

Spinal Cord Injury Manual

A Publication of the
Regional Spinal Cord Injury Center
of Delaware Valley

The Regional Spinal Cord Injury Center of Delaware Valley provides a comprehensive program of patient care, community education, and research. It is a federally designated program of Thomas Jefferson University and its affiliated institutions of Thomas Jefferson University Hospital and Magee Rehabilitation Hospital.

Advanced Medicine.
Superior Care.™

Thomas Jefferson University Hospital
and Magee Rehabilitation

 *Jefferson Health System*

Spinal Cord Injury Patient-Family Teaching Manual

**A Publication of the
Regional Spinal Cord Injury Center
of Delaware Valley**

Researched and prepared by the clinical personnel
of Thomas Jefferson University Hospital and
Magee Rehabilitation Hospital

© 1993, 2001 Thomas Jefferson University. This publication is the property of Thomas Jefferson University. All rights reserved. This Manual is intended for use in a total system of care that meets all applicable CARF standards for SCI Centers. Neither Thomas Jefferson University Hospital, nor Magee Rehabilitation Hospital is responsible for any liability, claims, demands or damages asserted to be the result, either directly or indirectly, of the information contained herein. The use or reprinting of any part of this manual requires the express permission of Thomas Jefferson University.

Dedication

The Handbook Committee of the Regional SCI Center of the Delaware Valley gratefully acknowledges the hard work and dedication of all who contributed to this manual.

Credits

The Handbook Committee of the Regional SCI Center of the Delaware Valley would like to acknowledge the assistance of all of the people in the Center who have helped to develop this Handbook:

Amy Bratta, MPT

Catharine M. Farnan, RN, MS, CRRN, ONC

Karen Fried , RN, MSN, CRRN, CCM

Joshua Giblin

Dane Hawley

Cynthia Kraft-Fine, RN, MSN

Frank Lindgren

Mary Grace Mangine, OTR/L

Mary Patrick, RN

Katheleen Reidy, PhD

Michael Saulino, MD, PhD

Mary Schmidt-Read, MS, PT

Theresa M. Smith, RN

Cheryl West, MPT

Geraldine Zelazny, RN

and all of the others who worked so hard to make this Handbook a reality.

Cynthia Kraft-Fine, RN, MSN
Chairperson

This publication is supported in part by Thomas Jefferson University, a grant received from the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education, Washington, D.C. and by the Geoffrey Lance Foundation.

Introduction

About This Manual	1
Introduction to the Regional Spinal Cord	
Injury Center of Delaware Valley	1
System of Care	2
Acute SCI Units (NICU or INICU)	2
Acute Rehabilitation Unit at TJUH or	
Ongoing Inpatient Rehabilitation at Magee	2
Lifetime Follow-Up System	3
Outpatient Therapy / Day Hospital /	
Community Re-Entry	4
Introduction to the Medical and Treatment Team	4
Trauma	5
Neurosurgery and Orthopedic Surgery	5
Rehabilitation Medicine	5
Rehabilitation Nurse	6
Physical Therapist	6
Occupational Therapist	6
Speech-Language Pathologist	6
Social Worker / Case Manager	7
Psychologist	7
SCI Project Office	7
Selecting a Rehabilitation Center for Spinal Cord Injury	8
Introduction	8
Accreditation	8
How Many Patients with SCI Are Treated?	8
Provision for Peer Interaction of Patients	9
Specialized SCI Rehabilitation Team	9
Attending Physician	9
Bladder Management	9
Equipment	9
Patient and Family Education	9
Sexual Counseling	10
Medical Consultation	10
Acute Care Hospital	10
Community Integration Services	10
Other Services	10

Follow-Up	10
Glossary	11
References	12

Introduction

About This Manual

This Spinal Cord Injury Manual is designed for use by the person with a spinal cord injury or dysfunction and his or her family. It is a guide to provide information on the many aspects of spinal cord injury and dysfunction. This handbook will help you and your family prepare for discharge from our comprehensive rehabilitation program and supplement lifelong learning about spinal cord injury and dysfunction.

