Learning About Spinal Cord Injury

Developed by:

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This booklet was developed as a project of the Training Office of the Medical Rehabilitation Research and Training Center in Prevention & Treatment of Secondary Complications of SCI at the University of Alabama at Birmingham. It is intended as an easy-to-read, basic description of spinal cord injury and its management for use with patients and their family members. A 5th grade reading level is needed for the best comprehension of the information. After reading this booklet, patients may request additional information about medical, psychological, social or vocational issues.

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What Happens When You Get A Spinal Cord Injury

The backbone is the number one support for your body. It has many bones stacked on top of each other like building blocks. The bones stacked on top of each other are called vertebrae (ver-te-brae). The spinal cord runs through these stacked bones. The bones help protect the spinal cord.

Your spinal cord is part of your nervous system. It is like a group of telephone wires. It goes from your brain, down the middle of your back, to your buttocks. The spinal cord is about 18 inches long. It has many nerves in it that are like wires in a telephone cable. With a spinal cord injury (SCI), your spinal cord can be hurt any place from your neck to your buttocks. The spinal cord acts like a telephone cable. It sends messages to and from the brain to all parts of your body. The brain is like a computer and sorts all the messages.

What happens when you get a spinal cord injury? All of the nerves above the injury keep working like they always have. Below the injury, it is like when your telephone is not working right. The spinal cord nerves can not send messages to and from the brain to parts of the body like before your injury. If you cannot move your legs, but you can move and use your arms like always, your spinal cord is hurt in your "back" area. Look at Picture #1 on page 2. This person cannot use his legs. He has paraplegia (par-a-ple-gi-a). If you cannot move your legs and your arms do not move like they did before your injury, your spinal cord is injured in your neck area. Now look at Picture #2 on page 2. This person cannot use his legs. He also cannot use his arms as he did before his injury. He has tetraplegia (tet-ra-ple-gi-a), formerly called quadriplegia (quad-ri-ple-gi-a).

The closer the injury of the spinal cord is to the brain, the higher the level of injury. Fewer parts and systems of the body work normally when there is a higher level of injury.

Will you be able to move again like you used to? That depends on how hurt the nerves in your spinal cord were when you had your injury. Your doctor will stick pins
in your legs and arms and also ask you to try to move. This tells the doctor how the nerves are working. Ask your doctor if you have any questions.

The nerves that go from your brain down your spine go to other parts of your body, too. Your lungs (to help you breathe), your bladder and your bowels are some parts that do not work the same as before your injury.

**Working With Your Rehabilitation Team**

Rehabilitation (re-ha-bil-i-ta-tion) includes a team of people. You will go to classes and learn exercises to help you become more independent. They work with you to learn about your injury. Your family is a part of rehabilitation too. The team of people who may help you are:

**Doctor (M.D.)**

Your doctor will:

- take care of you to help you feel better;
- order medicines and tests;
- talk with other team members who work with you;
- help you and your family learn about your injury;
- help you to become more healthy.

**Nurses (R.N.)**

Your nurses will:

- teach you how to take care of yourself;
- teach your family your care;
- show you how to take care of your body—your bladder, your bowels, your skin, and your lungs;
- listen to you when you are sad;
- teach you to be more independent.
Physical Therapist (P.T.)
Your physical therapist will:

- help you exercise to get stronger;
- keep your leg muscles and arm muscles stretched out;
- teach you to use your wheelchair;
- teach you to move in and out of your wheelchair;
- teach you and your family your exercises;
- help you order your equipment to take home; and
- teach you to walk again, if your leg muscles are strong enough and if your level of injury allows it to be possible!

Occupational Therapist (O.T.)
Your occupational therapist will:

- test to see how much you can do for yourself;
- teach you to do things for yourself, if you can, like feeding yourself, brushing your teeth and hair, dressing yourself, and other daily activities;
- teach you to drive a car with special equipment;
- help you to exercise your arms to get stronger;
- teach your family your care;
- order equipment that helps you do things for yourself at home.

