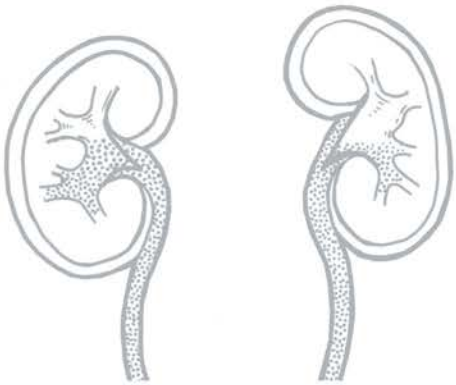
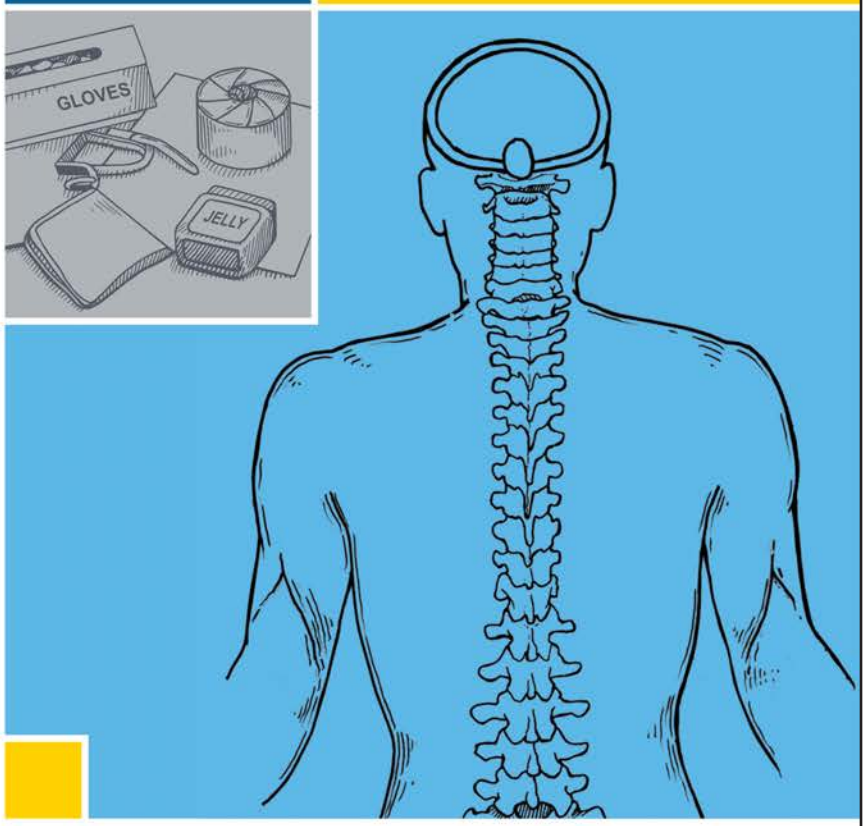
PERSONAL CARE MANUAL

EDUCATION: THE KEY TO INDEPENDENCE





Shepherd Center

PERSONAL CARE MANUAL

EDUCATION: THE KEY TO INDEPENDENCE

Developed and Created by **Shepherd Center**

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Shepherd Center, located in Atlanta, Ga., is a private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury or brain injury. Founded in 1975, Shepherd Center is ranked by *U.S. News & World Report* among the top 10 rehabilitation hospitals in the nation and is a 152-bed facility. For more information, visit Shepherd Center online at shepherd.org.

Table of Contents

Spinal Cord Injury

1 **CHAPTER CONTENTS**

What You Will Learn In This Section

After reading this section you will be able to:

1. Describe how to use the medicine information sheet and medicine card.
2. List the medicines you take and when to take them.
3. Explain how to take each medicine the doctor orders.
4. List the side effects of all the medicines you take.

New Words

Abdomen
The middle front part of the body (stomach area).

Cauda Equina
A bundle of nerves which branch off the end of the spinal cord and carry messages about bowel, bladder, and sexual function. It is located below the lumbar area of the spinal cord and looks like a horse's tail.

Cervical
The neck area, where 8 cervical nerves carry messages for movement and feeling to the arms, hands, fingers and diaphragm.

Diaphragm
The main muscle of breathing located under the rib cage.

Disc
Cartilage pad found between each vertebrae, serves to cushion the bones.

Flexibility
The ability to bend.

Fuse
To come together.

Harrington Rods
Stainless steel rods placed on the back part of the spinal column during surgery to stabilize thoracic and lumbar injuries.

Ligaments
Tough bands of tissue which connect bones to bones.

Medical Precautions Program
Patients with Harrington Rods are placed on "Medical Precautions Program." While on this program, a person is not allowed to do certain activities that may put pressure on the rods, until healing has taken place.

Lumbar
Lower area of the back. The 5 lumbar nerves carry messages for movement and feeling to the legs and hips.

Motor Nerve
A nerve which carries movement messages.

Nerve
Connects the brain and spinal cord with parts of the body; carries messages for movement and feeling.

Nervous System
Includes the brain, spinal cord, and nerves. It controls almost all body functions.

Paralysis
Loss of movement and feeling.

Paraplegia
Paralysis affecting the chest and/or stomach area and legs.

Paresthesias
Abnormal sensation or feeling.

Tetraplegia
Paralysis affecting the arms, chest, stomach area and legs.

Sacral (tailbone)
The lowest part of the back, includes 5 nerves which carry messages for movement and feeling to the legs, feet, bowel, bladder, and sexual organs.

Sensory Nerve
A nerve which carries feeling (touch, pressure, pain, temperature) messages.

Spasm
An uncontrolled muscle movement.

Spinal Column
The backbone, made up of many sections of bone (vertebrae) stacked one on top of the other. The spinal cord runs down through a canal in the middle of this column.

Spinal Cord
Carries messages about movement, reflexes and feeling to and from the brain.

Spinal Fluid
Fluid which flows around the brain and spinal cord, protecting them from injury.

Spinal Shock
A period of time when reflexes, movement and feeling are absent below the level of injury.

Stabilize
To make stable.

Stimulate
To arouse to action, to set off.

Thoracic
The upper and mid back area, where 12 nerves carry messages for movement and feeling to the mid body.

Reflex
Movement of a muscle caused by a signal (pain, heat, pressure) that does not come from the brain. It goes from the muscle to the spinal cord and then back to the muscle.

Vertebrae
Bones which make up the backbone.

The Spinal Column

The Backbone

- The spinal column or backbone is made of many small bones called vertebrae.
- The backbone begins in the neck and ends at the tailbone.
- A major job of the backbone is to surround and protect the spinal cord.
- The backbone is strong and flexible. It supports the body and allows you to move. Muscles and ligaments attached to the spinal column help to keep the bones together.
- Each section of the backbone is given a name and each vertebra is given a number. The areas of the backbone are as follows.

The Cervical Area

There are 7 cervical vertebrae (bones) located in the neck. They are called C1 - C7. (See Figure 2)

The Thoracic Area

There are 12 thoracic vertebrae (bones) located in the chest. They are called T1- T12. (See Figure 3)

The Lumbar Area

There are 5 lumbar vertebrae (bones) located in the lower back. They are called L1 - L5. (See Figure 4)

The Sacral Area

There is only one sacral bone (tailbone) located at the lowest part of the back. (See Figure 5)

The Discs

- Between each vertebra are cartilage pads called discs. (See Figure 1)
- These pads keep the bones from rubbing together and serve as shock absorbers for the spinal column.

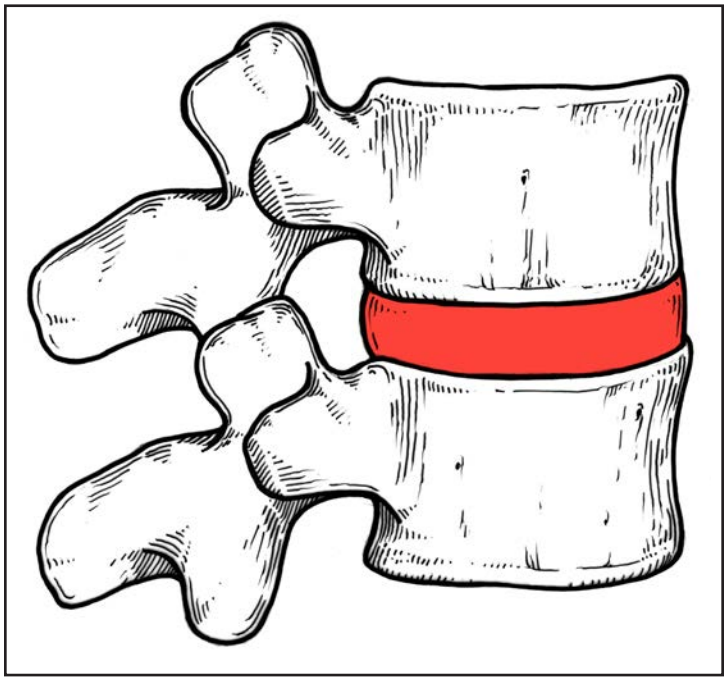


Figure 1 - Disc

Muscles and Ligaments

- Muscles and ligaments surround the backbone.
- Muscles help keep the backbone stable and cause movement.

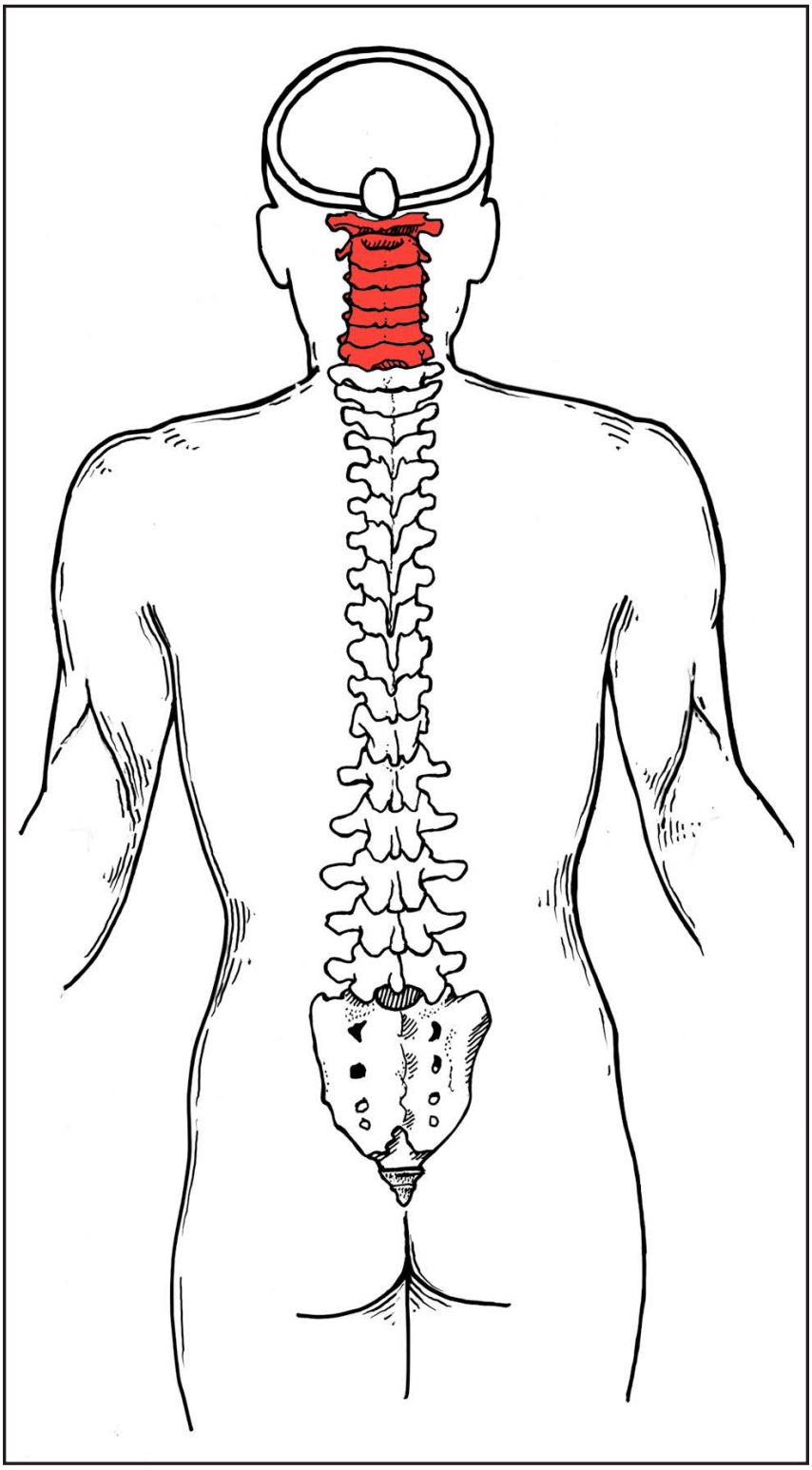


Figure 2 - There are 7 cervical vertebrae (bones) located in the neck. They are called C1 - C7.

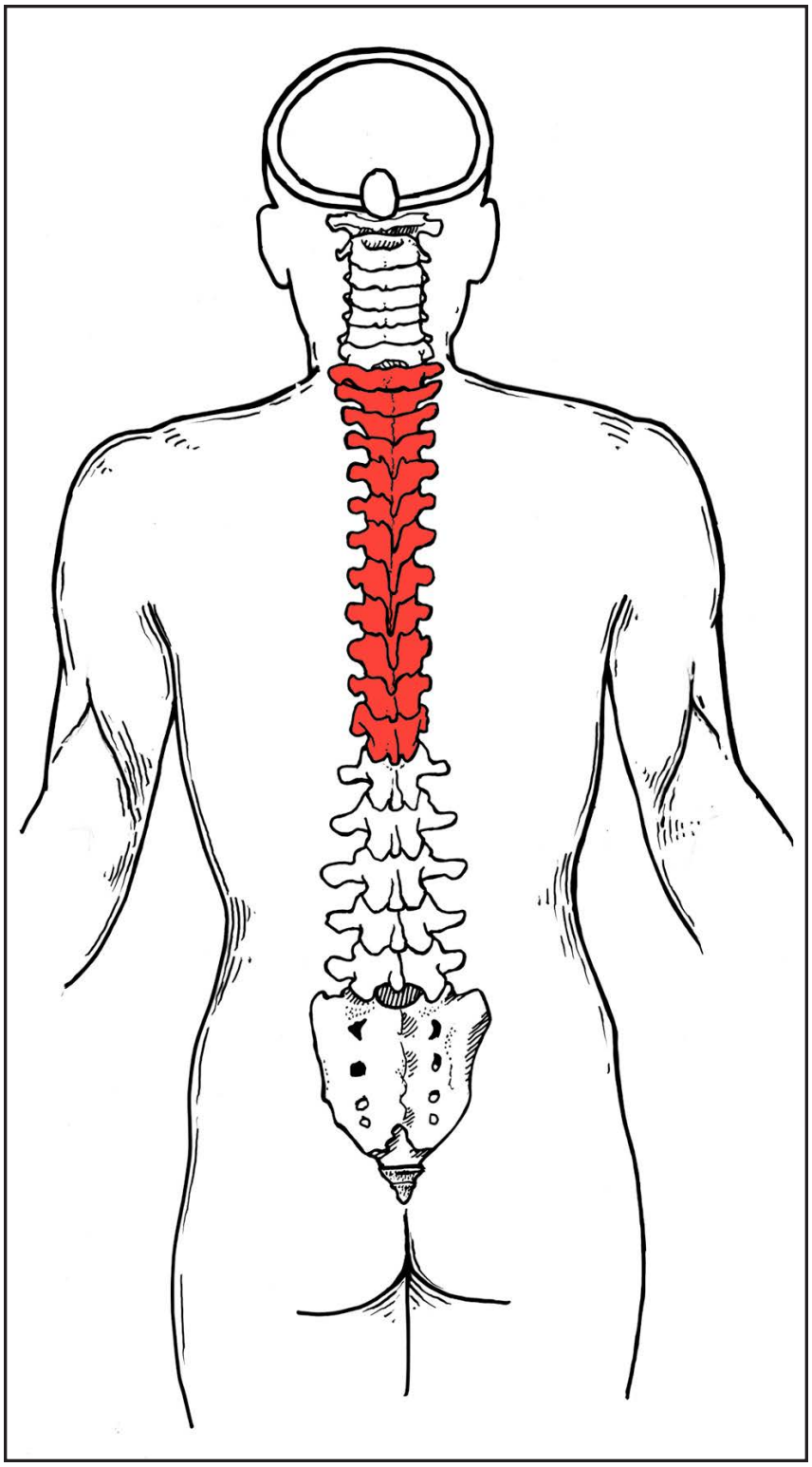


Figure 3 - There are 12 thoracic vertebrae (bones) located in the chest. They are called T1 - T12.

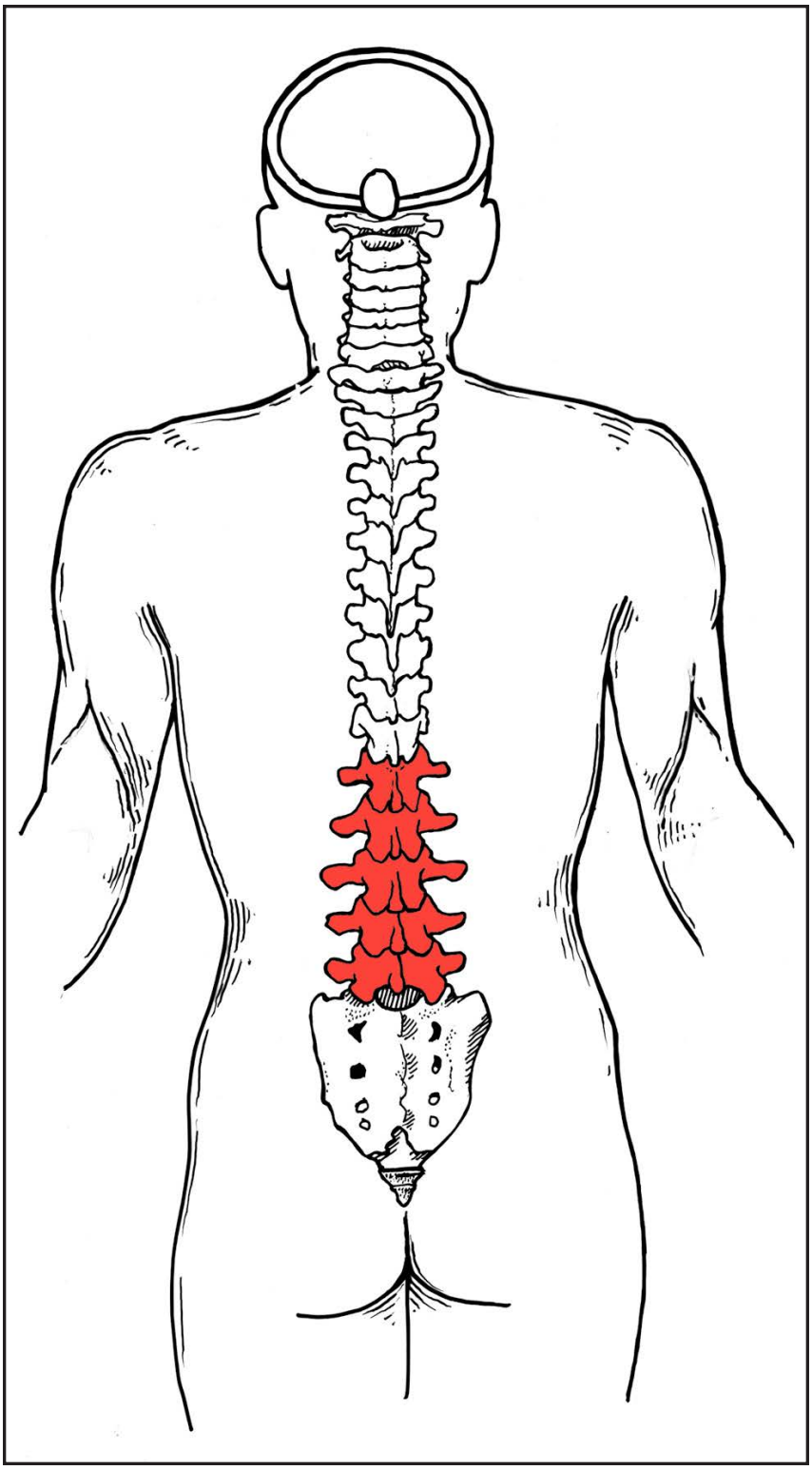


Figure 4 - There are 5 lumbar vertebrae (bones) located in the lower back. They are called L1 - L5.

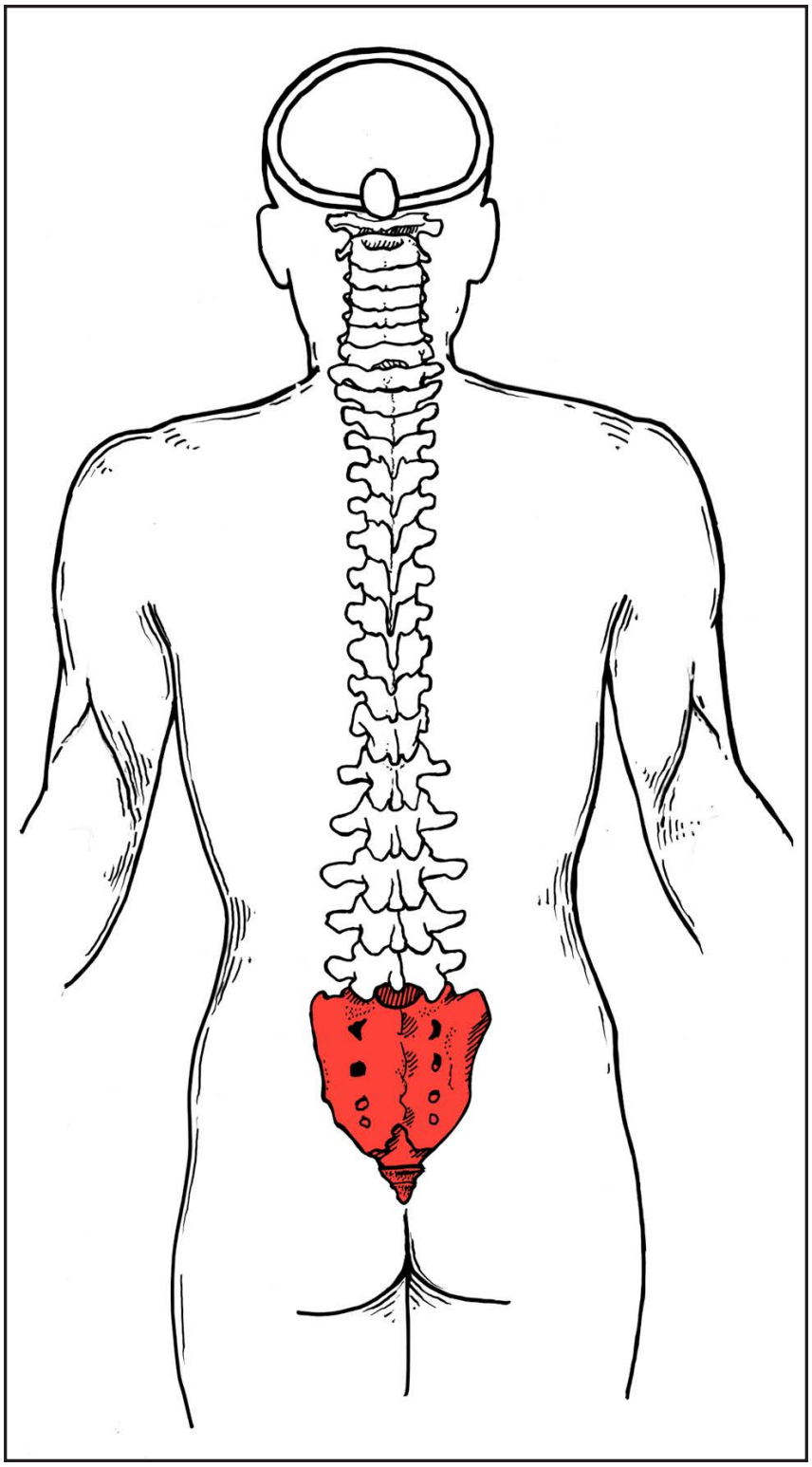


Figure 5 - There is only one sacral bone (tailbone) located at the lowest part of the back.

The Nervous System

The nervous system includes the brain, spinal cord, and spinal nerves.The nervous system helps control all body functions.

Some of the things the nervous system controls are:

1. Movement.
2. Sensation (feeling).
3. Reflexes.
4. Bowel Control.
5. Bladder Control.
6. Sexual Function.
7. Breathing.
8. Body Temperature.
9. Digestion.
10. Sweating.
11. Shivering.
12. Heart Rate & Blood Pressure.

The Brain

- The brain is the body's control center.
- Messages travel to and from the brain by way of the spinal cord and spinal nerves.
- Messages travel from the brain out to all the different parts of the body. Then, the body knows what to do and how to work.
- Messages from the body travel to the brain. The brain receives the messages and lets you know what your body is doing.
- Spinal fluid, a clear liquid, flows around the brain and spinal cord. This fluid cushions the brain and spinal cord and helps protect them from injury.

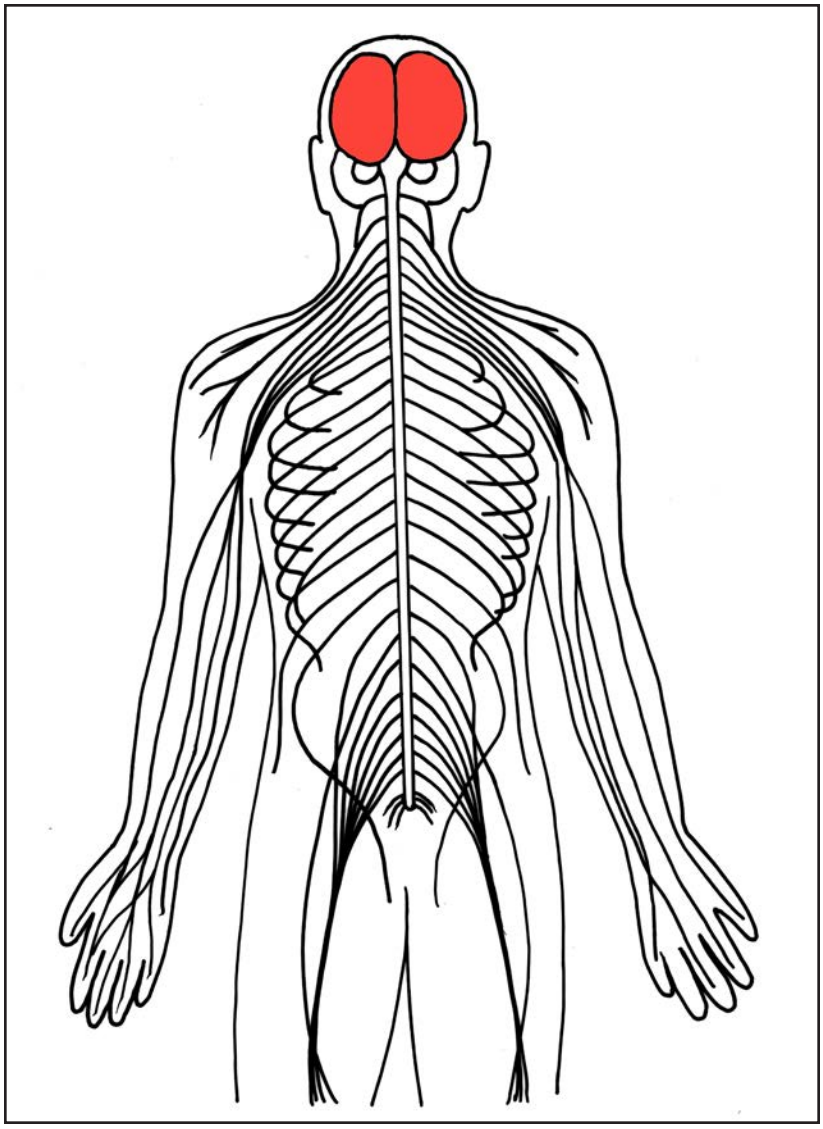


Figure 6 - Brain

The Spinal Cord

- The spinal cord attaches to the brain at the base of the skull.
- The spinal cord runs almost the length of the back inside the backbone.
- The spinal cord ends at the second lumbar vertebra. It is here that the spinal cord branches out into a bundle of nerves. This bundle of nerves, the cauda equina, looks like a horse's tail.

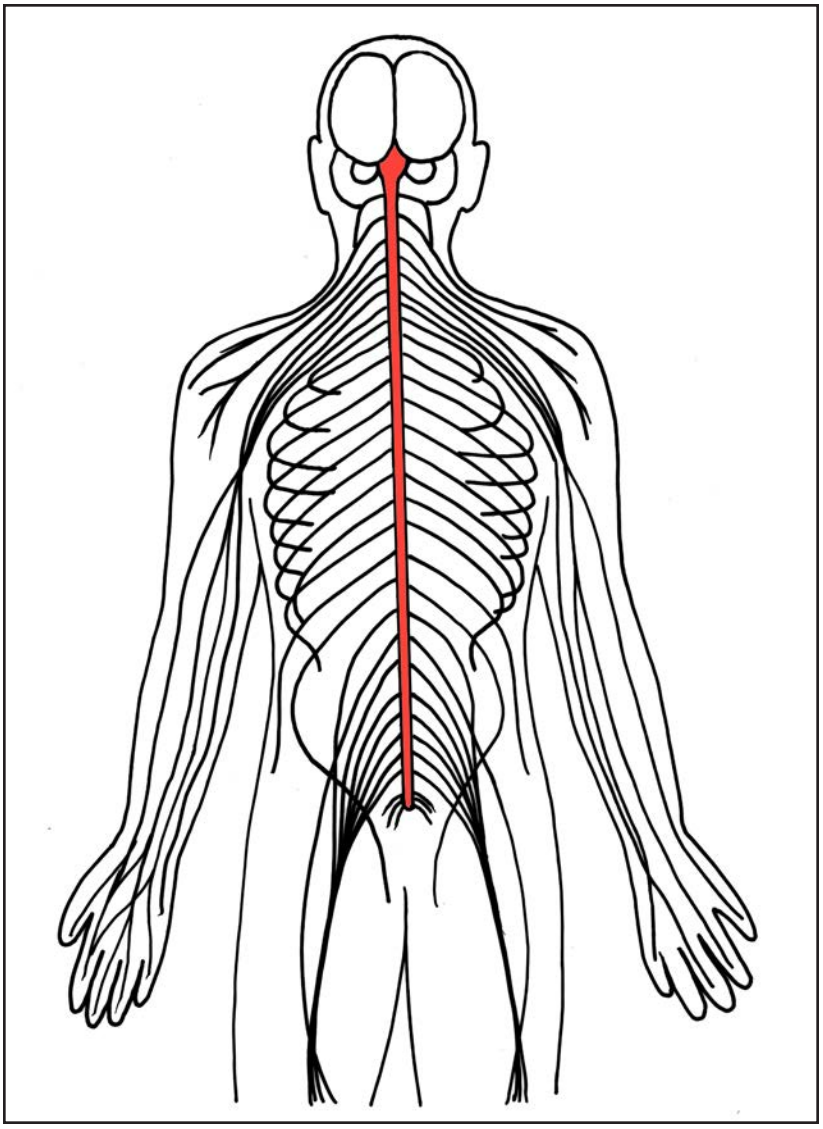


Figure 7 - Spinal Cord

What Does the Spinal Cord Do?