The handbook is divided into topic sections and bound in loose-leaf form so that a member of the health care team may use each section in addition to teaching and demonstration. Teaching will be individualized to meet your specific needs. You and your family will continually participate in your rehabilitation program in order to allow you to achieve as much knowledge and comfort as possible.

Please feel free to request information. We would appreciate any comments you may have about the handbook.

Introduction to the Regional Spinal Cord Injury Center of Delaware Valley

The Regional Spinal Cord Injury Center of Delaware Valley (RSCICDV) at Thomas Jefferson University and the affiliated institutions of Thomas Jefferson University Hospital and Magee Rehabilitation Hospital first received federal designation as a Model System Spinal Cord Injury Center in October 1978. Since then, the RSCICDV has developed a nationally recognized program of patient care, research and education.

The RSCICDV received the Model SCI System designation from the National Institute for Disability and Rehabilitation Research (NIDRR). It is one of 16 federally designated Model SCI Demonstration and Research Centers. The government has designated these centers because they have shown the ability to provide high-quality, specialized services to persons who have sustained traumatic spinal cord injury. They also have shown the ability to conduct quality research studies regarding spinal cord injury. Admission to the Model SCI System will enable you to receive care from a professional staff who has expertise in spinal cord injury management from the time of injury throughout your lifetime. In addition, you can be sure that you are receiving the most up-to-date management of your injuries.

System of Care

There are five primary areas at Thomas Jefferson University Hospital (TJUH) and Magee Rehabilitation Hospital, which make up the Regional Spinal Cord Injury Center of Delaware Valley:

1. **Acute SCI Units** – The Neurological Intensive Care Unit (NICU) and the Intermediate Intensive Care Unit (INICU) are located on the ninth floor of the Gibbon Building at Thomas Jefferson University Hospital.
2. **Acute Rehabilitation Unit** – Located on the third floor of the Thompson Building at Thomas Jefferson University Hospital.
3. **Ongoing Inpatient Rehabilitation Unit** – Located on the 5th floor of Magee Rehabilitation Hospital.
4. **Lifetime Follow-Up System** – Outpatient clinic located on the first floor of Magee Rehabilitation Hospital.
5. **Outpatient Therapy / Day Hospital / Community Re-Entry** – Located at the Magee Riverfront Outpatient Center, 1500 South Columbus Boulevard.

Acute SCI Units (NICU or INICU)

While you are in the NICU or INICU, a team of specialists works to stabilize your spine and medical problems. The team meets weekly to discuss your progress, problems, goals and treatment plans. Physical and occupational therapists, social workers / case managers and psychologists begin to see you in the NICU or INICU to prepare for future rehabilitation. In addition, if you have a tracheostomy, a speech pathologist may begin to work with you and your family to facilitate communication and swallowing. Other rehabilitation goals include: starting bowel and bladder management, maintaining healthy skin, maintaining and increasing the range of motion in each joint and strengthening active muscles in preparation for intensive rehabilitation.

Acute Rehabilitation Unit at TJUH or Ongoing Inpatient Rehabilitation at Magee

The rehabilitation care phase begins when you are medically stable. If you require continued medical monitoring, stabilization or both, you will be transferred to Jefferson's

Acute Rehabilitation Unit. When your medical care needs are met, you will be transferred to Magee Rehabilitation Hospital for ongoing rehabilitation. The goals of the Acute Rehabilitation Unit at TJUH and Magee Rehabilitation Hospital are to provide a comprehensive rehabilitation program to facilitate a smooth transition with the ultimate goal of going home. During your rehabilitation, the specialty trained rehabilitation nursing staff initiates bowel and bladder retraining, medication teaching, skin care, respiratory care and patient and family education on all medical and functional aspects of spinal cord injury care. You and your family are encouraged to participate in all weekly SCI education groups. Physical therapists will teach you to regain sitting balance and work on all forms of mobility training, including walking, wheelchair mobility, transfers with all surfaces, etc. Occupational therapists work with you to maximize independence in daily living activities. Using adaptive equipment, individuals with a spinal cord injury or dysfunction relearn how to feed, dress and care for themselves. Recreational therapists carry over functional skills training into community and leisure activities. All therapies also include building strength and endurance, and increasing coordination and flexibility. Psychological intervention focuses on emotional reactions as you and your family begin to confront your injury. You can discuss your feelings and concerns with others that have spinal cord injuries or dysfunction and share coping strategies. Individual and group counseling sessions also offer peer and family support.