Recreational Therapist (R.T.)
Your recreational therapist will:

- talk to you about things you like to do for fun;
- teach you how to go outside and how to get around using your wheelchair; and
- teach you new ways to have fun like swim, play tennis, bowl, dance, go out to eat, fish, hunt and more!

Social Worker
Your social worker will:

- work with you and your family on your plans to go home;
- help you and your family find help (where you live) to get your home ready; and
- talk to you and your family about problems you have.

A rehabilitation team works with you to help you become more independent.
Psychologist
Your psychologist will:

• help you and your family learn about your injury;
• listen to you and your family when you are sad;
• teach you what to do when you feel sad;
• help you learn to live with your injury;
• teach you and your partner about sex; and
• test you to see what kind of job or classes you can do.

You will see these people every day. Other people who might work with you are a: Dietitian, Vocational Rehabilitation Counselor, Respiratory Therapist, and a School Teacher. You and your family are a very important part of this Rehabilitation Team.

Taking Care of Your Skin

Your skin is the largest organ of your body. It helps to protect your body from harm. Your skin sends messages to your brain when there is harm to the skin, like sunburn or a cut. Since the nerves are not working right after your spinal cord injury, your skin cannot send these messages back to your brain. So, you cannot feel when you get a cut, burn, or have too much pressure on your skin. Since you cannot feel, you will learn to remind yourself to keep your skin healthy. If you forget or get lazy, your skin will break open. Learning how to take care of your skin will keep you healthy and out of the hospital.

What can you do to keep your skin healthy?

• Sit on a cushion (your P.T. will order one for you) when you are in your wheelchair, in the car, on the sofa, or where ever you sit.
• Move your bottom every 20-30 minutes. You will learn to move or how to teach your family to move you.
• Check your skin every day during your bath or teach your family to check your skin. You will learn to use a mirror to check for red places, pimples, blisters, wrinkles, "hot" or hard places. If you see a place that looks like this on your skin, stay off that place until it goes away! These could turn into pressure sores. Your buttocks, your heels, your knees, your hips and your elbows are bony places to check.

• Be aware of hot things that can burn you. Learn to be safe around stoves, ovens, and hot water pipes. Wear sunscreen and a hat when outside or stay in the shade. If you are in the sun, keep your body cool. Cool off with wet towels or a plant sprayer filled with water.

• Keep your skin clean and dry. If your catheter (cath-e-ter) leaks and you wet yourself, clean it up. Change into clean dry clothes. Clean any scrapes or scratches with soap and water.

• If your skin does break open or burns, call your doctor.

• Your doctor will tell you how to take care of it.

• Turn yourself in bed to keep your skin healthy. Put pillows between your knees to keep from getting sores.

• Protect your feet from sores. Make sure you wear shoes that are big enough. Keep your toenails cut. Keep your feet clean and dry. Watch for blisters and red areas. Do not wear your shoes if you get sore areas.

• When you go swimming, always wear socks to protect your feet from scrapes.

• If you smoke, try to quit smoking. Smoking cuts off oxygen to your skin so your skin may not stay healthy.

• Eat good foods. Meats, chicken and fish have protein to keep your skin healthy.

• Drink 8-10 glasses of water each day. Water helps keep your skin healthy.

• Eat 3 good meals each day. Do not eat fried foods.
Learning About Your Bladder

Your bladder holds your “water” or urine before you go to the bathroom. From your kidneys urine flows down to your bladder through small tubes. Your bladder is like a big balloon that fills and empties your urine. Your bladder sends a message to your brain when it is ready to empty. This is when you used to feel like you had to urinate (“pass your water”). After your injury, nerves do not send this message to and from the brain like before your injury. Now, you may not know when it is time to go to the bathroom.

How will you urinate, "pass your water," "go to the bathroom"?

• At first, a tube called a catheter will be put into your bladder. Your urine (“water”) will empty into a container or bag. A catheter that stays in place in the bladder is called an "indwelling catheter".
• After you are at the rehabilitation center, you may learn to put a catheter (tube) in and out of your bladder at certain times to empty your urine (“water”). This is called "In and Out" catheterization.
• Most men wear a condom (“rubber”) with a hose that drains into a bag attached to their leg, called a leg bag. This is called an "External Condom Catheter".
• A person with SCI can use any one or a combination of these methods to drain his bladder.
• If you cannot learn how to put the catheter (tube) in, your family or personal care assistant will learn how to do it for you.
• You will learn how often to do this from your doctor or nurse.

