



CONSUMER GUIDELINES

Choosing a rehabilitation program after a spinal cord injury (SCI) can be a difficult and confusing decision. Most people don't know the important questions to ask before choosing a program. Figuring out which acute rehabilitation facility is best for a particular individual will require planning and thought with regards to: the expectations you have about rehabilitation, the health care coverage (insurance) you have and what it may cover, the different services you may need, and what your future needs may be.

This publication attempts to guide the consumer in identifying the best possible options for comprehensive SCI care. There are many rehabilitation programs in the U.S. that offer services for a person with SCI. Some programs are housed in a free-standing rehabilitation hospital while others are located on a designated unit within an acute care hospital; these different settings often convey a different feel. The consumer should also know whether the facility is private or public and whether it is affiliated with an academic medical center. Obviously, the facility will need to be covered under the terms of the insured's health insurance to be considered, as cost of care after SCI is extremely high. The following information about the program and the treatment team should be considered.

The Program

> **Find out how long the SCI program has been in existence.** A newer program may or may not offer all the needed services or have a team of rehabilitation professionals who are skilled and expert in the care of people with spinal cord injury.

> **Ask how many persons with new SCI are admitted each year to the program.** To develop and maintain the necessary skills to manage a person with SCI, a program should regularly admit persons with SCI each year, and a substantial portion of those admitted should have traumatic injuries. Be sure that the program has experience with SCI patients with similar levels of injury, particularly if the injured person has a cervical level injury since those with cervical injuries are susceptible to a wider variety of medical complications. The average length of stay for persons with similar injuries may be useful information to know. In addition, the existence of an outpatient program that follows the inpatient phase of rehabilitation is an attractive feature.

If you are a parent of a child with SCI, look for centers that admit between 5-10 new traumatic SCI each year and that have rehabilitation programs for children with other traumatic injuries such as brain injury. Children with spinal cord injury should not be admitted to adult programs nor should they be placed in programs that are primarily tailored for children with spina bifida. If a center has an active pediatric spinal dysfunction program that sees both children with SCI as well as children with spina bifida, that is acceptable, assuming there is unique programming for the children with respect to education, recovery, and psychosocial support.

>**Ask to see the program’s “report card” or outcome measures.** This is information that tells you how much patients admitted to the program improve, how long they stay in the hospital and how frequently they are able to be discharged directly to home, rather than to a secondary facility providing a lower level of care. Many programs can describe how their program compares to others in the region and nation.

> **Inquire as to whether the facility has special certification or recognition.** Certification or accreditation by agencies such as the Commission on Accreditation of Rehabilitation Facilities (CARF) or the Joint Commission is important. These organizations survey and accredit rehabilitation programs that meet very high standards. These standards include a patient-focused and team-based approach that considers the best interests of the patient during and after their involvement in the program. CARF certification is available specifically in the area of SCI, which is preferable to the more general accreditation for comprehensive inpatient care. CARF accredited programs have met strict requirements established by CARF and have the services necessary to provide high quality rehabilitation. A small number of programs throughout the country are designated as Model Systems of SCI Care. This designation means that the program receives an annual grant from the National Institutes for Disability and Rehabilitation Research and infers that the program offers comprehensive SCI care and is involved in original research related to SCI.

>**Proximity to Home.** The support of family and friends during rehabilitation is crucial to the person sustaining an SCI. The advantages and disadvantages of choosing a program that is not near home must be carefully considered. Some rehabilitation programs provide housing for family members who are far from home. Even if available, this may not be financially manageable. The parent of a child with SCI should ask how the program implements family-centered care and whether there are parental accommodations; specifically if there are there accommodations for one or both parents. If applicable, ask how siblings are integrated into the rehabilitation process.

> **Facility and Staffing.** Although plush environments and high tech equipment look attractive and create a positive first impression, the skills and experience of the team members and their ability to work together are more important. Ask about staffing levels for physicians, nurses, and therapists, including all shifts and weekends. Nurses and nurse’s aides should be staffed adequately to allow for individualized care. Ask about the staffing mix to understand the ratio of nurses to nurse’s aides, physical therapists (PT) to physical therapist assistants and occupational therapists (OT) to certified occupational therapy assistants. Ask about the number of therapy hours that are provided each day. While 3 hours of therapy per day is the minimum standard, many programs offer supplemental therapies. Ask if the weekend nurses and therapists are “weekend coverage only” or if they are a part of the regular team. Understanding how information about you or your loved one’s care is communicated from shift to shift is important, as well.