Lifetime Follow-Up System

The RSCICDV recognizes that people with spinal cord injury or dysfunction need lifetime follow-up care. The Follow-Up System at Magee Rehabilitation Hospital offers medical, nursing, functional, psychological, social and vocational support and services after discharge. You will have a formal evaluation one month after discharge, and then annually after discharge, to help monitor your needs. If necessary, you may be seen more frequently. The Spinal Cord Injury Follow-Up Clinic also offers telephone assistance 24-hours a day for patients who develop medical complications while living in the community and for consultation to primary care physicians and home health agencies. The telephone number is 215-587-3000.

Outpatient Therapy / Day Hospital / Community Re-Entry

The RSCICDV offers a variety of outpatient service options within the continuum of care depending on your individual needs, goals and circumstances. Traditional outpatient services are available at Magee Rehabilitation Hospital's Riverfront facility for individual therapies, such as physical or occupational therapy. For those in need of a more comprehensive therapeutic program, Magee Day Rehabilitation is available at the Riverfront outpatient facility as well as the Community Re-Entry Program. Magee Day Rehabilitation is appropriate for any person who requires multiple therapies, but does not need round-the-clock nursing care. In this program, you would take part in structured day-long rehabilitation activities, returning to your home each evening. The Community Re-Entry Program is headed by a community-based facilitator and is a structured approach to reintegrate you back to your home, neighborhood, school or workplace. One of the goals is to ensure that the skills learned in rehabilitation are applied in the real-world settings.

Please see the enclosed SCI Brochure for a full list of specialty programs and support groups available through our System of Care and the Lifetime Follow-Up Clinic and Magee Rehabilitation Hospital.

This systematic approach to the management of persons with spinal cord injury or dysfunction at the Regional Spinal Cord Injury Center of Delaware Valley places a strong emphasis on a team approach. There is an orderly progression through the system designed to meet each person's individual needs. The goal of the program is to assist each individual to return to his or her community, functioning at the highest level of independence possible.

Depending on your medical condition and the length of time since your injury, you may be admitted to any one of these primary areas. In some situations, persons may receive their total rehabilitation program at TJUH or Magee Rehabilitation Hospital or be transferred to other rehabilitation settings. As a rule, however, every effort will be made to assist each person to achieve maximum results.

Introduction to the Medical and Treatment Team

The team of physicians at the Regional Spinal Cord Injury Center of Delaware Valley includes specialists in four major fields of medicine: trauma, neurosurgery, orthopedic surgery and rehabilitation medicine. Each physician has an interest and

expertise in applying his or her specialty to the management of persons with spinal cord injury or dysfunction. These physicians work with the team of professionals who care for you from the time of your injury, during your hospitalization and throughout your lifetime follow-up care.

Trauma

If you are admitted to the Regional Spinal Cord Injury Center of Delaware Valley within 24 to 48 hours after a traumatic injury, you will be on the trauma service for general management and acute stabilization for a minimum of 24 hours. While on the trauma service, you will be followed by neurosurgery, orthopedic surgery and rehabilitation medicine to make sure you receive the most appropriate treatment for your spinal cord injury.

Neurosurgery and Orthopedic Surgery

After your initial period of stabilization on the trauma service, you will be transferred to either the neurosurgical service or orthopedic surgery service. Neurosurgeons and orthopedic surgeons order the appropriate x-rays and diagnostic tests needed to determine the extent of your spinal cord injury and bony injury and the most appropriate treatment. The treatment may involve prescribing medications to reduce swelling of the spinal cord, surgery to relieve pressure off a damaged spinal cord and to stabilize the spine, ordering the appropriate brace for you to wear until healing of the bones occurs or a combination of these options.

