



Jefferson | Magee Rehabilitation

Regional Spinal Cord Injury Center of the Delaware Valley
NIDRR-designated

Spinal Cord Injury Manual

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

The Regional Spinal Cord Injury Center of the 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.



Spinal Cord Injury Patient-Family Teaching Manual

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

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

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Dedication

The Handbook Committee of the RSCICDV gratefully acknowledges the assistance and dedication of all who contributed to this manual, and all the others who worked so hard to make this Handbook a reality.

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Psychosocial Issues

Introduction

A sudden trauma like a spinal cord injury will have a significant impact on you and the people close to you. You may see parts of your life change a great deal. Other parts of your life may not change at all. Regardless of the extent of your injury and disability, being hurt and having a disruption to your life may present unexpected problems or changes. This chapter provides information about services that are available at Thomas Jefferson University Hospital, Magee Rehabilitation Hospital and in the community to provide assistance.

Coping with a Spinal Cord Injury

After a spinal cord injury, you may experience many different feelings at one time or another, such as anger, worry, sadness, even hopelessness. These feelings are more likely to occur when you are under stress — as when your body undergoes dramatic changes in its functioning or when you have been in the hospital for a long time. Sometimes they are aimed in the wrong direction, like when you are really angry with one person or situation and you are nasty to someone else.

While you are still basically the same person inside, there are many adjustments that you are going through. Rehabilitation is aimed at helping you learn new things — both physical and emotional, so that you can learn to live with your change of body functioning and all the changes in your life that it may bring.

The emotional changes and behaviors you see in yourself may surprise you. It is important to recognize that what you are experiencing is normal, and also that what is normal for you may be very different from how someone else reacts. Really, if you think about it, it would be unnatural **not** to have some sort of reaction. Another aspect of dealing with this whole business of coping has to do with change. This is a transitional period for you. What is true for you today or this week may be different next week or next month. People change at their own speed.

Is there anything you can do to feel better? Here are a few suggestions to consider:

- Recognize your feelings and behavior as normal.
- Recognize your situation as difficult for you and for those close to you.

- Try to figure out what it is about your condition that is the most stressful for you.
- You will probably want to talk to people you feel close to – family and friends, other persons with spinal cord injury.
- Consider exploring your feelings with a professionally trained person. There are many advantages to talking with someone who has had special training in this area. In addition to the knowledge and skill available, you are likely to get some more objective input from a person who cares about you but is not emotionally involved in your life. Also, depending on the professional, what you say will be kept in strict confidence; the exceptions to this are if you pose a physical threat to yourself or another.
- Be aware of what helps to relieve tension for you. This is a very personal thing: some people listen to music, engage in meditation or prayer, others close the door and scream, some pound a pillow, some want to be alone and others need company.

Remember that everyone has good days and bad days. Occasionally, you may feel overwhelmed. But in time, you will develop ways to adjust to your situation.

Psychological and Social Services / Case Management Support Services

Individual Psychological Counseling

During rehabilitation, you may find it helpful to meet with a professional to discuss the changes in your life because of your injury. Rehabilitation psychologists are on staff at both Jefferson and Magee to meet with you while you are in the hospital. This service can help you understand your reactions and begin to feel like yourself again as you sort through all the challenges that SCI and rehabilitation presents to you. For example, you may want to learn about stress management techniques, explore ways to feel physically and emotionally comfortable with an altered body image or prepare yourself to resume your roles at home, work and in the community. Psychologists at Magee who are certified in addictions counseling are also available.

Symptoms of depression and anxiety are a particular concern for many people following SCI. For example, you may not find as much pleasure and interest in activities that you usually enjoy, or you find yourself sad or blue most of the time. In addition to counseling, your rehabilitation physician may

prescribe medication, in addition to psychological services, to help alleviate these symptoms and to enable you to fully benefit from your rehabilitation program.

After you leave the hospital, you may want to continue to receive psychological counseling to help you with the adjustment and community re-entry process. You may be able to return to Magee or Jefferson for outpatient services, or your psychologist or case manager can assist you with finding treatment in your community.