>**The SCI Team.** The importance of teamwork in SCI care cannot be over-emphasized. It is not an easy task to determine the strength and cohesiveness of a team and the experience and skill level of team members but one should understand whether the team members work together every day and how much SCI experience each team member has. SCI rehab services must address a patient’s medical, physiologic, functional, psychological and social issues. Therefore, the team should include, at minimum, a rehabilitation physician experienced in SCI Medicine (usually a physiatrist), a rehabilitation nurse, PT,

OT, psychologist, and social worker/case manager. A comprehensive education orientation plan for new staff should be in place for optimal training. For the parent of a child with SCI, ask if there is a teacher as part of the rehab team; as your child should continue with his or her education while undergoing rehabilitation.

>All team members should be licensed and/or certified by their professional licensing boards.

>All team members should understand the system that is used internationally to classify injuries (International Standards for the Neurological Classification of SCI) and how these standards relate to a person's recovery from SCI.

>All team members must understand common medical complications seen after SCI and work together to prevent them.

>All team members must understand the impact of SCI on a person's psychological health and social situation and assist with their adjustment to disability.

>All team members must be able to communicate effectively with the patient and family to develop a workable plan for returning home or to another facility.

> All team members must educate. Patients and families receive a large amount of new and often complex information and team members should be able to identify strategies to effectively convey this information.

>Ideally, therapists communicate to the nursing staff the skills a patient is working on in therapy and how those skills can be incorporated into the patient's activities during non therapy hours. For example, if a patient is learning to dress themselves, the OT should share information about the techniques so they can be encouraged to practice dressing each morning. Often, occupational therapists will treat at the patient's bedside to assist with the important morning care skills.

>Inquiries should address whether there is a weekend therapy program and how weekend therapy compares to the regular weekday program. In addition, the proportion of therapy time that is individual, that is, where the therapist works one on one with a patient, should be compared to therapy time that is administered to a group of patients. It is very useful to understand which staff provides training in bowel and bladder management.

Ventilator dependent patients will want to know whether they will receive therapy in the therapy area or if treatment will be limited to the bedside.

>One should inquire about special, additional programs outside the standard therapy services such as a community re-integration program or peer support program.

Inquire as to the educational program for persons with SCI including the range of topics covered and the method the institution uses to provide education.

The Team

What does each of these team members do and what special skills does each need? What medical services should I be looking for?

- The person who has a spinal cord injury often has other injuries at the same time and is often susceptible to many complications. It is crucial that the physician directing your care have expertise in SCI, either by frequently treating persons with SCI or by completing an accredited fellowship training program in SCI medicine. (A fellowship is a one year program in which the physician focuses only on care of patients with SCI.) Board certification in SCI Medicine is desirable.

- Find out what type of physician consultants are available should complications arise. For example, you may need a lung specialist available in the case of potential respiratory complications, a plastic surgeon for substantial skin breakdown, a spine surgeon, or a psychiatrist.
- One specialist who should be available to all patients with SCI is a urologist who has experience evaluating and managing the bladder after SCI. The rehab program you choose should be able to evaluate bladder function and offer various types of bladder management programs.
- Most hospitals provide basic radiology, laboratory, and pharmacy services. In addition, a rehab program should have access to CT scan, MRI, nuclear medicine, diagnostic ultrasound, and other types of diagnostic procedures.
- If you are a parent of a child with SCI, your child may benefit from consultation with a pediatric orthopedist who understands pediatric SCI and its implication on muscle and bone growth and development.
- If the facility you choose doesn't have some of these medical specialists on staff, make sure they are able to offer referrals to such providers in the area.
- Follow up care after your initial rehab stay will also be important. Most SCI centers will have provisions for medical, nursing and therapy needs on an ongoing basis.