The main job of the spinal cord is to relay messages or signals from the body to the brain and from the brain to the body.

There are three kinds of messages or signals which travel along the spinal cord:

1. Sensory (feeling)
2. Motor (movement)
3. Reflexes

Sensory Messages

Sensory messages are sent along nerve pathways from the body to the spinal cord and then to the brain. When the signal reaches the brain, feeling occurs. This happens so quickly you are not aware of it. There are many kinds of sensory messages. These include the feelings of hot, cold, touch, pain, and pressure. Another sensory message is body position. This message tells you if you are sitting, standing, or lying and where your body parts are in relation to your body.

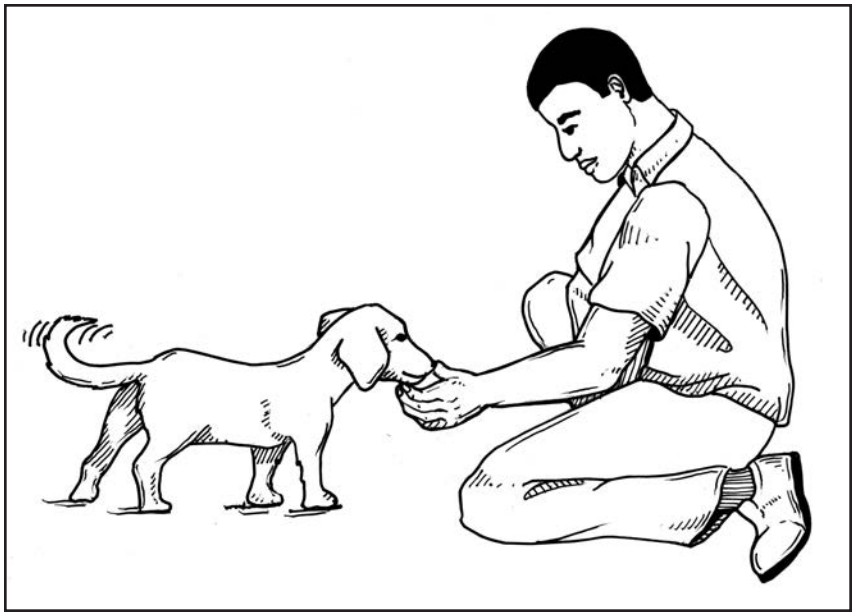


Figure 8 - "Touch, Soft" (feeling)

Motor Messages

Motor or movement messages begin in the brain, travel through the spinal cord, then out the spinal nerves to the rest of the body. These signals tell the muscles in your arms, hands, fingers, legs, toes, chest and other parts of your body how and when to move. Again, this happens so quickly you are not aware of it.

Figure 9 - Hug (movement)

Reflex Messages

A reflex is a movement of a muscle caused by some signal that does not come from the brain. Some body signals only need to reach the spinal cord. These signals loop through the spinal cord and quickly go back to the part of the body the message came from. This causes the body to react. Reflexes protect your body. Reflex signals occur more quickly than feeling (sensory) or movement (motor) messages. They do not have to reach the brain before the body reacts. There are many kinds of reflexes. Reflexes may cause some bowel and bladder emptying. Spasms are reflex actions.

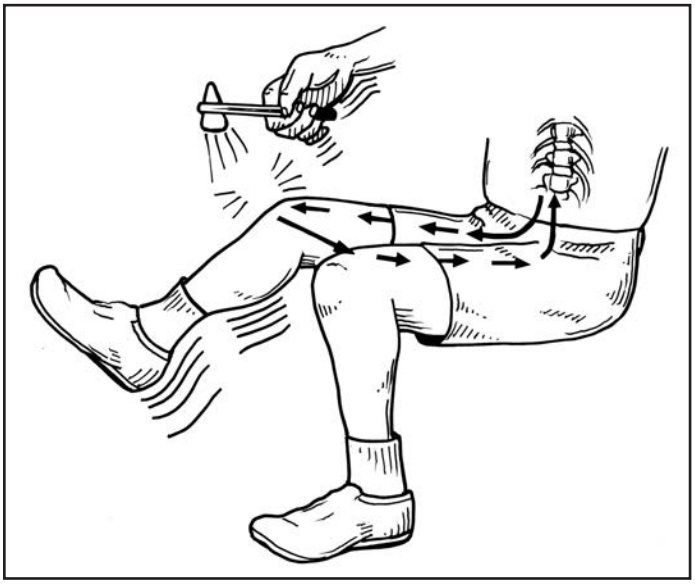


Figure 10 - Reflex

This is how a reflex happens:

- The muscle receives a signal. This signal is caused by stretching or pushing on the nerves in the muscle.
- The signal triggers the nerves in the muscle to send a message to the spinal cord.
- When the signal reaches the spinal cord, the message loops through the spinal cord at the level it comes in.
- The signal leaves the spinal cord and goes back to the muscle.
- When the signal reaches the muscle, it causes the muscle to squeeze or contract.
- People with spinal cord injuries may have different amounts of reflex activity.

KEY POINT: You will be learning more about the reflexes affecting bowel and bladder emptying and reflex spasms in other sections of this book.

Spinal Nerves

- The spinal nerves carry messages to and from the spinal cord.
- The nerves leave the spinal cord through openings in the vertebrae.
- Spinal nerves branch off the spinal cord in pairs, one going to each side of the body.

The names and numbers of the spinal nerves correspond to the names and numbers of the vertebrae. Every nerve has a special job for movement and feeling.

The Cervical Spinal Nerves

There are 8 pairs of spinal nerves in the cervical area numbered C1-C8:

C1
C2 Neck
C3
C4 Shoulder Shrug, Neck, Diaphragm

C5 Shoulder Muscles, Front Arm Muscles

C6 Wrist Muscles, Shoulder Muscles

C7
C8 } Lower Arms, Fingers

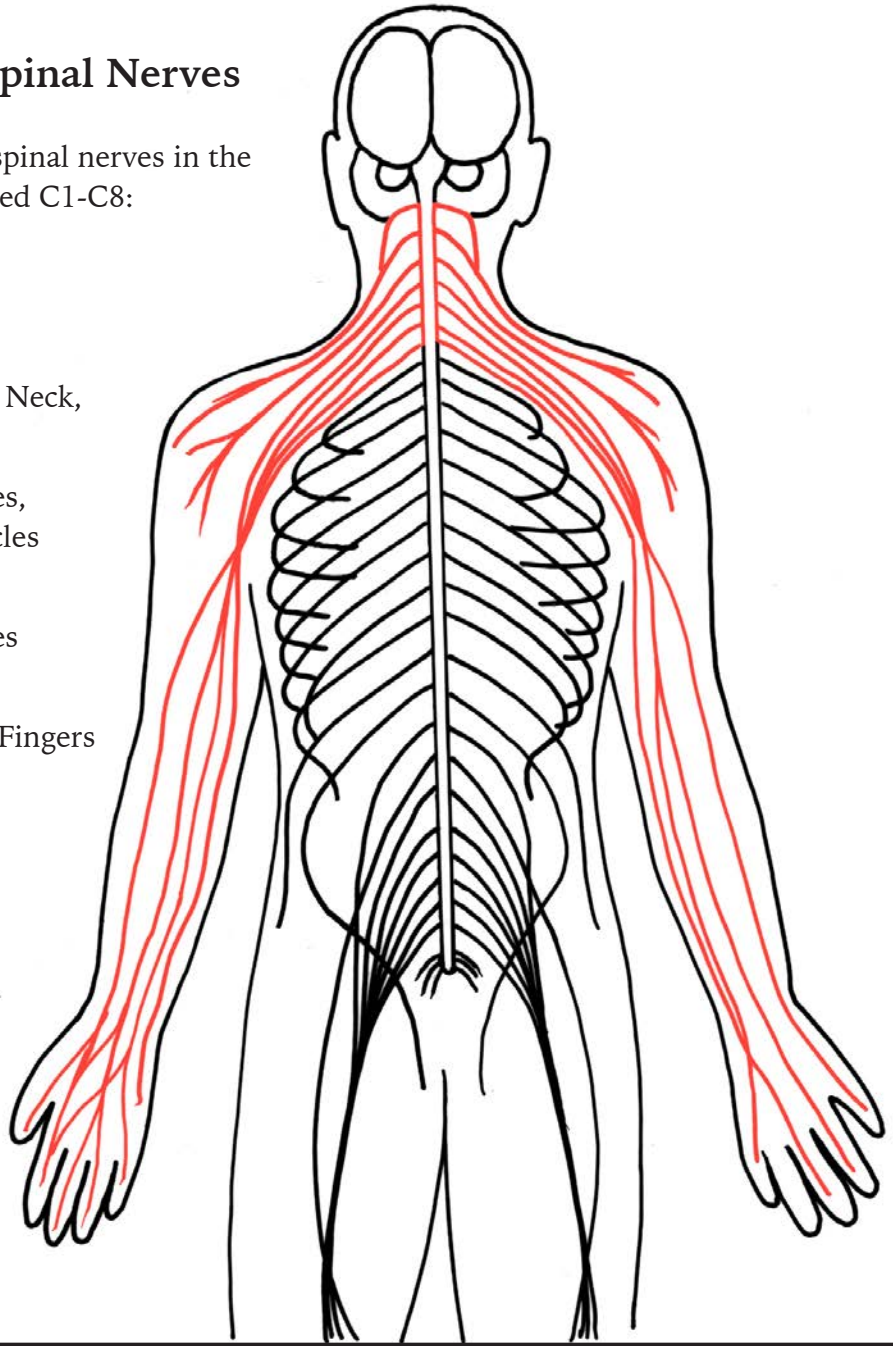


Figure 11 - The Cervical Spinal Nerves

The Thoracic Spinal Nerves

There are 12 pairs of spinal nerves in the thoracic area numbered T1-T12.

T1 Hand

T2
T2 Middle part of
T2 the body (trunk), chest
T2 and stomach area
T6

T7 Coughing and laughing
T8 muscles
T9
T10
T11
T12

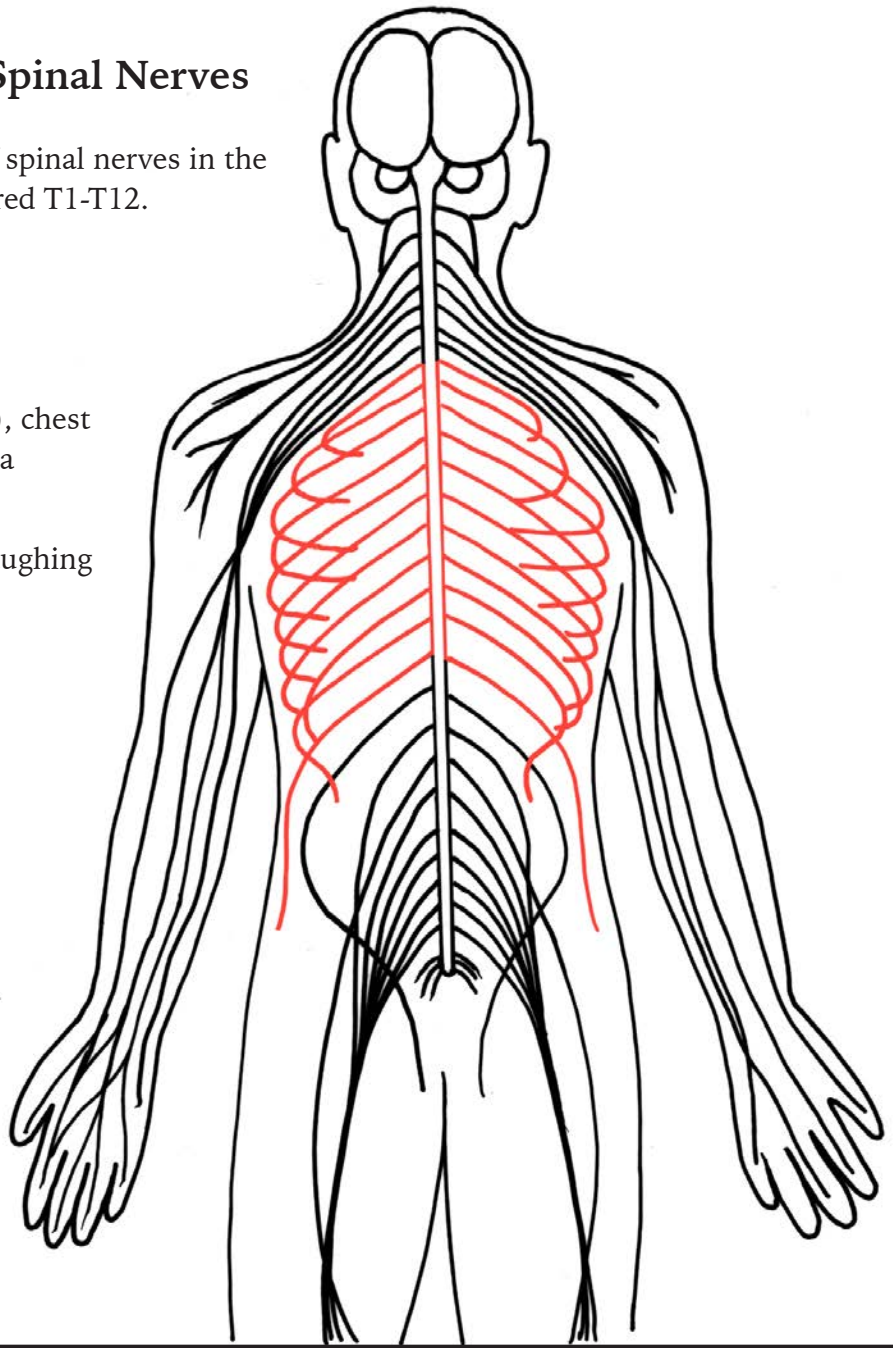


Figure 12 - The Thoracic Spinal Nerves

The Lumbar Spinal Nerves

There are 5 pairs of spinal nerves in the lumbar area, numbered L1-L5.

L1 Hips

L2

L3 Knees

L4 Top of Foot and Ankle

L5

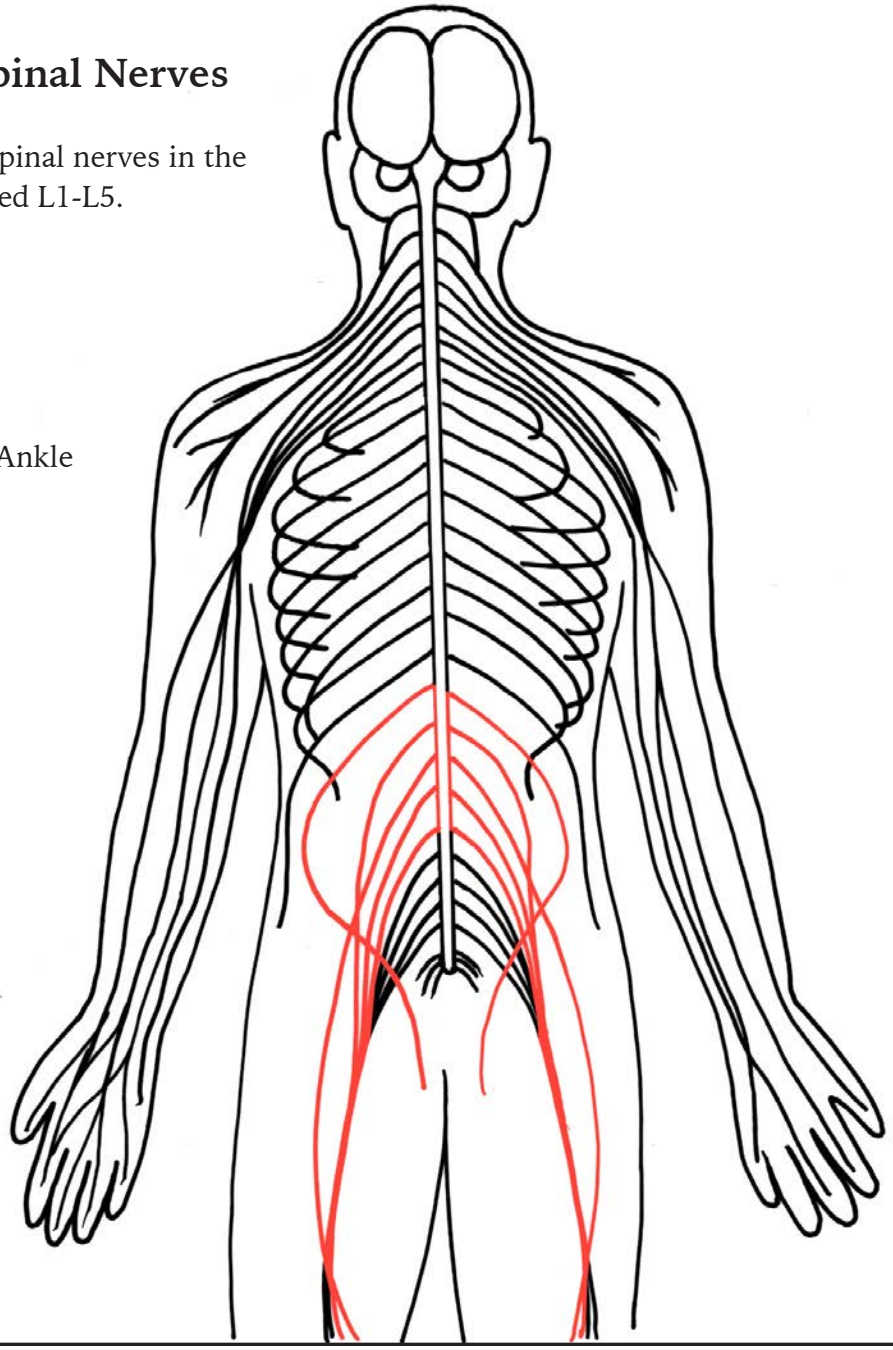


Figure 13 - The Lumbar Spinal Nerves

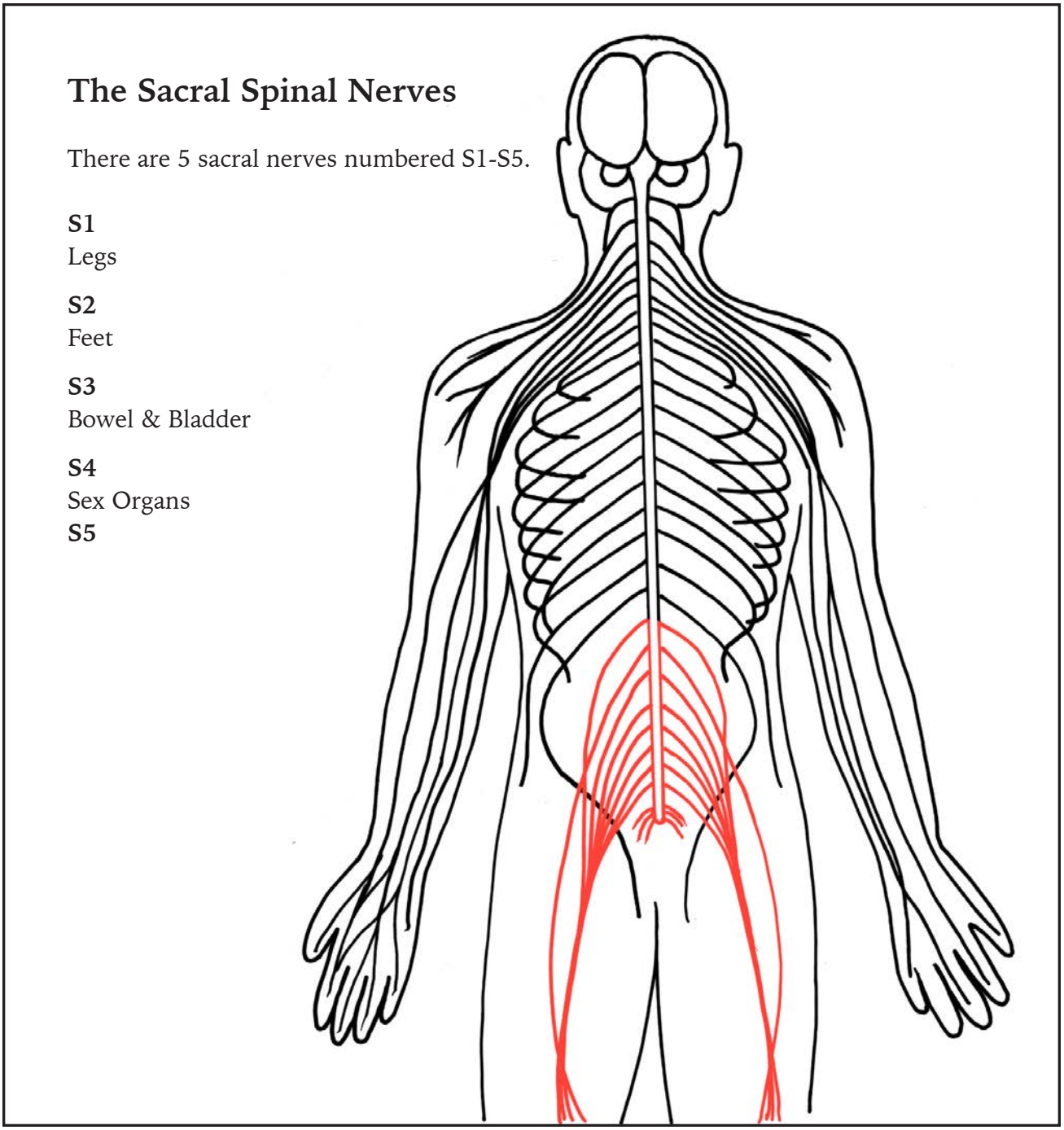


Figure 14 - The Sacral Spinal Nerves

This is an example of how the brain, spinal cord and spinal nerves work together:

- If you place your hand over a pot of hot water, messages or signals travel up the nerves in the hand and arm to a specific nerve and into the spinal cord.
- The signals reach the spinal cord and travel along nerve pathways to the brain.
- When the message reaches the brain, the heat is felt. "Ouch! That is hot!"
- Then a motor message is sent from the brain down the spinal cord.
- The motor message travels down the spinal cord, along the spinal nerve, out to the nerves in the arm, hand, and fingers.
- This message tells the muscles in your arm, hand and fingers to move away from the heat.

Figure 15 - How the Nervous System Works

What Is A Spinal Cord Injury?

Spinal cord injury occurs when there is any damage to the spinal cord which blocks communication between the brain and the body. After a spinal cord injury, messages below the level of injury are unable to get past the damage in the spinal cord. This means feeling or sensory messages cannot get to the brain. Feeling will be lost below the level of injury. Motor messages are unable to get past the damage in the spinal cord. This means your brain cannot tell the muscles below the level of injury how and when to move. Bowel, bladder, and sexual control may also change after a spinal cord injury. There may be changes in breathing, temperature control, heart rate, and blood pressure.

What Is Guillain Barré Syndrome?

Guillain Barré, which is pronounced ghee-yan bah-ray, is a rare illness that affects the spinal nerves as well as the cranial nerves. Spinal nerves are the nerves which branch off the spinal cord in pairs.They carry messages for movement, feeling, reflexes, and for bowel and bladder emptying. For more information about spinal nerves, see pages 11-13. Cranial nerves are the nerves which branch off the underside of the brain (brainstem) in pairs. They carry messages that enable a person to swallow, taste, hear, see, blink and smell. The brain and spinal cord are not affected by Guillain Barré.

When Guillain Barré occurs, the myelin (my-eh-lin) covering the nerves is damaged. Myelin surrounds the nerves and helps messages travel along pathways. Sometimes, even the nerve itself can be damaged when myelin is severely damaged. This may result in paralysis and loss of feeling.

What is the cause of Guillain Barré?

- The cause of Guillain Barré is unknown.
- Many times the person has had a virus a few days or weeks prior to the onset of Guillain Barré (cold, sore throat, stomach virus, or Epstein Barr virus - which causes Mononucleosis).
- Guillain Barré does not run in families. It is not contagious.

How is Guillain Barré diagnosed?

- Symptoms can occur from hours to days or sometimes even weeks.
- Because the early symtoms may only be numbness and tingling, it can be hard for a doctor to diagnose.
- When the doctor is trying to determine what the problem is, 5 things are evaluated:
  - Rapid onset from one to four weeks with weakness to paralysis of legs, arms, breathing muscles, or loss of bowel and bladder control
  - Decreased feeling and movement
  - Increased protein in the fluid that surrounds the spinal cord (a "spinal tap" is done to check this)
  - Decreased function of nerves (nerve conduction tests are done)
  - No other possible cause for changes in movement and feeling

How does Guillain Barré progress?

- The way Guillain Barré affects a person can vary greatly from just tingling to total paralysis.
- When the nerves are damaged, the person may describe decreased feeling with numbness and tingling.
- Guillain Barré usually affects both sides of the body equally.
- Usually, the changes in movement and feeling begin in the feet, moving up to the legs, hands and face.
- Many times the first sign of weakness is seen when the person is unable to get out of a chair or bed. This signals the person to go to the doctor.
- Sometimes the bowel and bladder muscles are affected.
- Blood pressure, heart rate and body temperature control may be affected.
- During the early part of Guillain Barré, a person can have many emotional reactions due to the uncertainty of how it will affect the body.
- Sometimes Guillain Barré can progress so that the person cannot blink, swallow, or smile. This is called "locked in" syndrome.
- Current statistics about Guillain Barré are:
  - 40% of the people are on a ventilator for some period of time
  - 50% and up to 90% reach complete recovery
  - 5 to 15% have a long term disability
  - 35% have a mild disability like numbness
  - Recovery may continue 6 months to 2 years after onset

What is the treatment of Guillain Barré?

- Corticosteroids are usually given. These are hormones naturally made by the adrenal glands in the body. Extra doses are given by mouth or intravenously.
- Plasmapheresis may be done. This is a procedure where the plasma (liquid part of the blood) is separated from the red blood cells. The liquid part is removed and the red blood cells are returned to the body. To do this, an I.V. is put into a vein in the arm. This I.V. is for removing the blood. A second I.V. is put in a vein in the other arm for returning the red blood cells.
- The whole process takes 2-3 hours. Because special equipment is used, usually only larger hospitals can do this procedure.

What are the possible complications of Guillain Barré?

- Breathing problems due to the diaphragm muscle being weak or paralyzed. Pneumonia (lung infection) can occur.
- Blood flow problems due to the blood moving slower in the legs. Blood clots can occur in the legs.
- Constipation due to the bowel muscles not working.
- Bladder infections due to the bladder muscle not working to empty the urine.

- Skin sores due to changes in movement and feeling.
- For other information about the previously mentioned problems, see the skin, bowel, bladder, respiratory and special concerns sections of this book.
- Parasthesias (abnormal sensations) due to the changes in the nerves. For example, the person may feel vibration even though lying still.
- Fatigue due to the changes in the nerves. The person may have normal strength but when repeating the muscle movement, fatigue and even exhaustion can occur. Pacing of the person's activity is very important to prevent fatigue.

Summary:

Guillain Barré is a rare illness that affects the spinal nerves and can affect the cranial nerves. This results in weakness or paralysis and partial or complete loss of feeling. The cause of Guillain Barré is unknown, but many times the person has had a virus (cold, sore throat) prior to developing Guillain Barré. It is not hereditary or contagious. There are several ways that Guillain Barré can be diagnosed. Many times a spinal "tap" is done. Rehabilitation can be a long process. Many complications can occur but with proper rehabilitation many of these problems can be prevented. The prognosis for recovery is good, with 50% to 90% making a complete recovery.

What Is Transverse Myelitis?

Transverse Myelitis (sometimes called Acute Transverse Myelitis) is a disease that affects the spinal cord. The spinal cord carries messages to and from your brain. The messages that travel along your spinal cord help you feel and move.

Transverse Myelitis causes damage to the spinal cord. The spinal cord becomes inflamed or swollen. Because of the inflammation, messages can no longer move normally along the spinal cord. This usually happens at your mid-back level.

What is the Cause of Transverse Myelitis?

No one really knows why this happens. Transverse Myelitis sometimes happens after a viral infection like the measles or pneumonia. Transverse Myelitis does not run in families. It is not contagious.

How is Transverse Myelitis diagnosed?

The most common signs of Transverse Myelitis are sudden localized back pain, sudden or gradual muscle weakness and/or sudden paralysis (where you can't move a part of your body). The paralysis usually starts in your toes, feet, then your legs. Some people may have loss of bladder and bowel control.

A myelogram is usually done to rule out a growth, like a tumor. A myelogram is done by injecting dye into the space around the spinal cord and then watching the flow of the dye with an x-ray machine. A special test called a spinal tap or lumbar puncture is done to obtain spinal fluid. The spinal fluid is checked for increased protein and white blood cells. High levels may indicate an infection. Some blood tests may be done to show a previous infection. Some nerve tests are also performed. These are called Evoked Potential tests.

How does Transverse Myelitis progress?

The way Transverse Myelitis can affect a person varies greatly. The signs can happen as quickly as one hour or as long as four weeks. Recovery can take one to eighteen months. About 50% of those with Transverse Myelitis have full recovery. The other 50% either have no movement or feeling in their lower bodies or slight feeling or movement in their lower body.

What is the treatment of Transverse Myelitis?

Corticosteroids are usually given. These are hormones naturally made by the adrenal glands in the body. The most common one given is Methylpredni-solone. Steroids help decrease the inflammation or swelling so the spinal cord won't be as damaged.

What are the possible complications of Transverse Myelitis?

About 50% of people with Transverse Myelitis recover completely. The other 50% can have any of the following problems:

- Coughing problems due to the stomach and rib muscles being weak or paralyzed
- Blood flow problems due to blood moving more slowly in the legs; blood clots can occur in the legs
- Constipation due to slowing down and loss of feeling and control when empty-ing the bowel
- Bladder infections due to loss of control in emptying the bladder
- Skin sores due to changes in movement and feeling, especially in the buttocks and legs
- Paresthesias (abnormal sensations) due to changes in the nerves. You may feel vibrations even though you are lying still.

Summary:

Transverse Myelitis is a disease that affects the spinal cord. It usually happens at the mid-back level. The most common signs are back pain with muscle weakness and sometimes paralysis. No one really knows what causes Transverse Myelitis. The most common treatment is steroids. Steroids decrease the swelling of the spinal cord. The usual recovery time is from one to eighteen months. Some have Transverse Myelitis and recover completely, while others may have some paralysis and loss of feeling.

