (groceries, personal items)
- Yard or care of home
- Checking mail
- Who's managing finances???



Photo by Louie Favorite, Courtesy of Shepherd Center

Use Online Apps to Organize Yourself and Volunteer Efforts



Photo by Louie Favorite, Courtesy of Shepherd Center

Caring Bridge

www.caringbridge.org

Signup Genius

www.signupgenius.com

Meal Train

www.mealtrain.com

GoFundMe

www.gofundme.com

Help Hope Live helphopelive.org

If you use a fundraising app, please explore the tax and financial ramifications.



Expected Length of Stay in the Trauma Center



Photo by Louie Favorite, Courtesy of Shepherd Center

The length of stay in a trauma center is usually one to three weeks depending on the extent of the spinal injury and other injuries your loved one may have. It is important to begin looking at rehabilitation centers immediately, so that you have reviewed and are prepared to select a rehabilitation center that fits your loved one's needs upon discharge.

Your loved one may be admitted to the intensive care unit (ICU) for specialized care of injuries and complications, including surgery for stabilizing the spine and treatment of other injuries. Once medically stable, the doctors can begin to prescribe a limited amount of physical therapy, occupational therapy and speech therapy. The length of time in the hospital depends on the severity of the spinal cord injury and any other injuries and/or complications that might arise, such as:

- Breathing issues that might require assistance from a ventilator
- Broken ribs or additional complex fractures
- Belly and/or chest trauma
- Infections such as pneumonia, urinary tract infections, bloodstream infections
- Traumatic brain injury

Factors Affecting Transfer to Rehabilitation

Most acute rehabilitation centers require patients to be medically stable and demonstrate the ability to handle intense therapy for at least three hours per day. Patients who cannot handle intense therapy for at least three hours per day may be transferred to another type of rehabilitation center.

Some factors may prevent or delay your loved one from moving to acute rehabilitation. This may be due to ongoing medical issues, insurance or whether the rehabilitation facility can manage your loved one's medical needs.

For example:

- Need for mechanical ventilation
- Infections (C. diff, UTI)
- Orthopedic injuries that require non-weight bearing restrictions
- Pressure sores

Rehabilitation Centers Offer a Variety of Levels of Care and Services

You have the right to select...What are your options?

In some cases, the trauma center may move your loved one within its own hospital system to a rehabilitation or long-term care facility.

Make sure you discuss these moves with the attending physician, case manager and insurance company. You may have other options and frequently insurance companies will only pay for one rehabilitation stay. **CHOOSE CAREFULLY!**

Explore Options: How to Choose a Rehab Facility - Start Investigating Immediately

Choosing a spinal cord injury rehabilitation facility is one of the most important decisions you will have to make. **It is important to be confident about the quality of care your loved one will receive.**

All spinal cord injury rehabilitation programs have features that can be evaluated, regardless of your prior knowledge of rehabilitation or catastrophic injury. The final decision will ultimately depend upon individual circumstances, such as insurance and location.



Photo by Louie Favorite, Courtesy of Shepherd Center

Specialty Centers and Accreditation

When considering rehabilitation facilities for spinal cord injury, it is essential to choose a facility that has high standards of care, well developed with programs to achieve the best outcomes for your loved one's level of injury or diagnosis. Facilities with a **proven** track record will be a current SCI Model System facility and have CARF accreditation.

SCI Model System designated facilities are national leaders in medical research and patient care providing the highest level of comprehensive specialty services, from the point of injury, through rehabilitation and re-entry into full community life. Each SCI Model Systems Center treats more patients with an SCI diagnosis than other rehabilitation facilities. They also contribute to the SCI Model Systems Data Center, participate in independent and collaborative research, and provide information and resources to individuals with SCI, their family/care givers, health care professionals and the general public.

- Facilities with this designation are some of the best specialty rehabilitation centers in the world.
- Find a facility that is currently a **SCI Model System Center** msktc.org/sci/model-system-centers.