How do you keep your bladder healthy?

It is very important to use care and cleanliness when emptying the bladder. This will help you prevent urinary tract infections,(UTI's). Repeated UTI's may cause serious damage to your kidneys and/or bladder.
• Learn the proper way to put the catheter (tube) in and out
of your bladder to drain it.
• Drink 8 - 10 glasses of water a day.
• Keep your bladder supplies clean.
• Watch how many canned drinks (sodas) and glasses of milk you drink. Try not to drink more than 1 glass a day.
• See your doctor to have tests done to check your bladder.
• Take medicines when told to.
• See your doctor if you run a fever, chills, or see blood when you urinate or "pass your water".
• Drink more water if your urine is a dark color, cloudy (not clear yellow), or smells bad.

Your Bowel Program

The food you eat moves through your body like the picture on the right side of this page. Some of it is broken down into waste called bowel movements (BM). It moves through your stomach and intestines and out of your body as a BM. Normally your bowel sends a message to your brain when it is ready to go to the bathroom. After your injury, the nerves ("wires") do not send the message to and from your brain like before your injury. So, you may not know when it is time to go to the bathroom. You may not be able to hold your BM until you are ready to go.

How will you have a bowel movement (BM)?

Unless you train your bowels when you want to have a bowel movement (BM), your bowels will move when you are not ready! So, your nurses will teach you how to move your bowels when you want them to.
• You will have a suppository (sup-pos-i-to-ry), also called a "silver bullet", put in your rectum after you eat. It is shaped like a bullet but is medicine that helps your bowels move at the right time.
• You will learn, if you can, how to give yourself a suppository ("silver bullet"). Your family will also learn.
• You might be on medicine to keep your BM soft, too.
• If you can transfer to a commode (toilet) seat, your BM will work faster. Sitting helps it come out better.
• Your doctor or nurse will tell you when to take your suppository ("silver bullet").
• If you have problems, call your nurse or doctor.
Remember to always drink plenty of fluids and eat foods with fiber.

A Good Diet Helps Your Health

You need to eat a balanced diet to stay healthy. A balanced diet will help your bladder, bowels, skin, and lungs stay healthy along with the rest of your body. Foods that are good to eat are:

**Meats** - fish and chicken are best. Eat only small amounts of red meat.

**Vegetables** - fresh and raw are the best. Most vegetables have fiber in them. Fiber helps your bowels move. Salads and greens are very good for you to eat.

**Fruits** - fresh and dried are the best. Stay away from orange and grapefruit juices. Bananas can cause hard BMs in some people.

**Breads/Cereals** - dry cereals, brown rice, bran, whole grain bread, noodles, popcorn.

**Milk/Dairy** - milk, yogurt, ice cream, cheese, eggs. Yogurt and buttermilk help if you get loose BMs (“the runs”). Too much cheese can make you have hard BMs.
Try to eat healthy foods. Foods with fiber are important in your diet. Drink 8 - 10 glasses of fluids each day. Fried foods and “junk” food are not healthy for you.

Watch your weight! The more weight you gain, the harder it will be to move and fit into your wheelchair! Ask your doctor about how much you should weigh.

Stay healthy and keep your bladder, bowel and skin in good shape! You’ll feel better, look better and have more energy to do all the things you enjoy.

**Autonomic Dysreflexia (AD) and What to Do If It Happens to You**

Autonomic Dysreflexia (au-to-nom-ic dis-re-flex-i-a), also called AD or autonomic hyperreflexia, may be a life threatening emergency. It may happen to you if your injury is to your neck or upper back (T6 level and above). It is like an alarm to tell you that your body has a problem that needs to be fixed now! Anything that causes pain to your body can lead to AD.