Psychological and Neuropsychological Assessment

Many people who have a traumatic SCI, also have some level of head injury. During the course of your rehabilitation, it may be recommended that you participate in a more in-depth psychological or neuropsychological assessment to help in planning your rehabilitation program and establishing long-term goals. The testing usually takes several hours and focuses on areas such as memory, problem solving and visual-spatial skills as well as personality and coping styles. Your psychologist will supervise the test administration and will assist you in understanding the test results.

Social Work / Case Management Services

Shortly after your admission to Jefferson and Magee, the case manager who is assigned to you will begin to meet with you and your family, providing emotional support, helping to make arrangements with your insurance provider and beginning the process of obtaining community resources and benefits if needed. Discharge planning is a collaborative process and actually begins from day one. As you progress through rehabilitation, your case manager will guide you and your family through the discharge planning process, discussing where you will live, assistance you may need and services and equipment that will help once you are discharged. Each patient and family with the guidance of the case manager learns to identify the special resources that they can draw upon to ease the transition to home.

SCI Patient Group

The Spinal Cord Injury Support Group at Magee and TJUH provides an opportunity for persons with recent spinal cord injuries to share their experiences and concerns with one another during their rehabilitation. It offers a time when people can learn more about SCI, find better ways to cope with stress

and help one another with problems. This group meets weekly and is led by psychologists. Each week a specific topic or theme is discussed such as stress management, vocational issues, family coping and adjustment after discharge home. Films, which are relevant to SCI, are shown in the group also. Your input in group is essential. The goal is for group leaders to serve as facilitators and resource persons for group members by using this time to raise issues, concerns and questions about SCI.

Women's SCI Support Group

The Women's SCI Support Group at Magee is available for all women (both in the hospital and living in the community) who have a spinal cord impairment. This weekly group is lead by a psychologist with expertise in women's issues and SCI. It provides women with the opportunity to explore their thoughts and feelings about life with SCI with other women in similar situations. Often, discussion addresses relationships, career issues, intimacy and sexuality. For information about this group, contact the Psychology Department at Magee at 215-587-3210.

SCI Peer Counselors

The SCI Peer Consultant Program offers newly spinal cord injured persons the opportunity to benefit from the knowledge and experience of those who have "been there and done that." During your hospitalization, or after discharge, you can request a referral to a *peer mentor* (someone who functions successfully following a spinal cord injury and has received training in peer counseling skills). The peer can be matched according to injury level, social situations, gender, marital status, recreational interests and vocational experience. Many people find that meeting with a mentor can be reassuring and informative. If you would like a peer mentor to meet with you, speak with your case manager or psychologist who can assist you with the referral. Training sessions are held regularly for those who would like to volunteer their time and knowledge as a peer mentor consultant. To learn more about peer mentor training, call 215-587-3174.

SCI Resource Group

The SCI Resource Group meets monthly at Magee. It is an opportunity for people with SCI from the community and inpatients to continue to learn about the latest information about their injury and resources available in the community

after they have finished inpatient rehabilitation. It also provides opportunities for recreation, socialization and support with others who have SCI. For more information about the SCI Resource Group, call 215-587-3174.

SCI Family CARE (Connections, Assistance, Resources, Education)

Having a loved one in the hospital or at home with a spinal cord injury is a unique and sometimes stressful experience for families. It helps, at times, to get to know other people who are coping with similar situations. Families frequently get to know each other informally when visiting in the hospital. Magee also has an SCI Family CARE Group that meets monthly. This group provides an opportunity for families to share their experiences, knowledge and mutual support with each other. The group is open to all families of persons with SCI (both in the hospital and at home). You can find out the exact date, time and location of the next SCI Family CARE Group meeting by calling Magee at 215-587-3174.

SCI Family Peers

In addition to family counseling, Magee offers the opportunity for families to receive peer consultation services, which are similar to the SCI Peer Consultant Program described above. Experienced families can be matched with adjusting families to provide some guidance in the adjustment to a loved one's injury and care. For more information about the SCI Families Program, call 215-587-3412.

Drugs, Alcohol and SCI

Drug and alcohol use is common in our society. Studies have shown that up to 50 percent of traumatic injuries are related to alcohol or drug use. For example, alcohol intoxication may lead to an increased chance of falling or having a motor vehicle accident. The purpose of this section is to outline some of the specific effects of alcohol and other drugs after spinal cord injury, increase awareness of your alcohol and drug use patterns and provide information about how to seek counseling, if desired.