Causes of Spinal Cord Injury – National Averages

1. Motor Vehicle Accidents
2. Falls
3. Gunshot wounds/Violence
4. Recreational Sports
5. Diseases:
   Guillain Barré Syndrome
   Transverse Myelitis
   Multiple Sclerosis (MS)
6. Birth Defects
7. Tumors of the spine
8. Bone disease
9. Problems with blood supply to the spinal cord

Tetraplegia

Tetraplegia occurs when there is injury to the spinal cord in the cervical area. This may cause loss of feeling and/or movement in the arms, chest, stomach area and legs.

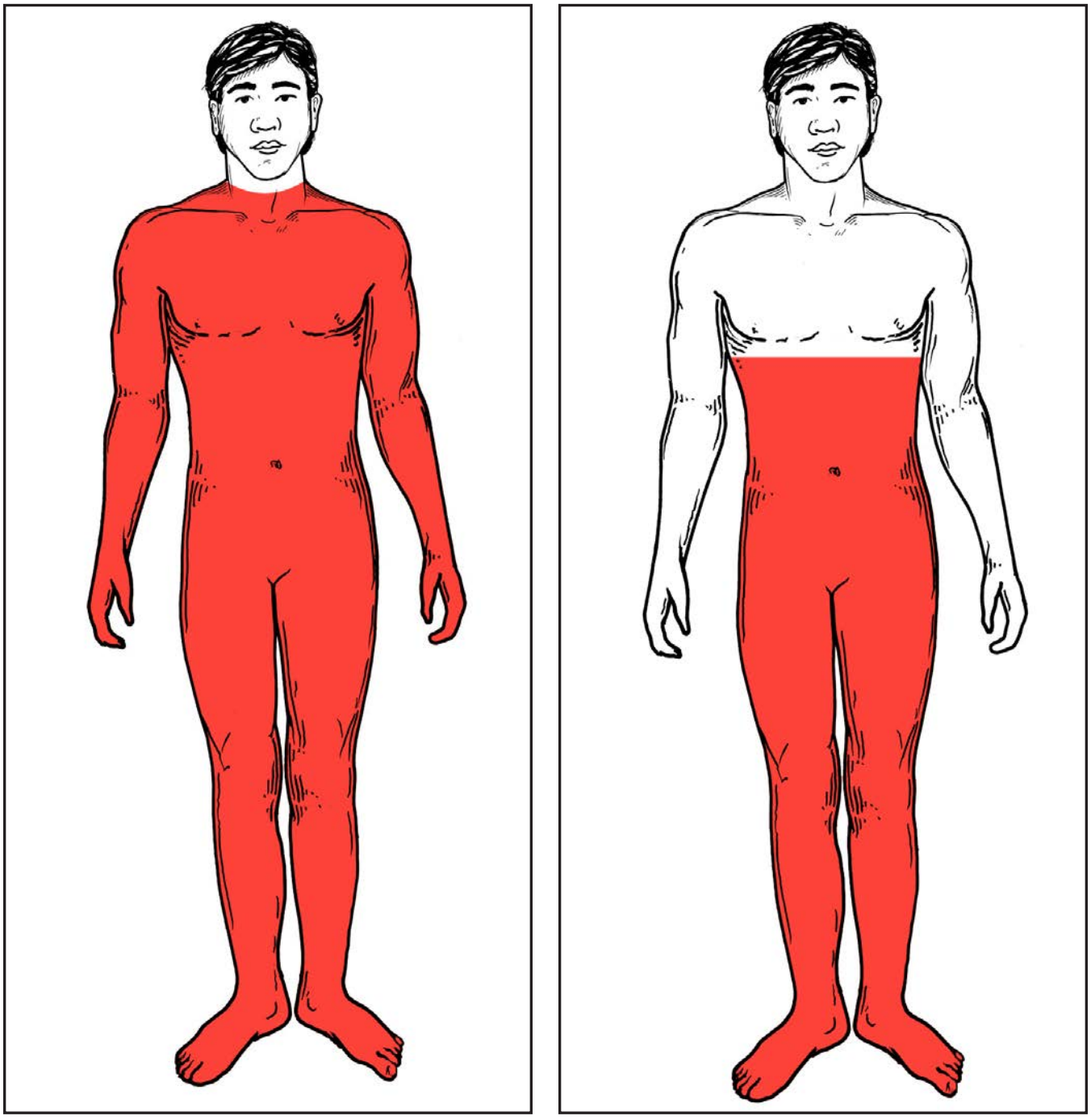


Figure 16 - Tetraplegia; Figure 17 - Paraplegia

Paraplegia

Paraplegia occurs when there is injury to the spinal cord in the thoracic, lumbar, or sacral area. This may cause loss of feeling and/or movement in the chest, stomach area and legs.

Complete and Incomplete Spinal Cord Injury

A complete spinal cord injury means there is a total blockage of signals at the point of injury. There will not be any feeling or movement below the level of injury. A complete spinal cord injury can change the control of all the functions of the nervous system.

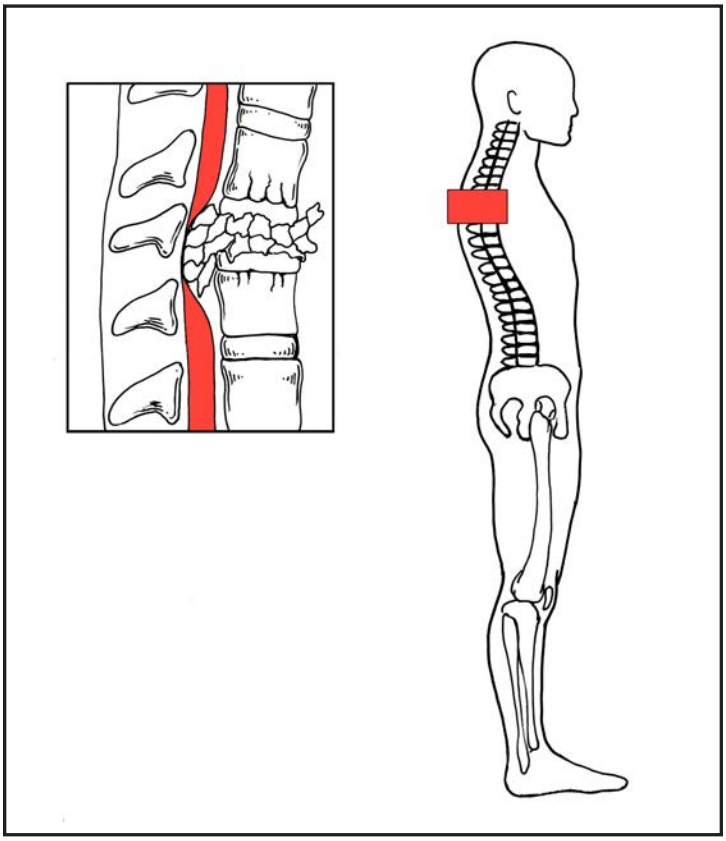


Figure 18 - Complete Spinal Cord Injury

An incomplete spinal cord injury means that there is partial damage to the spinal cord. Some feeling or movement remains below the level of injury. The amount of feeling and movement lost will depend on how much damage is done to the spinal cord. The way that the bowel and bladder empty often changes too.

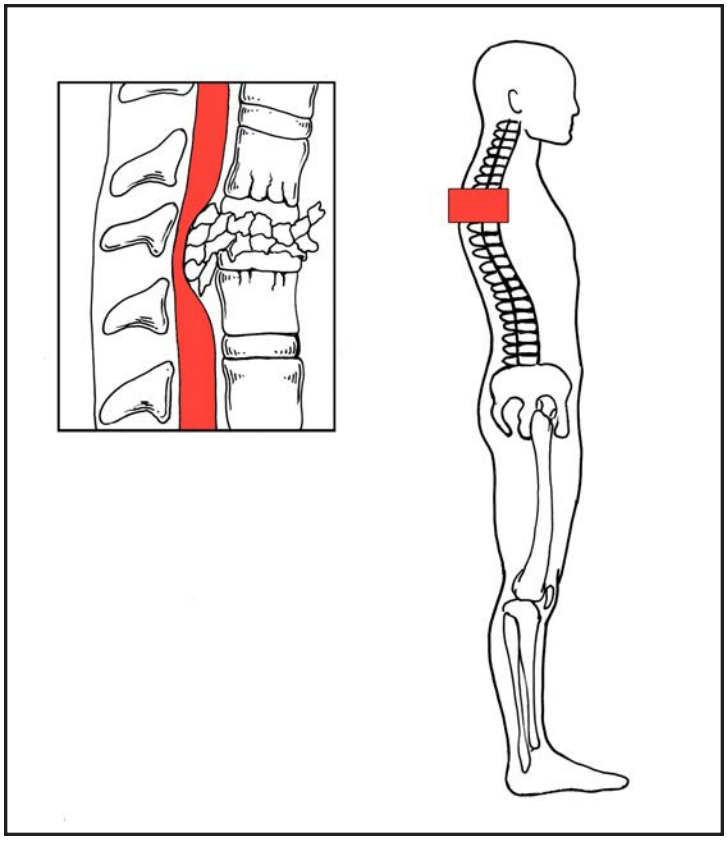


Figure 19 - Incomplete Spinal Cord Injury

Today, as far as we know, injury to the spinal cord is permanent. Whether your spinal cord injury is complete or incomplete is not always known right after a spinal cord injury.

The Reflex Function

After spinal cord injury, reflexes will remain intact above the level of injury.

If the spinal cord injury is above T12, some reflexes will probably be present below the level of injury. If the spinal cord injury is below L1, you probably will not have reflexes below the injured level. It is important to know if you have reflexes below your level of injury so you will know how to care for your bowel and bladder.

Spinal Shock

Immediately following a spinal cord injury, the spinal cord goes into spinal shock. Spinal shock is a period of time when reflexes, movement, and feeling may be absent below the level of injury.

Spinal shock may take hours, days, weeks, or months to resolve. The return of reflex activity below the level of injury is a sign that the person is coming out of spinal shock. The reason for spinal shock is not known.

Surgery to the Spinal Column

Surgery is most commonly done to stabilize the spinal column and to prevent more spinal cord damage. Damage may continue to occur if pressure remains on the cord. The type of surgery needed will depend on the type and level of injury.

Wiring and Fusion

- It is most often done on cervical injuries.
- The surgery may be done from the front or back of the neck, depending on the type of injury.
- Surgery is done to the back of the neck most often.
- The bones (vertebrae) are put back into place if needed.
- The neck is positioned correctly, bone chips are removed from the hip and placed in the damaged area.
- The broken bones are wired together with the bone chips from the hip.
- A Philadelphia (hard) collar is usually worn for 6 to 8 weeks after surgery to add support to the repaired area until healing takes place. (See Figure 20)
- After 6 to 8 weeks, x-rays may be taken to make sure the bone chips have fused with the broken bones.

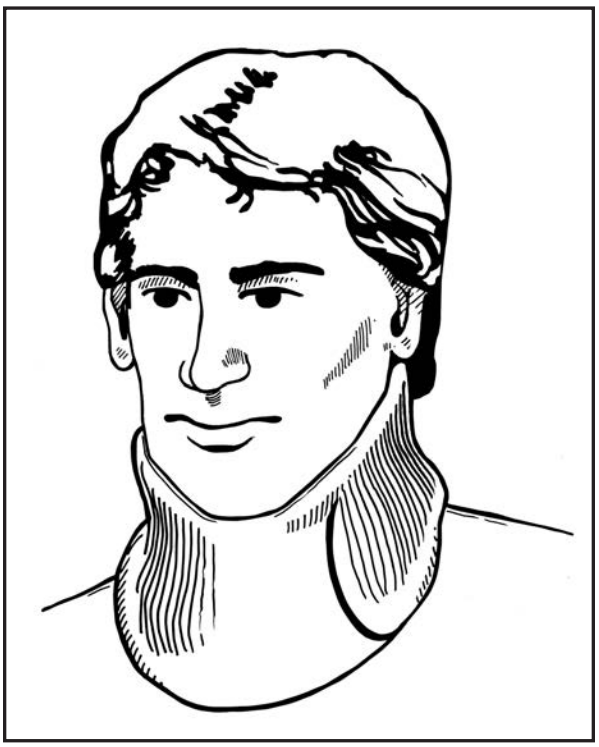


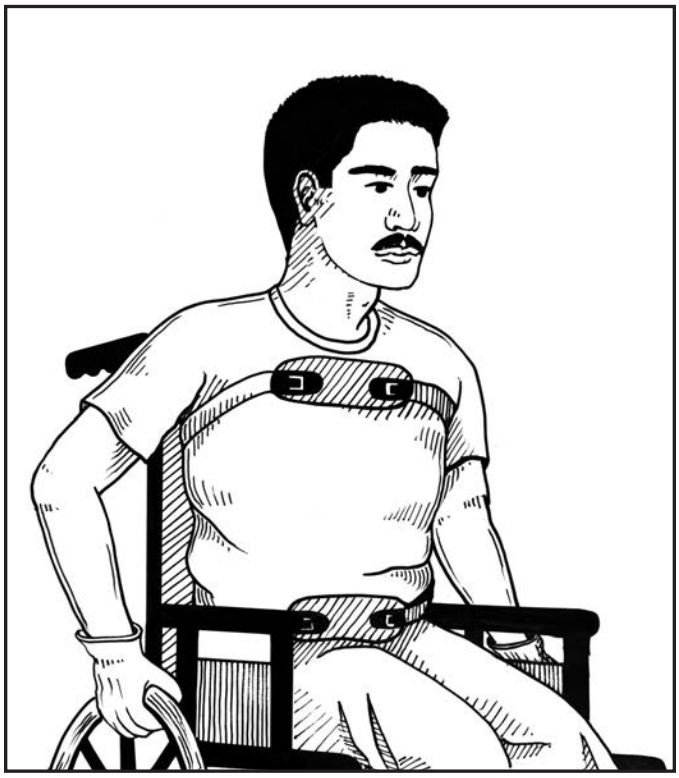
Figure 20 - Hard Collar; Figure 21 - Halo

Halo

- A Halo device may be used when there is a cervical injury.
- The halo ring is attached to the bones of the head.
- The ring is then attached to a halo vest with bars, to keep the head and neck in one position while the injured area is healing.
- The halo is usually worn for 8 to 12 weeks.
- X-rays are taken to make sure the bones have healed together.

Harrington Rods

- Harrington rods stabilize the thoracic and lumbar areas of the spinal column.
- The rods are about 6 inches long and are made of stainless steel.
- During surgery, the rods are placed behind and on both sides of the spinal column.
- After this surgery, a person will follow a medical precautions program to avoid certain activities that may put pressure on the back until healing has taken place. A Jewett brace will also be worn to limit activities that may stress the backbone. (See Figure 22)
- X-rays are taken to make sure the bones are healing and the rods are in position. (See Figure 23)



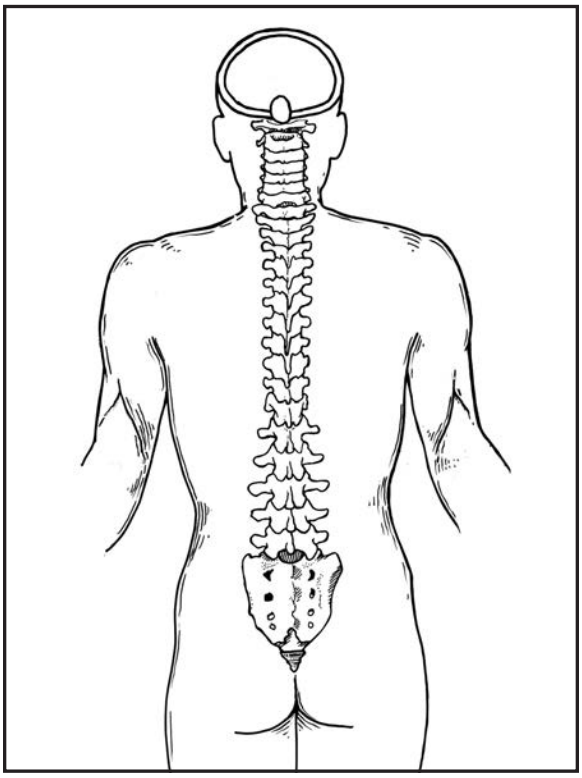


Figure 22 - Jewett Brace; Figure 23 - Harrington Rods

Summary

The spinal column provides support for the body and protection for the spinal cord. Structures of the spinal column include vertebrae, discs, muscles, and ligaments. The spinal column is divided into sections. Each section has a name and each vertebra has a number. There are seven cervical, twelve thoracic, five lumbar vertebrae, and one sacral vertebra.

The nervous system includes the brain, brainstem, spinal cord, and spinal nerves. The brain is the master control for all body functions. The spinal cord serves as the main line of communication between the brain and the body. The spinal nerves relay messages to and from the spinal cord and other parts of the body. There are three types of messages which travel along the spinal cord. They are: sensory, motor, and reflex.

Injury to the spinal cord results in loss of feeling and/or movement below the injured area. A complete injury means that there is total loss of feeling and movement below the injury. With an incomplete injury, some feeling and/or movement will remain below the level of injury.

Tetraplegia is an injury in which the arms, chest, abdomen, and legs are affected. Paraplegia is loss of function in the chest and/or stomach area and legs.

There are many causes of spinal cord injury. The most common causes are accidents like automobile, diving, and falls. Other problems that cause spinal cord injury are Guillain Barré, Transverse Myelitis, tumors, and Spina Bifida.

Spinal shock occurs immediately after a spinal cord injury. The result is a loss of reflexes, movement and feeling below the level of injury. The return of reflex activity signals the end of spinal shock.

The reflex function of the spinal cord may remain after spinal cord injury. Depending on the level of injury, reflexes can be used for bowel and bladder emptying and for sexual functioning.

Surgery may be needed to stabilize the spinal column and to prevent further injury to the spinal cord. For cervical injuries, a wiring and fusion may be done. A halo device may be used to stabilize some types of cervical injuries. Harrington rods may be inserted for thoracic and lumbar injuries.

What You Have Learned About Spinal Cord Injury?

1. What is the level of your spinal cord injury?
2. Do you have a complete or incomplete injury?
3. Do you have tetraplegia or paraplegia?
4. Do you have reflexes below your injury?
5. Did you have surgery on your spinal column? If so, what type of surgery did you have?

Managing Your Bowel Program

2 **CHAPTER CONTENTS**

What You Will Learn In This Section

After reading this section you will be able to:

1. Name the parts of the digestive system.
2. Describe how the digestive system works before and after a spinal cord injury.
3. Describe the methods you use for emptying the bowel.
4. List the causes, signs, treatment and prevention of bowel problems.
5. Define the basic food groups and their role in keeping your bowel working well.
6. Name and describe the most common medications that help regulate your bowel.

New Words

Abdomen
The middle front part of the body (stomach).

Activaid
A portable toilet chair used for bathing and bowel programs. It must be lifted into a tub or over a commode.

Anus
The opening at the end of the bowel where stool comes out of the body.

Bowel
The part of the digestive system which digests food and forms stool.

Buttocks
The backside.

Calcium
A mineral found in food (especially in dairy foods) which helps with bone growth and strength.

Calories
The amount of energy in food.

Carbohydrates
Sugars and starches found in food which give the body energy.

Shower Chair
A portable toilet; a roll-in chair used for bowel programs and bathing. It can be rolled over a commode or into a shower.

Constipation
Hard stool.

Diarrhea
Liquid stool.

Diet
The kinds and amounts of food and drink you usually have for your meals.

Digital Stimulation (Dil)
Stimulation of the bowel reflex caused by placing a finger or dilstick into the rectum to empty stool from the bowel.

Digestion
The process by which food is broken down in the digestive tract so that absorbtion of the nutrients can take place.

Dilstick
A piece of equipment shaped like a finger used by some patients to do a bowel program.

Distended
When the abdomen becomes hard and bloated, sometimes because of a full bowel.

Esophagus
A tube-like part of the digestive system that connects the mouth with the stomach.

Fat
A source of energy found in animal foods and oils; high in calories.

Fiber
Found in foods such as fruits, vegetables and whole grains; helps regulate the bowel.

Grain
A small hard seed such as wheat, rice, oats; used to make flour and cereal.

Impaction
Hard stool which is stuck in the bowel.

Involuntary
An unplanned bowel movement.

Intestines
The tubular part of the digestive system that goes from the stomach to the anus.

Iron
A mineral found in foods, such as liver and spinach. Needed by your body to keep your blood healthy.

Laxative
A medicine to make the bowels move.

Legumes
A dried vegetable coming from an herb, shrub or tree such as beans, peas, lentils and peanuts.

Lubricate

To put a lubricant, Vaseline or KY jelly on your finger or dilstick or suppository so it can easily be put into the rectum.

Minerals

Found in different foods. Minerals such as zinc, copper and iron keep the body healthy.

Nutrients

The vitamins and minerals your body needs in certain amounts to stay healthy.

Nutrition

The way that food helps you to live, grow, heal from illness or injury and get energy for work and play.

Protein

Found in foods such as meat, cheese and eggs. Protein helps healing by building new body tissue.

Raised Toilet Seat

A piece of equipment that attaches to a regular toilet bowl for doing bowel programs.

Rectum

Lowest part of the bowel; collects stool before it leaves the body.

Reflex

Movement of a muscle caused by a signal that does not come from the brain. A digital stimulation (dil) causes a bowel reflex.

Stool

Solid waste material, a bowel movement.

Sphincter

A small muscle in the rectum which closes to keep the stool in the bowel and opens to let the stool out of the bowel.

Suppository

A medication, when put into the rectum causes the bowel to empty.

Vitamins

Found in different foods. Vitamins such as A, C, D and E, keep the body healthy.

The Parts of the Digestive System

The digestive system includes the mouth, esophagus, stomach, small intestine, large intestine, rectum, anus and sphincter muscles. The digestive system breaks down foods, takes the nutrients and water from them and removes the solid wastes from the body.

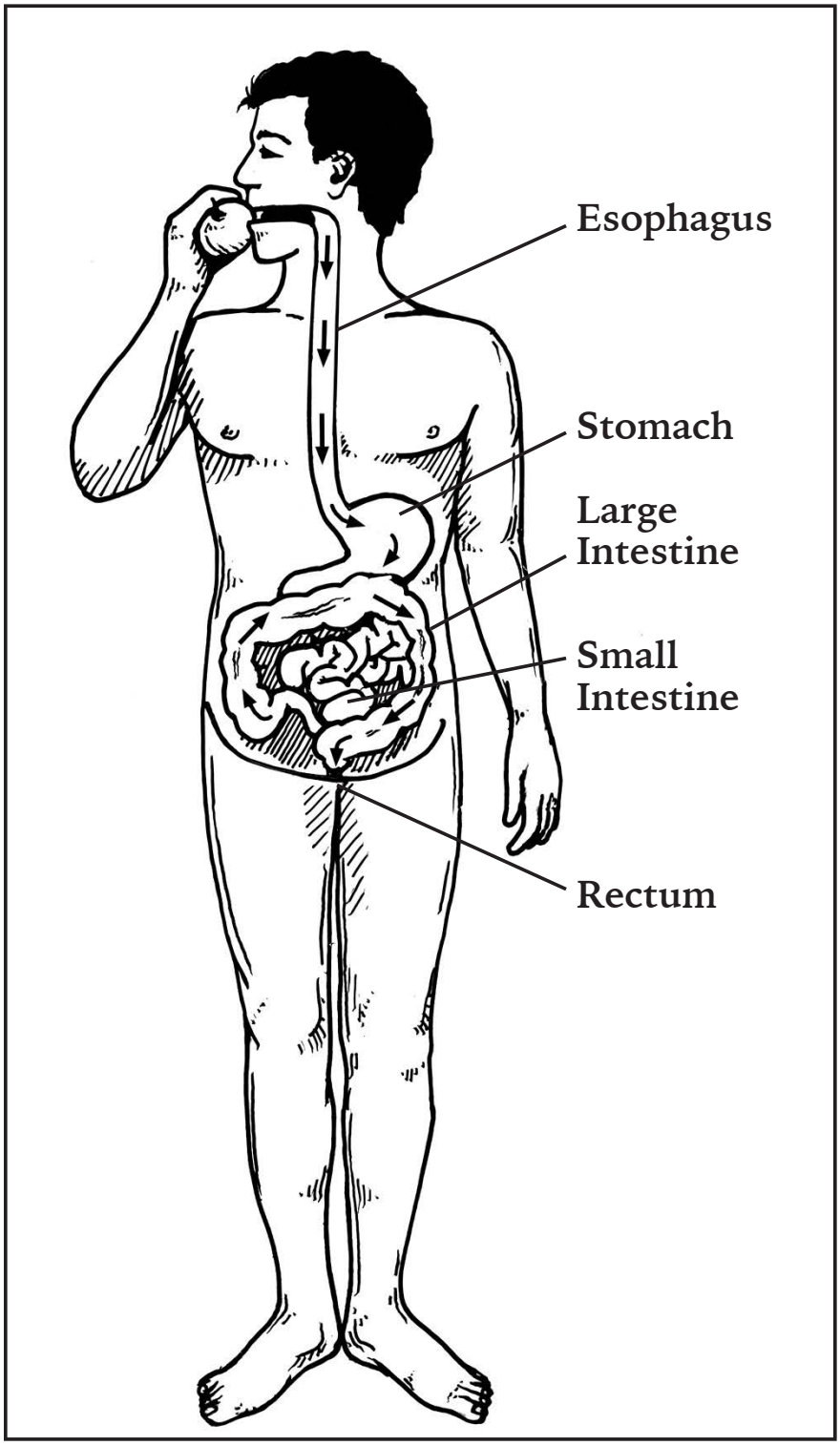


Figure 1

The Mouth

- Digestion begins when food is first put in the mouth.
- The breakdown of food begins when food mixes with saliva during chewing.

The Esophagus

- As you swallow, food moves down a long tube called the esophagus.
- The esophagus leads to the stomach.

The Stomach

- Special acids in the stomach break down the food into smaller pieces.

The Small Intestine

- Food passes from the stomach into the small intestine.
- It is in the small intestine that nutrients are taken out of the food you eat.
- The material left in the small intestine after nutrients are absorbed, is liquid waste.

The Large Intestine

- The waste material moves into the large intestine where it is made ready to leave the body.
- The large intestine removes extra water and forms the stool.

The Rectum

- Stool passes from the large intestine into the rectum.
- The rectum holds the stool until it is ready to leave the body.

The Anus

- The anus is the opening where stool comes out of the body.

The Sphincter Muscle

- The external sphincter muscle is near the anus. The sphincter is a small muscle which closes to keep stool in the bowel and opens to let stool out of the bowel.

How the Bowel System Works Before A Spinal Cord Injury

Messages sent from the brain travel along the spinal cord and sacral nerves to allow the bowel to empty.

Here is what happens:

1. The bowel contains a large number of nerves.
2. When the rectum is full of stool it stretches.
3. The stretching of the rectum pushes on these nerves.
4. This sends a sensory (feeling) message from the rectum to the sacral nerves and then to the spinal cord.
5. When the message reaches the spinal cord, part of the message loops through the spinal cord, setting off a reflex.
6. This causes the bowel to squeeze.
7. The other part of the message goes to the brain.
8. When this message reaches the brain, the urge to have a bowel movement is felt.
9. When the person decides to have a bowel movement, a message is sent from the brain, down the spinal cord, through the sacral nerves, to the bowel and to the sphincter.
10. This message tells the sphincter to relax, open and let the stool out.
11. If it is not a good time to have a bowel movement, a message is sent from the brain, down the spinal cord, through the sacral nerves, to the bowel and to the sphincter.
12. This message tells the sphincter to stay closed and to keep the stool in the bowel until there is a better time to empty.

How the Bowel System Works After A Spinal Cord Injury

The Reflex Bowel

After a spinal cord injury, the bowel will no longer work as it did before the injury. If the injury is above T12, the bowel can empty by reflex. With a reflex bowel, signals about a full rectum are not able to reach the brain, but they can reach the spinal cord.

Here is what happens:

1. The rectum gets full with stool.
2. The rectum stretches.
3. As the rectum stretches, it pushes on the nerves in the bowel.
4. This causes a signal to be sent out from the bowel through the sacral nerves to the spinal cord.
5. When the signal reaches the spinal cord, it will make a loop.
6. The signal goes from the spinal cord, along the sacral nerves and back to the bowel and sphincter muscle.
7. When the signal reaches the rectum, the bowel muscles squeeze (contract).
8. When the signal reaches the sphincter muscle, it tells it to relax, open and let the stool out.
9. This reflex will happen when the rectum gets full; when a digital stimulation (dil) is performed; or when suppositories are used.

Figure 2 - Reflex Bowel

Remember, messages can no longer get past the spinal cord injury to the brain. This means the sensory message from the bowel cannot get up to the brain. The urge to have a bowel movement is not felt. The signal from the brain cannot get down to the bowel. Therefore, there is no voluntary control over the sphincter muscle. The reflex occurs when the message loops through the spinal cord and back to the bowel, causing the bowel muscles to squeeze (contract).

The bowel program for a reflex bowel is usually digital stimulation (dil). A digital stimulation (dil) is a method used to empty the bowel after a spinal cord injury. It works by using the reflex activity present in the spinal cord after a spinal cord injury. A digital stimulation (dil) is performed by inserting a finger tip into the rectum and moving it around in circles. The finger movement signals the nerves in the rectum much like when the bowel is full of stool. This causes the bowel muscles to squeeze or contract, moving the stool into the rectum where it leaves the body. If the bowel reflex is present after a spinal cord injury, the digital stimulation (dil) method is best for emptying the bowel. The digital stimulation (dil) helps the bowel to empty completely at a scheduled time to prevent accidents.

Suppositories may be used for persons who have feeling around the rectal area. Suppositories work by signaling the nerves in the rectum. This too causes the bowel muscles to squeeze by reflex, moving the stool into the rectum where it leaves the body. It is difficult to predict how long it will take a suppository to work. For this reason, a digital stimulation (dil) is preferred when possible.

The Non-Reflex Bowel

If the spinal cord injury is at T12 or below, the bowel will probably not have the reflex action to empty. This is because the spinal cord comes to an end around L1 or L2. If the injury is below where the spinal cord ends, signals will stop before reaching the spinal cord. This means signals from a full bowel cannot get to the spinal cord in order for the reflex to occur.

Here is what happens:

1. The rectum fills with stool.
2. The rectum stretches.
3. As the rectum stretches, it pushes on the nerves in the bowel.
4. This starts a signal going out from the bowel through the sacral nerves.
5. The signal cannot get to the spinal cord because of the injury to the nerves below the end of the spinal cord.
6. No reflex occurs.
7. The bowel muscles will not squeeze.
8. The sphincter muscle stays loose.
9. The pressure from a too full bowel may cause the stool to leak out of the rectum.

To prevent stool leakage, the non-reflex bowel will need emptying regularly by putting a finger into the rectum and gently pulling pieces of stool out. This is called a rectal clear.