Rehabilitation Medicine

The physicians who specialize in rehabilitation medicine (also known as physiatrists) participate in your care from the time of admission to the Center throughout the lifetime follow-up care program. Physiatrists work with you and the team of medical, surgical and allied health professionals to insure that appropriate services are implemented on a timely basis to maximize your independence and help prevent the secondary complications of spinal cord injury or dysfunction. This may include medical care, prescribing therapy, medications and counseling. Your doctor and team members will also evaluate your “functional abilities,” meaning your ability to carry out your daily activities. Your rehabilitation doctor will see you daily while you are an inpatient to check your progress and answer your questions.

Rehabilitation Nurse

Rehabilitation nurses are specially trained in caring for persons with disabilities. They will teach you and your family all of the special rehabilitation skills needed to care for yourself so that you are safe and comfortable. The nurses will help you progress from being dependent in care, to being a partner in care, to eventually being independent in directing your care or caring for yourself. This is an important expectation in the rehabilitation phase of care. Rehabilitation nurses also provide all your medical care, medications and treatments needed to improve your health during your hospital stay.

Physical Therapist

Your physical therapist (PT) will evaluate your many mobility skills and design a treatment program specifically for you. The physical therapist will focus on flexibility, strength, endurance, coordination, wheelchair management, balance, all forms of transfers, work-related skills and walking, if applicable. Your program will be designed to help you return home and be as independent as possible in your community environment. It may also include equipment to help you be safe and independent. Also, the physical therapist will teach your family and friends how to assist you as needed and help in your recovery. Depending on your progress, your physical therapist may recommend continued therapy after discharge from the inpatient phase and continuation to another setting.

Occupational Therapist

An occupational therapist (OT) will evaluate your ability to perform activities of daily living (called *ADLs*). *ADLs* include everything from putting on clothes, dialing a telephone, planning a meal, a trip to the supermarket or work-related skills. He or she will teach you other ways to perform those activities that may be difficult for you. This may include special equipment, adjustments to your home or workplace or simply a different way of doing things. Your occupational therapy treatment may take place in your room, the therapy clinic (group or individual), outside or a combination of these options.

Speech-Language Pathologist

A speech-language pathologist will be included in your treatment team if you have a communication or swallowing problem. Communication problems may include difficulty in

thinking of what you want to say, producing words clearly or understanding spoken or written information. An evaluation and treatment plan will be developed to help you communicate effectively. If you have difficulty with eating, drinking or both, the speech-language pathologist will develop a treatment plan that will allow you to eat and drink safely.

Your family members and friends are part of the treatment plan and are encouraged to participate in treatment with you at any time throughout the continuum of care.

Social Worker / Case Manager

The social worker / case manager may provide counseling, guidance and emotional support to you and your family. He or she can help you and your family cope with social, emotional or environmental problems related to your disability. He or she will function as your program manager during your rehabilitation by coordinating your care from the various interdisciplinary team members. He or she will help you understand your rehabilitation program, represent your needs to the staff and insurance companies, help you participate in patient care planning and assist with your discharge arrangements. The social worker / case manager may arrange meetings and training sessions with your family or caregivers. They will also provide resource information and suggest referrals to appropriate agencies for your care after you leave the hospital.

Psychologist

Physical illness, serious injury and disability may be emotionally stressful for you and your family. Your doctor may ask you to meet with a psychologist on the SCI team. They can provide supportive counseling, relaxation training, stress management and family counseling to help you understand and cope with your disability and changes in your life. They may also give you tests to determine whether your illness or injury has affected your memory, concentration, language or other such skills. Their services are available on an inpatient or outpatient basis. They may also recommend appropriate support group resources for you and your family.

SCI Project Office

As one of the 16 Model SCI Systems designated by the National Institute for Disability and Rehabilitation Research, we are required to collect information on all traumatic spinal cord

injured persons who meet certain criteria. Once your eligibility is determined, a representative from the Project Office will discuss the project with you in further detail (see attached Consent Form).

