

## **MEDICAL AND REHABILITATION**

One of the most important needs of a person with a spinal cord injury is quality medical services. Quality medical services are needed from the moment of injury and through hospitalization and rehabilitation. In addition, comprehensive care is also necessary when one returns home and/or the community. Specialized care is needed to ensure you are maintaining your health and activity level. In addition, regard to the economic and psychological impact of the injury is vital. This chapter provides essential information about comprehensive medical facilities and rehabilitation centers. For more definitive information, contact the health department or physicians' medical society in your city or state.

### **WHAT IS SPINAL CORD INJURY?**

The spinal cord is a bundle of nerve fibers and cells that connect your brain with your muscles, skin and internal organs. Operating much like a telegraph line, the spinal cord relays messages from the brain to the intended body part or function. In essence, the spinal cord allows task accomplishment and body functions.

It is the spinal cord that acts as the transmitter of two-way communication between the brain and body part. When the cord has been damaged the messages may become confused and/or simply do not make it through. As a result, the involved physical functions are unable to trigger themselves to work (e.g., bladder control, leg or arm use, or the feeling of sensation). For example, in the case of the bladder, the problem lies not with the bladder itself but with its inability to communicate to and from the brain. In the simplest of terms, an injury to the spinal cord means a short circuit between the brain and body function.

The spinal cord can be injured anywhere along its approximate seventeen inch length. Each level of injury has its own unique characteristics, but the higher the injury point, the higher level of involvement. The parts and functions which are located above the injury point will continue to function correctly, however those below the injury point are affected. Injury to the spinal cord can be complete or incomplete. The effects of an injured spinal cord may include paralysis of arms, legs and/or trunk, bowel and bladder dysfunction, respiratory dysfunction and impairment of sensation.

The previous diagram of the spine depicts the vertebrae and the spinal nerves as well as the muscles and organs controlled by the various nerves. If the cervical spine is damaged the result is tetraplegia and/or quadriplegia (four extremities and trunk affected). If the spine below the cervical level is damaged, the result is paraplegia (two extremities and/or trunk affected).

The level at which all systems are still functioning normally is the "functional" level. Each spinal cord injured person has individual needs that must be assessed by qualified medical personnel. An individual's determination and attitude also affects the degree of independence that can be achieved. For additional information, please refer to the section in the next chapter, "Functional Goals and Potential Equipment for Persons with Spinal Cord Lesions".

## HOW DOES IT AFFECT PEOPLE?

Most injuries to the spinal cord result in some paralysis-the loss of motor function or the ability to move your arms, legs, etc. This may also be accompanied by a change in your level of sensation or your ability to feel things.

All of these changes may also affect you psychologically as well. This can be an overwhelming and challenging time, not only for you, but also for your family and friends. Advances in medical science and technology can now enable you to resume a full and active life in the community and environment of your choice. You can go to school or work, have relationships, marry, have children, travel, participate in a wide variety of sports and recreational activities, maintain old friendships and start new ones, etc., etc., etc.!!! The possibilities are endless if you set your mind to it. Take advantage of all the resources offered to assist you.

In addition to the content of this Resource directory, here are three key ingredients to get you started:

- (1) **Communicate** with those around you-family, friends, and care providers. Some of your questions/concerns may be difficult to put into words, but it is very important to do this.
- (2) **Take care of yourself** This includes your daily needs as well as your preventive medical care, physically and psychologically.
- (3) **Focus on the things you will be able to do.**

## EMERGENCY MEDICAL SERVICES (EMS)

Emergency services at most large acute care hospitals and university medical centers are well equipped to handle spinal cord injuries. For further information contact the state office of Emergency Medical Services (EMS) at **(860) 509-7975, 410 Capital Ave., MS 12 EMS P.O. Box 340308, Hartford, Ct, 06134-0308.**

## PATIENT'S BILL OF RIGHTS

“A Patient’s Bill or Rights,” prepared by the American Hospital Association (AHA), is intended to contribute toward more effective patient care and be supported by member hospitals on behalf of the institution, its medical staff, employees and patients. The following information is adapted from the revised bill approved by the AHA on October 21, 1992.