CARF accreditation www.carf.org demonstrates a provider's commitment to continuously improve service quality with a focus on satisfaction of the persons served. CARF's high standards of care and programmatic requirements enable providers to achieve higher outcomes and enhance the quality of life of the person served.

- **Find a CARF Provider**
www.carf.org/advancedProviderSearch.aspx
 - Search Program Focus: Spinal Cord Specialty Program
- **Consumer Resources**
www.carf.org/Resources/ConsumerResources

Treating a patient with a spinal cord injury is complex and requires the skill and collaboration of a team of specialists. Some of the professionals you are likely to encounter in rehabilitation are:

Physiatrist – A doctor specializing in physical medicine and rehabilitation. The physiatrist is the team leader and he or she will coordinate medical treatment and care. They may be assisted by a Nurse Practitioner or Physician Assistant. They will also consult any specialists needed to provide medical care, such as a pain specialist, registered dietician, cardiologist, or pulmonologist.

Rehabilitation Nurse – A nurse with specialized training in rehabilitation care. They are experts in the management of changes that effect the body after a spinal cord injury. Some of these changes might include bladder function, bowel function, health of the skin, and breathing. Rehab nurses also provide education and training to patients and



Photo by Louie Favorite, Courtesy of Shepherd Center

caregivers regarding the management of these complications. Rehab nurses may be assisted in their duties by unlicensed caregivers such as a care technician or nursing aide.

Respiratory Therapist - A respiratory therapist helps treat and manage breathing difficulties after a spinal cord injury. They may provide breathing treatments and will also coordinate any training or education necessary to promote respiratory health.

Physical Therapist (PT) - A physical therapist is trained to assess and treat patients with movement, pain management, and other functional activities. They are specialists in improving strength, coordination and endurance. They also help manage complications such as muscle spasms, joint stiffness, and skin breakdown. Physical therapists are responsible for recommending any equipment necessary for movement (such as wheelchairs, canes or braces).

Occupational Therapist (OT) - An occupational therapist is skilled in helping individuals learn or relearn their daily activities necessary for independence. These activities can include bathing, dressing, eating, managing bowel and bladder functions, housekeeping tasks, and childcare. They will also recommend and train patients in the use of any adaptive equipment needed to perform these tasks. They may also offer suggestions for home modifications that would help promote independence.

Speech Language Pathologist (SLP) - A speech language pathologist, often referred to as a speech therapist, is an expert in treating swallowing problems, diet management, and talking. They can also help with providing strategies for dealing with injuries to the brain that result in difficulties with memory and problem solving.

Recreation Therapist - A recreation therapist helps patients discover the wide range of recreational options they may be able to participate in and trains them to do so.

Vocational Therapists - A vocational therapist helps people assess their job skills and readiness to return to work.

Case Manager - A case manager helps to coordinate all aspects of care for rehabilitation patients. They serve as the contact between the hospital and insurance companies and help make sure patients have all the needed resources available when they return home.

Rehabilitation Psychologist - A rehabilitation psychologist provides counseling to patients and caregivers. They help individuals process the emotional trauma that frequently accompanies spinal cord injury.



Photo by Louie Favorite, Courtesy of Shepherd Center



Photo by Louie Favorite, Courtesy of Shepherd Center



Photo by Phil Skinner, Courtesy of Shepherd Center

What Services Does My Loved One Need?

The rehabilitation process is different for each person, but supports the person achieving the highest level of independence and returning to their previous level of function. When choosing a rehabilitation facility, you will want to consider not only the person's current abilities and needs for medical management, but also what services are needed to achieve this and what is most important to your loved one, you and your family.

To determine what medical and rehabilitation services may be needed, consider the following questions:

Does your loved one...