What specialized skills am I looking for in a Nurse?

- A *rehabilitation nurse* is specially trained to work with patients with SCI and other disabling injuries and illnesses. Some rehab nurses have a special accreditation -CRRN – which means they have at least 2 years of practice in rehab nursing and have passed a certification examination.
- Rehab nurses are critical members of the team because they interact with the patient more than any other team member. It is a good idea to try to get a sense of how nurses communicate regularly with physicians, therapists, and other team members and how they work together with therapists to practice and implement skills and activities that a patient has learned in therapy sessions.
- Rehab nurses need to have extensive knowledge of bladder, bowel, and skin management after SCI, as well as autonomic dysreflexia, nutrition, spasticity, pain management, sexuality, and medications.

Physical Therapists (PT) and Occupational Therapists (OT)

- The PT will help you get as strong as possible and then use that strength for different functional tasks including transfers, balance and moving around on a mat and in bed.
- In some cases, the PT may help you re-learn how to walk, as appropriate for your specific injury. This can be with and without braces as well as with and without equipment such as walkers, crutches or specialty equipment.
- The OT will help with the activities that “occupy” your time, activities that everyone does in their daily life which are known as activities of daily living (ADL), such as bathing, grooming, dressing and toileting. The OT may provide special equipment that can help accomplish these activities more independently.
- Therapists working with SCI should have experience working with patients with SCI including additional training courses in SCI beyond their basic educational programs.
- Therapists should have extensive knowledge of functional and mobility skills for all different levels of SCI. This includes adaptive equipment, wheelchair use and prescription, seating options, modifications that will make one's home or car accessible to someone using a wheelchair, equipment options for bathing and toileting, and assistive technology (such as phone, computer and other devices to make it easier to be independent with limited hand function).

- Some therapists may have certification as an Assistive Technology Practitioner (ATP). This means they received advanced training in prescribing and fitting wheelchairs and other technological equipment.

Speech Therapist:

- Patients with tracheostomies or those whose injury has affected their breathing may need the services of a speech therapist (also called a speech language pathologist or SLP). A SLP can evaluate and treat a patient who experiences difficulty with their voice.
- Sometimes when a person has had surgery on their neck, they may have trouble swallowing. A speech therapist can help them safely eat food and swallow liquids.
- Ask about the extent of the speech therapist's experience with SCI, particularly for a person with a cervical level injury.
- Since it is not uncommon for someone who has had a traumatic spinal cord injury to also have a head or brain injury, a speech therapist may help with cognitive abilities such as daily planning and social interaction skills.

Case Manager

- Most rehabilitation facilities employ case managers who will make sure that the rehab program is progressing in an efficient and timely manner during hospitalization.
- The case manager is the team member who communicates directly with insurance companies. Case managers are experts in navigating the insurance field and will assist with insurance issues as they come up.
- The case manager can also assist with making medical appointments and finding qualified medical professionals after discharge from the inpatient setting.
- Insurance companies often have their own case managers who are separate and distinct from the hospital based case manager. The insurance case manager should be licensed and/or have certification. They are often the primary contact a patient has with their insurance company and can answer questions about the patient's insurance benefits including identifying what services and items may be covered.

Psychologist and/or Social Worker and Psychosocial Services

- A spinal cord injury is a traumatic, life changing event that may require the assistance of a psychologist and/or a social worker to aid in adjustment to the disability. These are the team members who will help patients and their families cope with the stress.
- A psychologist or social worker may offer services such as couples counseling, individual and family psychotherapy, sexual counseling and stress management techniques.
- A social worker may also work with the case manager to arrange for services after discharge and to identify resources that may be needed after discharge to the community.

Therapeutic Recreation Specialist

- Therapeutic recreation specialists, who are also known as "Rec Therapists" use recreation and leisure activities to assist with enhancing quality of life after SCI.
- Rec therapists have knowledge and resources in areas including adaptive sports and recreation as well as support groups and advocacy.

Transportation Specialist

- Some facilities may have a Certified Rehab Driving Instructor on staff. If not, the facility should be able to provide a referral to a driving assessment and training program.