Effective health care requires collaboration between patients and physicians and other health care professionals. Open and honest communication, respect for personal and profession values, and sensitivity to differences are integral to optimal patient care. Hospitals must ensure a health care ethic that respects the role of patients in decision-making about their treatment choices and other aspects of their care. Hospitals must be sensitive to cultural, racial, linguistic, religious, age, gender, and other differences, as well as the needs of persons with disabilities. All

hospital activities must be conducted with an overriding concern for the patient and, above all, the recognition of his/her dignity as a human being.

Likewise, patients, or their families/surrogates, have the responsibility to participate in their care by providing accurate information related to health status, participate in decision making, providing the health care institution with a copy of written advance directives, providing necessary information for insurance claims and for working with the hospital to make payment arrangements, when necessary. Patients and their families are responsible for making reasonable accommodations to the needs of the hospital, other patients, medical staff, and hospital employees. Patients are also responsible for recognizing the impact of their life-style on their personal health.

In summary the PATIENT has the RIGHT to:

1. Considerate and respectful care.
2. Obtain from physicians and other direct caregivers current information concerning diagnosis, treatment and prognosis that is easily understood.
3. Make decisions about the plan of care and course of treatment and to refuse a recommended treatment or plan of care to the extent permitted by law and hospital policy.
4. Have an advance directive (such as living will, health care proxy, or durable power of attorney for health care) concerning treatment decisions or designating a surrogate decision maker.
5. Every consideration of privacy.
6. Expect that all communications and records pertaining to care will be treated as confidential by the hospital, except in cases such as suspected abuse and public health hazards when reporting is required by law;
7. Review the records pertaining to medical care and to have the information explained or interpreted as necessary, except where restricted by law.
8. Expect that, within its capacity and policies, a hospital will make reasonable response to the request of a patient for appropriate and medically indicated care and services.
9. Be informed of the existence of business relationships among the hospital, educational institutions, other health care providers, or payers that may influence the patient's treatment and care.
10. Consent to or decline to participate in proposed research studies.
11. Expect reasonable continuity of care when appropriate and to be informed by physicians and other caregivers of available and realistic patient care options when hospital care is no longer appropriate.
12. Be informed of hospital policies and practices that relate to patient care, treatment and responsibilities.

Resource: The Specialty Practice of Rehabilitation Nursing A Core Curriculum, Third Edition, 1993.

## **How Do You Know If You Are Getting the Best Care?**

Spinal cord injury is an extremely complex medical diagnosis. The treatment of this injury requires a team approach. Descriptive lists of the recommended medical specialists and rehabilitation team members are found later on in this chapter. When evaluating a facility in which you are being treated for spinal injury, it is extremely important to determine whether or not these team members are present and participating in your treatment program. If they are not, you have the right to request their expertise as consultants.

It will be most beneficial for you if the hospital or facility in which you are hospitalized participates in a system of care designed for spinal cord injury. An inquiry as to how many persons with spinal injury have been treated in the system of care will give you some idea as to the experience of the facility in which you are located. Make similar evaluations of facilities to which you may be sent for further care. It is also important to discuss these issues with your physician(s) to determine your individual needs.

Your medical needs should be met on a daily basis. This may include intermittent catheterization for your bladder, a regulated bowel program, a planned turning schedule to protect your skin from breakdown, strengthening and range of motion exercises, mobility training, specialized medical equipment and comprehensive education regarding spinal cord injuries.

The psychological aspects of spinal cord injury are also very important. Understanding the impact that spinal cord injury has on a person and how best to handle these changes are also necessary in a comprehensive spinal cord program. Attention to medical detail, the use of the team concept and sensitivity to the psychological issues are the heart and basis for a good spinal cord injury system of care.