- Yes No Have a traumatic accident (car wreck, fall, etc.?)
- Yes No Have severe medical issues from the trauma (spinal cord injury, brain injury, neurological disorder, stroke, multiple broken bones, recovering from multiple surgeries)?
- Yes No Have paralysis in multiple limbs?
- Yes No Require a comprehensive wound care program for large wounds or infections?
- Yes No Have issues with breathing or is there a need to wean from a ventilator?
- Yes No Have organ system failure due to the traumatic injury?
- Yes No Have a complete loss of function from their injuries? (Unable to move arms or legs, unable to get out of bed on their own, unable to feed themselves?)
- Yes No Is there a need for customized rehabilitation services? (comprehensive rehabilitation involving physical therapy, occupational therapy, speech therapy, recreational therapy, respiratory, psychology/counseling, rehab nursing, physical medicine and rehabilitation (PMR), vocational services)

If you answered “YES” to the majority of these questions, your loved one may be best served in a Specialty Rehabilitation Program.

Does your loved one....

- Yes No Have minimal loss of function or mild weakness?
- Yes No Have a stable chronic condition such as chronic pain, stenosis, arthritis, diabetes, cardiac pacemaker/defibrillator, atrial fibrillation, congestive heart failure or seizures?
- Yes No Have a joint replacement?
- Yes No Have a stroke?

If you answered “YES” to many of these questions, your loved one may be best served in a Traditional Independent Rehabilitation Facility (IRF) in an acute rehabilitation program.

Does your loved one....

- Yes No Have a stroke?
- Yes No Have chronic medical conditions prior to the spinal cord injury that would make it difficult to wean from a ventilator?
- Yes No Have a chronic or severe illness prior to the spinal cord injury involving the kidneys, lungs, heart, wounds or infection?
- Yes No Have received an organ transplant prior to the spinal cord injury?
- Yes No On dialysis?
- Yes No Receiving chemotherapy?
- Yes No Is there a need for long-term antibiotics?
- Yes No Require a comprehensive wound care program for large wounds or infections?

If you answered “YES” to many of these questions, your loved one may be best served in a Traditional Long-Term Care Hospital (LTCH).



Photo by Louie Favorite, Courtesy of Shepherd Center

Comparison of Levels of Rehabilitation

	Level of Rehabilitation	Rehabilitation Services Offered	Nursing Care Offered	Amount of Rehab Therapy Provided	Respiratory Care Services Provided for Ventilator Weaning
Specialty Rehab Program	<p>Acute rehabilitation for severely injured and medically complex, catastrophic injuries</p> <p>Intensive and coordinated interdisciplinary team approach to the delivery of rehabilitative care</p>	<ul style="list-style-type: none"> • Medical Care • Physician supervised by a rehabilitation physician • PT • OT • SLP • Vocational Rehab • Recreation Therapy • Psychological services • Respiratory Therapy 24 hrs., 7 days/week • If under 18, educator to maintain school requirements • Patient education • Family education & training • Assistive technology • Seating clinic • Driving program • Advocacy • Long-term follow up care 	<p>24-hour nursing care</p> <p>Nurses have advanced certification for rehabilitation nursing (CRRN)</p>	<p>Minimum of 1-3 hours of therapy/day progressing to > 3 hours/day</p> <p>5-6 days/week</p>	Yes
Traditional IRF (Independent Rehabilitation Facility)	<p>Acute rehabilitation</p> <p>Intensive and coordinated interdisciplinary team approach to the delivery of rehabilitative care</p>	<ul style="list-style-type: none"> • Physician supervision by a rehabilitation physician • PT • OT • SLP • Vocational Rehab • Recreation Therapy • Psychological services 	24-hour nursing care	<p>3 hours of therapy/day</p> <p>5 days/week</p>	No
Traditional LTCH	Long-Term Care Hospital (LTCH)	<ul style="list-style-type: none"> • Complex Medical Care • PT • OT • SLP • Respiratory Therapy 24 hrs., 7 days/week • Psychological services 	24-hour nursing care	<p>1 to 3 hours of therapy/day,</p> <p>3 to 5 days/week</p>	Yes