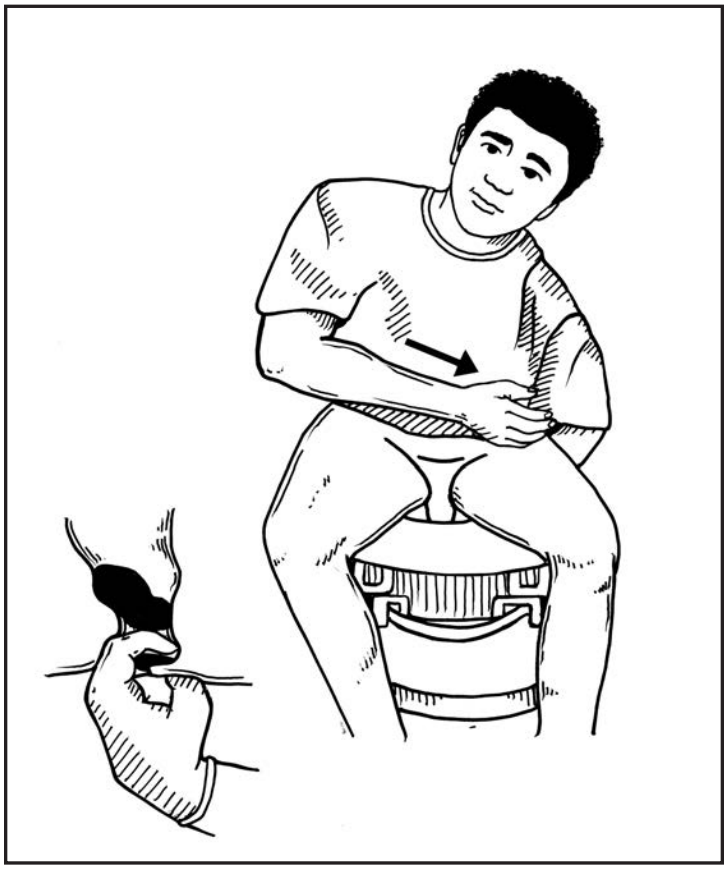


Figure 3 - Non-Reflex Bowel

KEY POINT: Remember in a non-reflex bowel, there are no messages for the bowel to squeeze and empty completely.

Methods for Emptying the Bowel

Digital Stimulation (Dil)

- Used to empty a reflex bowel.
- A fingertip or dilstick is inserted into the rectum.
- By moving the finger or dilstick around in a circle, the sphincter muscle opens and the bowel muscles squeeze to push stool out.
- This is best done at the same time every day or every other day to keep the bowel emptying on a regular schedule.
- The time and how often a digital stimulation (dil) is done depends on the individual.

How to Do a Digital Stimulation (Dil)

Supplies Needed:

Gloves
Dilstick, if needed
Lubricant (like Vaseline or K-Y Jelly) Plastic bag to throw waste in (if not done over toilet)

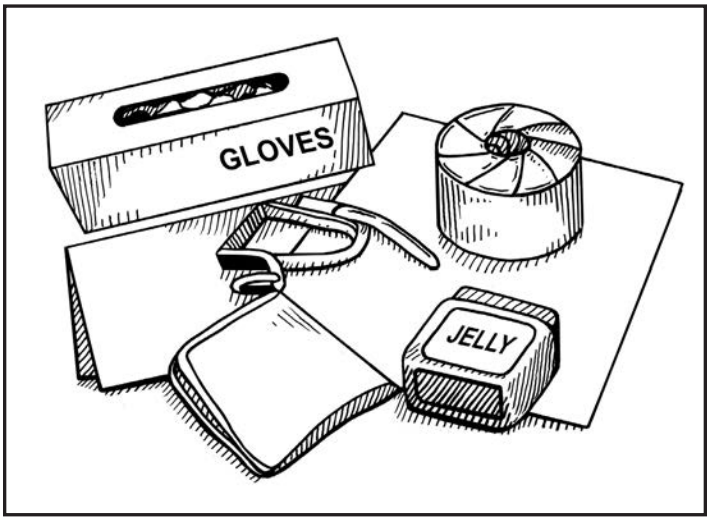


Figure 4 - Supplies for Bowel Program

Soap, water, washcloth and towel
Toilet paper
Blue pad or underpads to protect the bed, if done in bed Raised toilet seat, shower/commode chair, or Activaid (if not done in bed).

What To Do:

1. Wash your hands. (See Figure 5)
2. Prepare all needed supplies.
3. A dil may be done in bed, on a raised toilet seat, shower/commode chair, or Activaid. (See Figures 6, 8, 9, and 10)
4. If doing in bed, lie on your left side.
5. Then place a disposable pad or blue pad under the buttocks.
6. Put gloves on both hands.Place dilstick in your hand if needed. Be sure that fingernails are short.
7. Lubricate the pointer finger or the dilstick.

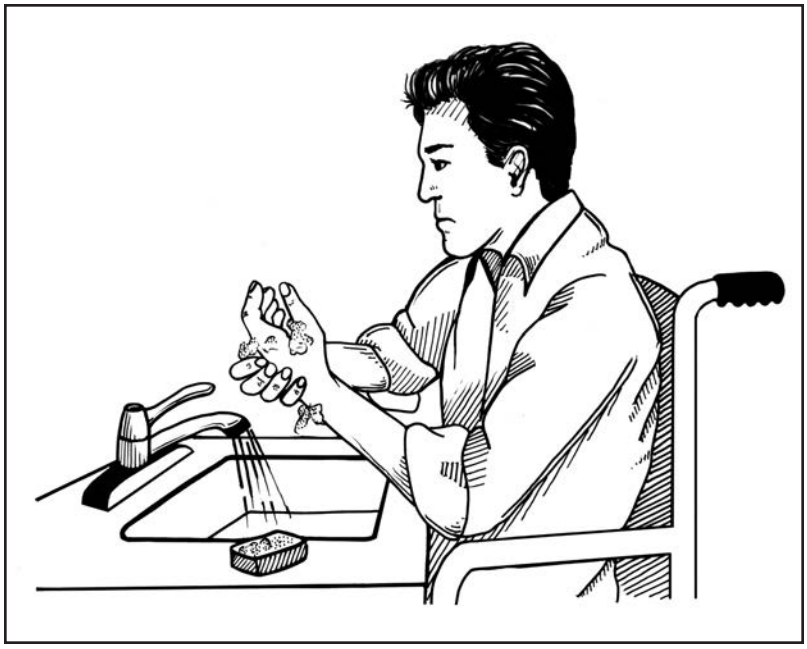


Figure 5 - Clean Hands Help Prevent Infection

8. Gently put the pointer finger or dilstick into the rectum no more than one inch.
9. Gently move the finger or dilstick around in circles. This causes the sphincter to relax and the bowel to squeeze.
10. When the stool begins to empty from the rectum gently move your finger or the dilstick to one side or remove completely so the stool can pass out of the rectum.

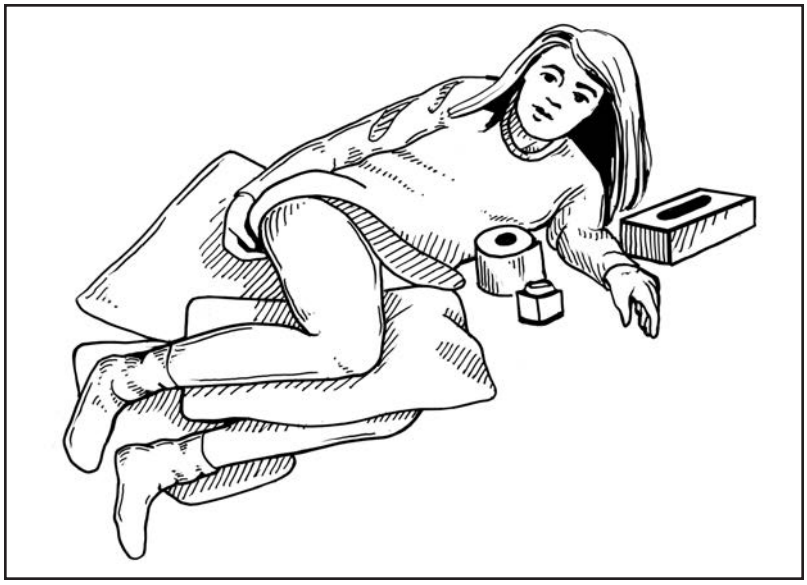


Figure 6 - Preparing for Bowel Program

11. If the digital stimulation (dil) produces stool, remove stool and continue the dil until there is no stool for 5 minutes. If the digital stimulation (dil) is done for 20 minutes with no stool, you have finished this program.
12. If sitting on a raised toilet seat or commode chair, massage the abdomen. This helps empty the bowel along with doing the digital stimulation (dil).
13. When finished, wipe rectal area and buttocks with toilet paper. Wash with soap and water and dry.
14. Clean dilstick with soap and water, dry well.
15. Throw out waste.
16. Wash hands.

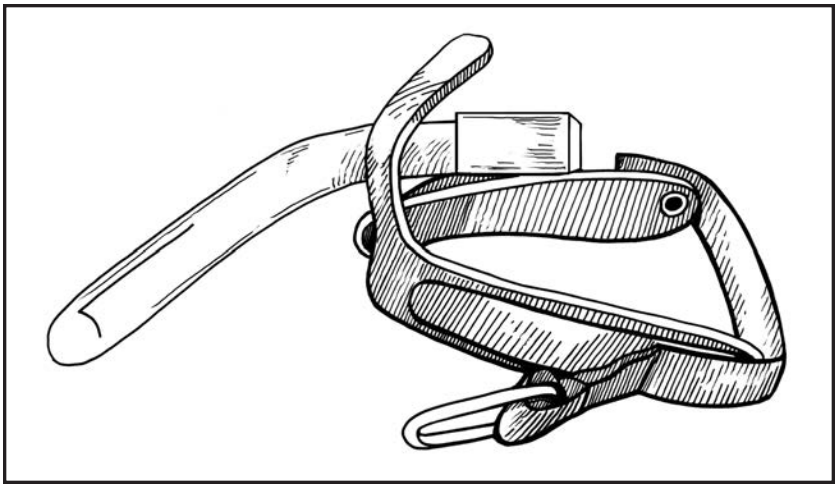
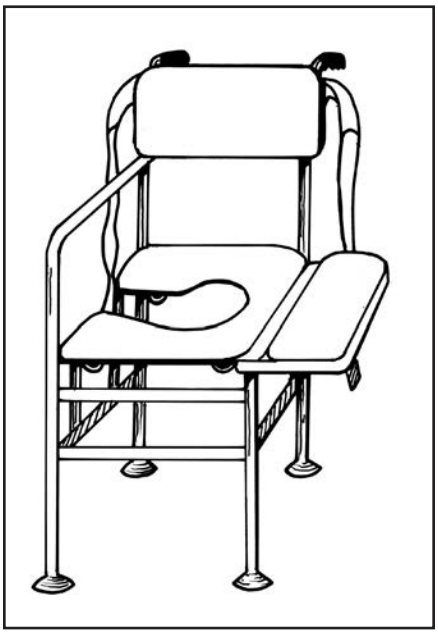
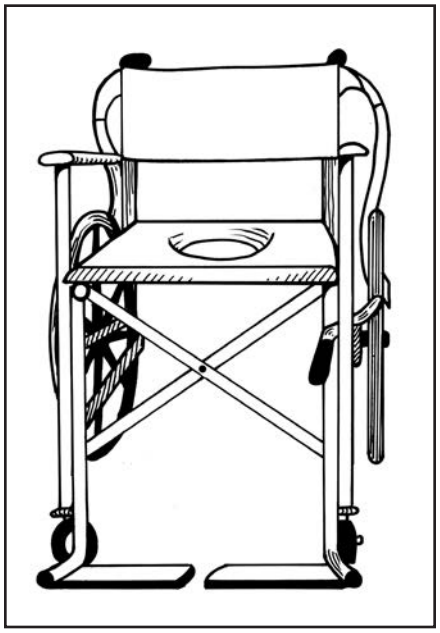


Figure 7 - Dilstick

KEY POINT: The digital stimulation (dil) may cause dysreflexia in persons with a spinal cord injury at T6 and above. (See Special Concerns section to learn more about dysreflexia.)





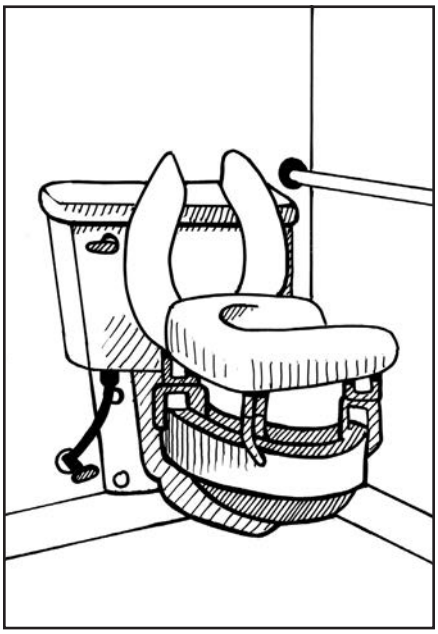


Figure 8 - Activaid; Figure 9 - Shower Chair or Commode Chair; and Figure 10 - Raised Toilet Seat

Suppositories

There are 3 common kinds of suppositories:

- Magic Bullet
- Enemeeze
- Dulcolax
  - Used to empty the bowel.
  - Best used when a person has sensation or feeling around the rectal area or when a digital stimulation (dil) does not empty the bowel.
  - Usually done at the same time every day or every other day in order to train the bowel.

How To Insert A Rectal Suppository

Supplies Needed:

- Gloves
- Lubricant (K-Y Jelly)
- Suppository (See "Common Bowel Medications" at the end of this section for more information.)
- Plastic Bag to throw waste in Soap, water, washcloth & towel
- Toilet paper
- Blue pad or underpads, to protect bed, if done in bed
- Raised toilet seat, commode chair or Activaid (if not done in bed)

What to Do:

1. Wash your hands.
2. Prepare all needed supplies.
3. Lie on left side.
4. Next, place a disposable pad or a blue pad under the buttocks.
5. Put gloves on both hands.
6. Lubricate the pointer finger and gently remove any stool in the rectum. This is called a rectal clear. Throw stool in trash.
7. Place a little lubricant on the pointed end of the suppository. (See Figure 11) If using an Enemeeze, cut off the tip of the Enemeeze and squirt the liquid into the rectum.

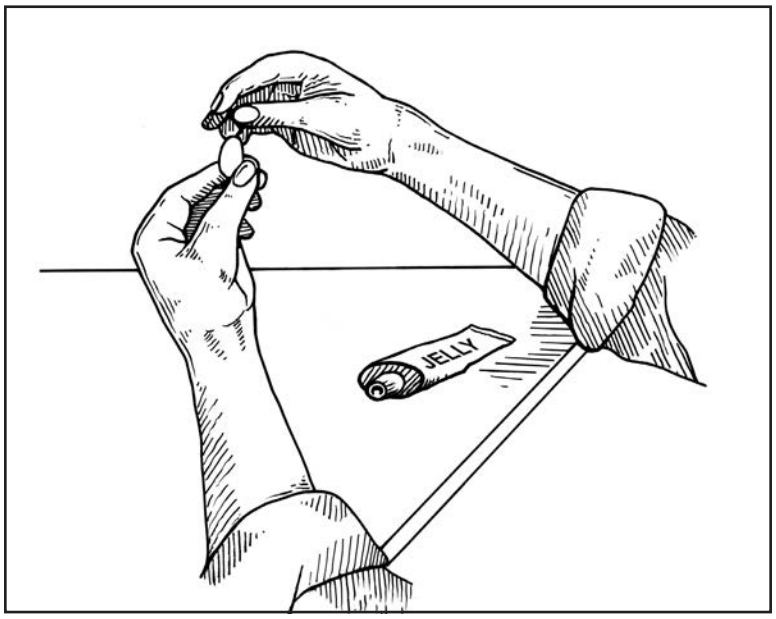


Figure 11 - Preparing a Suppository

1. Insert suppository into rectum. Guide the suppository along the side of the rectum. Do not push the suppository into any stool.
2. Leave the suppository in place for 30 to 45 minutes if possible.
3. If able, transfer to a shower chair, raised toilet seat or Activaid.
4. Wait 30 to 45 minutes after inserting the suppository. Lubricate your pointer finger and then gently remove the stool from the rectum.
5. When there is no more stool, wipe the rectal area with toilet paper and wash with soap and water. Dry with a towel.
6. Throw out waste.
7. Wash hands.

Emptying The Bowel For A Non-reflex Bowel (Rectal Clear)

- Used to empty a non-reflex bowel.
- Stool is gently removed by inserting a finger into the rectum.
- This is usually done every day or after meals.

How To Empty A Non-reflex Bowel (Male or Female)

Supplies Needed:

Gloves
Lubricant
Plastic bag to throw waste in
Soap, water, washcloth, and towel
Toilet paper
Blue Pad or underpads to protect the bed, if done in bed
Raised toilet seat, shower chair or Activaid (if not done in bed)

What To Do:

1. Wash your hands.
2. Prepare all needed supplies.
3. If doing in bed, lie on left side whenever possible. This may also be done on a raised toilet seat, shower chair or Activaid.
4. If in bed, place a disposable pad or blue pad under the buttocks.
5. Put gloves on both hands.
6. Lubricate pointer finger.
7. Gently put the finger into rectum.
8. Gently pull out small pieces of stool.
9. Continue until no more stool is present.
10. When done, wipe rectal area and buttocks with toilet paper. Wash with soap and water and dry.
11. Throw out waste.
12. Wash hands.

KEY POINT: For all bowel programs, it is important to keep fingernails trimmed to avoid injuring the bowel during a digital stimulation (dil or when inserting a suppository.

Things Which May affect Your Bowel

Medications

Almost all medications can change the way your bowel works. New medications may cause diarrhea or constipation. If you start taking a new medication or have problems with diarrhea or constipation, call your doctor.

Foods

During times when constipation or diarrhea is a problem, it may be necessary to avoid certain foods for a few days which can worsen the problem.

Foods Which May Make Diarrhea Worse

- Spicy foods
- Raw fruits and vegetables
- Alcohol
- Beer
- Wine

Foods Which May Make Constipation Worse

- Milk and dairy products
- Meat
- White bread
- Crackers without wheat
- Fatty foods
- Fried foods

The Key to Keeping Your Bowel Working Well

1. Pick a regular time for your bowel program and stick to it.
2. Do your bowel program the way you were taught in your rehabilitation program.
3. Drink water every day.
4. Get as much exercise as you can.

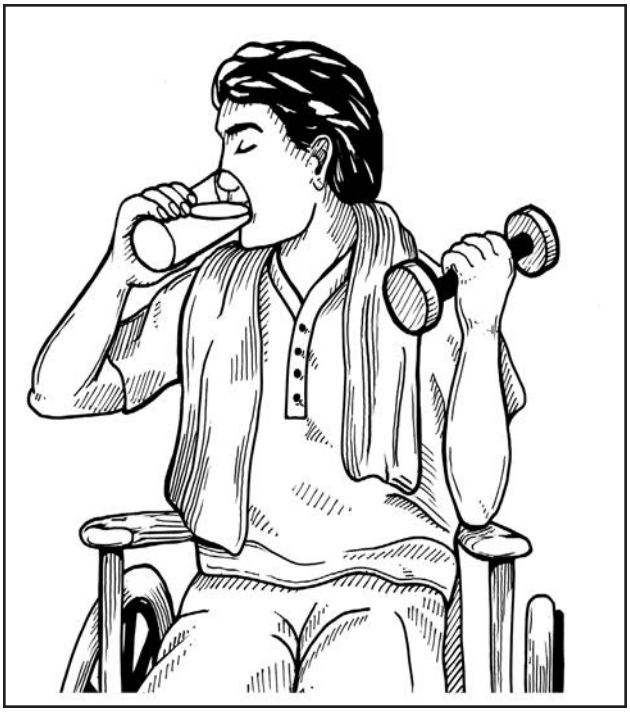


Figure 12 - How to Keep Your Bowel Working

5. Eat a healthy diet, including fruits, vegetables and whole grain foods.
6. Drink 1 to 2 cups of a hot drink 30 minutes before doing your bowel program. This will help your bowel empty more easily.
7. Do your bowel program 30 minutes after a meal. This will help the bowel empty more easily.
8. Massaging the abdomen during your bowel program may help your bowel empty.

KEY POINT: Skipping a bowel program or not doing a bowel program correctly can cause constipation and bowel accidents.

Figure 13 - MyPyramid.gov has good information about nutrition.

Common Bowel Problems

- Constipation
- Impaction
- Diarrhea
- Accidents or Involuntaries
- Rectal Bleeding
- Autonomic Dysreflexia
  (See Special Concerns section)

Constipation

Constipation happens when too much water is taken out of the stool in the large intestine. The stool becomes hard, making it difficult to pass through the bowel.

Causes:

- Not enough fiber in the diet (fruits, vegetables, whole grain breads and cereals).
- Not drinking enough water.
- Not doing your bowel program right or on time.
- Changing the time of your bowel program.
- Not emptying the bowel all the way.
- Not exercising.

How To Tell When You Have Constipation:

- Very hard stool when doing your bowel program.
- No stool from your bowel program for 2 days.
- Hard, tight or bloated abdomen.
- No appetite.
- Nausea.
- Small amounts of blood in the stool.

KEY POINT: Constipation can lead to dysreflexia in persons with a spinal cord injury at T6 and above. (See Special Concerns section to learn more about dysreflexia.)

Preventing Constipation:

- Eat fiber (foods such as fruits, vegetables, whole grain breads and cereals).
- Use a stool softener if needed.
- Drink water every day.
- Do your bowel program on time and do it right.
- Exercise as much as possible.
- Drink a hot drink 30 minutes before your bowel program. If you have had no stool for more than 2 days, you should call your doctor.

Impaction

An impaction means hard stool is stuck in the bowel.

Causes:

- Untreated constipation.

How To Tell If You Have An Impaction:

- No stool when doing bowel programs for more than 2 days.
- Hard, tight or bloated abdomen.
- No appetite.
- Nausea.
- Loose stool leaking around the hard stool.
- Small amounts of blood in the stool.
- To treat impaction, you may purchase a commercial enema product. You should follow package directions for correct use.

What To Do If You Have An Impaction:

- Your doctor will need to order a special laxative for you to take.
- Once the laxative starts working, you will have to help remove the harder stool.
- Insert a finger into the rectum and gently pull out the hard stool.

How to Remove an Impaction

Supplies Needed:

Gloves
Lubricant (Vaseline or K-Y Jelly)
Plastic bag to throw waste in (if needed).
Soap, water, washcloth and towel Toilet paper.
Blue Pad or underpads to protect bed if done in bed.
Raised toilet seat, shower chair or Activaid (if not done in bed).

What to do:

1. Wash your hands.
2. Prepare all needed supplies and place on a clean towel.
3. May be done on a raised toilet seat, shower chair or Activaid.
4. If doing in bed, lie on left side; then place a disposable pad or plastic bag under the buttocks.
5. Put gloves on both hands.
6. Lubricate pointer finger.
7. With the finger, gently take out the hard stool.
8. After you have taken out the impaction, do the regular bowel program.
9. When done, wipe rectal area and buttocks with toilet paper. Wash with soap and water. Dry with a towel.
10. Throw out waste.
11. Wash hands.

KEY POINT: Stop this procedure if there is any pain or dysreflexia. This procedure is done only if absolutely necessary because the rectum can be hurt if done too often. It is best to have someone help with this procedure even if you usually do your own bowel program. If you or whoever is helping you are unable to take out the impaction, call your doctor.

Diarrhea

Diarrhea happens when the large intestine does not absorb enough water from the stool. This is usually because the waste moves through the intestines so fast there is not enough time for the removal of the extra water.

Causes:

- Flu, illness
- Some foods.
- Some medicines (antibiotics).
- Too many stool softeners or laxatives.
- Drinking alcohol, beer or wine.
- Stress.
- Possible impaction.

Signs of Diarrhea:

- Loose, watery stool.
- Many loose bowel movements.

What To Do If You Have Diarrhea:

- Be sure you are not impacted by reviewing the past 2-3 days of stool results. If you ahve had no stool in 2-3 days, you may be impacted.
- Stop taking stool softeners until the diarrhea has stopped.
- Stop doing your bowel program.
- Do not eat foods that can make diarrhea worse (spicy foods, fruits and vegetables).
- Drink a lot of clear liquids (more than 6 to 8 glasses a day).
- If diarrhea lasts for more than 24 hours, call the doctor.
- When the diarrhea has stopped for 24 hours, begin your normal bowel program schedule again.
- For occasional diarrhea, you may use medications which can be bought over the counter.

Prevention:

- Eat a well balanced diet.
- Limit alcohol, beer or wine, and spicy or rich foods.
- Eat yogurt or drink buttermilk when you start taking antibiotics if you do not have allergies to milk products.

Involuntaries or Accidents

- An involuntary is an unplanned bowel movement of formed or soft stool (not diarrhea).

Causes:

- Not doing the bowel program on time.
- Not emptying the bowel completely.
- Not doing the bowel program for the right amount of time.
- Illness or flu.
- Not eating the right foods.
- Drinking beer, wine or alcohol.
- Impaction.

What To Do If You Have An Involuntary:

- Do a complete bowel program after each involuntary.
- Repeat your Bowel Program at your regularly scheduled time unless the involuntary is within 4 hours of that time.

How to Prevent Involuntaries:

- Do not miss a scheduled bowel program.
- Perform your bowel program completely each time to empty the bowel completely.
- Eat the right foods (including fiber).
- Don't drink alcoholic beverages.

Rectal Bleeding

Causes:
- Impaction
- Constipation
- Doing digital stimulation (dil) too hard
- Hemorrhoids
- Nails that are too long or sharp (this can hurt the tissue in the rectum).

How to Tell If You Have Rectal Bleeding:

- Blood in stool, on glove or dilstick.
- Blood on washcloth or toilet paper.

What To Do If You Have Rectal Bleeding:

- Stop digital stiumulation (dil) if there is a large amount or continual oozing of blood and call the doctor right away. (There may be hemorroids or a tear in the rectum).
- The doctor may order a stool softener.

How To Prevent Rectal Bleeding:

- Do a gentle digital stiumulation (dil) and keep fingernails trimmed short and straight so the rectum and sphincter are not hurt.
- Use lots of Vaseline or K-Y Jelly with every digital stiumulation (dil) or rectal clear.
- If bleeding continues, call your doctor.

Nutrition

After a spinal cord injury, the need for a nutritious and well-balanced diet is very important. The kinds of food you choose to eat will affect your health and how well you feel. A variety of foods will provide the nutrients and vitamins you need to stay healthy.

In general, there are three major nutrients: protein, carbohydrates and fat.

PROTEIN is used to build new cells and replace damaged ones and is vital for wound healing. It also helps boost the immune system so that you do not get sick as easily when you are eating adequate amounts.

CARBOHYDRATES (starches and sugar) are the main energy source for the body. They provide the fuel needed for wound healing and cell repair.

FAT is used by the body for padding around bones and to keep the skin supple and soft. It is also a major energy source.

VITAMINS AND MINERALS are available in most foods. They aid the protein, carbohydrates and fat in keeping your body healthy.

The Food Guide Pyramid indicates daily food choices that will provide the nutrients you need and the amounts that are right for you. The pyramid is divided into these basic groups: grains, fruits and vegetables, dairy, and meat.

Grains

The grain group is an excellent source of carbohydrates, B-vitamins and fiber. This group includes whole grain breads, cereals, rice and pasta. A serving is about 1/2 cup cooked grain or pasta or a slice of bread.

Fruits

Fruits provide vitamins A and C and fiber. They are also a good source of carbohydrates. A serving of fruit is 1/2 cup chopped or one small piece. Fruit juice (1/2 cup) also counts as a serving.

Vegetables

Vegetables are a good source of vitamins A and B, fiber and carbohy-drates. A serving of vegetables is 1/2 cup cooked or 1 cup raw. Vegetable juices (1/2 cup) may also be counted as a serving.

Dairy

The dairy group is the main source of calcium in our diets. It also provides protein, carbohydrates and some B-vitamins. If you cannot eat or drink dairy products, a calcium supplement is a good idea. A serving is 1 cup of milk, butter-milk or yogurt or 1 ounce of cheese.

Meat

Meat is the main source of protein and iron in your diet and also provides some B-vitamins. Meats include beef, pork, lamb, chicken, turkey, fish and wild game. A serving of meat is 3 ounces (about the size of a deck of cards).

Meat substitutes such as eggs, peanut butter and dried beans and peas are also good sources of protein and iron. Beans and peas contain fiber as well. (1 egg or 1/2 cup beans is equal to 1 ounce of meat).

Fats And Sweets

Fats and sweets may be eaten in moderation. Remember, these foods have little nutrient value and can quickly add extra calories that could lead to excess weight gain.

Fiber And Fluid

Fiber is part of the plants that your body cannot digest. It can help lower your cholesterol, prevent some types of colon cancer and help stool move through the bowel more easily. Gradually increasing the fiber in your diet works best. 25-30 grams of fiber per day is recommended.

Key: Ways to Add Fiber to Your Diet

1. Eat the skin of fruits and vegetables.
2. Eat more whole grain breads and cereals.
3. Eat more dried beans and peas.
4. Sprinkle granola or bran cereal on yogurt or ice cream.
5. Add bran or wheat germ to meat loaf, cookies and muffins by using it in place of 1/3 cup flour.
6. Add grated fruits and vegetables to muffins, casseroles and salads.
7. Eat high fiber cereals such as All Bran and Fiber One. Mix them with your favorite cereals if you do not like the flavor.
8. Try whole grain, brown and wild rice.
9. Light popcorn is a good high fiber snack.
10. Add nuts and seeds to muffins and casseroles.
11. Read labels to find the most fiber per serving.
12. Steam vegetables rather than boiling.

Ask your doctor or go to MyPyramid.gov for more in-depth information about what foods to eat and how many calories to consume.

Figure 14 - MyPyramid.gov has good information about nutrition.

Bowel Medications

Class of Agent	Examples	Class of Agent	Important Information
Bulk forming	Psyllium (Metamucil) Methylcellulose (Citrucel) Polycarbophil (FiberCon)	Bulk forming agents increase the weight & amount of water that stool absorbs stimultating bowel movements.	Onset: 48-72 hours Take with a full glass of water. *Do not use with fecal impaction or bowel obstruction.
Stool Softeners	Docusate (Colace)	Mixes water and fat in stool causing the stool to soften. This makes the stool easier to pass.	Onset: 24-72 hours
Osmotic Laxative	Lactulose (Enulose) Polyethylene glycol (Miralax) Magnesium Hydroxide (Milk of Magnesia)	Draws water into the intestines allowing stool to pass easier.	Onset: 30 mins - 3 hours for Milk of Magnesia; all others 24-72 hours.
Stimulant Laxative	Bisacodyl (Ex-Lax, Dulcolax) Senna (Sennokot)	Irritates the smooth muscle of the intestines thus increasing water and motility.	Onset: Oral 6 - 10 hours Rectal Suppositories: 15-60 mins. minimum

Summary

The digestive system begins with the mouth and includes the esophagus, stomach, small and large intestine, rectum, sphincter muscle, and the anal opening. When the foods we eat pass through the digestive tract, nutrients are removed. These nutrients are used for energy and to build new body tissue. Waste material left from the digestive process is then passed from the body.