In addition, the Regional Spinal Cord Injury Center of the Delaware Valley is involved in a number of research projects regarding spinal cord injury for which you may be eligible to participate. Participation in the demonstration project and any of the research projects is completely voluntary and all information is kept strictly confidential.

The SCI Project Office is located in Room 375 of the Main Building at TJUH. Questions, concerns and comments regarding the RSCICDV program may be directed to 215-955-6579.

Selecting a Rehabilitation Center for Spinal Cord Injury

Introduction

The information in this section was provided by the Arkansas Spinal Cord Injury Commission and is used with permission.

The following guidelines may be helpful in evaluating rehabilitation facilities for the treatment of a new spinal cord injury (SCI). Whenever possible, it is advisable to visit any center that you are considering and ask to see the program in action.

Accreditation

Is the center CARF accredited for SCI? The Commission on Accreditation of Rehabilitation Facilities (CARF) offers several types of accreditation, so it is important to be specific. Accreditation for general rehabilitation (or other non-SCI programs) is good, but does not indicate any special expertise in the care of SCI. A center that is accredited for spinal cord injury has met a series of standards that are considered important in the care of patients with SCI.

The CARF requirements for SCI are listed below. If a center is not accredited, it may be helpful to ask which of these services are available.

How Many Patients with SCI Are Treated?

CARF recommends a minimum of 30 new SCI admissions per year to maintain a viable SCI program.

Provision for Peer Interaction of Patients

How many patients with SCI are currently in the hospital? Patients need to interact with the medical staff, but they also benefit from interaction with other patients with SCI. Is there a designated area (beds) within the nursing unit where these patients are assigned?

Specialized SCI Rehabilitation Team

The rehabilitation team should have training and experience in the unique needs of patients with SCI and should consist of at least a rehabilitation nurse, physical therapist, occupational therapist, social worker, physician, respiratory therapist, and recreational trainer.

Attending Physician

Does the physician who will be in charge of the rehabilitation program have a special interest and competence in the care of SCI? Is there 24-hour physician coverage seven days per week?

Bladder Management

Is there an organized program for urological examination (including urodynamics) and bladder management? Is it under the direction of a urologist (or other qualified physician) with special interest and competence in the care of SCI?

Equipment

Is there access to a supply of specialized wheelchairs, cushions, and other equipment that can be used for trial until individual needs can be determined?

Patient and Family Education

Is there a formally organized program (with mandatory attendance) for education of the patient and family about the unique medical problems of SCI, including:

- Bladder Management and Prevention of Complications
- Bowel Management
- Skin Care and Prevention of Pressure Ulcers
- Autonomic Dysreflexia
- Sexuality and Fertility
- Instruction in Medications and Drug Abuse

- Nutrition
- Equipment Care and Community Resources for Availability and Repair

Sexual Counseling

Since most patients with SCI are young adults and SCI has a significant effect on sexual function, accurate information is essential.

Medical Consultation

Are specialists available for consultation (if needed) in specialties such as neurosurgery, orthopaedics, urology, plastic surgery, internal medicine, pulmonary medicine, general surgery and pediatrics?

Acute Care Hospital

Is there immediate access and safe transport to acute hospital services in the event of medical emergencies?

Community Integration Services

Is there an organized program to help patients adapt to activities outside the hospital? This includes supervised community excursions and provisions for overnight therapeutic home visits prior to discharge (as appropriate).

Other Services

The following services should be provided by the rehabilitation center staff or through consultation arrangements:

- Psychological Evaluation and Counseling
- Vocational Counseling
- Driver's Training
- Special Education for School-Age Children
- Orthotics (Braces and Splints)

Follow-Up

Is there an organized program for long-term follow-up to maintain or improve the health status after discharge? The SCI program should provide follow-up care for patients remaining in the geographic service area. A specific written plan should be provided for each patient on discharge.