When comparing rehabilitation facilities, consider the following to help you make the best decision:

- Call the facility and see how they respond – how was customer service?
- Look online (facility website, Google, Facebook, etc.)
- Ask about how to get a referral for the rehab facility of choice
- Schedule a tour
- Prepare for your visit(s) by reviewing and answering questions on **pages 26-30**.
- When possible, have the same individual evaluate or visit each facility for consistency
- Prepare yourself for questions from the facility by answering the questions on **pages 34-36**.

Questions to Consider When Selecting a Rehabilitation Treatment Program

It is best to compare at least three rehabilitation programs to make an informed decision on the best facility for your loved one. Admissions personnel will be able to answer these questions for you.

1. How many people are admitted to the spinal cord injury rehabilitation program each year?

Facility A: _____ Facility B: _____ Facility C: _____

2. How many people has the facility treated with injuries similar to your loved ones?

Facility A: _____ Facility B: _____ Facility C: _____

3. What is the average age of people served in the spinal cord injury program?

Facility A: _____ Facility B: _____ Facility C: _____

4. Are there people in the program of the same age and sex as the person considering admission?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

5. Does the facility specialize in spinal cord injury rehabilitation services, or is it just one of the many medical services offered?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

6. Is the facility equipped to manage life-threatening emergencies?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

7. Is respiratory care provided on a 24-hour basis?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

8. Does the facility offer services for every stage of recovery, including:

Intensive Care

Facility A: Yes No Facility B: Yes No Facility C: Yes No

Inpatient Rehabilitation

Facility A: Yes No Facility B: Yes No Facility C: Yes No

Day Program Rehabilitation (Comprehensive, Multi-Service Outpatient Program)

Facility A: Yes No Facility B: Yes No Facility C: Yes No

Outpatient Services (Single Services for Physical, Occupational and/or Speech Therapy)

Facility A: Yes No Facility B: Yes No Facility C: Yes No

9. For how long each day do people receive treatment by specialists, such as physical, occupational, speech and recreational therapists?

Facility A: _____ Facility B: _____ Facility C: _____

10. Is the person treated by the same team (physical therapy, occupational therapy, speech therapy) every day?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

11. Are outings and activities planned for people on weekdays, as well as weekends and evenings?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

12. Are there opportunities to participate in research?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

Durable Medical Equipment

1. Does the facility have equipment available in house for your loved one to trial? (i.e. various power wheelchairs)

Facility A: Yes No Facility B: Yes No Facility C: Yes No

2. Does the facility offer a seating clinic, while admitted to inpatient services, to evaluate and prescribe a wheelchair customized to fit your loved one's needs?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

3. Does the facility prescribe other durable equipment (i.e. bathroom or shower equipment, assistive devices)?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

4. Does the facility order the necessary durable medical equipment?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

5. Does the facility have processes to make sure that your loved one will have the needed equipment upon discharge from rehabilitation?

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

Counseling Services

1. What types of coping and support services are available?

Peer Support (Opportunities to meet and talk with others with a similar injury level, age and lifestyle who are successfully living with their diagnosis)

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

Individual and Group Therapy

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

Psychotherapy

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

Neuropsychology

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

Family Support

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

Vocational Counseling to return to school or work

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

Substance Abuse Counseling

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

Family Members

1. Are family members encouraged to participate in rehabilitation?

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

To what extent?

Facility A: _____ Facility B: _____ Facility C: _____

2. Does the facility have a family education program to prepare me for future caregiving responsibilities?

Facility A: Yes No

Facility B: Yes No

Facility C: Yes No

3. What type of support does the facility offer after we return home?

Facility A:

Facility B:

Facility C:

4. Are living arrangements available for family members participating in training?

Facility A: _____ **Facility B:** _____ **Facility C:** _____

Outcomes

1. What percentage of people return to home or community rather than long-term care facilities?

Facility A: _____ **Facility B:** _____ **Facility C:** _____

2. Rehabilitation hospitals measure results in terms of “functional improvement.” What is the facility’s average functional improvement measure (FIM) score change for people with spinal cord injuries?