## **COMPREHENSIVE CARE FACILITIES AND SYSTEMS**

Many hospitals in the U.S. provide the complete range of medical and rehabilitative care required for the spinal cord injured person. Necessary services for a comprehensive care facility are:

- 24-hour emergency service with 24-hour on-site physician coverage
- Provision of resuscitation and immediate life support
- Neurosurgery
- Orthopedics
- Physical Medicine and Rehabilitation
- Pulmonology and respiratory care practitioners
- Urology
- Medical and surgical consultation
- Plastic surgery
- X-ray Department including specialized neuroradiologic capabilities
- Physical, Occupational and Speech Therapy
- Nursing and medical support services

- Specialized medical equipment specifically designed for persons with spinal cord injuries
- Full medical, surgical and laboratory services.
- Trained staff to manage patients with unstable spines in special beds
- Trained staff in all phases of care such as bladder and bowel management (including technique of intermittent catheterization), skin care and positioning, joint range maintenance and muscle strengthening.
- Orthotic/prosthetic facilities capable of providing and fitting all necessary adaptive and supportive devices such as electric beds, wheelchairs, traction equipment, braces, corsets, splints, adaptive eating utensils, etc.
- Social work, psychology, case management and vocational rehabilitation services necessary to return a person to the community, school and vocational placement.
- A program of patient, staff, and family education in spinal cord injury.
- A program of lifetime follow-up care and maintenance of records.

### **Medical Specialties**

Common physician specialties dealing with spinal cord injury are as follows:

**Neurosurgeon** - a physician who specializes in evaluation and management and surgery of the nervous system (primarily brain and spinal cord).

**Orthopedic Surgeon** - a physician who specializes in disorders of the musculoskeletal system, both operatively and non-operatively.

**Physiatrist** - a physician who specializes in the medical management of individuals with severe impairment such as spinal injury and traumatic brain injury. The goal of the physiatrist is to maximize function and to promote independence. He/she works with the many members of the rehabilitation team to achieve these goals.

**Plastic Surgeon** - a physician who specializes in reconstructive surgery. In cases of spinal injury, the primary involvement is with skin breakdown problems and appropriate coverage of opened areas with skin flaps.

**Urologist** - a physician who specializes in the medical and surgical management of the urinary system (kidneys and bladder) and related organs and structures.

To locate a physician in your area experienced in treating persons with spinal cord injury, contact your city or state medical society, or local spinal cord group.

### **Rehabilitation Team Members**

The mission of rehabilitation is to successfully treat the multiple needs of the whole person. Coordinated efforts by many specialists are necessary to assist the patient in reaching his/her maximal potential. Each member of the multi-disciplinary team works closely with patient, family and friends to deal with the physical and emotional impact of spinal cord injury.

In all disciplines the emphasis is on the patient/family education for effective carryover following discharge from the rehab setting. The rehabilitation team consists of the following professionals:

**Physician** - Establishes a medical diagnosis and prognosis and provides medical management. Prescribes treatments, medications and therapeutic aids; guides progress of the treatment plan.

**Rehabilitation Nurse** - Responsible for direct day-to-day care of patient. Performs activities that help to maintain and restore function and prevent complications and further loss; directs carryover of skills taught and practiced during therapies; responsible for health teaching the patient, his/her family, and/or caregiver, in all aspects of personal care with specific emphasis on bowel and bladder management and skin care. Emphasis is on maximizing the patient's independence in performing or directing all care needs.

**Physical Therapist** - assists patient in optimizing functional mobility (including bed mobility, transfer training, wheelchair propulsion and management, and gait when feasible). Coordinates wheelchair assessment and evaluation of necessary durable medical equipment and makes recommendations to modify existing equipment.

**Occupational therapist** - Assists patient in achieving the optimal level of participation in activities of daily living, including work, school, family, community and leisure activities. Assists patient in learning to feed, groom, dress, bathe, and manage home tasks as independently as possible; guides use of adaptive equipment and orthotic devices; engages patient in activities to achieve general strengthening and work tolerance to increase range of motion, coordination and dexterity; evaluates home management; participates in adaptation of physical and social environment.

**Speech-Language Pathologist** - Assesses and assists with communication and dysphagia (swallowing) disorders. Treat disorders of verbal and written language, articulation, fluency and interactive communication; treats comprehension, memory and cognitive deficits; directs plan for patients with dysphagia.