Alcohol

Alcohol use (beer, wine, liqueur, and mixed drinks) is common and enjoyed socially in moderation by many people without negative physical or emotional effects. The effect of alcohol on a person depends upon a number of factors, including body

weight, metabolism, genetics, medications being taken, and of course, the amount of alcohol consumed. Because of physical changes after SCI, there are special concerns for people with SCI when using alcohol. Weight and metabolism following SCI are usually different than before the injury, which can create a lower tolerance for the effects of alcohol. Alcohol is a central nervous system depressant, which can cause problems in judgment, muscular coordination and drowsiness, which result in an increased risk of accidents and falls.

The affect of alcohol on the bladder is a particular important concern of people with SCI. Alcohol is a diuretic, causing the kidneys to eliminate fluid in the body. The bladder may be over-stretched when one drinks alcohol, causing problems particularly for those on an Intermittent Catheterization Program or ICP. Alcohol may increase the risk of bladder and kidney infections also.

Skin breakdown or pressure sores are a serious risk when an individual with SCI uses alcohol. Intoxication may result in neglecting routine weight shifts, which will result in the development of pressure sores. Poor nutrition, which often accompanies heavy alcohol use, also increases the chance that pressure sores will develop.

Narcotics

Narcotics (e.g., Morphine®, MS Contin®, Demerol®, Roxicet®, Percocet®) are used to control moderate to severe pain, usually prescribed during the initial period after injury. Prolonged use of narcotics can lead to physical and psychological dependency. In addition to this risk of dependency, people with spinal cord injury should be aware of the following effects of narcotics on their bodies.

Heroin is also a narcotic, but is one that people obtain illegally. It has the same effects on your body as prescribed narcotics. Heroin is not controlled, and therefore, has added risks. Methadone is a controlled substance that is used as a part of some substance abuse treatment programs.

Narcotics may depress the functioning of the central nervous system, resulting in impaired judgment, muscular coordination and drowsiness, increasing the risks of falls and other accidents. Narcotics tend to slow the functioning of the bowel significantly, which may lead to problems of the bowel becoming impacted, particularly with a neurogenic bowel. Respiratory rate and depth may be reduced also, which is of concern for those with limited respiratory capacity due to their

injury. In combination with alcohol the effects of narcotics are increased, which may lead to respiratory failure and death.

Stimulants

Stimulants such as caffeine in coffee, tea and soft drinks and nicotine in tobacco products are widely used to increase mental alertness and energy. Amphetamines and cocaine are used for similar effects. Possible negative side effects of all stimulants, particularly with frequent, heavy use include: insomnia, headache, irritability, tremors, fast heart rate and irregular heart beats. There is a risk of autonomic dysreflexia as stimulants cause blood pressure to rise. With prolonged use of stimulants, decreased appetite may lead to weight loss and increased risk of skin breakdown. Depression, significant mood changes and psychological dependence may occur also.

Hallucinogens

Hallucinogens include marijuana, ecstasy, LSD and PCP. While not physically addicting, these drugs may cause psychological dependence. As with other mood altering drugs, use of hallucinogens may impair judgement and reasoning. Difficulty with memory and slowed reaction time may occur also.

Self Evaluation of Drug and Alcohol Use

Alcohol or drug use is involved in about half of all traumatic injuries, including spinal cord injuries. Motor vehicle accidents are more likely to occur when the driver is intoxicated or impaired by substance use. Pedestrians are more likely to be struck by a car if they are high. Falls are more likely to occur, resulting in injury. Diving and recreational accidents may occur in part due to poor judgment or loss of physical control when drugs or alcohol are present. Gun shot wounds resulting in SCI may be the outcome of drug-related violence. In short, drugs and alcohol may directly lead to SCI. It is suggested that you take a few moments to reflect on your alcohol and drug use habits and patterns. The following are several questions that may help you to consider if your drug and alcohol use patterns are causing problems:

- Have you ever tried to cut down on your drinking or drug use?
- Have your friends or family ever been annoyed about your drinking or drug use?
- Do you ever feel guilty about your drinking or drug use?

- Do you ever need an “eye opener” to wake up?

If you find that you can answer “yes” to any or all of these questions, then it is recommended that you consider taking the next step by seeking assistance from someone trained to provide guidance about your alcohol and drug use.