Facility A: _____ **Facility B:** _____ **Facility C:** _____

3. What is the facility’s average length of stay for people with injuries similar to your loved one’s?

Facility A: _____ **Facility B:** _____ **Facility C:** _____

On-Site Review

1. Were staff members helpful and friendly when information was requested?

Facility A: Yes No **Facility B:** Yes No **Facility C:** Yes No

2. Were you offered an opportunity to tour the facility?

Facility A: Yes No **Facility B:** Yes No **Facility C:** Yes No

3. What were your impressions of the overall atmosphere?

Facility A:

Facility B:

Facility C:

4. Did you have the opportunity to speak with people currently participating in the program?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

5. Were they satisfied with their rehabilitation program?

Facility A: Yes No Facility B: Yes No Facility C: Yes No

NOTES:



How Do I Prepare For Rehab?

During your stay at the rehabilitation center, personal items from home can make your loved one feel more comfortable. This could mean bringing books and photographs or a favorite T-shirt and sweater. The checklist on the next page will help you pack for your stay at rehab.

Items to Bring:

- Toothbrush and floss
- Comb or brush
- Shaving supplies (recommend electric razor)
- Deodorant
- Makeup
- Shampoo and other hair care products
- Hair dryer
- Eyeglasses and/or contact lenses
- Prescription and over-the-counter medications in their original containers
 - Your doctor will need information on the exact brand and dosage you receive.
 - You will need to provide all of these medications to your nurse to give to the in-hospital pharmacist for distribution to you.



Photo by Louie Favorite, Courtesy of Shepherd Center

Patients in rehabilitation typically get up and get dressed every day for therapy. An assortment of comfortable, loose-fitting clothes may be needed. For all clothes, be sure to label them with your name in permanent marker.

Clothing Suggestions:

- Pajamas
- Pants or shorts with elastic waistband, such as cotton or nylon sweatpants (consider going up one size)
- Comfortable, stretchy, oversized V-neck shirts

- Lightweight jacket
- Swimsuit (optional)
- Socks
- Undergarments
- Athletic shoes (1 size larger)
- Outdoor wear during the colder months, including warm jacket, heavy sweater and hat



Photo by Louie Favorite, Courtesy of Shepherd Center

Wait on recommendations from rehabilitation team before you:

- ***Modify your home***
- ***Purchase any equipment (wheelchair, bathroom equipment)***
- ***Purchase a van***

How long will we be at rehab?

The length of stay at a rehab facility is determined by a combination of factors (insurance, medical status, progress towards goals, discharge plan, patient desire) and is directed by the team. For an individual with a higher level of injury (C1-C4), the length of stay may range from a few weeks to a few months. Length of stay for an individual with a lower level of injury (paraplegia) is often shorter than the stay required for a higher level of injury. The projected discharge date is fluid and will be adjusted as needed.

Where do I stay while my loved one is at rehab?

A facility may offer accommodations for family to stay in while their loved one is participating in rehab. This may be offered for a certain period of time and is often limited. Sometimes, staying in the patient's room is an option, although not an ideal long-term option for both the patient and family member. The facility may have discounted rates at local hotels.

What makes a good rehab candidate?

- Motivation and desire to improve
- Family involvement

What makes for a successful rehab experience?

