



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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Travel and Transportation

Introduction	1
Driving	1
Behind the Wheel Evaluation	1
Vehicles and Modifications	2
Special Parking Placard for the Handicapped	2
Traveling Tips	2
Passport	3
Durable Medical Equipment	4
Medications	4
Bowel and Bladder	4
Traveling By Plane	5
Plan Ahead	5
Checking Wheelchair In	5
Security Checkpoint	6
Traveling by Train	6
Traveling by Bus	6
Renting a Car	7
Traveling by Ship	7
Hotels	7
Information Guides	8
Travel Websites	8
Hotline for Air Travelers with Disabilities	8
Camping	8
Performing Arts	8
The Basics When Traveling with a Power Wheelchair	9
Glossary	11
References	12

Travel and Transportation

Introduction

Travel and transportation includes driving or being a passenger in a car or van, or traveling in an airplane, bus, train or ship. After a spinal cord impairment, traveling for business or pleasure can be an overwhelming experience. Being well prepared in advance will decrease stress and make your trip enjoyable.

This chapter provides tips regarding traveling with a power or manual wheelchair, purchasing or renting durable medical equipment, medication management, bowel and bladder issues, traveling registrations and organizing recreational activities.

Driving

When you are ready to consider driving, it is suggested that you discuss financial coverage with your occupational therapist and case manager. If you are a vocational rehabilitation client, please consult with your therapist or rehabilitation counselor regarding driving evaluation, training and equipment coverage.

A referral can be made to link you up to the appropriate programs that evaluate your potential to drive safely. A comprehensive evaluation will be completed to evaluate your visual skills, motor skills, reaction time, transfer skills, hand function and driving knowledge. As a result of the evaluation, a recommendation can be made as to your ability and readiness to drive.

Behind the Wheel Evaluation

A behind-the-wheel evaluation can be scheduled when you are medically cleared and have satisfactorily completed the pre-driving evaluations at the facilities chosen. For example, the driving evaluator will perform the evaluation in the type of vehicle most appropriate for you to drive, either a car or van. There are two types of van evaluation:

1. A passenger evaluation for a lift and tie-downs only.
2. The driver: A full evaluation behind the wheel of a modified vehicle, including recommendations for modifications of your vehicle.

You must have a valid driver's license or the appropriate permit in your possession prior to the behind the wheel evaluation. If you are not currently licensed or do not have a permit, you

should contact the case manager and driving program in your area. Following the evaluation behind-the-wheel, training sessions may be recommended, and you may be referred to a driver's education school for these lessons.

Vehicles and Modifications

If you are considering the purchase of a car or a van, your case manager or physical / occupational / recreational therapist will discuss special vehicle requirements with you prior to your shopping for a vehicle or contact a local driver evaluation site. You are expected to arrange the purchase of a vehicle yourself if you do not already have one. Hand controls or modifications to a car or van may be covered by insurance or alternative funding sources such as the Office of Vocational Rehabilitation. Your physical, occupational, or recreational therapist can provide you with names of companies from whom you can purchase equipment or have modifications done. Remember not all vans / minivans can be modified to meet specialized needs. Be sure to seek advice of trained professionals prior to any adaptations.

Special Parking Placard for the Handicapped

The parking placard is a special cardboard sign approximately 6" x 12" that is displayed on the rear view mirror of the vehicle in which you are riding. It allows for parking in designated handicapped spaces for the legal period of time. It is issued to you, not the vehicle, and can be used in any vehicle with a gross weight of less than 9000 lbs.

You do not have to be a licensed driver or own the vehicle. Your age does not matter. The placard is valid for a period of years and can be renewed by reapplying when it expires. This parking placard can be acquired by asking your Occupational therapist or your case manager for the appropriate forms.

Traveling Tips

- Make your transportation and room reservations early. Inform them that you are in a wheelchair and be specific about your needs. Always confirm your request 48 hours prior to your departure.
- Join a nationwide auto club. They can be of invaluable assistance in planning trips and helping out in emergencies.
- When traveling by car, never let your gas tank get below half-full on long distance trips.