**Respiratory Therapist** - Assists patients who require tracheostomy, ventilator or ongoing respiratory care. Assesses, treats, and teaches patient and family in use of respiratory equipment, the use of oxygen and the use of various breathing techniques.

**Dietitian/Nutritionist** - Works closely with the patient and other members of the health care team to formulate a nutrition care plan for the patient. Emphasis is placed on proper nutricontrol and overall health maintenance.

**Psychologist** - Assesses cognitive, affective, and personality-related factors that may impact on the rehabilitation process. Provides education and support to assist the patient and his/her family as they adapt and adjust to the spinal injury/illness. Facilitates communication between patient, family and staff when necessary.

**Social Worker/Rehabilitation Counselor** - Assists patient and family with personal-social issues affected by disabilities so that optimal outcome can be achieved. Assesses availability of family members and support networks; provides counseling and support; discusses housing, living arrangements, healthcare costs and coverage, financial resources, and transportation issues; facilitates discharge planning and acts as liaison between patient, family and community resources.

**Case Manager** - Manages the patient's resources. Liaison between the patient, family, team and the payer to advocate for the patient's needs.

**Vocational Counselor** - assists the individual in developing career plans in light of their injury. Capable of performing vocational evaluations, job analysis, work modification, and working with adaptive equipment directly related to educational or vocational training as recommended.

**Recreational Therapist** - Advocates the use of leisure and recreation to promote a healthy, productive lifestyle. Assesses and provides appropriate services for individuals and encourages participation in activities such as leisure discussion groups, community reintegration and supervised recreation activities.

### **American Spinal Injury Association (ASIA)**

Physicians who are recognized experts in the treatment of persons with spinal cord injury are elected to membership in the American Spinal Injury association (ASIA). This organization has two main purposes: (1) continuing education programs and publication and (2) coordination of pertinent advances in medical care. If you are having difficulty identifying a physician in your geographic region who has expertise in the area of spinal cord injury, ASIA may be able to assist you.

American Spinal Injury Association  
2020 Peachtree Road, NW  
Atlanta, GA 30309  
(404) 355-9772  
FAX (404) 355-1826

### **Model Spinal Cord Injury Systems**

There numerous SCI Rehabilitation programs designated as Model Systems by the National Institute of Disability and Rehabilitation Research (NIDRR). To qualify for designation as a Model System and to receive funding from NIDRR, rehabilitation programs must utilize and evaluate a prototype of SCI treatment based on providing continuity of care through the development of five areas within a system.

Model Spinal Cord Injury Systems must have:

1. Emergency medical services
2. Expertise in treating trauma
3. A comprehensive rehabilitation program
4. Vocational and psychological counseling services
5. Community reintegration services

Model systems must also conduct research of interest to NIDRR and collect data on SCI. In order to gain and maintain expertise in treating SCI, designated systems are expected to provide care to a significant volume of people with SCI, although consumers should be advised the designated systems are not evaluated for their quality of care. As with any treatment decision, it is recommended that persons who have spinal injuries thoroughly investigate any medical or rehabilitation treatment facility before deciding to be admitted.

Medical Science Program, NIDRR  
600 Independent Avenue, SW  
MES #3430  
Washington, DC 20202-2572  
Phone: 202-205-9194  
Fax: 202-205-3119

MODEL SYSTEM CENTERS: (Updated May 2002)

University of Alabama at Birmingham SCI Care System  
Amie B. Jackson, MD  
University of Alabama at Birmingham  
Spain Rehabilitation Center  
1717 6th Avenue South, Room 190  
Birmingham, AL 35233-7330  
Contact: Pam Mott  
voice: (205) 934-3334  
TTY: (205) 934-4642  
fax: (205) 975-4691  
e-mail: [mott@uab.edu](mailto:mott@uab.edu)  
URL: <http://main.uab.edu/show.asp?durki=10712>