- Always try your hardest
- Willingness to learn
- Making the most of a limited resource

Helpful Resources and Credible Organizations

The American Trauma Society

Dedicated to the prevention of trauma and improvement of trauma care

amtrauma.org 800-556-7890

Christopher & Dana Reeve Foundation - Paralysis Resource Center

Promoting the health and wellbeing of people living with spinal cord injury, mobility impairment and paralysis by providing comprehensive information, resources and referral services

ChristopherReeve.org 800-225-0292

Commission on Accreditation of Rehabilitation Facilities (CARF)

CARF International is an independent, nonprofit accreditor of health and human services in aging services, behavioral health, child and youth services, and medical rehabilitation amongst other fields.

carf.org 888-281-6531

Disabled Sports USA

A network of community-based chapters offering sports rehabilitation programs to anyone with a permanent disability

disabledsportsusa.org 301-217-0960

Facing Disability

A network specifically created to connect people and their families, who are coping with new injuries, with others who have had a similar experience.

facingdisability.com 312-284-2525

Family Voices

Aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities

familyvoices.org 888-835-5669

Help Hope Live

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

helphopelive.org 800-642-8399

Model Systems Knowledge Translation Center

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

msktc.org 202-403-5600

Model Systems Knowledge Translation Center—Directory of Spinal Cord Injury Model System Centers

Provides a listing of spinal cord injury model system centers throughout the U.S.

msktc.org/sci/model-system-centers

Office of Disability Employment Policy

Federal government agency within the U.S. Department of Labor helping ensure that people with disabilities have equal employment opportunities

dol.gov/odep 866-487-2365

Paralyzed Veterans of America

Since 1946, Paralyzed Veterans of America has been a leading advocate for life-changing care, spinal cord research, VA benefits and civil rights for veterans and all people with disabilities.

pva.org 800-424-8200

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

American Heart Association

Works to build healthier lives, free of cardiovascular diseases and stroke

heart.org 800-242-8721

American Stroke Association

Works to build healthier lives, free of cardiovascular diseases and stroke

stroke.org 800-242-8721

Brain Injury Association of America

Dedicated to increasing access to quality health care and raising awareness and understanding of brain injury through advocacy, education and research

biausa.org 800-444-6443

Brain Trauma Foundation

Dedicated to improving the outcome of traumatic brain injury (TBI) patients worldwide by developing best practices guidelines, conducting clinical research, and educating medical professionals and consumers

braintrauma.org 800-934-6866

Preadmission Questionnaire

Please answer the questions below so prospective rehabilitation facilities know more about your loved one.

Legal name: _____ Preferred name: _____

Marital status: _____ single _____ married (if yes, how long? _____)
_____ widow _____ divorced _____ separated

Who lives in the household:

Name	Relationship	City/State	Phone	Age
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Has anyone in your family ever been disabled? _____ Yes _____ No

If yes, please explain: _____

Education: _____ Highest level through 12th grade _____ Vocational school
_____ College _____ Major

Occupation: Employed: _____ Yes _____ No (if yes, when? _____)

Activities at work: _____

Retired: _____ Yes _____ No (if yes, when? _____)

Homemaker: _____ Yes _____ No Unemployed: _____ Yes _____ No

Military service:

Veteran: Yes No Received any veteran benefits: Yes No

What are your loved one's favorite activities, hobbies, interests, or church affiliations?

Does your loved one have a vision or hearing problem? Yes No

Does your loved one wear: glasses contacts hearing aid

Patient's health status prior to his illness/injury: good fair poor

Any chronic medical conditions:

high blood pressure diabetes heart disease cancer

asthma COPD other: please describe _____

Patient's feeling about going to rehabilitation: _____

What were you told by the doctor regarding your loved one's recovery: _____

Source(s) of income: _____

Has power of attorney/guardianship been initiated? Yes No

If yes, name of power of attorney: _____

Has patient's or family's income been affected by recent disability? Yes No

If yes, please explain: _____

Is there patient/family psychiatric history that would affect current disability?