- Get an inexpensive gym bag or travel bag and put in those articles that you cannot be without. Keep it with you during all phases of your trip.
- Include the following in your packing:
 - Several coat hangers: hotels and motels hook theirs onto a rack, and they are difficult to use.
 - A flashlight to use when there is no bedside light or if the power fails.
 - Prescriptions and a letter from your doctor regarding special needs.
- Travel light regardless of your means of transportation. Do your laundry more frequently rather than traveling with a larger wardrobe. You will have enough to carry around without carrying useless extra clothing.
- Light weight, portable ramps are available for purchase. Ask your occupational therapist for assistance regarding these.
- Always arrive approximately 1 - 2 hours early so that you can get on before other passengers.
- Be sure to have all luggage and your wheelchair labeled securely with name and address.
- Be aware of liquid intake before departure if bathroom facilities are not accessible during travel.
- Always keep your seat cushion with you to prevent loss. It should be used while traveling to provide pressure distribution.
- People who cannot independently care for personal hygiene while traveling or feed themselves should be accompanied by an attendant.

Passport

Not all U.S. embassies or consulates are accessible to wheelchairs. Personnel are unable to offer physical assistance to complete applications. Applications may be made by mail or obtained and completed elsewhere and returned to the embassy or consulate. If the application process cannot be completed by mail and the facility is inaccessible, arrangements can be made to meet personnel at another accessible location.

Durable Medical Equipment

Plan ahead. Complete maintenance on all of the equipment you are taking with you several days to two weeks before you leave. Allow time for any necessary equipment to be obtained.

Bring spare tires if the trip will require wheelchair use on uneven or unpaved surfaces in the event of getting a flat.

Travelers abroad should be aware that European sizes and parts vary from American sizes and parts. Bring extra parts if necessary.

Some equipment may be rented at your destination. This could eliminate unnecessary baggage. Examples include a wheelchair for travelers who are ambulatory but may need it for long distances, a shower chair or a mechanical lift.

There are several commercially available products to assist with bathing while you are traveling that are lightweight and portable. Contact your occupational, physical, or recreational therapist for information.

Medications

All containers with medications must be clearly identified with the medications name, dosage and name of the prescribing physician. A letter from a physician should accompany medications. All medications should be kept with carry-on luggage so they will not be lost. Also, always have several extra days of medication and supplies in case of an emergency. Never assume that you can purchase medication at your destination. Have all medication well stocked before you leave. Worldwide medical assistance, medical ID cards, directory of physicians and the language they speak are some of the services provided by the International Association of Medical Assistance to Travelers (IAMAT). IAMAT is a voluntary service that has no cost for joining or to obtain information. The organization can be contacted at IAMAT, 417 Center Street, Lewiston, NY 14092 or at IAMAT@sentex.net. Travelers abroad need to check the restrictions on their prescription medicines in case they need to purchase medications while abroad.

Bowel and Bladder

As with any medication, always bring extra supplies in case of an emergency. Have a two to three days supply in your carry-on luggage of bowel and bladder equipment in case your luggage is lost or unexpected bad weather causes delays. Pick more than you need in case of an emergency. Always bring an extra change of clothes in case of an accident.

Traveling By Plane

Plan Ahead

Flying can be easy as long as you plan ahead and anticipate problems before they occur. The Federal Aviation Administration (FAA) has issued regulations to ensure that persons with physical limitations enjoy the benefits of air travel. The airlines have been allowed to develop procedures for their own operations and aircraft. The airlines must include rules and practices for transporting people with disabilities that require help to evacuate the aircraft in an emergency. Some airlines are more accessible than others because of the method of loading and the type of equipment used. Before you make confirmed reservation, call the special needs center of the airline and inform them of your needs. Depending on the airport you use, accessibility to the plane will differ. Be sure to check both airports you will be using. A jet way for entering the aircraft eliminates steps and weather factors. Some airlines use forklifts to load wheelchairs and these must be arranged in advance by the airline. Try to get a nonstop flight to eliminate transferring from one plane to another.

Within the United States, air travelers with disabilities have certain legally protected rights. The FAA as well as the Department of Transportation (DOT) play a role in the regulation of air travel based on several different laws, The Air Carriers Access Act (ACAA) is one such law. Once you goes outside of the United States, your rights will differ depending upon the laws of the various countries in which you are traveling.

Checking Wheelchair In

It is advisable and strongly recommended that you arrive early at the airport — at least one hour to one and one-half hours before your departure. Also, it is wise to take photographs or video record your wheelchair from multiple angles before traveling in the event that damage or missing parts occur. Check your chair at the boarding gate and request that it be brought to you at your arrival gate. Make sure your name and address is on any removable wheelchair equipment along with an arrival gate delivery. Consider adding any simple instructions that might be helpful for the wheelchair handlers to know. Airlines are required to allow you to take your chair directly to your departure gate where it is collapsed (if a folding chair) or prepared for transport (if a non-folding chair) after you transfer out of it. As you board the plane in the airline's special transport chair, your wheelchair will be placed with the

plane's cargo. Before landing, remind the flight attendant that you need equipment brought to the gate so that he or she can make the proper arrangements. If you have any problems, or if your equipment is damaged, ask to speak with the complaint resolution officer. If traveling with a scooter or power wheelchair, make sure that you arrange transportation that can accommodate your equipment at your destination. (Also, see "The Basics When Traveling with a Power Wheelchair" on pages 16-8 and 16-9.)