Northern California Regional Spinal Cord Injury System  
Peter C. Werner, MD and Tamara Bushnik, PhD  
Santa Clara Valley Medical Center  
950 South Bascom Avenue, Suite 2011  
San Jose, CA 95128  
Contact: Tamara Bushnik  
toll free: 1 (800) 352-1956 ext. 24

voice: (408) 295-9896  
fax: (408) 295-9913  
e-mail: [tamara@tbi-sci.org](mailto:tamara@tbi-sci.org)  
URL: <http://www.tbi-sci.org/>

Regional Spinal Cord Injury Care System of Southern California  
Robert L. Waters, MD and Rob Adkins, PhD  
Rancho Los Amigos Medical Center  
Los Amigos Research and Education Institute, Inc. (LAREI)  
7601 East Imperial Highway, HB 206  
Downey, CA 90242-4155  
Contact: Robert L. Waters, MD  
voice: (562) 401-7161  
TTY: (562) 803-4533  
fax: (562) 803-5623  
e-mail: [rwaters@dhs.co.la.ca.us](mailto:rwaters@dhs.co.la.ca.us)

Rocky Mountain Model Spinal Cord Injury System  
Daniel P. Lammertse, MD and Gale G. Whiteneck, PhD  
Craig Hospital, Research Department  
3425 South Clarkson Street  
Englewood, CO 80110  
Contact: Susan B. Charlifue, MA  
voice: (303) 789-8306  
TTY: (303) 789-8375  
fax: (303) 789-8567  
e-mail: [susie@craighospital.org](mailto:susie@craighospital.org)  
URL: [http://www.craighospital.org/C\\_researchInfo.html](http://www.craighospital.org/C_researchInfo.html)

Georgia Regional Spinal Cord Injury Care System  
David F. Apple, Jr., MD and Lesley M. Hudson, MA  
Shepherd Center, Inc.  
2020 Peachtree Road, NW  
Atlanta, GA 30309  
Contact: Lesley M. Hudson, MA, Project Co-Director  
(404) 350-7580  
fax: (404) 355-1826  
e-mail: [lesley\\_hudson@shepherd.org](mailto:lesley_hudson@shepherd.org)  
URL:  
<http://www.shepherd.org/shepinfo/depts/research/abstract/model.htm>

Midwest Regional Spinal Cord Injury Care System

Paul R. Meyer, Jr., MD, MM and David Chen, MD  
Northwestern University  
Northwestern Memorial Hospital  
250 East Superior Street, Suite 619  
Chicago, IL 60611  
Contact: Marta Slechta  
(312) 908-3425  
fax: (312) 908-1819  
e-mail: m-slechta@nwu.edu  
URL: <http://www.nwu.edu/spine/>

Massachusetts  
Special Projects and Demonstrations for Spinal Cord Injuries  
Shanker Nesathuria, MD and Stanley Ducharme, PhD  
Boston Medical Center  
New England Regional Spinal Cord Injury Center  
88 East Newton Street, F-511  
Boston, MA 02118  
Contact: Stanley Ducharme, PhD  
voice: (617) 638-7358  
fax: (617) 638-8170  
e-mail: ducharme@bu.edu  
URL:  
<http://www.bumc.bu.edu/Departments/HomeMain.asp?DepartmentID=91>

Southeastern Michigan Spinal Cord Injury System  
Marcel Dijkers, PhD  
Rehabilitation Institute of Michigan  
261 Mack Boulevard  
Detroit, MI 48201  
Contact: Dr. Marcel Dijkers, Co-Project Director  
(313) 745-9770  
fax: (313) 966-7502  
e-mail: mdijkers@med.wayne.edu

University of Michigan Model Spinal Cord Injury Care System  
Austin Nobunaga, MD and Denise G. Tate, PhD  
University of Michigan Health System  
Dept. of Physical Medicine and Rehabilitation  
300 North Ingalls, Room NI2A09  
Ann Arbor, MI 48109-0491  
Contact: Rosalie Karunas, MPH, Database Manager  
(734) 763-0971  
fax: (734) 936-5492  
e-mail: rosakaru@umich.edu

URL: [http://www.med.umich.edu/pmr/model\\_sci/](http://www.med.umich.edu/pmr/model_sci/)