Yes No If yes, what type? _____

Does your loved one have a primary care physician? Yes No

If no, please explain: _____

Personality profile: please check words best describing patient before disability.

happy many friends private solves problems

quiet short tempered serious forgetful

stubborn ignores problems nervous moody

homebody shy depressed joker

hard working talkative perfectionist easygoing

other (explain) _____

How is your loved one coping/behaving now? _____

What are the most important goals for your loved one to achieve? _____

Discharge planning information:

Where will the patient live at discharge? _____

Describe the potential home environment:

Type of home: _____ house _____ apartment _____ trailer

How many floors (levels) does it have? _____

_____ Own _____ Rent

How many steps are there to get into the front door? _____ Backdoor? _____

Can changes be made to get the wheelchair inside where your loved one will live?

Who will be taking care of your loved one at home? _____

Are there others who live nearby who can help care for your loved one? _____ Yes _____ No

If more help is needed at home, are there finances available to hire an attendant?

_____ Yes _____ No

If your loved one cannot come to live with you, is there any other place for them to live or another friend/family member to help take care of them? _____ Yes _____ No

Would you be willing to participate in research to further treatment of spinal cord and/or brain injury? _____ Yes _____ No

Are you or your loved one concerned about:

_____ making discharge plans

_____ affording medical care

_____ finding lodging while in rehab

_____ paying bills, debts, or making ends meet

_____ finding transportation to visit

_____ welfare of another family member

Are you concerned about providing these types of care after discharge?

_____ toileting (bowel/bladder)

_____ tube feeding

_____ trach/respiratory/suctioning

_____ giving medications

_____ taking blood pressures

_____ bathing



ASIA - American Spinal Injury Association

Atelectasis - a condition where the airways and air sacs in the lung collapse or do not expand properly

Bradycardia - an abnormally slow heart rate

Cardiac Pacemaker - a small implanted device to help control heart rhythms

Cervical Discectomy and Fusion - a surgical procedure to remove a damaged disc and fuse the vertebrae on either side of the removed disc. This can be performed from the front (anterior) of the neck, called an ACDF, or from the back (posterior) of the neck, called a PCDF.

Chest Tube - a tube inserted into the chest to drain fluid or air from the chest cavity

CT or CAT Scan - a scan using a combination of x-rays and computer imagery to produce a highly detailed view of body structures

Corpectomy - a surgical procedure where an entire vertebra is removed

Diaphragm - a large, sheet-like muscle that controls the expansion of the lungs (breathing)

Diaphragmatic Pacing System - a small implanted device that helps a person to breathe without the use of a ventilator

Epidural - a procedure that involves injecting medication into the space surrounding the spinal cord

Facet Fracture - a broken bone involving the joints between and behind vertebrae

Facetectomy - a surgical procedure relieving pressure on the spinal nerve roots near the facet joints in the spine

Foley Catheter - a tube inserted into the bladder to allow urine to drain

Hemorrhage - internal or external bleeding caused by damage to a blood vessel

Hemothorax - a collection of blood between the chest wall and the lung

Hypoxia - the lack of sufficient oxygen to the body and its organs

Ileus - a lack of movement in the intestines that can lead to a blockage or obstruction of the intestine

Impaction - a severe bowel condition in which a hard, dry mass of stool blocks the lower intestine

Intubation – a procedure to keep a person’s airway open by inserting a plastic tube into the mouth, nose, or throat

ISNCSCI – International Standard for Neurological Classification of Spinal Cord Injury

IVIG (intravenous immunoglobulin) - a blood product used to improve the immune response and replace antibodies that attack the body. IVIG is used to treat a range of diseases such as Guillain-Barre Syndrome and Multiple Sclerosis.