*What alarms go off to tell you that you have a problem?*

One or more of these may happen to you:

- sweating on face, arms, or chest (above your injury)
- bad headache
- red, blotchy skin on face, arms, or chest
- sudden high blood pressure
- sudden stuffy nose
- blurry vision or spots before your eyes
- “Goosebumps” on arms, chest
- slow pulse
Why does this happen?

It is your body telling you that you have a problem that needs to be fixed. It happens because of your spinal cord injury. If you have this problem, you need to:

• Take off tight clothes. Sit up in bed.
• Empty your bladder. Put the catheter (tube) in and empty your urine ("water") out. If you don’t feel better, then -
• Empty your bowels out. Put on gloves and take out all BM that you, or someone who is helping you, can reach. If you do not feel better, then -
• Go to the Emergency Room now. You will need medicine to get your blood pressure down. You need a doctor and nurse to find the cause of your problem.
• Keep this handout on A.D. handy. It could save your life. Take it with you to the Emergency Room. Make a copy to tape up in your kitchen or bedroom. Look at it every day.

Medical Alert for Autonomic Dysreflexia

Is subject to the above syndrome. This is a serious medical problem that can occur in people with spinal cord injury at or above the 6th thoracic level. The symptoms of autonomic dysreflexia (AD) can be caused by many types of stimuli below the level of the spinal cord injury, but the most common emergency causes are: (1) full or spastic bladder or (2) bowel distention (usually from stool in rectum). Severe AD is a medical emergency which if not treated can result in cerebral vascular hemorrhage (stroke).

Symptoms:
1. Pounding headache
2. Flushing of skin and sweating above the level of injury
3. Increased blood pressure (as high as 250/150), slow pulse
4. Apprehension/anxiety
5. Nasal stuffiness
6. Vision changes: blurring, spots before the eyes
7. “Goose bumps”

What To Do: (First Aid)
1. Place patient in a sitting position
2. Drain the bladder
   (a) If catheter is in place, check for kinking.
   If catheter is plugged, do not try to irrigate.
   Change Foley by using Lidocaine jelly for lubrication.
   (b) If no catheter is present, insert a catheter using Lidocaine jelly for lubrication. Do not crede (push on) the bladder.
3. If emptying the bladder has not decreased the blood pressure and there is stool in the rectum, apply Lidocaine jelly to the anal sphincter and wait three minutes. Then, using a Lidocaine-lubricated gloved finger, gently remove stool from rectum.

Medical Treatment:
1. If the AD episode is not resolved after the previous measures, medical treatment is necessary. Ask the patient if he has his own supply of any AD medications. If not, transport patient to an emergency room as soon as possible.
2. If the AD episode is not resolving and/or the blood pressure reaches 160 systolic, give the patient Nifedipine 10 mg sublingual. Instruct patient to bite through the capsule and hold it beneath his tongue. May repeat Nifedipine dosage after 15 minutes if blood pressure has not responded.
3. Continue to look for causes of AD by checking the patient’s entire body. Other causes include fractures, sores and tight clothing.
4. Alternate treatments (if Nifedipine not available or does not work):
   (a) Nitroglycerine ointment: 1 inch to upper chest or back. If no resolution in 15 minutes, add additional 1 inch.
   (b) Markedly elevated blood pressure not responding to the above measures should be treated with IV Apresoline (20mg/1 cc) inject. 5c SLOWLY. May repeat dosage after 15 seconds if no response. Other IV medicines may be substituted.
5. Blood pressure may be safely lowered to 90/60 which is typical of quadriplegics in the sitting position.
6. After an episode of AD, it is not uncommon for a second episode or rebound to occur, so blood pressure should be checked every 30-60 minutes for the next 4-5 hours.
7. Patient should be monitored for hypotension after treatment of AD.
**Keeping Your Lungs Healthy**

After your injury, your muscles for breathing are weak or not working like they used to. The muscles to help you cough may not work. Also, bedrest keeps you from breathing deeply. If you cannot breathe deeply or cough strongly, you might get a lung infection called pneumonia (*pneu-mo-ni-a*).

**What can you do to help your lungs?**

- Drink at least 10 glasses of water a day.

- Sit up in bed or in your wheelchair.

- Do the lung exercises that your doctor orders.