Normally, bowel emptying is controlled by the brain. The brain sends messages down the spinal cord and out the sacral nerves. This causes the sphincter muscles to relax so that the bowel can empty.

After spinal cord injury, voluntary control of bowel emptying may be lost. Signals from the brain cannot get past the injured area to control the sphincter muscles. In order to prevent constipation and bowel accidents (involuntaries), a planned program for bowel emptying needs to be established.

Digital stimulation (dil) is used to cause the bowel to reflex (squeeze) and the sphincter to open. The digital stimulation (dil) is the most reliable method for bowel emptying. Rectal Clear is used for patients without the reflex. Suppositories may also be used for some people.

Key points to remember:

1. Find a regular time for your bowel program and stick to it.
2. Do the digital stimulation (dil) for the right amount of time.
3. Get as much exercise as you can.
4. Drink water every day.
5. Eat a healthy diet including fruits, vegetables, whole grain breads and cereals.

If problems occur with constipation, impaction, diarrhea or rectal bleeding, call your doctor. There are also edications available to help you manage your bowel program. If things begin to go wrong with your bowel program, ask yourself these questions:

1. Have I changed my eating habits?
2. Am I doing my bowel program on time?
3. Am I taking any new medications?
4. Have I been eating very spicy foods?
5. Have I had an increase of stress in my life?

Managing your bowel program means looking at all of these questions and how they might affect you. If you need help, call your doctor.

What You Have Learned About the Digestive System

1. How do you empty your bowel?
2. How often do you perform your bowel program?
3. Are you taking any bowel medications? What are the names of these medications? Why are these medications prescribed?
4. What will you do if you have rectal bleeding?
5. What will you do if you think you are constipated?
6. What will you do after an involuntary?

The Bladder Program

3 **CHAPTER CONTENTS**

What You Will Learn In This Section

After reading this section you will be able to:

1. Name the parts of the urinary system.
2. Describe how the urinary system works before and after a spinal cord injury.
3. Describe the methods used for emptying the bladder.
4. Describe the care and cleaning of urinary supplies.
5. Name the most common urinary tests.
6. List the causes, signs, treatment and prevention of urinary problems.
7. Name and describe the most common urinary medications.

New Words

Abdomen
The middle front part of the body (stomach).

Bladder
The organ which stores urine.

Bladder Augmentation
A surgical procedure to enlarge the bladder to prevent leaking.

Catheter
A tube which is put into the bladder to empty urine.

Coude Tip
A catheter with a curved tip.

Catheterization
To empty urine from the bladder through a tube (catheter).

Condom Catheter
A rubber device which covers the penis and allows urine to drain through a tube into a bag.

Condom Holder
A small strap that helps keep a condom on the penis.

Deflate
To take the air out. To make smaller.

Disinfectant
A chemical that kills germs.

Fourteen French
A common size catheter. Example: package will be labeled 14 Fr.

Foley
A common brand of an indwelling catheter.

Indwelling Catheter
A catheter which stays in the bladder all the time to drain urine.

Intermittent Catheterization (I.C.)
A catheter which is put into the bladder and removed right after the bladder is drained. An I.C. is usually done every four to six hours.

Intravenous Pyelegram (I.V.P.)
An x-ray of the bladder and kidneys. Should be done every 2 years after your injury for 10 years, then every 5 years.

Kidneys
Two organs which filter waste from the blood and make urine.

Labia
The folds of skin around the vagina.

Ostomy
A surgically created opening into the body.

Reflex
The movement of a muscle caused by a signal which does not come from the brain.

Renal Scan or Ultrasound
A test to evaluate the function of the kidneys.

Reflux
The back flow of urine into the kidneys from the bladder.

Shaft of the Penis
The main part of the penis closest to the body.

Suprapubic Catheter
A tube that goes through the abdomen into the bladder to empty urine.

Syringe
A device used for squirting water into the balloon of an indwelling catheter.

Ureter
A muscular tube connecting the kidney to the bladder.

Urethra
The tube leading from the bladder to the outside of the body.

Urinary System
The kidneys, bladder, ureters, urethra and urinary sphincters.

Urinary Tract Infection (U.T.I.)

Symptoms of a U.T.I. are blood in the urine, fever above 101°, leaking between I.C.'s if you usually do not, and frequent dysreflexia.

Urethral Sphincter

The small muscle that opens and closes to hold urine in the bladder. It is located at the bottom of the bladder.

Urinate

To let urine out of the body.

Urine

The liquid waste made by the kidneys.

Urodynamics

A test of the bladder which shows how much urine the bladder holds and how it empties.

Vagina

Often called the "birth canal." It is the canal from the uterus to the outside of the body.

The Parts of the Urinary System

The urinary system includes the kidneys, ureters, bladder, sphincter muscles and urethra. The urinary system removes harmful wastes from the body.

The Kidneys

- Thre are two kidneys in the body, on either side of the back part of the abdominal cavity and below the rib cage.
- As blood flows through the kidneys, the kidneys filter harmful wastes.
- The kidneys combine the wastes with water and create urine.

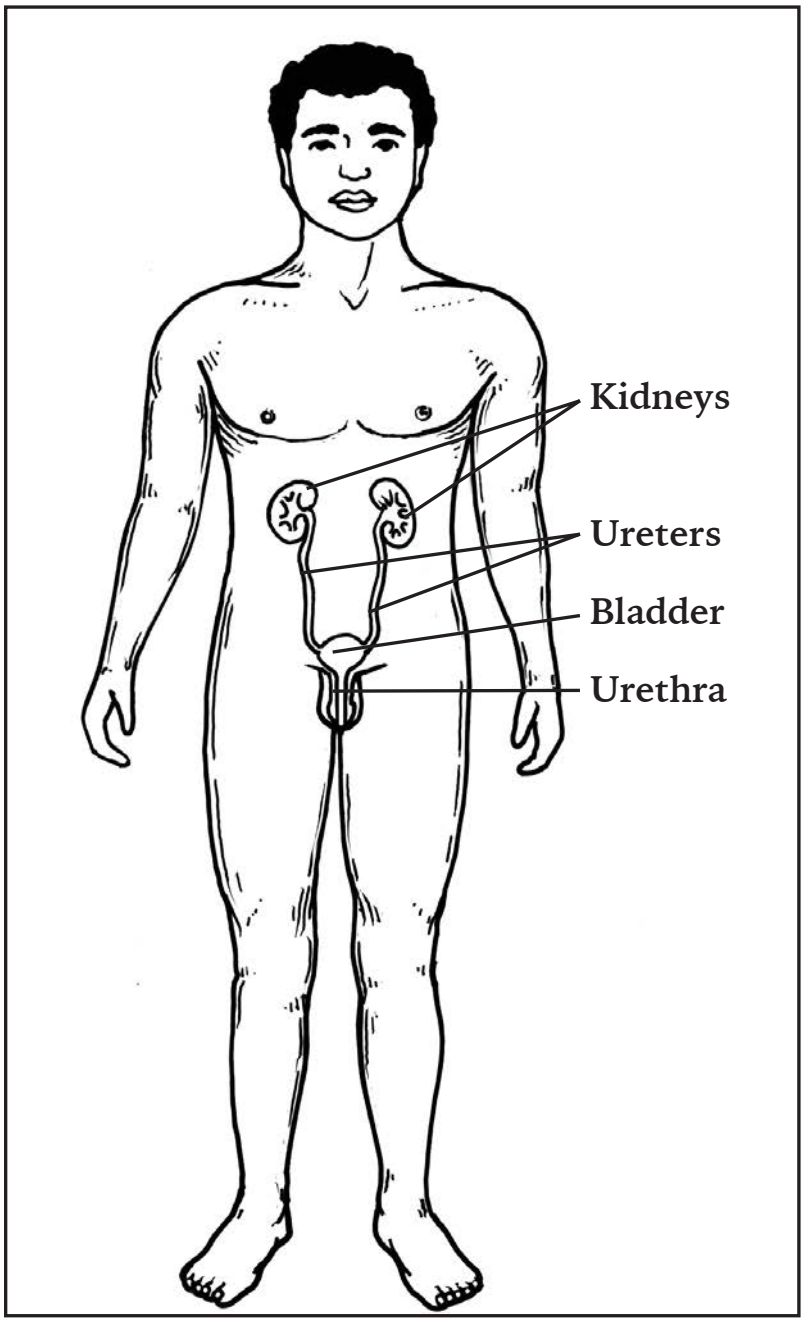


Figure 1 - The Urinary System

The Ureters

- There are two muscular tubes called ureters in the body. Each ureter connects a kidney to the bladder.
- Urine flows from each kidney through the ureters and into the bladder.

The Bladder

- The bladder is a muscular organ which collects and holds urine.
- The bladder is like a balloon; it stretches when it is full and shrinks when it is empty.

The Sphincters

- There are 2 sphincters in the urinary system.
- Urinary sphincters are small muscles which stay closed to keep urine in the bladder and open to let urine out of the bladder.
- The first sphincter is located at the base of the bladder.
- The second sphincter is located in the urethra.

The Urethra

- The urethra is a muscular tube leading from the bladder to the outside of the body.

How the Urinary System Works Before A Spinal Cord Injury

Bladder emptying occurs when the brain sends messages through the spinal cord and sacral nerves. These messages cause the bladder to contract and the sphincter muscle to open. This drains the urine out of the bladder.

This is what happens:

1. The bladder contains a large number of nerves.
2. When the bladder is full of urine, it stretches.
3. The stretching of the bladder pushes on these nerves.
4. This sends a sensory (feeling) message from the bladder through the sacral nerves to the spinal cord.
5. When the message reaches the spinal cord, part of the message loops through the spinal cord, setting off a reflex.
6. This causes the bladder to squeeze (contract).
7. The other part of the message goes to the brain.
8. When this message reaches the brain, the urge to urinate is felt.
9. If it is not a good time to urinate, a message is sent from the brain down nerve fibers in the spinal cord, through the sacral nerves, to the bladder and to the sphincter muscle.
10. This message tells the sphincters to stay shut and keep the urine in the bladder.
11. If it is a good time to urinate, a message is sent from the brain down the spinal cord through the sacral nerves to the bladder and to the sphincter.
12. This message tells the sphincter to relax, open and let urine out.
13. A normal bladder completely empties when urinating.

How the Urinary System Works After A Spinal Cord Injury

During spinal shock, the bladder will not reflex. Spinal shock leaves the bladder limp and unable to empty. The bladder becomes full and over-stretched. During this time, intermittent catheterizations (I.C.s) must be done to empty the bladder. Spinal shock lasts from a few days to weeks following injury. Sometimes spinal shock can last for months. When the spinal cord recovers from spinal shock, the bladder will be either a reflex or a non-reflex bladder. Your bladder may be non-reflex after spinal shock and change several weeks or months later to a reflex. You may have a choice in the way you can empty your bladder, so stay in touch with the urologist to assist you.

The Reflex Bladder

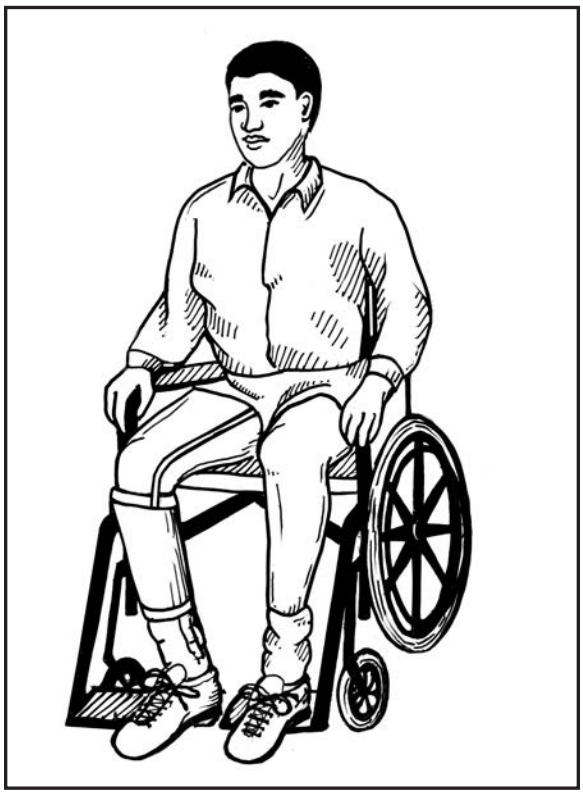


Figure 2 - Condom Catheter with Leg Bag

After a spinal injury, the bladder will no longer work as it did before the injury. If the injury is above T12, the bladder may empty by reflex. With a reflex bladder, messages from a full bladder are not able to reach the brain, but they do reach the spinal cord.

Here's what happens:

1. The bladder fills with urine.
2. The bladder stretches.
3. The stretching of the bladder pushes on these nerves.
4. This sends a message from the bladder through the sacral nerves to the spinal cord.
5. When the message reaches the spinal cord, it loops through the spinal cord, setting off a reflex.
6. The message then goes back down the spinal cord through the sacral nerves to the bladder and sphincter muscles.
7. When the message reaches the bladder, the bladder squeezes or contracts.
8. When the message reaches the sphincter muscle, it will open and let urine out.
9. This reflex will happen when the bladder gets full and stretches.

Remember, messages can no longer get to and from the brain past the spinal cord injury. This means the sensory message from the bladder cannot get to the brain. The urge to empty the bladder will not be felt.

Reflexes can occur because these messages do not need to get to the brain. They only need to get to the spinal cord. The bladder program for a reflex bladder is usually a combination of I.C.'s and condom catheter for the male. For the female, the choice is either I.C.'s or an indwelling catheter.

Figure 3 - "I.C." in a Wheelchair

The Non-Reflex Bladder

If the spinal cord injury occurs at L2 and below, the bladder probably will not have the reflex action to empty. Because the spinal cord ends around L2, signals from a full bladder cannot get to the spinal cord.

Here's what happens:

1. The bladder fills with urine.
2. The bladder stretches.
3. As the bladder stretches, it pushes on the nerves in the bladder.
4. A message will be sent from the bladder through the sacral nerves.
5. The signal cannot get to the spinal cord because of the injury to the nerves leading to the spinal cord.
6. No reflex occurs.
7. The bladder will not squeeze and the sphincter will not open and let urine out.

The bladder program for a non-reflex bladder will usually be I.C.'s done every four to six hours. Injuries between T10 and L2 may result in either reflex or non-reflex functioning of the bladder.

Ways of Emptying the Bladder

I.C.s (Intermittent Catheterizations)

Most common method used for emptying the bladder.

- Used for males and females.
- Are usually done every four to six hours by placing the catheter into the bladder through the urethra and draining the urine. The catheter is then removed.

How To Do A Clean I.C. – Male

Supplies needed:

1. Catheter
2. K-Y jelly or water soluble gel
3. Mild soap, water and wash cloth
4. I.C. bag, cup or urinal. The urine can also be drained directly from the catheter into the toilet.
5. Clean paper towel or hand towel

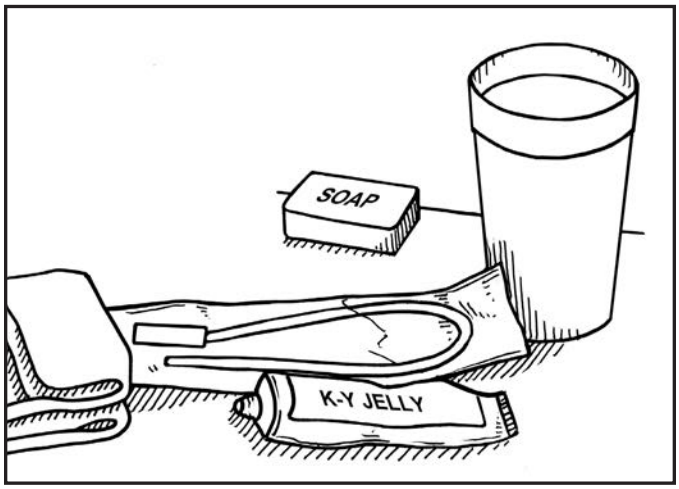


Figure 4 - Urinary Supplies

You may use moist towelettes that state "antibacterial" and contain the ingredient Benzethonium Chloride.

What to do:

1. Wash your hands with soap and water. Handwashing is one of the most important steps in the prevention of bladder infections. (See Figure 5)

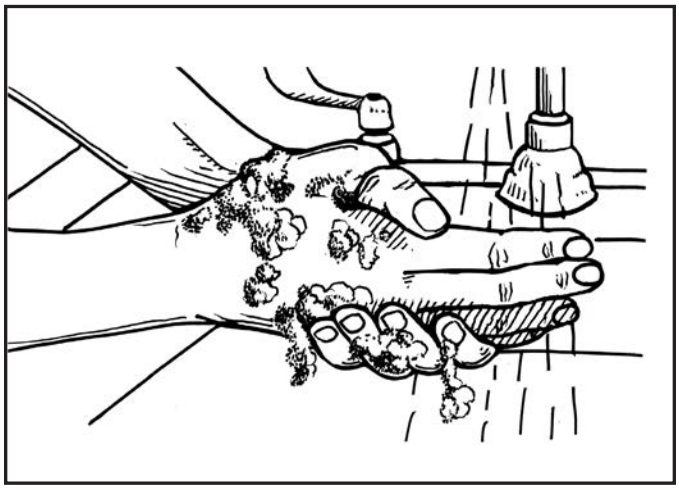


Figure 5 - Washing Your Hands

2. Prepare all needed supplies.
3. Place catheter, K-Y jelly, I.C. bag or container, a soapy cloth and a wet cloth on a clean paper towel or hand towel. Always have your supplies ready before beginning an I.C.
4. Wash penis with soapy cloth and then rinse penis with the wet cloth. Pull the foreskin back and clean the head of the penis well. (See Figure 6)

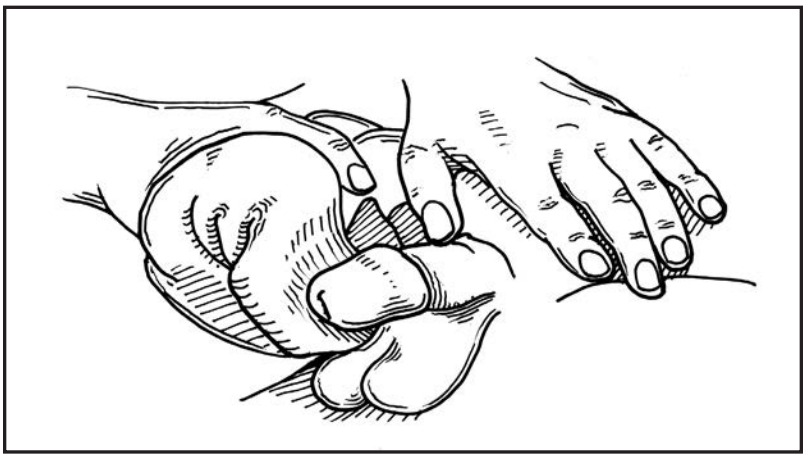


Figure 6 - Washing the Penis

5. Connect the I.C. bag to the catheter or place the container within reach.
6. Open the K-Y jelly and squeeze 4 inches onto the tip of the catheter. Do not let the tube touch the catheter. (See Figure 7)

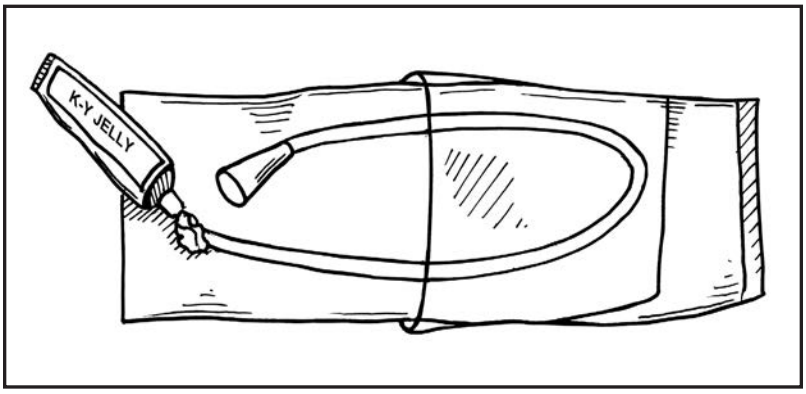


Figure 7 - Lubricating the Catheter

7. Wash your hands again with a clean, soapy washcloth or a moist towelette that states "antibacterial" and contains the ingredient Benzethonium Chloride. (See Figure 8)

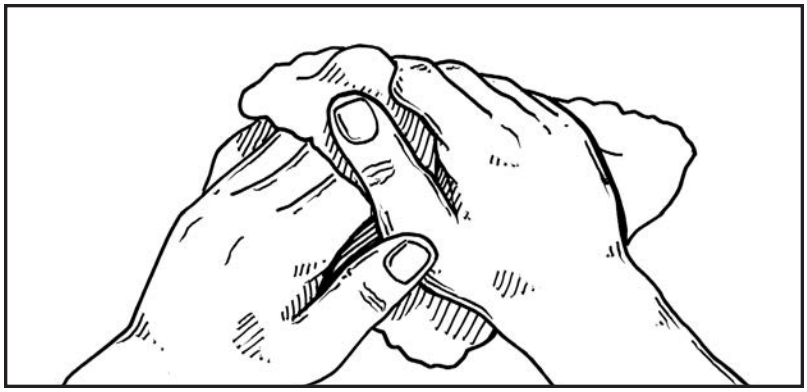


Figure 8 - Washing Your Hands

8. Pick up the catheter about 2 to 3 inches from the tip. When using a container, make sure the other end of the catheter is in the container. (See Figure 9)

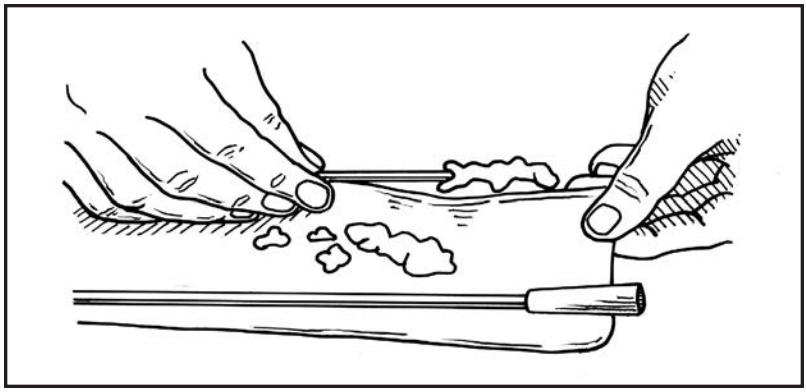


Figure 9 - Picking Up the Catheter

9. Hold penis straight up with the other hand and insert the catheter slowly until urine starts to drain. Then, push the catheter into the bladder one more inch. (See Figure 10)

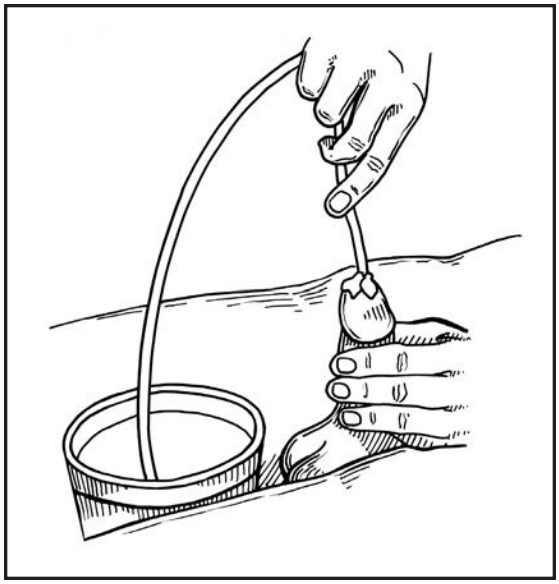


Figure 10 - Inserting the Catheter

10. As the catheter is pushed down, pull up on the penis with the other hand. This straightens out the passageway to the bladder, allowing the catheter to pass more easily. It will also help prevent damage to the urethra and sphincter.
11. Keep pushing the catheter in until urine flows through the catheter. Then insert the catheter 1 inch more and allow urine to drain. The bladder will empty better by letting the penis come down and holding the catheter in place. (See Figure 11)

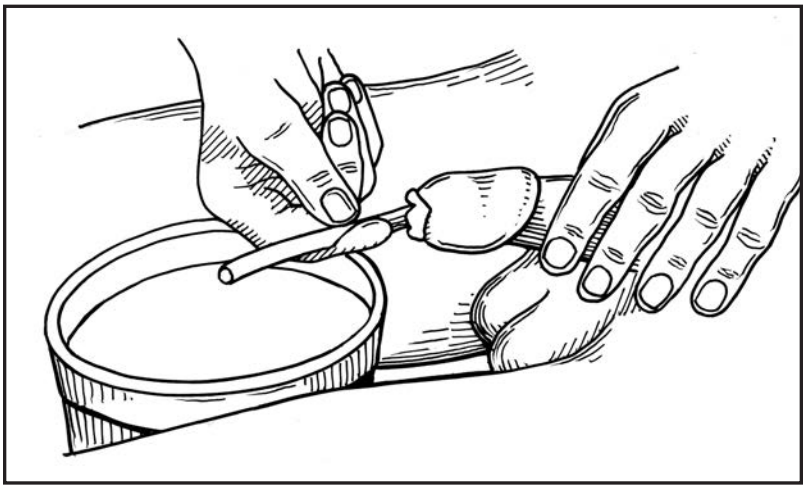


Figure 11 - Insert the Catheter Until Urine Flows

If it is hard to pass the catheter into the bladder, take a deep breath and while exhaling, re-attempt to pass the catheter. If that does not work, gently pull your penis up toward your belly and try to pass the catheter. If that also doesn't work, stop trying for 10 minutes, then re-try.

If you still cannot pass the catheter, call your doctor.

12. When the urine flow stops, gently push down on the bladder area. Pushing down on the bladder may be necessary to completely empty the bladder. Withdraw the catheter slowly. Removing the catheter slowly helps to empty the bladder completely. This will prevent urine from remaining in the bladder. Urine left in the bladder can cause an infection. Remove the catheter when the urine flow has stopped. (See Figure 12)

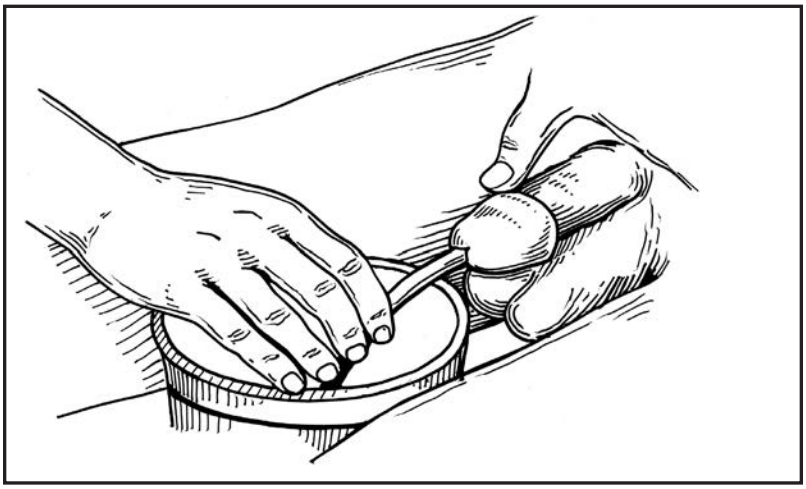


Figure 12 - Press Gently on the Bladder

13. While at Shepherd Center, a new catheter is used for each I.C. After discharge from Shepherd Center, a catheter can be used for 7 days. After each use, clean the catheter with anti-bacterial soap and water. Rinse with clean water, air dry and store the catheter in an envelope or paper bag (not a plastic bag). (See Figure 13)

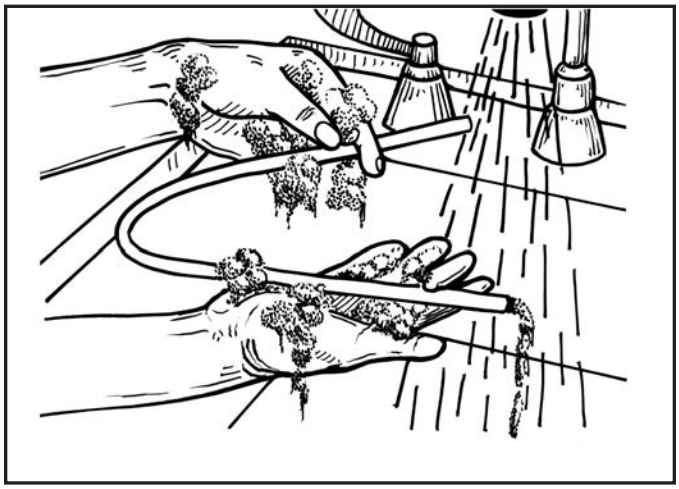


Figure 13 - Washing the Catheter

14. Wash the penis with a soapy cloth and rinse with a wet cloth. Dry penis well. Remember to pull the foreskin back down over the head of the penis. (See Figure 14)

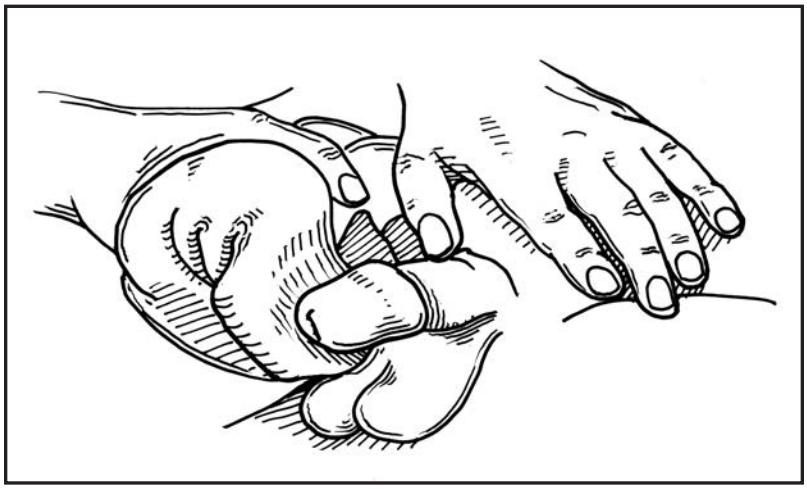


Figure 14 - Washing the Penis

15. Empty the I.C. bag or container. Rinse it out and clean with bleach water. (See Figure 15)

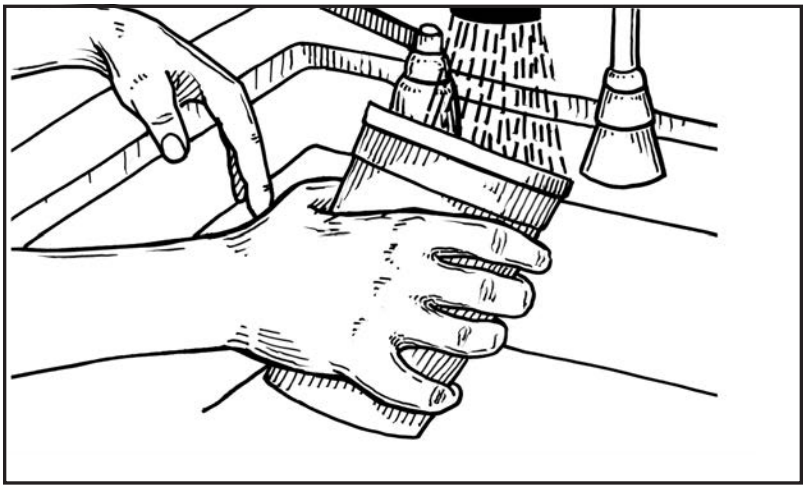


Figure 15 - Washing the Urine Container

16. Wash your hands. (See Figure 16)

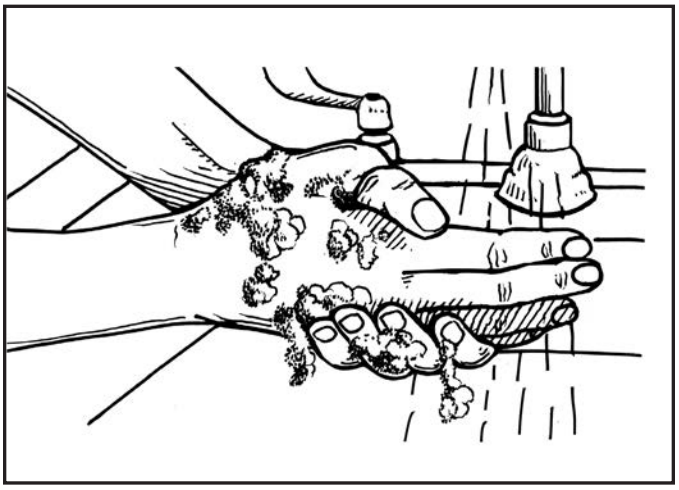


Figure 16 - Washing Your Hands

KEY POINT:

1. If you drop your catheter, clean it with soap and water before using again.

2. If a spasm occurs while doing the I.C., stop and wait for the spasm to pass before pushing the catheter any further.

3. If the catheter will not go in easily, call your doctor. Do not force the catheter into the bladder.

Ways of Emptying the Bladder

I.C.s (Intermittent Catheterizations)

Most common method used for emptying the bladder.