Pastoral Care

- A chaplain can respond to the different spiritual and religious needs that a patient may have after a traumatic injury, as well as provide religious support.
- A chaplain is trained to work with different religions and can help the patient transition back into their personal house of worship.

Peer Mentor

- Peer mentors are former patients who have successfully adjusted to life after SCI. Peer mentors are extremely helpful as they are easy to talk to and provide support based upon their own experience with SCI.

Pediatrics: Teacher

Pediatric rehabilitation programs have teachers who work closely with your child's teacher at home to continue the education of the child. Teachers in pediatric rehabilitation centers should be knowledgeable about SCI, particularly about how to respond to medical issues if they arise while in school.

Despite the uncertainty and anxiety that a new spinal cord injury can cause, please know that you and/or your family and loved ones are not alone. The support of the health care team, family, friends and community resources can help guide you and your loved ones into the direction of success.

Web sites that can provide useful material related to choosing a rehabilitation facility include:

The American Spinal Injury Association

Mission

(a) to promote and establish standards of excellence for all aspects of health care of individuals with spinal cord injury from onset throughout life.

(b) to educate members, other healthcare professionals, patients and their families as well as the public on all aspects of spinal cord injury and its consequences in order to prevent injury, improve care, increase availability of services and maximize the injured individual's potential for full participation in all areas of community life.

(c) to foster research which aims at preventing spinal cord injury, improving care, reducing consequent disability, and finding a cure for both acute and chronic SCI.

(d) to facilitate communication among members and other physicians, allied health care professionals, researchers and consumers.

<http://www.asia-spinalinjury.org>

The Academy of Spinal Cord Injury Professionals (ASCIP)

Academy of Spinal Cord Injury Professionals – (ASCIP)

ASCIP is an interdisciplinary not-for-profit association comprised of professionals dedicated to the care of individuals with spinal cord injury /diseases (SCI/D). Integrating the expertise of professions including physicians, psychologists, social workers, nurses and therapists, ASCIP provides perspectives that are shared via educational programming, publications (including the Journal of Spinal Cord Medicine), webinars, as well as serving as advocates within the field that will enrich the SCI/D continuum of care.

www.academyscipro.org

Commission on Accreditation of Rehabilitation Facilities (CARF)

www.CARF.org

CARF surveys and accredits specific rehab programs within a hospital. If the program you are looking at is accredited by CARF as a *SCI Specialty Program*

Hospital Compare

Find and Compare Hospitals

<https://www.hhs.gov/blog/tags/hospital-compare>

The Joint Commission

An independent, not-for-profit organization, The Joint Commission accredits and certifies more than 20,000 health care organizations and programs in the United States. Joint Commission accreditation and certification is recognized nationwide as a symbol of quality that reflects an organization's commitment to meeting certain performance standards.

Mission: To continuously improve health care for the public, in collaboration with other stakeholders, by evaluating health care organizations and inspiring them to excel in providing safe and effective care of the highest quality and value.

<https://www.jointcommission.org>

<https://www.qualitycheck.org>

Hospital Report Cards: Making the Grade

Harvard Medical School Family Health Guide

<http://www.health.harvard.edu/fhg/reportcards.shtml>

Paralyzed Veterans of America

Paralyzed Veterans of America membership offers resources and benefits to meet the needs of veterans who have sustained these injuries. Explore resources about spinal cord injury, and talk to PVA representatives if help is needed understanding and selecting treatment options.

<http://www.pva.org>

United Spinal Association

United Spinal Association is a national 501(c) (3) nonprofit membership organization dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), including veterans, and providing support and information to loved ones, care providers and professionals.

We believe no person should be excluded from opportunity based on their disability. Our goal is to provide people living with SCI/D programs and services that maximize their independence and enable them to remain active in their communities.

<https://unitedspinal.org>

A Patient's Bill of Rights

Available from the American Hospital Association.

Telephone: (312) 422-3000

Web site: <http://www.aha.org>

(Click on Resource Center; go to Search at bottom of page; type in Patient's Bill of Rights.) Also available from Fax on Demand, at (312) 422-2020; document number 471124.