Missouri Model Spinal Cord Injury System  
Kristofer Hagglund, PhD  
University of Missouri-Columbia  
Department of Physical Medicine and Rehabilitation  
One Hospital Drive, DC046.00  
Columbia, MO 65212  
Contact: Joanne Willett, Grant Administrator  
voice: (573) 884-7972  
TTY: (573) 882-4936  
fax: (573) 884-4540  
e-mail: [willettjm@health.missouri.edu](mailto:willettm@health.missouri.edu)  
URL: <http://www.muhealth.org/~momscis/>

Northern New Jersey Model Spinal Cord Injury System  
Joel A. DeLisa, MD and Marca Sipski, MD  
Kessler Institute for Rehabilitation  
1199 Pleasant Valley Way  
West Orange, NJ 07052  
Contact: Craig Alexander, PhD, Director of Psychology  
voice: (973) 243-6871  
fax: (973) 243-6866  
email: [calexander@kmrrec.org](mailto:calexander@kmrrec.org)  
URL: <http://www.umdnj.edu/pmrweb/sci.htm>

Mount Sinai Model Spinal Cord Injury System  
Kristjan T. Ragnarsson, MD and Wayne Gordon, PhD  
One Gustave Levy Place, Box 1240  
New York, NY 10029-6574  
Contact: Audrey Schmerzler, Project Coordinator  
(212) 659-9369  
fax: (212) 348-5901  
e-mail: [audrey\\_schmerzler@smtplink.mssm.edu](mailto:audrey_schmerzler@smtplink.mssm.edu)  
URL: <http://www.mssm.edu/rehab/home-page.html>

Northeast Ohio Regional Spinal Cord Injury System  
Patrick Murray, MD, MS  
MetroHealth Medical Center/  
Case Western Reserve University  
2500 MetroHealth Drive  
Cleveland, OH 44109-1998

Contact: Mary Joan Roach, PhD, Research Director  
voice: (216) 778-8781  
fax: (216)778-8782  
e-mail: mroach@metrohealth.org  
URL: <http://www.metrohealth.org/clinical/NORSCIS/>

Regional Spinal Cord Injury System of Delaware Valley  
John F. Ditunno, MD  
Thomas Jefferson University  
Jefferson Medical College  
132 S. 10th Street, 375 Main Bldg.  
Philadelphia, PA 19107  
Contact: Mary Call, RN, Project Coordinator  
voice: (215) 955-6579  
fax: (215) 955-5152  
e-mail: call1@jefflin.tju.edu  
URL: <http://jeffline.tju.edu/spinalcord>

Model Spinal Cord Injury System - Texas  
R. Edward Carter, MD and William H. Donovan, MD  
The Institute for Rehabilitation and Research  
1333 Moursund Avenue  
Houston, TX 77030  
Contact: Karen A. Hart, PhD  
voice: (713) 797-5946  
TTY: (713) 797-5790  
fax: (713) 797-5982  
e-mail: khart@bcm.tmc.edu  
URL: <http://bcm.tmc.edu/pm&r/sci/research/modelssystem/>

Virginia Commonwealth Regional Spinal Cord Injury System  
William O. McKinley, MD and David S. Cifu, MD  
Virginia Commonwealth University/  
Medical College of Virginia  
Department of Physical Medicine and Rehabilitation  
Box 980677  
Richmond, VA 23298-0677  
Contact: William O. McKinley, MD  
voice: (804) 828-0861  
fax: (804) 828-5074  
e-mail: wmckinle@hfc.vcu.edu

URL: <http://views.vcu.edu/html/pmr/sci/>

Northwest Regional Spinal Cord Injury System  
Diana D. Cardenas, MD and Walter C. Stolov, MD  
University of Washington, School of Medicine  
Department of Rehabilitation Medicine  
Box 356490  
Seattle, WA 98195-6490  
Contact: Cynthia Salzman, Public Information Specialist  
voice: (206) 685-3999  
fax: (206) 685-3244  
e-mail: [csalzman@u.washington.edu](mailto:csalzman@u.washington.edu)  
URL: <http://weber.u.washington.edu/~rehab/sci/>