- Used for males and females.
- Are usually done every four to six hours by placing the catheter into the bladder through the urethra and draining the urine. The catheter is then removed.

How To Do A Clean I.C. – Female

Supplies needed:

1. Catheter
2. Mirror (if needed)
3. K-Y jelly or water soluble gel
4. Mild soap, water and wash cloth
5. I.C. bag, cup or urinal. The urine can also be drained directly from the catheter into the toilet.
6. Clean paper towel or hand towel

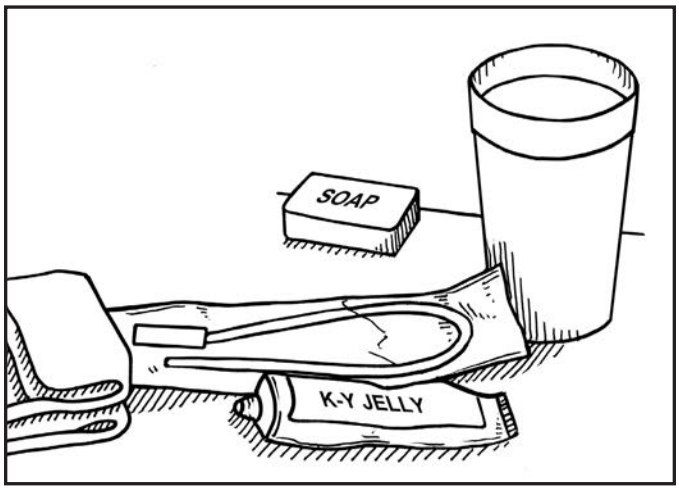


Figure 17 - Urinary Supplies

You may use moist towelettes that state “antibacterial” and contain the ingredient Benzethonium Chloride.

What to do:

1. Wash your hands with soap and water. Handwashing is one of the most important steps in the prevention of bladder infections. (See Figure 18)

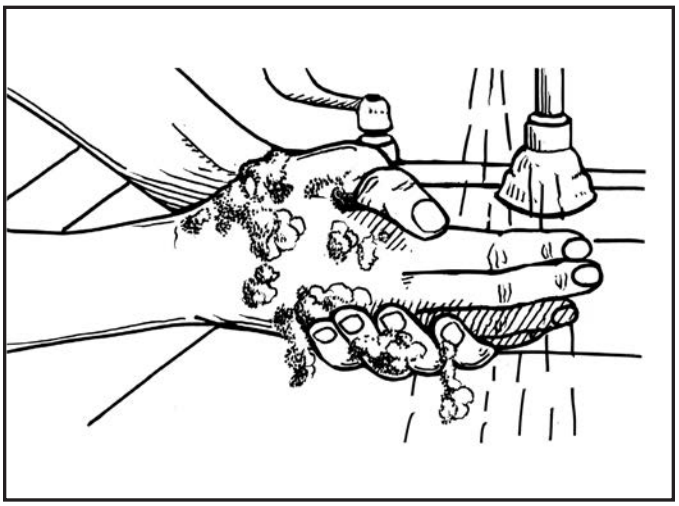


Figure 18 - Washing Your Hands

2. Prepare all needed supplies.
3. Place catheter, K-Y jelly, I.C. bag or container, a soapy cloth and a wet cloth on a clean paper towel or hand towel. Always have your supplies ready before beginning an I.C.
4. Open the K-Y jelly and squeeze 1 inch onto the tip of the catheter. (See Figure 19)

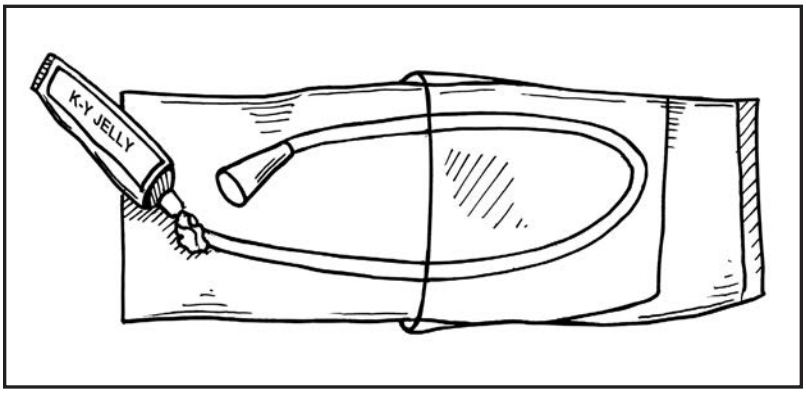


Figure 19 - Lubricating the Catheter

5. Place I.C. container within reach of catheter or connect catheter to I.C. bag.
6. Wash around the urinary opening with the soapy wash cloth and rinse off the soap with the wet cloth. Wash from above the urinary opening down toward the rectum. Always wash from the front to the back. This prevents any germs in the rectal area from entering the urethra. (See Figure 20)

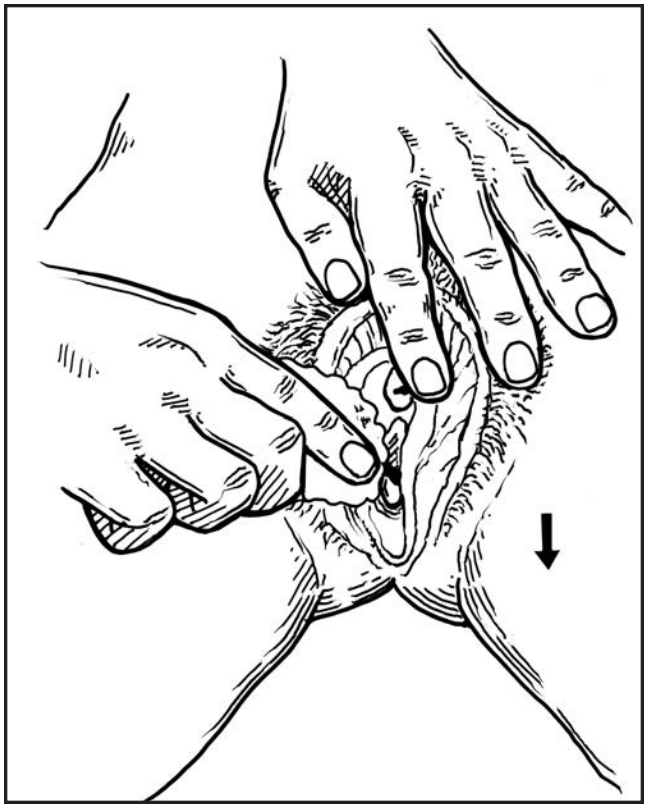


Figure 20 - Cleaning the Urethra

7. Wash hands again. With one hand, spread the labia apart with your ring finger and pointer finger. Locate the urethral opening with the finger located between the ring finger and the pointer finger. The third finger serves as a landmark for inserting the catheter. (See Figures 21 and 22)

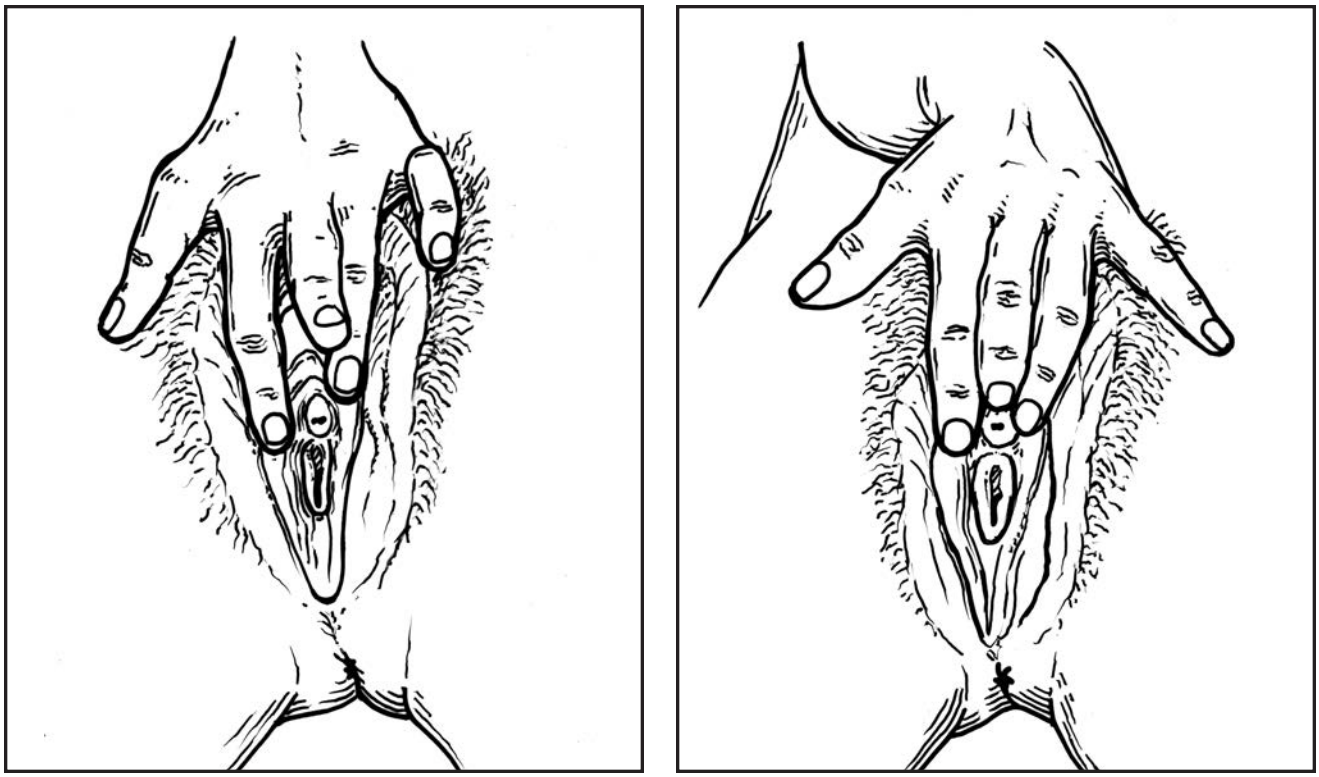


Figure 21 - Spreading the Labia; and 22 - Finding the Urethra

8. With your other hand, pick up the catheter by the clear tip directly behind the K-Y jelly. If using a container, make sure the other end of the catheter is in the container. (See Figure 23)

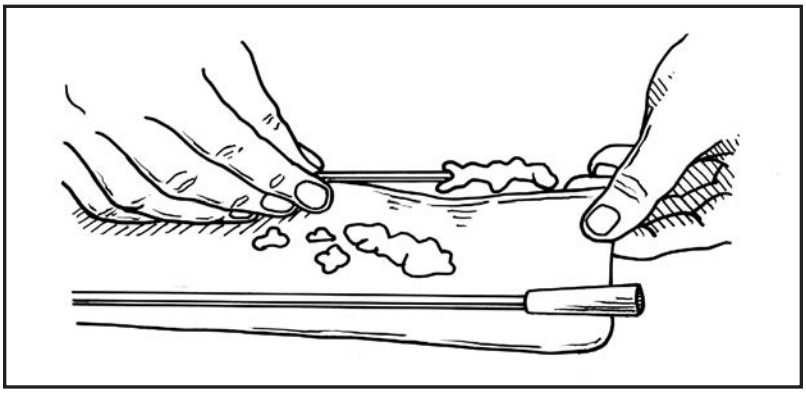


Figure 23 - Picking Up the Catheter

9. Insert the catheter slowly into the urethral opening until urine begins to flow. (See Figure 24)

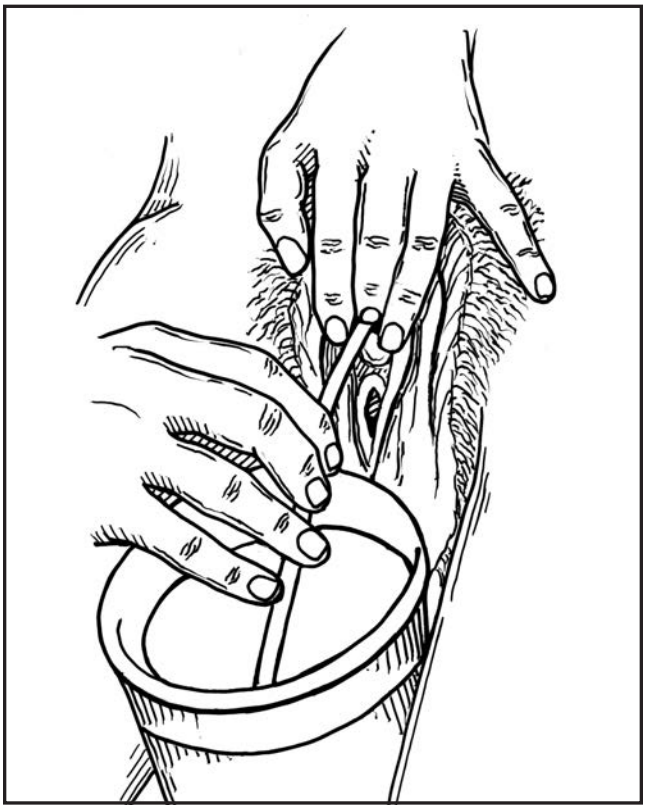


Figure 24 - Inserting the Catheter

10. Insert the catheter another inch and allow urine to drain. Hold the catheter in place. This will help the bladder empty better.

11. When urine flow stops, gently push down on the bladder area with your free hand. Pushing down on the bladder may be necessary to completely empty the bladder. Withdraw the catheter slowly. Removing the catheter slowly helps to empty the bladder completely and prevents urine from being left in the bladder. Urine left in the bladder can cause an infection. Remove the catheter when urine flow has stopped. (See Figure 25)

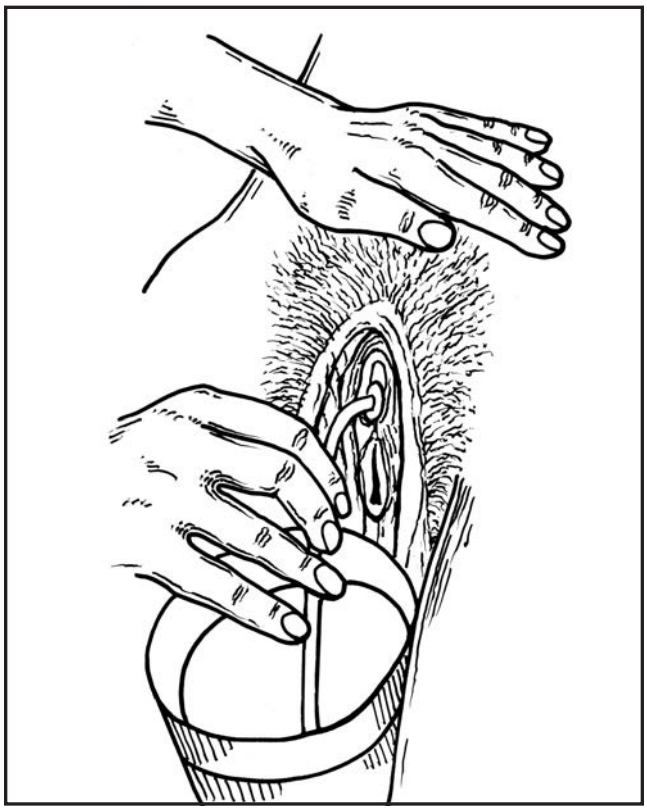


Figure 25 - Press Gently on the Bladder

12. While at Shepherd Center, a new catheter is used for each I.C. After discharge from Shepherd Center, one catheter can be used for 7 days.After each use, clean the catheter with antimicrobial soap and water. Rinse with clean water, air dry and store the clean catheter in an envelope or paper bag (not a plastic bag). (See Figure 26)

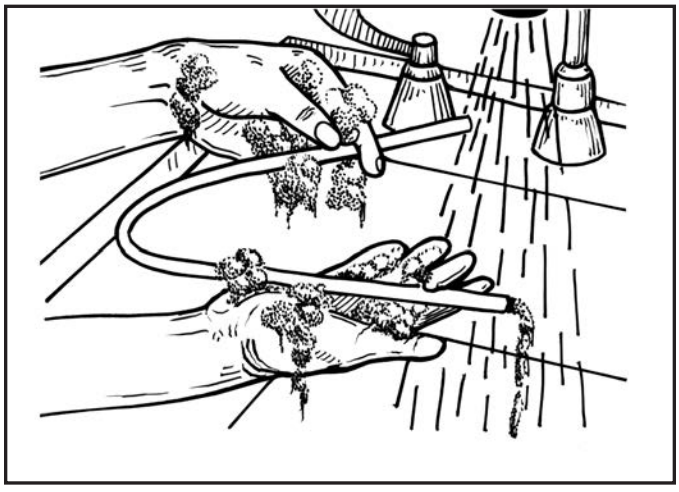


Figure 26 - Washing the Catheter

13. Wash around urethral opening with a soapy cloth and rinse with a wet cloth. (See Figure 27)

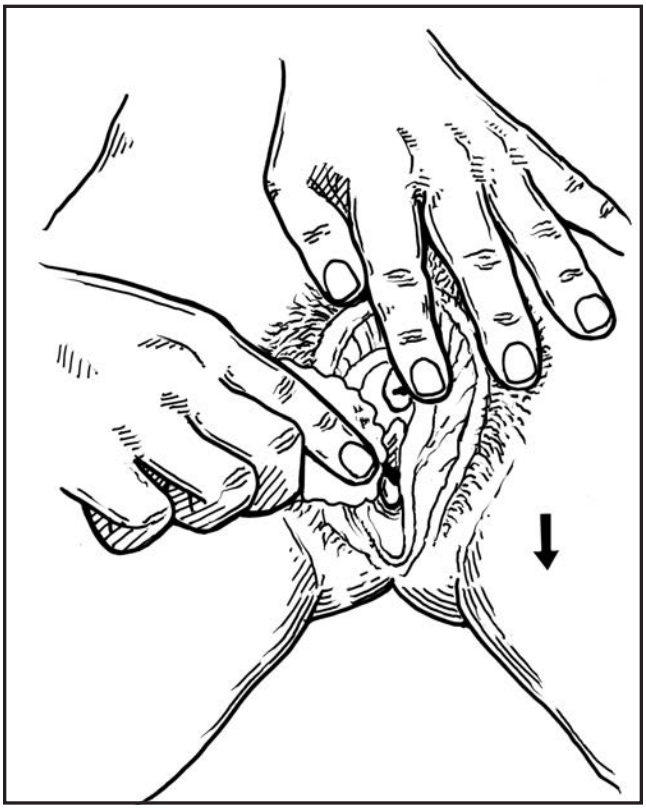


Figure 27 - Cleaning the Urethra

14. Empty the I.C. bag or container. Rinse it out 2 times and clean with bleach water. (See Figure 28)

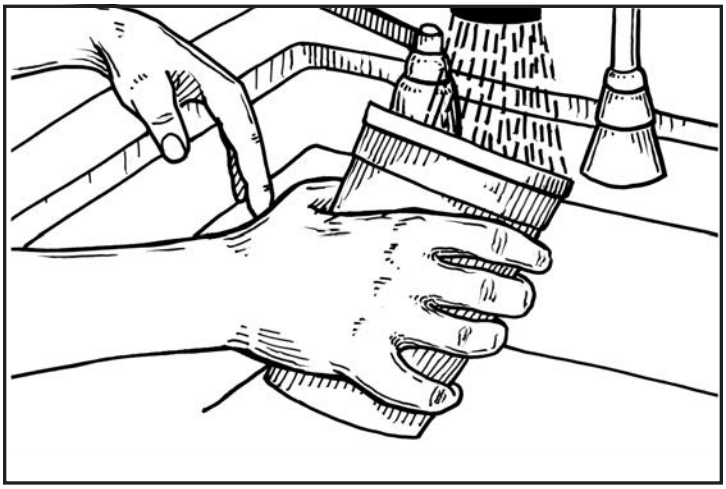


Figure 28 - Washing the Urine Container

15. Wash your hands. (Figure 29)

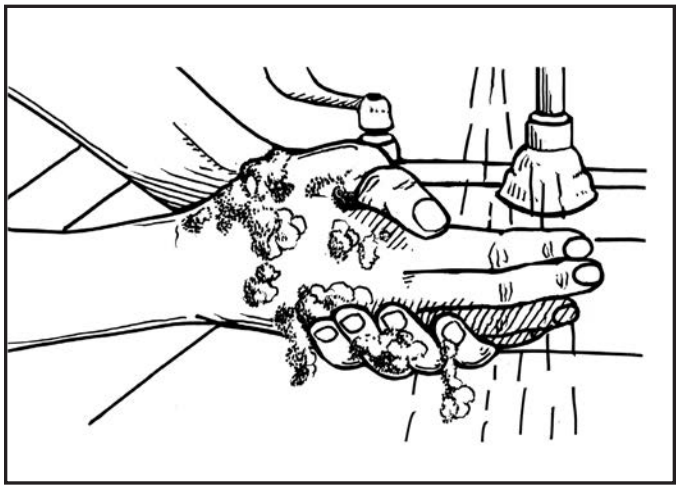


Figure 29 - Washing Your Hands

KEY POINT:

1. If you drop your catheter or insert it into the vagina by mistake, start over and use a clean catheter. You may want to leave the first catheter in the vagina to avoid inserting the new catheter there.

2. If a spasm occurs while doing an I.C., stop and wait for the spasm to pass before pushing the catheter any further.

3. Do not force the catheter into the bladder.

Indwelling Catheters

- Used for males and females
- The catheter is left in the bladder and drains the bladder continuously.

Types of Indwelling Catheters

1. Foley–The catheter goes into the bladder through the urethra A foley catheter is used early after a spinal cord injury. It can also be used for females who have a reflex bladder or who are unable to do I.C.s.

If a foley is worn for a long time, a leg strap may help to keep the catheter in place.

2. Suprapubic–The catheter goes in through an opening in the abdomen into the bladder. A suprapubic catheter is used when some problem makes it impossible to enter the bladder through the urethra.

How to Insert an Indwelling Catheter (Foley)–Male

Supplies needed:

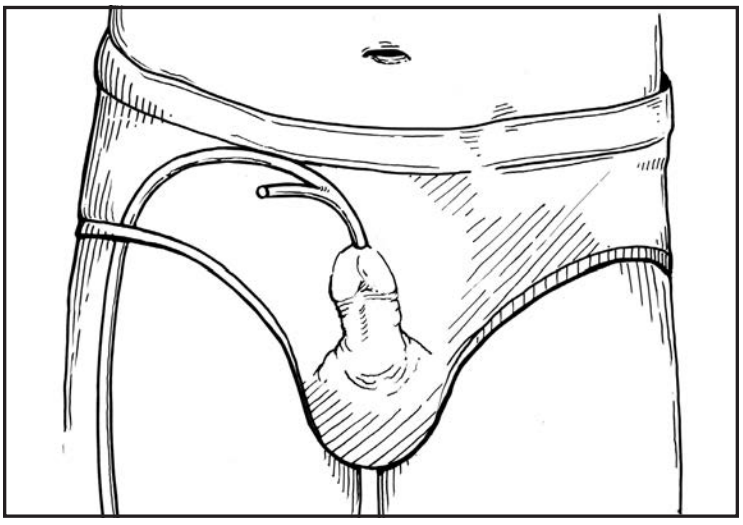
Indwelling catheter kit with a 10cc balloon. (The most common size adult catheter is a 16 Fr.) Syringe to deflate the old balloon. Soapy washcloth and wet cloth.

What to do:

1. Wash your hands with soap and water.
2. Gather all needed supplies.
3. Lie flat on back with legs flat.
4. If there is already a catheter in place, remove it by deflating the balloon. Attach the syringe to the end of the catheter not attached to the drainage bag. Remove water from the balloon using the syringe. Gently remove the old catheter.
5. Wash penis with soapy wash cloth and rinse with wet cloth.
6. Wash your hands again.
7. Open the indwelling catheter kit and set up supplies.
   - Place pad between legs and under hips.
   - Put on gloves
   - Wet cotton balls with betadine.
   - Remove the plastic cover from the catheter and squeeze 1 inch of K-Y jelly onto the catheter tip.
   - Remove the rubber cap from the syringe with water in it.
   - Make sure that is catheter is connected to the drainage bag in the kit.
8. Hold the penis with the other hand. This hand is now considered "dirty". Do not touch the catheter with this hand.
9. Clean the urinary opening with the cotton balls soaked with betadine. Use each cotton ball only once. Wipe from the tip of the penis downward to the shaft of the penis. Never reuse the cotton ball.
10. Insert the catheter slowly and gently into the urethral opening until you see urine flow into the catheter. Insert the catheter to the "Y" section of the catheter.
11. Blow up the balloon with the full 10ccs of sterile water from the syringe in the foley kit.
12. Do not blow up the balloon of the catheter until you see urine flowing from the catheter.
13. Flowing urine means the catheter is in the bladder.
14. Clean off any betadine left on the skin. Betadine can irritate the skin.
15. Wash hands.

Catheter Changing Schedule

The change schedule should be made to meet individual patient needs. Most foley catheters are changed monthly.



The optimal way to secure a foley for a man.

Daily Care

Daily care involves washing around the urethra and catheter twice a day using soap and water. The area should be dried thoroughly. Avoid using powders. The area will need to be washed after bowel movements.

KEY POINT:

1. If you drop your catheter or insert it into the vagina by mistake, start over and use a clean catheter. You may Change the catheter following the schedule given by your doctor.

2. Save the syringe from the tray. Clean it with soap and water. Use this syringe to deflate the balloon of the catheter the next time the catheter is changed.

3. If a spasm occurs while putting in the catheter, stop and wait for the spasm to pass before pushing the catheter any further.

4. If the catheter will not go in easily, call the doctor. **Do not force the catheter in.**

How to Insert An Indwelling Catheter (Foley) – Female

Supplies Needed:

Indwelling catheter kit with a 10cc ballon. (The most common size adult catheter is a 16 Fr.)
A syringe to deflate the old balloon.
Soapy wash cloth and wet cloth.

What to do:

1. Wash your hands with soap and water.
2. Gather supplies.
3. Lie flat on back with legs flat but apart.
4. If there is already a catheter in place, remove it by deflating the balloon. Attach the syringe to the end of the catheter not attached to the drainage bag. Remove water from the balloon using the syringe. Gently remove the old catheter.
5. Wash around the urinary opening with the soapy wash cloth and rinse with the wet cloth. Wash from above the urinary opening down toward the rectum. This prevents any germs from the rectum entering the bladder.
6. Wash your hands again.
7. Open the indwelling catheter kit and set up supplies. Place pad between legs and under hips. Put on gloves. Wet cotton balls with betadine. Remove plastic cover from the catheter; squeeze 1 inch of K-Y jelly onto the catheter tip. Remove rubber cap from syringe with water in it. Make sure catheter is connected to drainage bag in the kit.
8. Using the other hand, spread the labia apart so you can find the urinary opening. This hand is now considered "dirty". Do not touch the catheter with this hand.
9. Clean around the urinary opening with cotton balls soaked in abetadine. Squeeze cotton balls to get rid of excess betadine. Use each cotton ball only once. Wipe with cotton ball from front (above the opening) to back (below the opening). Never reuse the cotton ball.
10. Insert the catheter slowly and gently into the urethral opening. When urine flows into the catheter, insert the catheter 1 more inch. If you insert the catheter into the vagina by mistake, start over and use a new catheter kit.
11. Blow up the balloon with the full 10cc's of sterile water from the syringe in the foley kit.
    Do not blow up the balloon until you see urine flowing from the catheter tube. Flowing urine means the catheter is in the bladder.
12. Clean off any betadine left on the skin. Betadine can irritate the skin.
13. Wash hands.

Daily Care:

Daily care involves washing around the urethra and catheter twice a day using soap and water.The area should be dried thoroughly. Avoid using powders. The area will need to be washed after bowel movements.

Catheter Changing Schedule

The change schedule should be made to meet individual patient needs. Most foley catheters are changed monthly.

KEY POINT:

1. Change the catheter following the schedule given by your doctor.

2. Save the syringe from the kit. Clean it with soap and water. Use this syringe to deflate the balloon on the catheter the next time the catheter is changed.

3. If a spasm occurs while putting in the catheter, stop and wait for the spasm to pass before pushing the catheter any further.

4. If the catheter will not go in easily, call the doctor. **Do not force the catheter into the bladder.**

How to Insert an Indwelling Catheter: Suprapubic Male and Female

Supplies Needed:

A catheter recommended by your doctor. Size of catheter will vary based on your needs.
A syringe to deflate the old balloon.
Soapy wash cloth and wet cloth.