Community Resources

If you or someone you are close with has an alcohol or drug use problem, there are a variety of resources available in your community to assist you in seeking treatment. Your health insurance carrier may have contracts with substance use treatment programs for which you may be eligible. If you are working, your employer may have a contract with an Employee Assistance Program (EAP) to provide counseling. Many alcohol and drug treatment programs are listed in the telephone book, in both the yellow pages and in the blue pages. Self-help programs such as Alcoholics Anonymous, Narcotics Anonymous and Cocaine Anonymous are available in most communities. Meeting locations can be obtained by calling directory information (your area code-555-1212) and requesting the central number for the group in your area. Additionally, your minister, rabbi, priest or spiritual advisor is a good source for support and referral information regarding counseling needs. Your primary physician or your rehabilitation physician will be able to help link you with someone who can help you evaluate this issue further. Finally, family and friends can be a great source of information and support. Remember that the first step in seeking help may be the most difficult, but change and recovery is possible.

Community Resources for Independent Living

As you prepare for, or adjust to, your return home after rehabilitation, you may find that you can benefit from the services of community resources. Liberty Resources, Inc. is the “Center for Independent Living” for the Philadelphia area, which advocates for, and works with, persons with disabilities to ensure their civil rights and equal access. This organization, founded in 1980, grew out of the Independent Living Movement started in the 1960s. The goal of the Independent Living Movement has been to promote the independence and integration of persons with disabilities.

Liberty Resources provides information and referral services, community education programs, peer support services, individual and systems advocacy, skills training, personal assistance services, assistance in locating accessible housing,

transitioning services, service coordination, a resource library, equipment exchange and a quarterly newsletter. Liberty Resources also has a first-time home buyers program for disabled persons. For further information about Liberty Resources, call the main Philadelphia office at 215-634-2000. The Liberty Resources office in Allentown can be reached at 610-432-3800.

Glossary

Addiction	A physical or psychological need for a substance.
Alcohol	Examples include beer, wine, mixed drinks, and liqueur. Alcohol is a central nervous system depressant, which can cause problems in judgment, muscular coordination and drowsiness.
Anxiety	A feeling of apprehension, worry and fear, which can lead to physical symptoms such as an irregular heartbeat, shortness of breathe and sweating.
Case Manager/ Social Worker	A person who coordinates the services that a patient receives. Some case managers/social workers provide counseling as well.
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.
Depression	Low spirits or sad mood. A treatable condition where, without treatment, an individual often undergoes a never ending cycle of low self-image and low spirits. Symptoms of depression include change in appetite, sleep or lack of emotional expression (flat affect), social withdrawal and fatigue.
EAP	Employee Assistance Program.
Hallucinogens	Examples include marijuana, ecstasy, LSD and PCP. Although some of these drugs may not be physically addicting, these drugs may cause psychological dependence
Independent Living	Enabling an individual to live in a setting that is as non-institutional as possible.
Neuro	A prefix that refers to nerves.
Neuropsychological	How brain functioning influences our behavior and mental processes, frequently measured through testing.
Narcotics	Drugs used to control moderate to severe pain which can lead to physical and psychological dependence. Examples include Morphine, Demerol, Percocet, Roxicet, MS Contin. These drugs should only be used under the supervision of a physician.
Peer Mentor	An individual with a medical condition similar or identical to your own and who has special training to provide advice and support.

Physical Dependence	A physiological state that occurs with regular drug or alcohol use and results in withdrawal symptoms once the drug or alcohol use is stopped.
Psychological Dependence	The mental belief that a drug or alcohol is needed in order for the body to function as a result of repeated substance abuse.
Psychologist	A professional who provides supportive counseling, relaxation training, stress management and family counseling to help you understand and cope with your disability and changes in your life.
Psychiatry	A medical specialty that focuses on the prevention, diagnosis and treatment of mental illness. Psychiatrists hold a medical degree and can prescribe medication.
Psychology	The study of the mental processes as they relate to an individual's personality, behavior and social interactions.
Stress	A strong sense of feeling overwhelmed. Repeated exposure can dramatically affect heartbeat regularity and blood pressure.

References

1. Consortium for Spinal Cord Medicine. Depression: What You Should Know. Washington, DC: Paralyzed Veterans of America, 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,

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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					
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Suggestions and Comments

Chapter: _____

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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?

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