Security Checkpoint

All passengers must pass a security checkpoint. Hand luggage will be inspected by personnel using an x-ray. Wheelchair users, or if you use metal ambulation devices for support such as canes or crutches, will be searched by hand and will not pass through the metal detector. Notify the security personnel if you wear braces or have plates in you spine / body for stability. Airlines also have company-wide policies regarding transport of power wheelchairs. (See power wheelchair section below.) Individuals should question their airline for regulations at the time of their reservation. Most airlines will transport power wheelchairs. Individuals with disabilities will be boarded first and disembark last. Plan connecting flights or ground transportation accordingly.

Traveling by Train

Amtrak® has begun to make arrangements to be more accessible. Since 1984, each Amtrak® passenger train has at least one car with an accessible restroom and space for one wheelchair. Their staff can assist passengers getting on and off trains and assist with meals. As with any travel, it is best to call prior to departure to make sure that special services or accommodations are arranged for you. People with disabilities are entitled to a 25 percent discount for a round-trip coach fare ticket. In order to obtain the discount, you need to present an ID card issued by an organization for the handicapped, government entity or a transportation provider. A letter from a physician is acceptable also. Check accessibility of train stations at both ends as well as transportation available upon arrival.

Traveling by Bus

Greyhound® has a special program called *Helping Hands*. Under this program, a disabled individual and a companion may travel for a single adult fare. Terminals are becoming more accessible and include barrier-free design features. Before considering traveling on a bus, you should contact the carrier

and ask for the regulations regarding passengers who require assistance for boarding, exiting or traveling on a bus. Some carriers will allow a companion to travel with you for free. Drivers will seat disabled people close to the front due to the aisles being approximately 14 inches wide. These buses are not equipped with tie-down systems or lifts for wheelchairs in the bus. Some bi-level buses have room for power wheelchair in the baggage compartment. Ticket agents will explore accessibility of restaurants and restrooms at stations along the way upon a request made several days in advance. It is advisable to do this when making reservations.

Renting a Car

There are many car rental agencies that have programs for the disabled. Rental cars with hand controls are available (both right and left hand controls) at no additional cost. Reservations need to be made well in advance. It may require up to two weeks for the agency to locate and obtain the car. Hand control rental depends on the availability, and therefore, those agencies in larger cities will be better able to serve your needs than those agencies located in out of the way places. Adapted vans with hand controls and lifts are available also by contacting rental car agencies, car dealerships with vans or a conversion place that adapts vans. Adapted vans for rent may be used for independent driving or ones just for passenger transport.

Traveling by Ship

This is probably the easiest method of travel once you are aboard. As with any other means of travel, you should make your reservations well in advance and notify the shipping line of your special needs. You will want to investigate the width of doors, particularly into cabins and bathrooms. More ships are being constructed with wider doors to accommodate wheelchairs. There are usually elevators to take you from one deck to another. Obtaining necessary assistance is usually not a problem as stewards and other crew are usually more than willing to assist you if the need arises. Just remember, the bigger the ship, the better the possibilities of usable space.

Hotels

Many national hotel / motel chains have made accommodations for the disabled individual. There are no required specifications for these rooms and you need to ask when making the reservations as to the amount of accessibility, width of doors, grab bars, steps, door entrances and available lifts, if needed. You must call the individual chain for reservations and indicate what your needs are prior to your

arrival. Although these rooms are accessible, you need to talk about other facilities within the hotel / motel such as the restaurant. Often, reservations are done by computer and specific questions cannot be answered unless you call the hotel directly.

Information Guides

Major cities provide an access guide with information on accessibility for the wheelchair user. They are not updated often, and you will need to contact facilities before visiting to ensure accessibility. There are group tours that are organized with accommodations for the disabled and tour organizers who will organize a tour to meet your needs. Not all museums or historical homes are accessible and are not possible to be made accessible due to the nature of the buildings. However, if a museum or home receives federal funds, it should be accessible or make attempts to accommodate you.