Model Construct for Community Integration in Spinal Cord Injury  
Dennis J. Maiman, MD, and Irma Fiedler, PhD  
Medical College of Wisconsin  
Spinal Cord Injury Center  
Froedtert Memorial Lutheran Hospital  
9200 West Wisconsin Avenue  
Milwaukee, WI 53226  
Contact: Traci Tymus, MS, CRC, CDMS, Project Coordinator  
toll free: 1 (800) 272-3666  
(414) 259-2126  
fax: (414) 259-7927  
e-mail: [ttymus@mcw.edu](mailto:ttymus@mcw.edu)  
URL: <http://www.mcw.edu/spinal/>

### **Veterans Administration Spinal Cord Injury Centers**

The Veterans Administrations provides a full range of medical and rehabilitation services to eligible veterans. For information or a full listing of regional VA Spinal Cord Injury Centers, call 1-800-424-8200.

### **Spinal Cord Injury Programs Accredited by CARF**

The commission on Accreditation of Rehabilitation Facilities (CARF) is a non-profit organization established to adopt standards within facilities throughout the nation. Accreditation by CARF is voluntary. There are numerous CARF accredited Spinal Cord Injury Programs across the country and the accredited program in Connecticut include:

Gaylord Hospital

Gaylord Farms Road  
Box 400  
Wallingford, CT 06492  
(203) 284-2800  
[www.Gaylord.org](http://www.Gaylord.org)

Hospital for Special Care  
2150 Corbin Ave.  
New Britain, Ct 06053  
860 827-4841  
800 220-7723  
[www.hfsc.org](http://www.hfsc.org)

### **Additional Spinal Cord Facilities**

Lawrence and Memorial Hospital  
365 Montauk Ave.  
New London, CT 06920  
860-442-0711

The Rehabilitation Hospital of Connecticut  
490 Blue Hills Ave.  
Hartford, CT 06112  
860-714-3500

William W. Backus Hospital  
Norwich, CT

### **Shriners Spinal Cord Injury Programs for Children**

The Shriners have a network of hospitals for children in the U.S. They provide inpatient medical, surgical and rehabilitative care to children and youths 18 years of age or younger. The outpatient clinic follow-up care is available to persons until the age of 21. Individuals accepted for treatment at Shriners Hospitals are not charged for services.

Spinal Cord Injury Programs have been established at three Shriners Hospitals. These are listed below:

Shriners Hospital  
1701 19th Avenue  
San Francisco, CA 94122-4599  
Phone: 415-665-1100

Shriners Hospital  
2211 North Oak Park Avenue  
Chicago, IL 60635-3392  
Phone: 312-622-5400

Shriners Hospital  
8400 Roosevelt Boulevard  
Philadelphia, PA 19152  
Phone: 215-322-4500

## **Respiratory Needs**

It may be necessary for some individuals with spinal cord injury, because of their high level of injury or other complications, to be placed on a ventilator. For those persons who cannot resume normal breathing on their own, use of a ventilator may be necessary. In some cases, however, the individual may have the proper medical criteria for the installation of a diaphragm pacemaker to stimulate the lungs to function without a ventilator.

**Ventilator Dependency** – Some individuals with high level spinal cord injuries may require a ventilator. There are portable ventilators of many types now available which can be attached to an individual's wheelchair, be placed near the individual's bed for use at night, or be adapted to meet other needs. In order to obtain proper information about acquiring and using a ventilator on a temporary, regular or long-term basis, it is necessary to be at a specialty center that is used to dealing with high-level injuries where respiratory compromise is present.

**Treatment Facilities for Ventilator-Dependent Persons** - There are numerous long-term care and rehabilitation treatment facilities with expertise as well as the willingness to provide care to persons who are respirator-dependent. The best source of information to find such a facility is to call the nearest regional Model Spinal Cord Injury System supported by the National Institute on Disability and Rehabilitation Research.

**Diaphragm Pacing** - Diaphragm pacing stimulates the phrenic nerves to provide ventilator support to patients with muscle paralysis secondary to lesions of the cervical spinal cord (above the level of C3) or the brainstem. Pacing is recommended when it is certain that the lower motor neurons of the phrenic nerves are viable and that paralysis of the diaphragm has stabilized. This technique is also applicable to persons with chronic ventilatory insufficiency due to central alveolar hypoventilation.