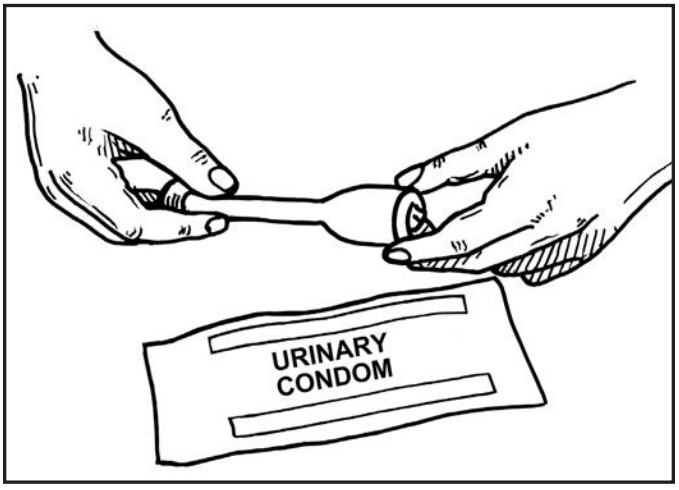


Figure 30 - Urinary Condom

What to do:

1. Wash your hands with soap and water.
2. Gather supplies.
3. Lie flat on back with legs flat. This position lines up the opening in the abdomen with the opening in the bladder.
4. Gently remove the old catheter by deflating the balloon using the syringe.
5. Wash around the abdominal opening with the soapy wash cloth and rinse with the wet cloth.
6. Wash your hands again.
7. Open kit, set up supplies. Place pad around abdominal opening. Put on gloves. Wet cotton balls with betadine. Remove plastic cover from the catheter and squeeze one inch of K-Y jelly on the catheter tip. Connect catheter tubing to leg bag Remove the rubber cap from the syringe that has water in it.
8. Clean around the opening site with cotton balls soaked in betadine. Wipe from the skin closest to the abdominal opening outwards. Use each cotton ball only once.
9. Wash your hands.
10. Insert catheter gently into the opening, push straight. Go in about 4 inches. You should be able to feel the catheter touch the bottom of the bladder.
11. While holding the catheter in place, blow up the balloon with the full 10cc's of sterile water.
12. Gently pull back on the catheter until it stops.
13. Clean off any betadine left on the skin. Betadine can irritate the skin.
14. Wash your hands.

Daily Care

Daily care involves washing around the opening and catheter twice a day using soap and water. The area should be dried thoroughly. Avoid using powders.

KEY POINT:

1. Change the suprapubic catheter once a month or more often if needed.

2. If the catheter tube is not draining well, flush the catheter with normal saline or sterile water. If it still does not drain well, change the catheter. Call the doctor if the problem continues.

3. At first there may not be any urine in the catheter because the bladder has not had time to collect any more urine since you removed the old catheter.

4. Cover the opening with a piece of gauze.

5. Save the syringe from the foley kit. Clean it with soap and water. Use this syringe to deflate the balloon of the catheter the next time it is changed.

Condom Catheter

How to Apply a Condom.

Supplies Needed:

Condom
Condom strap
Soapy wash cloth and wet cloth

What to do:

1. Gather supplies.
2. Wash hands with soap and water. (See Figure 31)

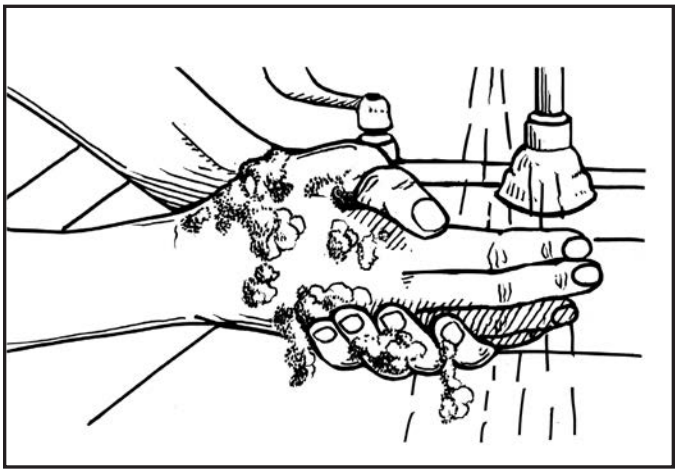


Figure 31 - Washing Your Hands

3. Take off old condom. Roll it gently down the penis. Do not pull the condom off because it may hurt the skin.
4. Wash penis with the soapy wash cloth and rinse with the wet cloth. Pull the foreskin back and clean the head of the penis well. (See Figure 32)

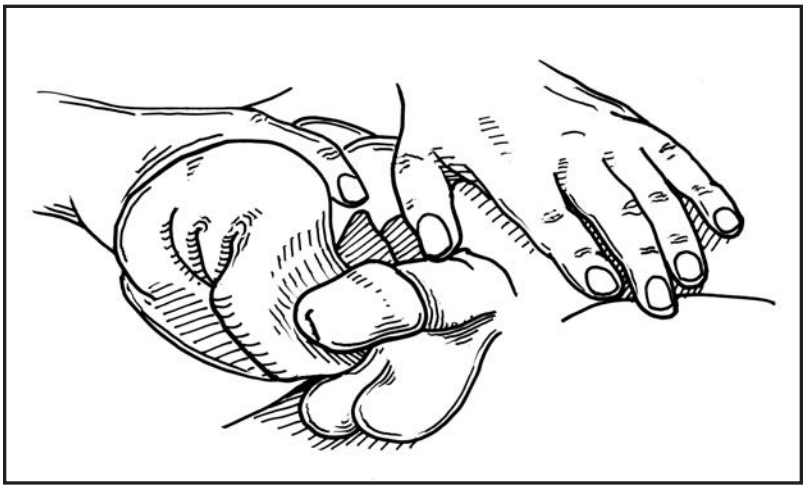


Figure 32 - Washing the Penis

5. Dry penis well. Remember to pull the foreskin back down over the head of the penis to prevent swelling of the foreskin.
6. Apply skin prep, if needed, and allow to dry.

7. Roll the condom up close to the funnel shaped end of the condom. (See Figure 33)

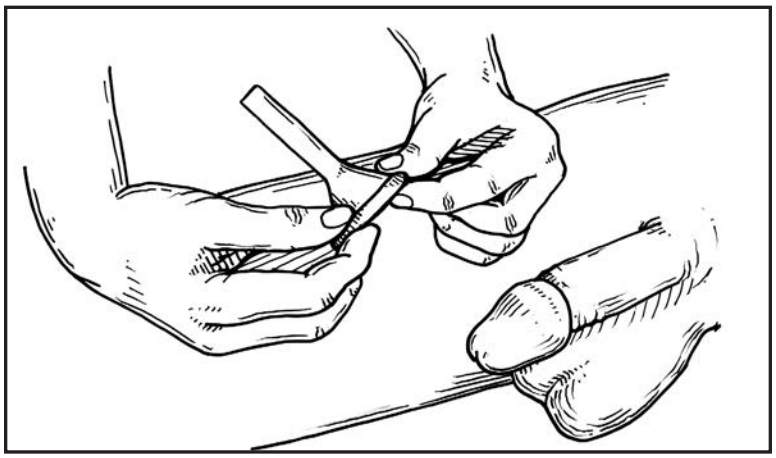


Figure 33 - Rolling Up the Condom

8. Place funnel end of condom on penis. Be sure the head of the penis is close to the funnel tip. (See Figure 34)

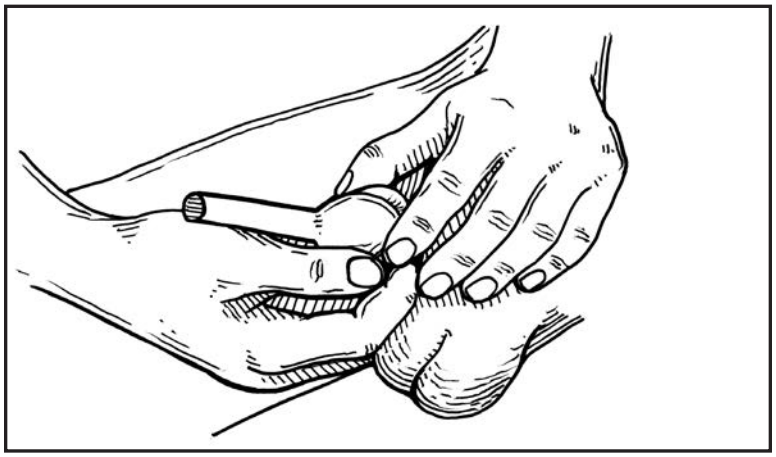


Figure 34 - Applying the Condom

9. Roll the condom over the penis to the base of the penis. (See Figure 35)

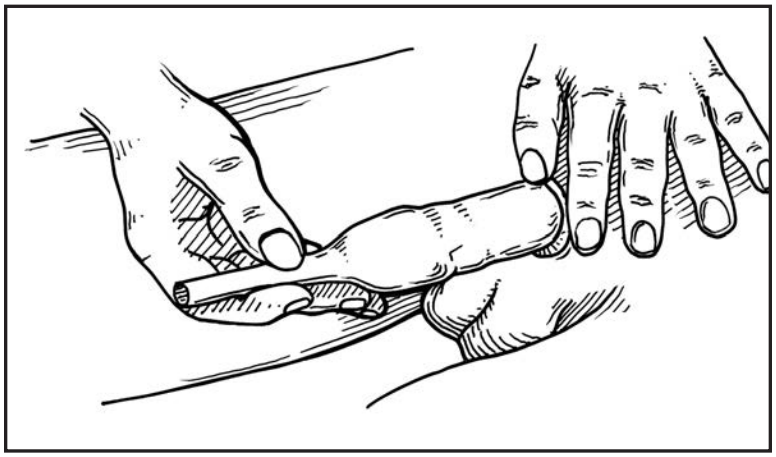


Figure 35 - Rolling the Condom

10. Wrap the condom strap about one inch above the base of the penis. (See Figures 36, 37 and 38)

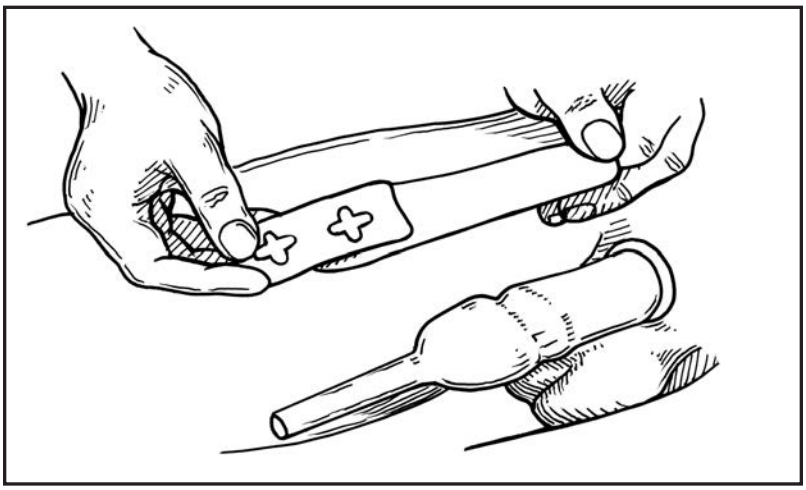


Figure 36 - Condom Holder

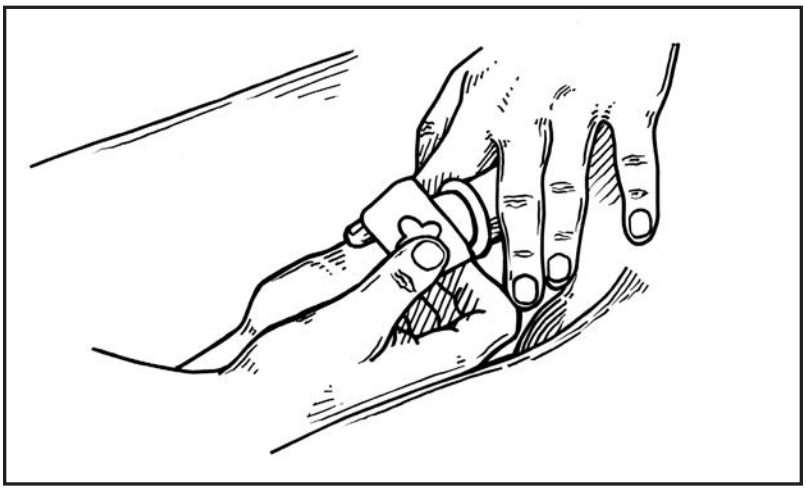


Figure 37 - Applying Condom Strap

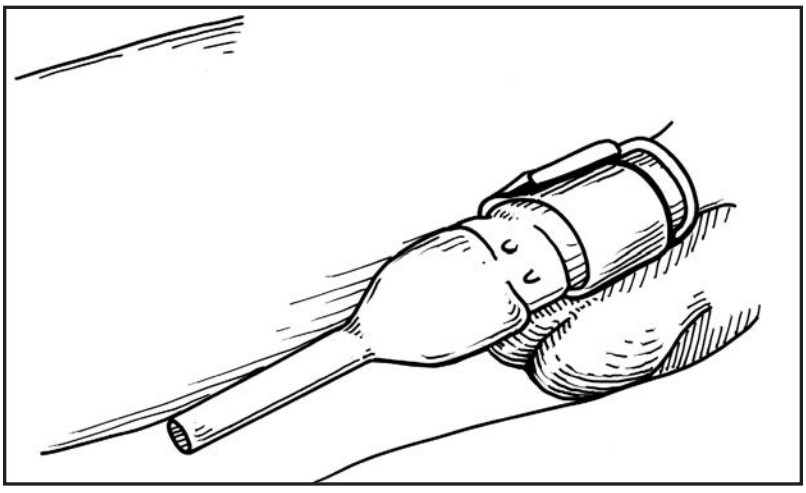
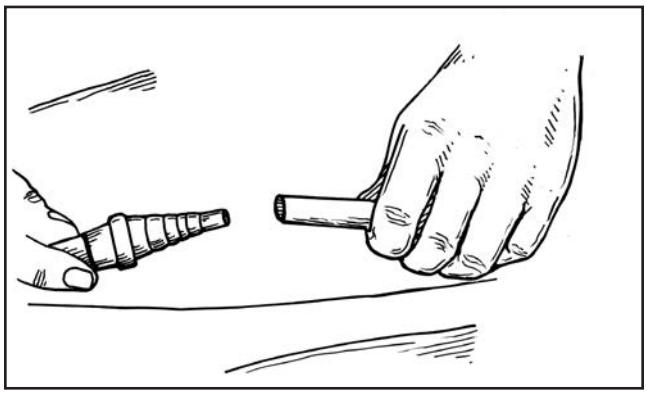


Figure 38 - Condom & Condom Holder

11. Connect the condom to a leg bag or bedside bag. (See Figures 39 and 40)



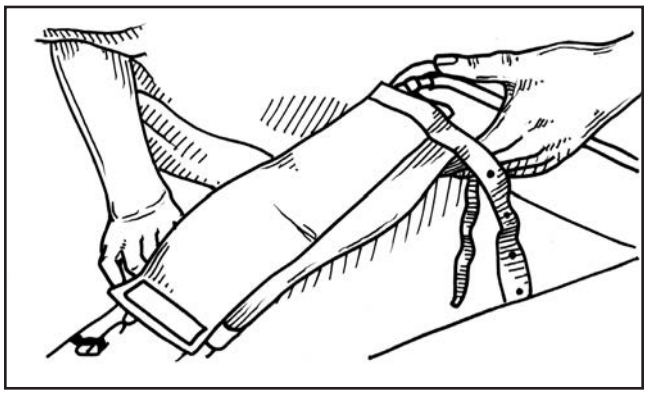


Figure 39 - Connect Leg Bag; Figure 40 - Apply Leg Bag

12. Position penis downward.
13. Wash hands.

Helpful Hints

1. Handwash the condom strap with soap and water, air dry and use again.
2. To reuse a condom, wash by hand with antibacterial soap and water. Make sure that the condom is not torn before using it again.
3. Always be sure to check the condom strap to make sure it is not too tight or loose.
4. Change the condom at least once a day to check the penis for skin problems and for cleaning.
5. After each I.C. use a clean, dry condom.
6. If you become sensitive to the condom, try a skin prep or change to a different brand condom.

Leg Bags

Always apply the leg bag with the arrow pointing up to the top. This keeps urine from backing up from the leg bag. The leg bag is best worn below the knee. This helps the urine to drain better.

Measure the distance from the condom to the leg bag (below knee) and cut tubing to the correct length needed.

Possible Skin Problems

- Look for discolored or swollen areas on the penis.
- Look for areas of broken skin every day.
- If skin problems are seen, do not place condom strap over the area.
- If a sore is found, take the condom off at bedtime and place the penis in a urinal. Hold the urinal in place with rolled up towels.
- If you develop a skin sore, you should call your doctor.
- Make sure the condom is the correct size.
- Call the doctor.

Care and Cleaning of Urinary Supplies (Bags)

Mixing Bleach and Water

Supplies Needed:

- One bottle of bleach
- Tap water
- Soap
- Paper or plastic cup

What to do:

1. Gather supplies
2. Wash hands with soap and water.
3. Get a paper or plastic cup.
4. Put 1/2 cup of cool tap water into the cup.
5. Add 1 tablespoon of regular liquid bleach.
6. Swish the cup to mix the bleach into the water.
7. Do not spill the bleach on anything metal or cloth, or on the skin.
8. Do not mix the bleach and water with anything else.
9. Pour bleach water into a squeeze container.

Care and Cleaning of Bedside Bag, Leg Bag, I.C. Bag, Cup or Urinal

1. Empty all urine from the bag, cup or urinal.
2. Rinse the bag, cup or urinal with water and swish it inside the bag for at least 10 seconds.
3. Empty the water into the toilet.
4. Rinse the bag, cup or urinal with water and swish it around again for at least 10 seconds.
5. Empty the water into the toilet.
6. Put 2 tablespoons of premixed bleach and water mixture onto the part of the bag that touches the catheter.
7. Put the rest of the bleach and water mixture into the bag, cup or urinal. Swish it inside all parts of the bag for at least 30 seconds.
8. Empty the bleach and water mixture into the toilet and flush the toilet.
9. Place bag, cup or urinal on a clean paper towel.
10. Leave any clamps open until the next time it is used.
11. The bag, cup or urinal can be used for 1 month.

Care and Cleaning of the IC Catheter

What to do:

1. Wash the catheter with antibacterial soap and water after every I.C. Do not use bleach.
2. Let the catheter dry on a clean paper towel.
3. Store catheter in a paper bag or envelope until it is time to use it again.
4. Change the paper bag or envelope every day.
5. A catheter can be washed and reused for 7 days.

Common Urinary Tests

Culture and Sensitivity (C&S)

A test which shows the number and type of germs growing in the urine. It will also show which antibiotic will kill the germs.

Urodynamics

This is a test that shows how much urine the bladder holds and how much urine will cause the bladder to reflex. It shows if the sphincter is working with the bladder as it should.

KEY POINT:

1. Clean I.C. bags after each I.C. Clean leg bags at least once a day.

2. It is important to clean your supplies after every use because it helps prevent germs from growing which can cause infections.

3. Urine sitting for hours in dirty supplies can cause germs to grow and makes it harder for the bleach to kill germs.

4. Change your leg bag once a month. It may last a lot longer if you take good care of it. Change it more often if needed.

5. Foley bags and I.C. bags should be changed once a month and more often if needed.

6. Keep a sterile I.C. kit at home in case you need to collect a sterile urine sample for a urine test.

Common Bladder Problems

- Urinary tract infections (U.T.I.'s)
- Over-full bladder
- Bladder stones
- Kidney stones
- Autonomic Dysreflexia
- Leakage around catheter
- Leaking in between I.C.'s

Urinary Tract Infections (U.T.I.)

Because your bladder no longer works the way it did before your spinal cord injury, urinary tract infections are common.

Germs will be in your urine most of the time.

Causes:

- Dirty hands, body and supplies
- Not doing I.C.s on time
- Not doing I.C.s properly
- Not emptying bladder completely

How to tell if you have an infection:

- Fever above 101°F
- Blood in your urine
- Leaking of urine between I.C.'s if you usually don't leak
- Burning pain when urinating and feeling like you have to urinate all the time
- Autonomic Dysreflexia of unknown cause

Prevention:

- Keep catheter, supplies and leg bag clean.
- Do I.C.s on time and correctly.
- Wash hands before emptying the bladder.
- Drink 6 to 8 glasses of water or cranberry juice a day.
- Eat a healthy diet.

What to do:

- Call the doctor to arrange for getting your urine tested and to report your temperature. Have available your local laboratory and pharmacy number. When getting a urine sample tested, it must be fresh. It must be kept on ice if you bring it from home. The sample must be collected with sterile equipment.
- Drink 6 to 8 glasses of water or cranberry juice a day.
- Stop drinking colas or other types of carbonated drinks.
- Stay on your regular bladder program.
- Take all the medicine ordered by the doctor to make sure the infection is gone.

KEY POINT:

1. Cloudy or smelly urine is not a symptom of a bladder infection.
2. Cloudy or smelly urine means you should drink more water, but you may need to do an extra I.C.

Over-full Bladder

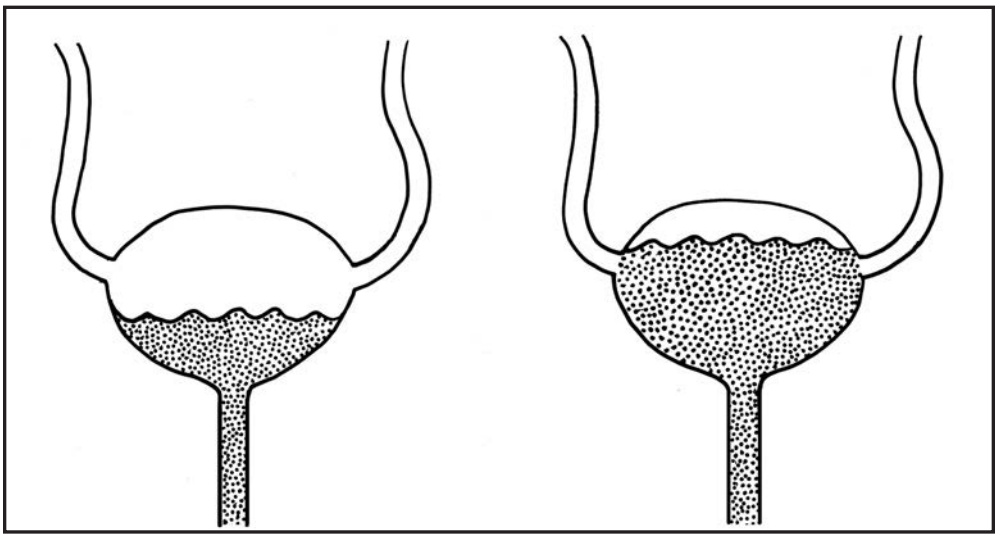


Figure 41 - Good Amount in Bladder; Over Full Bladder

The bladder is a muscular organ like a balloon. When the bladder gets over-full, it will become over stretched. A continuously stretched bladder will lose its ability to contract well. The bladder will become thickened and flabby. This also means that blood flow to the muscle wall is decreased, which makes the bladder more likely to become infected. Urine that stays in the bladder too long causes germs to grow, and this leads to infections. Infections can travel up to the kidneys, and can also cause stones to form in the bladder and kidneys. Stones can block the flow of urine out of the bladder and can interfere with the filtering system in the kidneys.

Causes:

- Not doing I.C.s on time
- Not emptying bladder completely when doing I.C.

How to tell if your bladder is over-full:

- Increased amount of urine when you do your I.C. (over 500cc)

What to do:

- Do I.C.s on time or more often when drinking more fluids.
- Be sure to totally empty the bladder when doing an I.C.
- Limit fluid intake after last I.C. of the day or before bedtime.

Prevention:

- Empty the bladder on a regular schedule and empty completely.
- Call your doctor or Shepherd Outpatient Department if you reflex more often with small amounts of urine.

Bladder or Kidney Stones

Bladder or kidney stones can cause serious problems. Stones that form in the bladder can block the flow of urine. Stones in the kidneys can interfere with the filtering of the blood and with drainage of urine to the bladder. (Fig. 42)

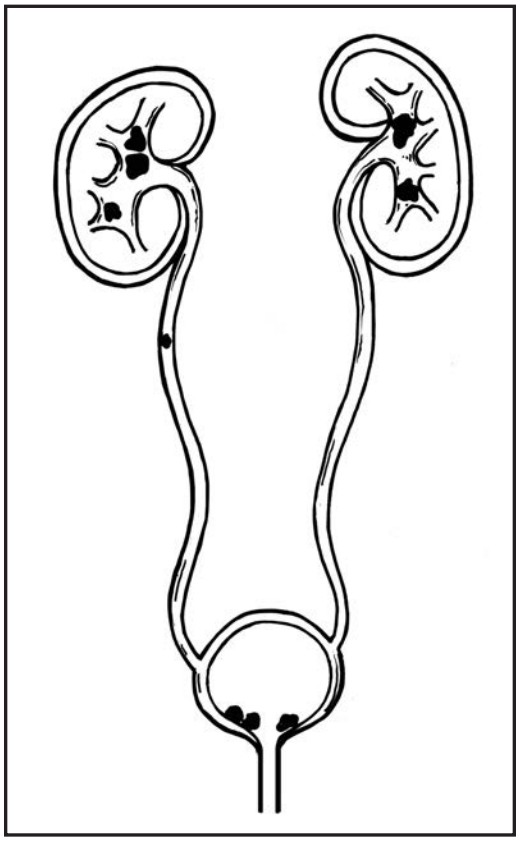


Figure 42 - Bladder and Kidney Stones

Causes:
- Not doing I.C.s on time
- Not doing I.C.s correctly
- Urine sitting in the bladder too long
- Many urinary tract infections
- Not enough exercise
- Backup of urine into the kidneys
- Not drinking enough water.

How to tell if you have bladder or kidney stones:
- Blood in the urine
- Increase spasms
- Increased sweating
- Seeing stones passed in urine
- Many urinary tract infections
- Pain in the lower back or abdomen may be present if spinal cord injury is incompete

What to do:
- Call the doctor if you think you might have a bladder or kidney stone.

Bladder or Kidney Stone Prevention:
- Do I.C.s correctly and on time.
- Drink 6 to 8 glasses of water every day.
- Exercise as much as possible every day.
- Have an I.V.P. done every two years until the doctor decides otherwise.

Reflux

Reflux is the back flow of urine into the ureters and the kidneys.

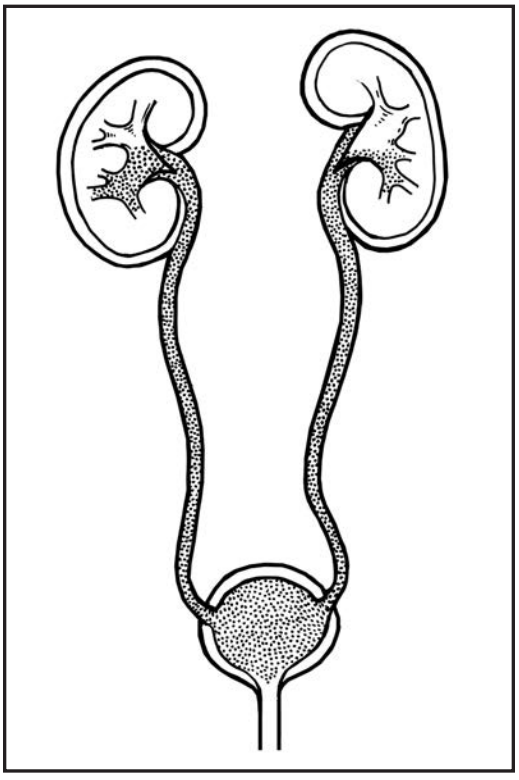


Figure 43 - Urine Backing Up into the Kidneys

Causes:
- An over-full bladder (from not emptying completely and on time.)

How to tell if you may have reflux:
- Many urinary tract infections with fever

What to do:
- Call the doctor right away.

Prevention:
- Do I.C.s on time and correctly.
- Have annual checkups.

Remember, prevention is the key.

Autonomic Dysreflexia

(See Special Concerns section)

Common Bladder Medications

Medicine	How does it work?	Important Information
Hytrin (Terazosin)	Relaxes the smooth muscle of the bladder	May cause drowsiness or dizziness. May cause a painful of prolonged erection. Ask your doctor before taking any other medications.
Tofranil (Imipramine)	Antireflex medication	May cause dry mouth, drowsiness and dizziness. Skin may be more sensitive to sunlight.
Ditropan & Ditropan XL (Oxybutynin)	Prevents bladder spasms and helps control urine leaking	May cause dry mouth, drowsiness or constipation.
Detrol & Detrol LA (Tolterodine)	Prevents bladder spasms and helps control urine leaking	May cause dry mouth, drowsiness or constipation.

Summary

The kidneys, ureters, bladder, sphincter muscles and urethra make up the urinary system. The kidneys filter waste from the blood. As a result, urine is formed. The urine is then removed from the body through the bladder and urethra.

When the spinal cord is injured, the way the bladder empties is changed. The body still needs to get rid of its waste. In order to stay healthy, you will need to know how to prevent problems and damage to this system. The level of injury will cause the bladder to function as either reflex (above T12) or non-reflex (below L1). Injuries between T10 and L2 may be either reflex or non-reflex.

For males with a reflex bladder, condom drainage with a leg bag will be the method used to empty the bladder. This may also include I.C.s if the reflex does not empty the bladder well enough. For females with a reflex bladder, medication may be needed to control the bladder in order to do I.C.s or an indwelling catheter may be used. For males and females with a non-reflex bladder, I.C.s will be the method used to empty the bladder.

Urinary problems are treated very conservatively. It is important to realize that bacteria in the urine is common for people with a spinal cord injury. You will be encouraged to drink fluids to reduce sediment and dilute your urine. You will not be placed on antibiotics unless you have blood in your urine, have a fever greater than 101°F, or if you begin to leak urine and you normally do not reflex. Antibiotics are only used when you have these three symptoms.

Suprapubic catheters are used when a catheter cannot be passed through the urethra. In this case, the catheter enters the bladder through an opening in the abodomen.

Infections or other problems may occur with the urinary system. The key to a healthy urinary system is prevention. To keep your urinary tract as free of problems as possible, you should:

1. Carefully clean all equipment, such as catheters, with each use.
2. Wash hands before and after the bladder is emptied.
3. Do the bladder program as taught at Shepherd Center.
4. See your doctor once a year for a check-up of your urinary system.

What You Have Learned About the Urinary System

1. How do you empty your bladder?
2. Do you have a reflex or a non-reflex bladder?
3. When are you due for an I.V.P.?
4. When will you go to the doctor for a culture and sensitivity?
5. How often will you clean your catheter? Your leg bag?
6. What did your urine look like when you had a U.T.I.? How did you feel?

The Skin

4 **CHAPTER CONTENTS**

What You Will Learn In This Section

After reading this section you will be able to:

1. Name the parts of the skin.
2. Describe how the skin works before and after a spinal cord injury.
3. Describe a skin sore.
4. Name the bony prominences.
5. List the causes, signs, treatment and prevention of skin sores.