Laminectomy – a surgical procedure to remove the back of one or more vertebra to reduce pressure on the spinal cord

Lumbar Puncture - a medical procedure used to collect a sample of spinal fluid to assist in the diagnosis of certain medical conditions

Motor Function – the ability to control muscles voluntarily

Magnetic Resonance Imaging (MRI) – a test that uses magnetic fields and radio waves to create detailed images of the organs and tissues inside the body

Mucous Plug – a buildup of thick mucus that blocks air from getting into the lungs

Myelography – a test that involves dye injected into the spinal canal, a series of xrays and CT scans to allow the doctor to see the spinal nerves and structures more clearly, such as a herniated disc

Nasogastric Tube (NG Tube) – a tube inserted through the nose, down the esophagus and into the stomach. This tube can be used to deliver food and medicine to the stomach when a person cannot eat or drink by mouth. The tube can also be used to remove toxic substances or contents from the stomach.

Neurogenic – caused by or controlled by the nervous system

Neurogenic Shock – a condition that can occur after damage to the spinal cord; causes low blood pressure and slowed heart rate

Orthostatic Hypotension – a drop in blood pressure that occurs when moving from laying down to sitting or sitting to standing

Plasmapheresis – a process of separating or removing the liquid part of the blood (plasma) from the blood cells. This process filters out antibodies that attack to the body. The plasma can be replaced or exchanged for another solution or treated and returned to the body.

Pneumonia – an infection in the lungs that causes inflammation in the air sacs (alveoli) causing them to fill with fluid or pus

Pneumothorax – a collapsed lung

Pressure Injury or Skin Sore – damage to the skin and underlying tissue caused by prolonged pressure, shear, moisture or related to equipment

Rectal Tube – a tube inserted into the rectum that allows liquid stool to drain into a collection bag

Respiratory Failure – a condition causing blood to not have enough oxygen or to have too much carbon dioxide

Spinal Cord Contusion – an injury caused by crushing of the spinal cord where part of its tissue is spared and remains intact

Spinal Cord Decompression – a surgical procedure to open the bony canals where the spinal cord and nerves pass, creating more space for them to move freely

Spinal Cord Injury – any damage to the spinal cord that disrupts communication between the brain and the body

Spinal Cord Transection – a complete tear of the spinal cord; rarely occurs

Spinal Fusion – a surgical procedure to permanently connect two or more vertebrae in the spine

Spinal Shock – a condition caused by spinal cord injury and results in a loss of reflexes, low blood pressure and slowed heart rate

Spinal Stabilization – a surgical procedure using hardware (screws, plates or rods) and bone grafts to connect segments of the spine after injury

Steroids – a medication that may help reduce swelling. They can be used short term in hopes of preserving spinal cord function. The exact risks versus benefits are not fully understood. Most experts no longer believe that steroids impact the outcome in spinal cord injury from trauma.

Surgical Stabilization – a surgical procedure to stabilize the spine

Tachycardia – an abnormally fast heart rate

TLSO – Thoracolumbar Sacral Orthosis – a brace that provides stabilization for the upper and lower back

Tracheostomy – a hole made in the front of the neck and into the windpipe (trachea) to allow for breathing

Ventilator – a machine used to support breathing; sometimes called mechanical ventilation

Ventilator Weaning – a program that allows for strength and endurance training of the respiratory muscles to allow for normal breathing while gradually withdrawing the support of the ventilator

Vertebral Fracture – a broken bone (vertebra) in the spinal column

IN MEMORIAM

JAMES H. SHEPHERD, JR.



We dedicate this booklet to honor the memory of James H. Shepherd, Jr. for his lifetime of advocacy and achievement. James H. Shepherd, Jr. was the chairman of the Board of Directors, chief of staff and a co-founder of Shepherd Center.



Shepherd Center

WE'RE HERE TO HELP.

Learn more today!

Christopher & Dana Reeve Foundation

636 Morris Turnpike, Suite 3A
Short Hills, NJ 07078
(800) 539-7309 toll free
(973) 379-2690 phone
ChristopherReeve.org

Shepherd Center

2020 Peachtree St NW
Atlanta, GA 30309
(800) 247-0257
(404) 352-2020 phone
Shepherd.org

This project was supported, in part, by grant number 90PRRC0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.