Glossary

Affiliated Institutions	Members of the RSCICDV include (Thomas Jefferson University, Thomas Jefferson University Hospital and Magee Rehabilitation Hospital).
Community Reintegration	A program to facilitate your transition and return to home, work, school, neighborhood, etc. to enable your active involvement and participation in the community.
Comprehensive Rehabilitation	Provides a range of rehabilitation services from a multidisciplinary team including inpatient, outpatient and follow-up care as well as a variety of specialized services.
Federally Designated SCI Center	A Center with an emphasis toward SCI that has been awarded grants by the National Institute on Disability and Rehabilitation Research to collect data on all persons admitted with SCI and participates in spinal cord injury research. The data collected includes demographic data (age, cause of injury, date of injury, race, sex, etc), level of function, medical complications, medical expenses, quality of life and surgery.
Model Spinal Cord Injury Center	A Center recognized by the National Institute on Disability and Rehabilitation Research as a “Center of Excellence” in providing care to persons with spinal cord injury, including emergency medical services, acute care, rehabilitation, lifetime follow-up care and community reintegration.
Multidisciplinary Team	A team of specialists who plan and provide medical treatment toward assisting you in becoming as independent as possible during and after rehabilitation. The team includes physicians, nurses, physical therapists, occupational therapists, speech pathologists, recreational therapists, dieticians, psychologists and social workers or case managers.
NIDRR	National Institute on Disability and Rehabilitation Research. This is the government agency that designates the Model Spinal Cord Injury Centers and provides grants to collect data and participate in research.
RSCICDV	Regional Spinal Cord Injury Center of Delaware Valley

References

1. Regional Spinal Cord Injury Center brochure published December 1999.
2. Thomas Jefferson University Hospital Inpatient Rehabilitation Handbook published June 1999.

Comments and Feedback

The staff of the center has recently spent a lot of time and effort in revising this manual. However, we realize that those who are actively reading and using the manual can improve it. As a part of our program of continuous quality improvement, we ask you to help guide our efforts to improve the manual.

In the next section of the chapter are two forms. The first form is an overview by chapter that seeks to identify those areas of the manual that could benefit the most from additional work. We also seek to identify any major areas of concern that have not been addressed.

The second section is a more focused questionnaire that has as its goal the specific items that should be targeted. For example, should an item be added to the glossary or the definition changed. Should a drug be added to the discussion of bowel programs?

The more specific the comments are the more likely that we will be able to make the improvements that form the basis of your idea. By communicating with the Regional Spinal Cord Injury Center of the Delaware Valley, however, users grant us permission to use any information, suggestions, ideas, drawings or concerns communicated for any purpose we choose, commercial, public or otherwise, without compensation or acknowledgement whatsoever.

Thank you for taking the time to assist us in improving this manual.

Sincerely,

SCI Manual Committee

Regional Spinal Cord Injury Center of Delaware Valley
Thomas Jefferson University Hospital
Main Building, Suite 375
132 S. 10th Street
Philadelphia, PA 19107

Feedback Form

Rate each chapter by placing an “X” on the scale underneath the term that best captures your opinion. Using the next page, provide specific comments regarding your ratings. Feel free to make copies of the next page.

	No Opinion	Fair	Satisfactory	Good	Excellent
Credits / Front Matter					
Table of Contents					
Introduction					
Spinal Cord Injury					
Bladder					
Bowel					
Respiratory					
Respiratory Dependent					
Skin					
Cardiovascular					
Nutrition					
Activities of Daily Living					
Equipment					
Mobility					
Psychology					
Vocational Services					
Recreational Therapy / Resource Guide					
Travel and Transportation					
Sexuality					
Spinal Cord Injury Follow-Up Care System					
Master Glossary					

Suggestions and Comments

Chapter: _____

Page(s): _____

Comments: _____

Any terms that need to be added to the glossary? How would you define the terms?

Any section or paragraph that was not clear?

Any drawing or sketch that would help to illustrate the material being covered?

Any additional topic that should be covered?

Any questions you have that you feel should have been answered by the manual?

What is the question?

What is the suggested answer?

Any references that should be added? Any other resources that should be mentioned?

By communicating with the Regional Spinal Cord Injury Center of the Delaware Valley, however, users grant us permission to use any information, suggestions, ideas, drawings or concepts communicated for any purpose we choose, commercial, public or otherwise, without compensation whatsoever.