All Hospitals Are Not Created Equal

Web site: <http://www.healthcareadministration.com/hospital-rankings/>

Choosing a Hospital and Hospital Safety Checklist

<https://www.webmd.com/health-insurance/choosing-hospital#1>

healthfinder®

Provides a gateway to reliable consumer health information from the Federal Government and other organizations.

Web site: <http://www.healthfinder.gov>

National Spinal Cord Injury Model Centers:

<https://www.sci-info-pages.com/spinal-cord-injury-model-systems.html>

Alabama

[UAB Model Spinal Cord Injury Model System](#)

University of Alabama at Birmingham, Birmingham, AL

(205) 934-3283

California

[Southern California Spinal Cord Injury Model System](#)

Rancho Los Amigos National Rehabilitation Center, Downey, CA

562-401-8111

Colorado

[The Rocky Mountain Regional Spinal Injury System](#)

Craig Hospital, Englewood, CO

(303) 789-8306

Florida

[South Florida Spinal Cord Injury Model System](#)

University of Miami, Miami, FL

(305) 243-4497

Georgia

[Southeastern Regional Spinal Cord Injury Model System](#)

Shepherd Center, Inc., Atlanta, GA

(404) 352-2020

Illinois

[Midwest Regional Spinal Cord Injury Care System \(MRSCIS\)](#)

Shirley Ryan AbilityLab, Chicago, IL

(312) 238-2802

Massachusetts

[Spaulding New England Regional Spinal Cord Injury Center](#)

Charlestown, MA

(617) 952-6174

New Jersey

[Northern New Jersey Spinal Cord Injury System](#)

Kessler Foundation, West Orange, NJ

(973) 324-3567

New York

[Mount Sinai Hospital Spinal Cord Injury Progra](#)

Department of Rehabilitation Medicine, New York, NY

(212) 659-9369

Ohio

[Northeast Ohio Regional Spinal Cord Injury System](#)

Case Western Reserve University, Cleveland, OH

(216) 778-8781

[Ohio Regional Spinal Cord Injury Model System](#)

Ohio State University, Wexner Medical Center, Columbus, Ohio

(614) 366-3877

Pennsylvania

[Regional Spinal Cord Injury Center of Delaware Valley](#)

Thomas Jefferson University Hospital, Philadelphia, PA

(215) 955-6579

[University of Pittsburgh Model Center on Spinal Cord Injury](#)

UMPC Rehabilitation Institute, Pittsburgh, PA

(412) 232-7949

Texas

[Texas Model Spinal Cord Injury System](#)

TIRR Memorial Hermann, Houston, TX

(713) 797-5972

Choosing a Rehabilitation Hospital Checklist

This list may help you with some of the important questions that you have regarding choosing a rehab hospital. It's a basic list, but it's a start!

Does this hospital treat patients with spinal cord injury regularly? How many are currently there? How many have my level of injury?

Yes No

If yes, how many? _____

Is this program accredited by CARF and/or JCAHO? Is this designated as a Model Spinal Cord Injury Center by the National Institute of Disability Research and Rehabilitation (NIDRR)?

Yes No

How many hours of therapy do I get every day? What kinds of therapy will I receive?

Physical Therapy? Yes No Occupational Therapy? Yes No Speech Therapy? Yes No
Recreational Therapy? Yes No Psychology? Yes No

Is there a special program for children? For adolescents? Yes No

How much experience does the team have?

How does this center deal with medical emergencies?

How much research is performed at this hospital? How do I become part of it?

Is there someone who can help me order the specialized equipment I might need?

Yes No

Is there someone who helps me with my discharge and what to do when my therapy is completed?

Yes No

What special therapy programs does this hospital offer?

Electric Stimulation? Yes No Adaptive Sports? Yes No Arm/Hand retraining? Yes No
Locomotor training? Yes No

Is there an assistive technology department?

Yes No

What can they help with?

Does this hospital have a driving program?

Yes No

Does this hospital help me get back to work?

Yes No

Does this hospital offer housing to family if they are far away?

Yes No

Is my family allowed to come to therapy?

Yes No

Does this hospital offer outpatient therapy after my inpatient stay is finished?

Yes No

Are there people who have my injury available for me to talk to?

Yes No