Travel Websites

- www.access-able.com
- www.abletotravel.org
- www.disabledtravelers.com
- www.tsa.gov
- www.aded.net

Hotline for Air Travelers with Disabilities

- 1-800-778-4038

Camping

There are campers and camping facilities that are accessible. Woodall's North American Campground Directory includes information on campgrounds and campsites in the U.S. that are accessible. There are several organizations listed in the handouts that specialize in outdoor wilderness and sport activities for the disabled. Events may be only for the disabled or for both the disabled and the able-bodied.

Performing Arts

Promoters often provide discounts for the disabled, up to 50 percent off of the price of a ticket. These discounts are for a limited number of tickets and performances. Performance arts organizations that receive federal funds must make the facilities and programs accessible.

The Basics When Traveling with a Power Wheelchair

If it is a vacation, you anticipate relaxation with good company and beautiful surroundings. If it's a business trip, you let your mind graze over your agenda. But in practice, if you are traveling with a power wheelchair, it is an act of hope and faith to get from Point A to Point B without having your power wheelchair demolished.

Inform the carrier when booking the airline flight that you will be traveling with a power wheelchair. If possible, travel with friends who are familiar with your personal and equipment needs. Arrive at the airport early. One hour is a minimum, and one and one-half hours is better. Arriving early allows you to pre-board the aircraft before other passengers. You do not need to leave your chair at the baggage check-in, no matter what you are told. There is no reason you can't wheel to the gate and usually to the far end of the jet way before transferring.

Wheelchair: Know your chair's product name / model number, dimensions and its specific height, which determines whether the chair will fit upright in the cargo hold. If your wheelchair does not fold, your instructions may say: "Do not try to fold this chair. Its steel-welded frame will not fold. Do not take the wheelchair apart." Tape enough bubble wrap around the joystick to protect it from damage. Give specific instruction on how to shut off the power to the wheelchair along with specific engaging and disengaging instructions so that the flight attendant can instruct the ground crew. One way to avoid damage to your motorized wheelchair might be to store your wheelchair in a locked metal box on casters before you check in. However, you would first need to determine how strong a box is needed to hold your wheelchair and the airline's size limitations on such a box.

Batteries: Also know the type, width, length and weight of your batteries. If the airline throws insurmountable obstacles your way, there is always the option of renting batteries at your destination, but this is a major hassle in the real world. Gel batteries are recommended for all power wheelchairs and they require no maintenance.

Cushions: Bring something to sit on — whatever works for you normally. Keep in mind that most aircrafts are pressurized to about 8,000 feet, so air-filled cushions will expand and even explode. Leave out some of the air before this happens and refill it when you reach your destination. Also, it is recommended that written instructions to the take-off crew and landing crew are beneficial. Each set of instructions should be

less than one-page long. The shorter the instructions, the more likely the airline personnel will read them.

Your occupational, physical, or recreational therapist will inform you and provide you with additional educational material regarding traveling with a manual or a power wheelchair. He or she also will provide you with information regarding specific driving programs and van conversion companies to allow you to become an independent driver. Traveling can be easy and fun when plans are made accordingly.

Glossary

ADA	Americans with Disabilities Act.
ACAA	Air Carriers Access Act.
DOT	Department of Transportation. Federal and state agencies that deal with transportation issues often use these letters as their short name. The Federal agency has power to regulate some aspects of the services airlines, buses, trains, paratransit agencies and car manufactures provide to disabled individuals.
FAA	Federal Aviation Administration. A Federal agency that, among other duties, issues regulations to ensure that persons with physical disabilities enjoy the benefits of travel.
Hand controls	Special hand devices used to drive cars without using the foot pedals. These assistive devices allow some individuals with disabilities to drive their own car or van.
IMAT	International Association of Medical Assistance to Travelers.
Paratransit	Federally subsidized mode of transportation for individuals with physical disabilities. Services are provided through state or regional agencies such as SEPTA, New Jersey Transit and DART.
U.S.C.	United States Code, a compilation of the Federal Laws of the United States of America.

References

1. Roberts R. *Air Travel Guide for Seniors and Disabled Persons*. International Aviation Development Corporation, 2001.
2. Rosen F. *How to Travel: A Guidebook for Persons with a Disability*. Science & Humanities Press, 1997.
3. Rosen F. *How to Travel in Canada: A Guidebook for a Visitor with a Disability*. Banis & Associates, 1997.
4. Smitner P. *Access for Disabled Americans: A Guide for the Wheelchair Traveler*. Access for Disabled Americans Publishing, 1996.
5. Smitner P. *Around the World Resource Guide*. Access for Disabled Americans Publishing, 2000.

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

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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					
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?

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