- Do not smoke or be in smoky rooms.

- Stay away from sick people who have infections or the flu.

- Eat healthy foods.
How to Deal With Your Feelings

Don’t worry if you or your family feel very sad right after your injury. This is normal. It is the way most of us deal with a big problem that we cannot change. It is said that "time cures all wounds." You may not believe it at first. As time passes, your sad feelings will start to go away. Individuals who have SCI tell us this.

SCI can happen to anyone. It does not matter if you were a good person or a bad person before your injury. Stop trying to figure out why SCI happened to you. Just get on with your life. Everybody handles problems in different ways. There is no perfect answer to give about how you should deal with your injury. One of the best things to do is to talk with your psychologist. You might also be able to talk to someone who has been through the same things you are now going through. Your psychologist, social worker, or nurse may send someone who has a spinal cord injury to talk with you. You will have up and down feelings. It helps to talk to other people about your feelings.

There are many ideas that people have about individuals with SCI. Some people think that all you want is pity. Others will feel "funny" around you. They don’t know how they should act or what they should say. Some people even think that just because you use a wheelchair, you may not be able to talk or think. Most people who use wheelchairs want other people to treat them "normally." You may not feel "normal" at first. As time goes by, you will find that you can do many things — you just do them in different ways now. You are still you. You just use a wheelchair now.

It is best to talk to your psychologist, social worker or nurse for help. You can learn how to deal with feelings of stress, anger, fear and being sad.
Many people don’t want to talk about sex. It’s even hard for some of us to talk about sex to our friends. You can talk to your therapists, psychologist or nurses. They are there to help you while you are in the rehabilitation hospital setting. You might also feel better talking to someone else who has SCI.

Some folks think that people with SCI don’t have sex. They also think you are not interested in sex anymore. Your feelings about things in life do not change a great deal just because you have SCI. If you liked sex before your injury, you probably still like it now.

Sex may be a little scary at first because you or your partner do not really know what to expect. Talking to each other and asking questions is the best way to deal with your feelings. SCI sex education is the place to start. Your psychologist can explain sex education to you and your partner.

Remember, the way you feel about things hasn’t changed just because your body has. People with SCI can still meet people and fall in love. Sometimes it is still possible to have a family. Women with SCI usually can get pregnant as easily as women who do not have SCI. It is much harder for men with SCI to become fathers because of their injury. Research is being done that can help some men with SCI father children. Your psychologist will teach you and your partner about ways that have been used. Don’t be afraid to ask questions.

You can still have a relationship after SCI.
**Going Back To Work**

Some people who have a spinal cord injury find it hard to get back to work. They think if they cannot do the work they did before their injury, then there is no job they can do.

The best advice that people with SCI give to a person with a new spinal cord injury is to just try working. See if you can do it. The best way might be to start part-time. You may be able to work part-time and still receive your benefits. It’s also better to start slow because you may have to get stronger to be able to work a full day again.

Many former patients with SCI tell us they think that people even live longer when they work. It seems to be healthier for the mind and the body!

One of the biggest problems for people with spinal cord injury is fear. You don't know how other people will treat you. You may be scared about how people at work will react to you. You may wonder if your boss will think that you cannot do your job. You have to be the one to show them that you can do it!

A new law should make it easier for a person with a spinal cord injury to get a job. It is called the **Americans With Disabilities Act of 1990** or **ADA**. It stops businesses and bosses from discriminating against people with disabilities. It also requires employers, agencies and businesses to make their buildings and services (like transportation) accessible to people with disabilities. The purpose of the law is to make it easier for you to get a job, hold your job and live in everyday society.

For more information, talk to your social worker, vocational rehabilitation counselor or your local Social Security Administration Office.

**DRIVING**

*You might learn to drive a new way with hand controls.*

**WHEELING**

*You will learn a new way to get around using a wheelchair.*

**WORKING**

*Try a new way of working back at your old job or start a new job.*
Let's See What You've Learned

Let's see how much you learned about spinal cord injury. This is a short test that asks a question about each chapter. Circle the correct answer under each question. If you learn all that you can, it will be easier for you to take care of yourself.