For resources for ventilator users and a listing by state of facilities that offer acute and/or rehabilitative services to individuals with high level tetraplegia who may use ventilators contact:

National Spinal Cord Injury Association

8300 Colesville Road, Suite 551  
Silver Springs, MD 20910  
Phone: 301-588-6959 or 800-962-9629  
Fax: 301-588-9419

In Connecticut, two facilities that offer rehabilitative and long term services to individuals who use ventilators include Gaylord Hospital (203) 284-2800 or Hospital for Special Care (860) 223-2761.

### **Medical Follow-Up**

Regular medical follow-up is necessary for maintenance of health and prevention of complications. Many medical issues, if identified early, can often be easily treated. Issues requiring attention includes one's general health, skin, bowel and bladder management, spasticity and any other specific medical issues such as autonomic dysreflexia and/or diabetes. Routine care should include education regarding important medical issues such as suggested immunizations. It is also highly recommended that individuals with SCI receive follow up care of their kidneys. Evaluations of the kidneys with ultrasound and other techniques have dramatically decreased the frequency of serious complication such as kidney failure.

### **Outpatient Services**

Most comprehensive rehabilitation centers with expertise in SCI offer a variety of outpatient services necessary for lifelong health maintenance (Including physical, occupational, and speech therapy, as well as counseling services, etc.). These services are also available at various other facilities throughout the state, as well as through private practice. Arrangements for initial services required should be made prior to discharge from an inpatient facility.

For services available in your area, check the Yellow Pages of your telephone directory under "Rehabilitation Services", "Hospitals" or the specific services of interest. You may also obtain assistance by contacting the hospital association in your state. (Connecticut 203-265-7611).

### **Home Health Services**

Health care services in the home are provided throughout the U.S. by visiting nurse associations and public health nursing programs. Not all of the services listed below are available in every home health agency. Services are provided under the orders of an attending physician and are most often covered by Medicare, Medicaid and/or private insurers. Those individuals not covered by insurance usually pay on a fee-per-visit basis.

Services provided may include:

- Skilled part-time nursing care
- Teaching others (e.g., family member) care at home
- Evaluation and referrals to other services as needed
- Medical social services
- Physical therapy
- Occupational therapy
- Speech therapy
- Home Health aides\*
- Nutritional guidance
- Home evaluations for architectural barrier
- Homemaker services\*\*

\*Home Health aide services, under the supervision of a Registered Nurse (R.N.) provide personal care assistance in dressing, ambulating, and transferring.

\*\*Homemaker services provide simple meal preparation, light laundry and ironing, light housework, childcare, grocery shopping, errand running, and other related activities.

To find home health agencies nearest you, check the Yellow Pages of your Telephone Directory under “Nurses”, or “Home Health Services”.

### **Obtaining Emergency Assistance**

It is extremely important for a person with a spinal cord injury to establish contact with a family physician upon returning to their community. Contact must also be established with an urologist and a rehabilitation specialist and/or a physiatrist. These contacts will enable a person with spinal cord injury to obtain assistance in those instances when a medical emergency exists. It is important that an individual with a spinal cord injured is educated and competent to handle medical situations, such as skin problems, autonomic dysreflexia, bowel and bladder difficulties.

The mental health of persons who have spinal cord injury also may need to be addressed. When emotional problems exist, the individual should feel comfortable in contacting either a personal physician or a local consumer group to attempt to find the best assistance for the particular problems. In addition, the Connecticut Chapter of the National Spinal Cord Injury Association provides a free of charge Peer Assistance Program to individuals with a spinal cord injury and/or disease. This program provides newly injured person an opportunity to talk with other persons with a spinal cord injury. Furthermore, the Chapter has various support and round table groups that are at various locations around the state. Contact the Chapter for further information.

Ultimately, if one has any concern and/or question regarding their medical condition, do not hesitate to utilize the Emergency Room or contact 911.