1. When you have a spinal cord injury, a part of your body that works different is:
   A. Your Lungs
   B. Your Bladder
   C. Your Bowels
   D. All of the above

2. You will be helped in your rehabilitation by:
   A. Doctors
   B. Nurses
   C. Social Workers
   D. All of the above

3. Ways to keep your skin healthy include:
   A. Checking your skin with a mirror everyday
   B. Getting a suntan
   C. Sitting in the same position all day
   D. Eating lots of sweets

4. A tube (catheter) is used to drain your urine ("water") from your bladder.
   A. True
   B. False

5. You always have control of your bowels after a spinal cord injury.
   A. True
   B. False

6. Which of these foods are good for you?
   A. Candy bar
   B. Apples
   C. Chocolate cake
   D. Potato chips

7. Which of these can be a symptom of Autonomic Dysreflexia (A.D.)?
   A. Blurred vision
   B. Severe headache
   C. Sweating on your face, chest, and arms
   D. High blood pressure
   E. All of the above

8. Smoking can increase your chances of getting an infection in your lungs.
   A. True
   B. False

9. Your psychologist or social worker can help you deal with:
   A. Stress
   B. Anger
   C. Feeling sad
   D. All of the above

10. Women with SCI can still get pregnant.
    A. True
    B. False

11. You can still hold a job after a spinal cord injury.
    A. True
    B. False

Answers are upside down on the last page of this booklet! Read this booklet again if you missed any questions.
Glossary

This is a list of rehabilitation terms, abbreviations and words used in this book. A short definition of each term/word is provided to help you learn what each term means.

**Catheter** - A small special tube used to empty a body cavity of fluid. One use is when this tube is placed in the bladder to empty your urine.

**Junk Food** - Food that has little nutritional value. It is usually not part of the four basic food groups. Snack foods such as candy, potato chips and cookies are junk foods because they are high in calories and fats, but low in nutrition.

**Leg Bag** - A collection bag placed at the end of your catheter tubing. The bag stores urine that comes out of your body. It is attached to the leg. The bag is disposable and can be emptied easily into a toilet.

**Nerves** - Pathways that carry messages between your brain and other parts of your body. The messages can be sensations or feelings such as heat, cold, pain, pressure and touch.

**Occupational Therapist (OT)** - A professional on your rehabilitation team who focuses on teaching activities of daily living and coordination of small or fine movement of your joints or muscles.

**Paraplegia** - A condition when the spinal cord is damaged so one does not have feeling and can’t use their lower body or legs.

**“Passing your water”** - Another term for urinating.

**Physical Therapist (PT)** - A professional on your rehabilitation team who focuses on the range of motion, strength and coordination of your large muscles.

**Pressure Sores** - Skin changes that occur when blood flow is decreased in the skin.

**Psychologist** - A professional on your rehabilitation team who focuses on your emotional and mental health needs.

**Quadriplegia** - A condition when the spinal cord is damaged so one does not have feeling or can’t use their lower body, legs and all or part of their arms or upper body.

**Rehabilitation** - The work you, your family, and team do to learn how to live your life with your disability. You will learn to adapt or compensate for your disability.
“Silver Bullet” - A slang term for a suppository.

Social Worker - A professional on your rehabilitation team who will help you and your family make plans for you to come home.

Spinal Cord - A rope-like bundle of nerves that runs from the base of your brain through the vertebrae to the lower part of your back.

Spinal Cord Injury (SCI) - An injury to your back or neck that also caused your spinal cord to be damaged. Many times a spinal cord injury leads to paralysis.

Suppository - Medicine used to help your bowel movements begin.

Tetraplegia (formerly called quadriplegia) - A condition when the spinal cord is damaged so one does not have feeling or can’t use their lower body, legs and all or part of their arms or upper body.

Urine - Body wastes that are removed from your body in a liquid form.

Vertebrae - The 29 bones in your spinal column that protect your spinal cord. Also called back bones.

Post-Test Answers:

1. D
2. D
3. A
4. A
5. B
6. B
7. E
8. A
9. D
10. A
11. A

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