New Words

Absorb
To soak up liquid

Barrier
A block which prevents passing.

Bridging
To place pads above and below a bony area or wound to protect the skin from pressure.

Buttocks
The backside.

Callus
Thick, hard place on the skin.

Clavicle
Collarbone.

Complication
A problem resulting from an illness.

Dermis
Inner layer of skin. Hair roots, sweat glands, nerves and blood vessels are found in this layer.

Epidermis
Outer layer of skin.

Exposed
Without protection.

Friction
The rubbing of skin against another surface.

Genitalia
Sex organ.

Hydrocolloid Dressing
A solid wafer that can be placed over a sore for protection, cushioning and drainage control.

Hygiene
Keeping clean.

Iliac Crest
Hipbone.

Internal
Inside.

Ischium
Sitting bones or bony areas of the buttocks.

Nutrient
The vitamins and minerals your body needs in certain amounts to stay healthy.

Nutritious
Well-balanced, healthy.

Paraplegia
Paralysis affecting two limbs, usually lower.

Power Recliner
A wheelchair that will lie back for weight shifts.

Prominence
Bony prominences are places on the body where the bones stick out, such as the knees, hips, heels, and elbows.

Prone
Lying down on your stomach.

Sacrum
Tailbone.

Scapula
Shoulder blades.

Sensation
Feeling.

Shearing
Shearing happens when something pulls and stretches the skin. This will block the blood flow.

Slouching
Drooping posture.

Tetraplegia (or Quadriplegia)
Paralysis affecting the arms and legs.

Tilt-in-Space Wheelchair
A wheelchair that tilts backward for weight shifts.

Tolerance
Amount of time you can stay in the same position without a change in skin color or damage to the skin.

Trochanter
Side-lying bone where the hip joins the leg.

The Parts Of The Skin

The skin is the largest organ of the body. The skin has two layers: the epidermis and the dermis.

The Epidermis

- The epidermis is the top protective layer of the skin.
- This layer protects the body from infections and germs.
- The epidermis is thicker on the palms of the hands and the soles of the feet.

The Dermis

- The dermis is the inner layer of the skin.
- The dermis contains blood vessels, nerves, hair roots, sweat glands and fat cells.
- These parts keep the skin alive and healthy.

Below the dermis is a layer of fatty tissue which cushions the body. Under the fatty tissue is muscle and bone.

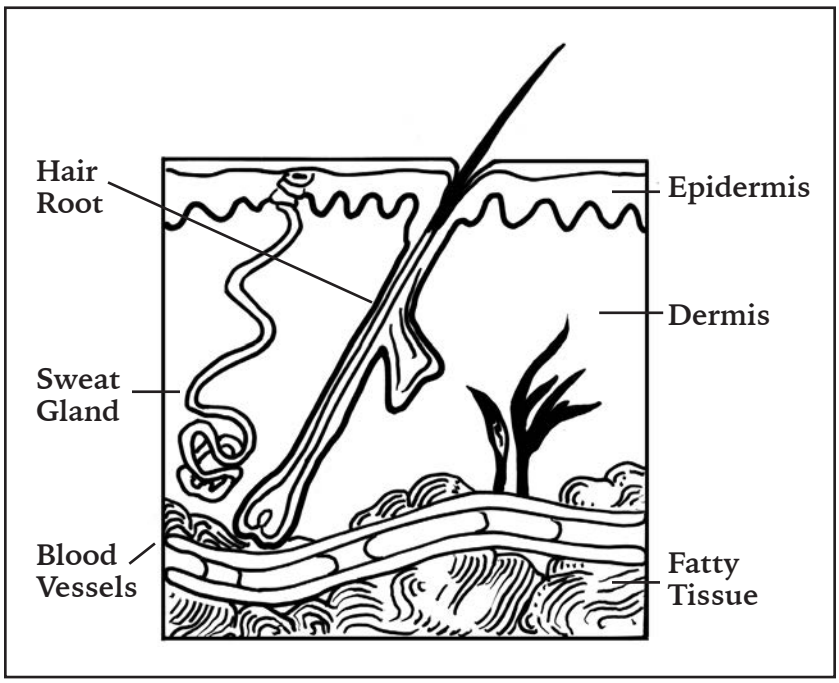


Figure 1 - Anatomy of the Skin

How The Skin Works Before A Spinal Cord Injury

Protection

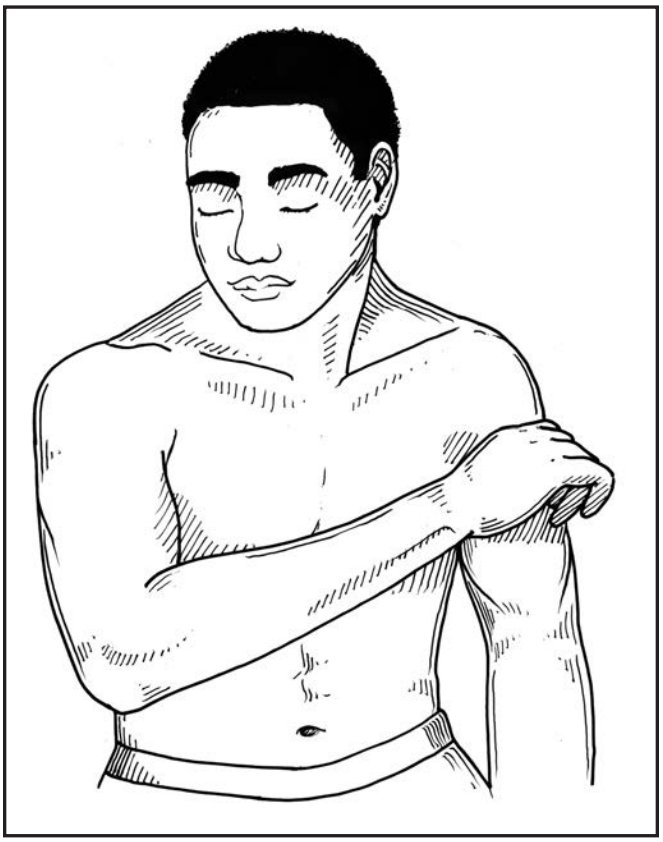


Figure 2 - Germs Cannot Get into Unbroken Skin

- The skin protects internal organs, bones and muscles, from injury. The skin also provides a barrier against things like germs, infection and harmful rays of the sun.

Temperature Control

- The skin helps control body temperature. When you are cold, the skin shivers (gets goose bumps) to keep you warm. When you are warm, the skin sweats to cool you off. (See Figures 3 and 4)

Figure 3 - Shivering and Goose Bumps

Waste Removal

- The skin produces sweat. Sweat moistens the skin and keeps it from getting too dry.

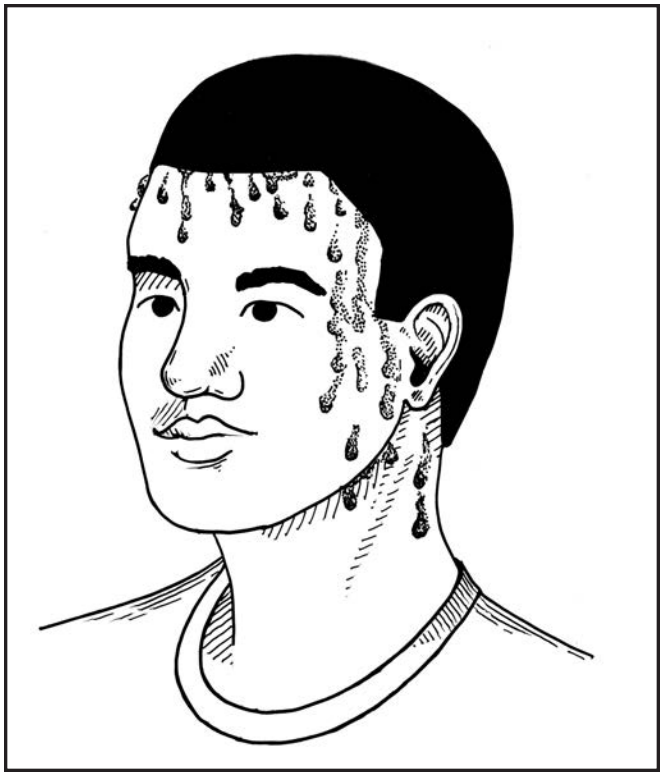


Figure 4 - Sweating

Sensation

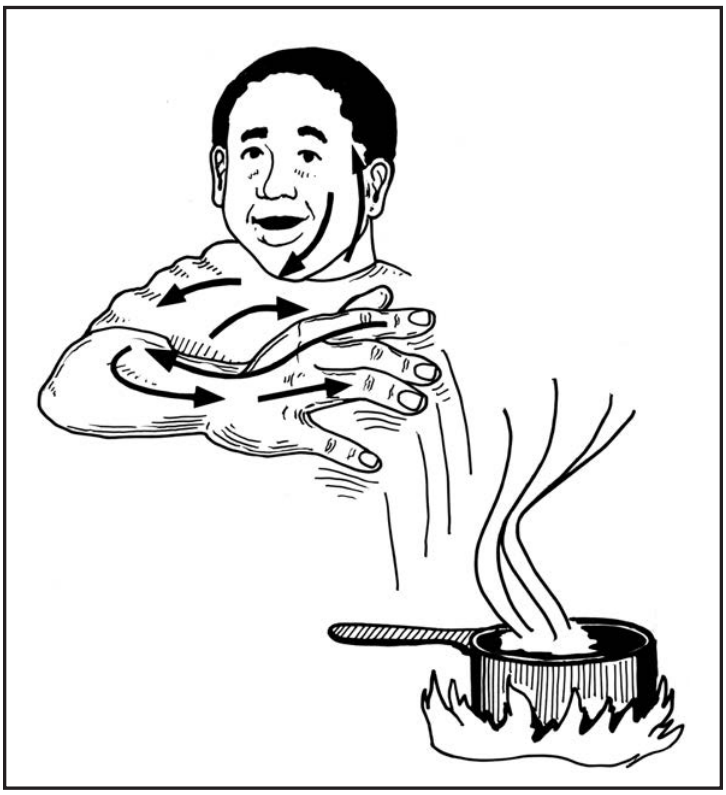


Figure 5 - Feeling

- The skin allows you to feel. The nerves in the skin send messages up the spinal cord to the brain so you can feel pain, touch, pressure and temperature.

How The Skin Works After A Spinal Cord Injury

After a spinal cord injury, the skin will still protect the body. It will also provide a barrier against infections. But there are changes in some of the other functions.

Loss of Feeling or Sensation

If there is no feeling below the injury level, no warning signals will tell you when you have hurt yourself. For example, you will not feel a bruise, cut or burn below the level of your injury.

Decreased Ability For Body Movement

Before a spinal cord injury, feelings of pressure, pain and discomfort caused you to move often and change your body position. After spinal cord injury, messages or signals are not able to get to the brain to tell you when to move. Sitting or lying too long cuts off the blood flow in the skin. Blood flow to the skin keeps it alive and healthy. If the skin does not get blood, it will die. Lack of movement and exercise below the injury level decreases blood flow to those areas. This is why it is important to be active after spinal cord injury.

Changes in Body Temperature Control

With a complete spinal cord injury, you will not sweat or shiver below the level of injury. Loss of sweating below the level of injury can cause the skin to become dry, flaky and sometimes crack. (See section on Special Concerns for more information on temperature control after spinal cord injury.)

What Is A Skin Sore?

The most common cause of a skin sore is pressure. Sitting or lying in one position too long will cause a skin sore. Certain areas of the body get more pressure than others. These areas are located over bony places such as the hip, heels and sacrum. The skin over these bony areas is squeezed between the bone and other surfaces such as a bed, a chair or clothing. When the skin cannot get the needed blood, the skin cells begin to die. This is the beginning of a pressure sore.

One of the first signs of a possible pressure sore is a change in the color of the skin. The area will become pink or red, warm and firm. Persons with dark skin will notice a darkened or shiny area. The area around the early skin sore also changes. It may also feel warm and firm. This is the first stage of a skin sore. The skin is unbroken on the outside. In the first stage, the skin heals quickly if the right steps are taken to relieve pressure.

If the pressure is not relieved, it will get worse. The skin will become red, purple or black.

Swelling will continue. A blister may be seen. At this point, the dermis (the bottom layer of the skin) is involved.

The skin often becomes open and infected. Treatment at this stage may involve weeks or even months of bed rest staying off the area. If the sore is deep into the muscle or bone, surgery may be needed to clean out the infection and close the sore.

Once you have had a pressure sore, the skin will never be as strong as before. This means it is even more likely to break down again.

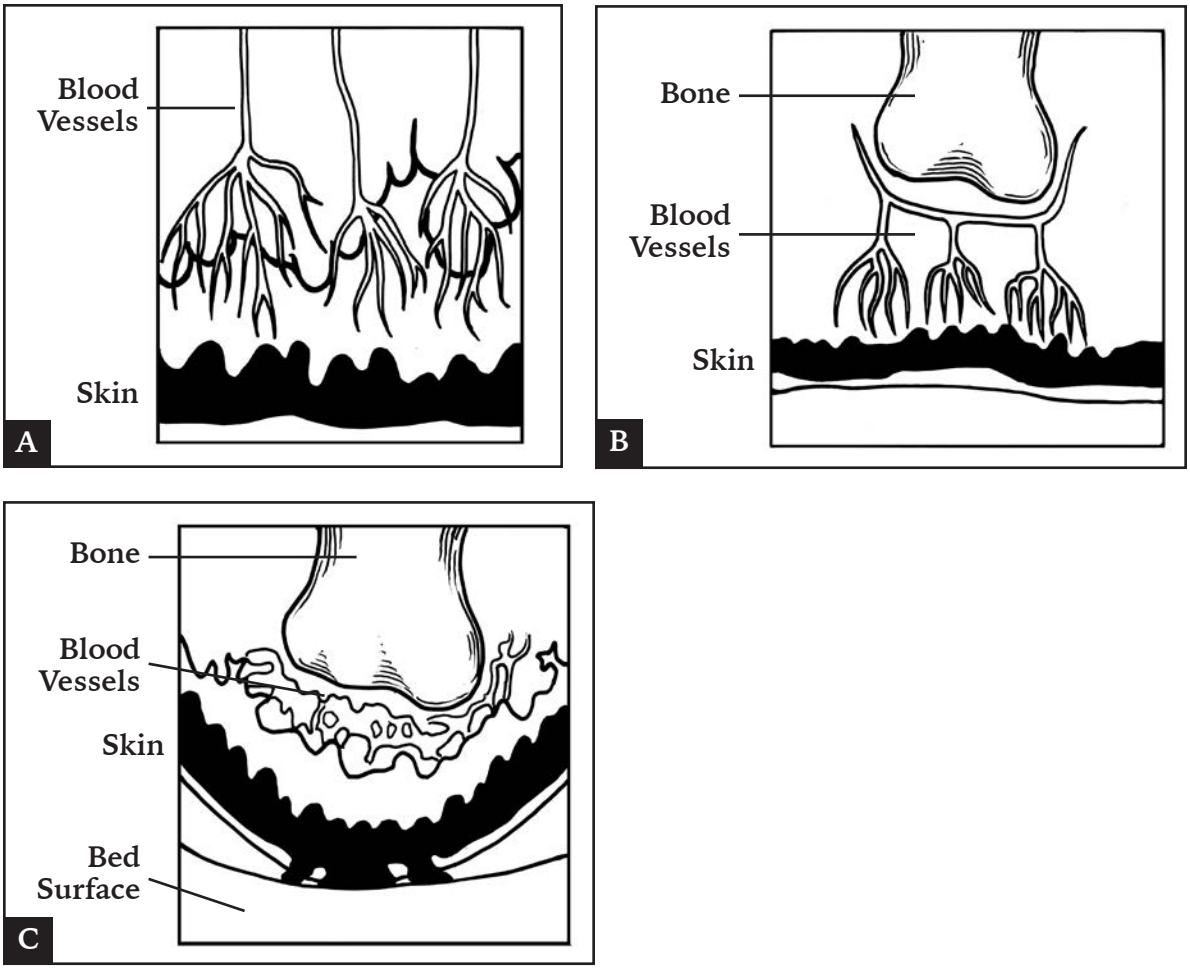


Figure 6 - Normal; Blood Vessels Not Under pressure; Blood Vessels Under pressure

Causes of Skin Problems

Pressure

Pressure is the biggest cause of skin breakdown and skin sores. Pressure over bony areas is most likely to cause break-down because blood flow is cut off to the skin. (See Figure 6)

Examples of pressure:

- Sitting in one position too long.
- Lying in one position too long.
- Tight clothing or shoes.
- Wrong sized wheelchair.

To prevent pressure sores, be sure to do weight shifts and turn in bed frequently.

Shearing

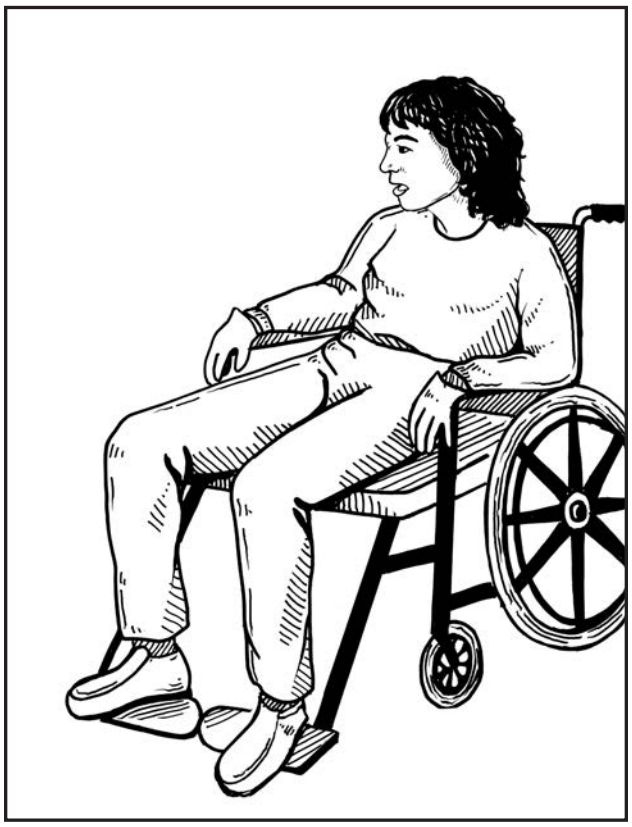


Figure 7 - Slumping in Wheelchair

Shearing happens when something pulls and stretches the skin. This will block the blood flow to the blood vessels in the skin and may lead to deep tissue damage.

Examples of shearing:

- Sitting in bed.
- Slumping in chair. (Figure 7)

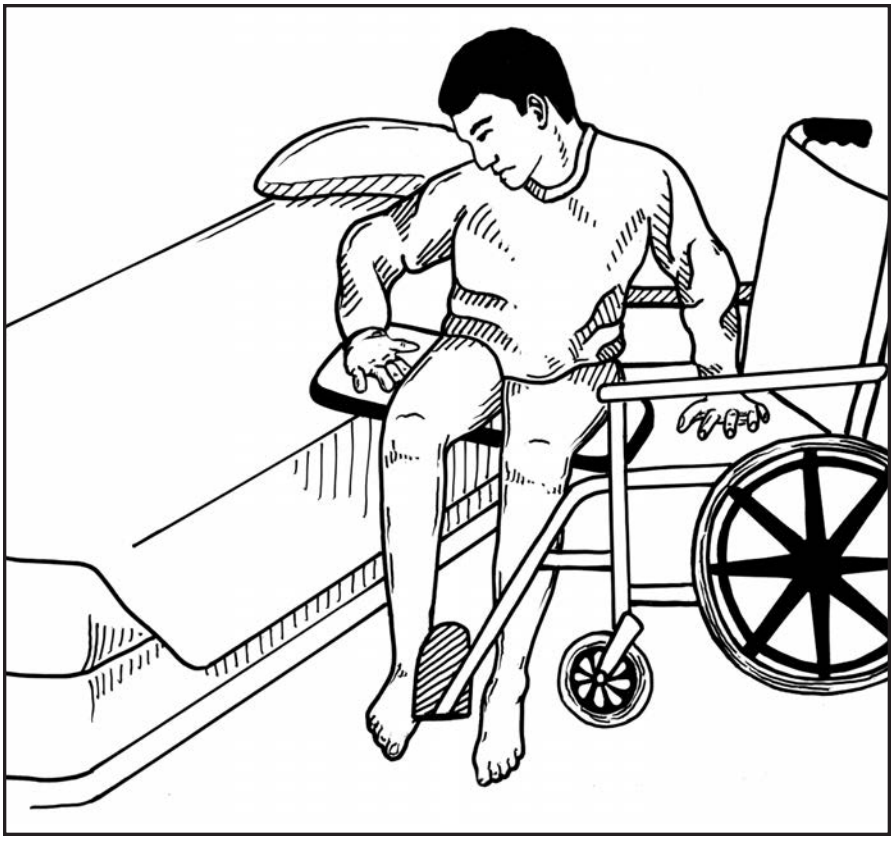


Figure 8 - Sliding Board Transfer

Friction

Friction is rubbing the skin hard across another surface. Friction can result in an open area.

Examples of friction:

- Spasms that cause legs or arms to rub against a surface.
- Rubbing buttocks on the wheels of chair during transfers.
- Sliding across sheets or transfer board with bare skin. (Figure 8)

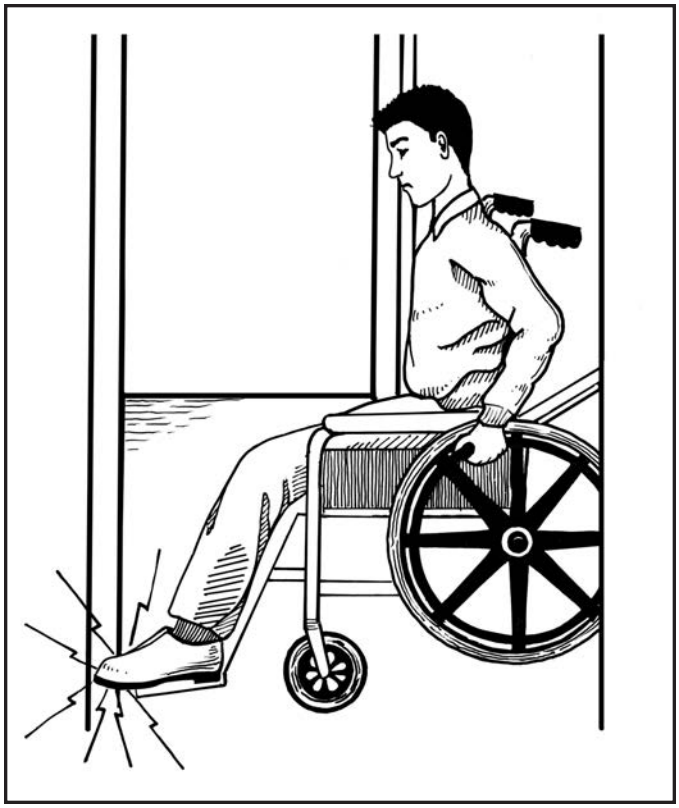


Figure 9 - Bumping Toes

Accidents

Accidents are bumps bruises, cuts or burns that injure the skin. Remember, nerves in the skin cannot get signals to the brain to let you know when you are hurting yourself.

Examples of accidents:

- Bumping feet in doorways when moving around in the chair.
- Coming in contact with things that are hot and may burn.
- Bumping any body part when transferring.

Moisture

Moisture softens the skin. Wet skin is more likely to break down. Light dusting of cornstarch-based powder may reduce moisture.

Examples of moisture:

- Urine
- Stool
- Sweat
- Water

Not Eating Healthy Foods

A nutritious diet is necessary for a healthy body and healthy skin. Vitamins and nutrients found in certain foods help keep the skin from breaking down.

(See Nutrition in the Digestive System section for more information.)

Dry Skin

Dry skin is caused by the loss of sweating below the injury level. Dry skin is flaky and may crack, causing an opening in the skin. This happens most often around the feet and hands. Lotion may be used sparingly.

Vinegar soaks can be used to remove dry calluses from feet and hands. Do not use if hands or feet have open areas.

Recipe

Mix 1 cup of white vinegar with 1 cup of warm water. Soak towels in solution and wrap around feet or hands. Remove towels in 30 minutes and wash feet or hands with soap and water. Do not peel skin.

Poor Hygiene

Figure 10 - Shower

Keeping clean helps the skin to stay healthy. It improves blood flow and gets rid of dead skin and body waste.

Examples of good hygiene:

- Cleaning with soap and water after a bowel program
- Cleaning with soap and water after a bladder program
- Showering or bathing

Worn Out Cushion

Pressure sores may occur when the wheelchair cushion is worn or damaged. Most wheelchair cushions last for 1 1/2 to 3 years. It is important to have a good quality wheelchair cushion. Follow directions for proper care of your cushion.

DO NOT use the following in place of your wheelchair cushion:

- Pillows.
- Eggcrate mattress.
- Doughnut shaped cushions.

Swelling

Swelling happens after spinal cord injury because of loss of movement in the arms and legs. This can cause the body fluids to collect in the tissues. If swelling is a problem, care should be taken to:

- Avoid pressure over swollen areas.
- Elevate the legs and hands several times during the day.
- Wear elastic stockings. (TED hose).
- Take care that shoes are not too tight.

If you notice that one limb (arm or leg) is bigger than the other, call the doctor. (See "Blood Clots" in the Special Concerns section.)

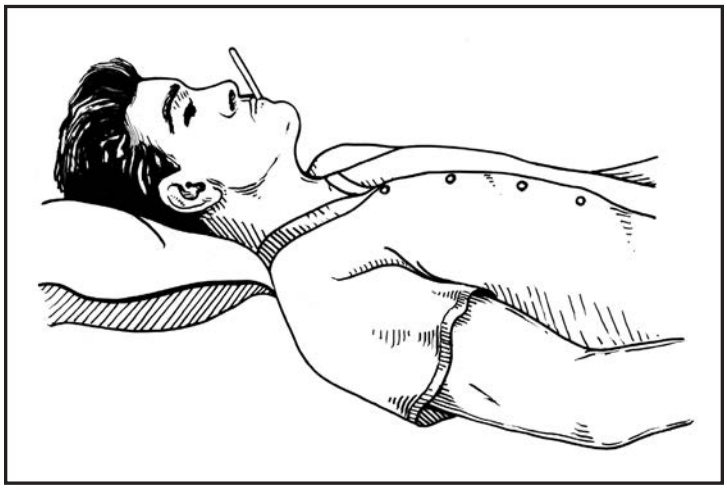


Figure 11 - Infections & Fever

Infections With Fever

If you are sick and have a fever, your skin will break down more easily. When you are sick, be sure to follow your skin care program. Sweating because of a fever can cause the skin to break down. Follow a turning schedule when in bed and do weight shifts while sitting.

Bony Prominences

Areas to watch carefully:

Back of head
Ears
Scapulae (shoulder blades)
Elbows
Wrists
Sacrum (tail bone)
Trochanters (side-lying bone)
Iliac crest (hips)
Ischia (sitting bones)
Knees
Shins
Heels
Ankles
Toes

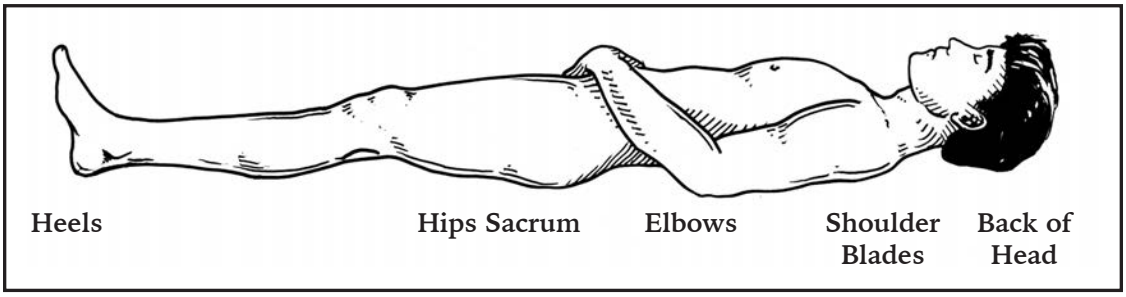


Figure 12 - Pressure Areas Likely to Break Down While on Your Back.

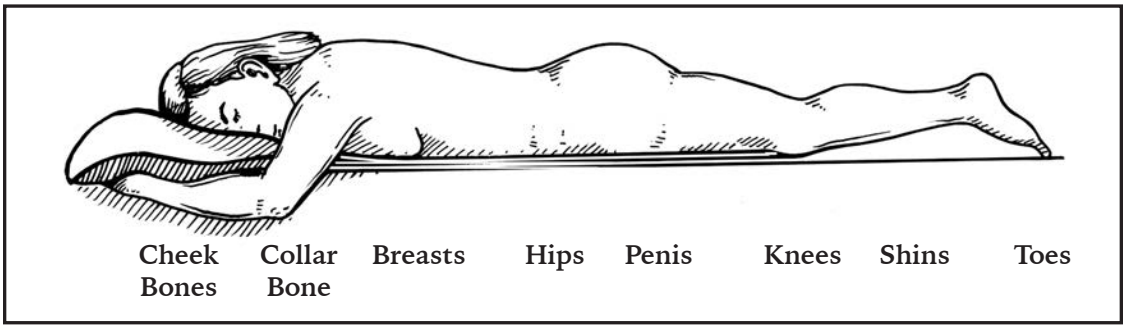


Figure 13 - Pressure Areas Likely to Break Down While Lying on Your Stomach (Prone).

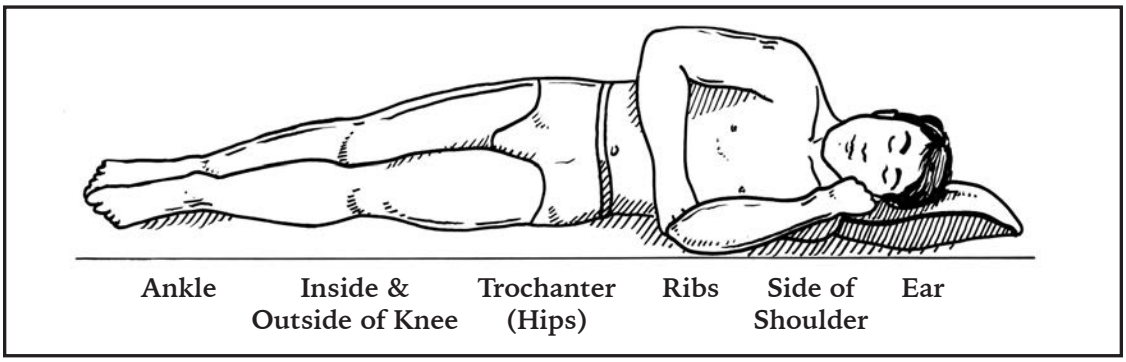


Figure 14 - Pressure Areas Likely to Break Down While Lying on Your Side.

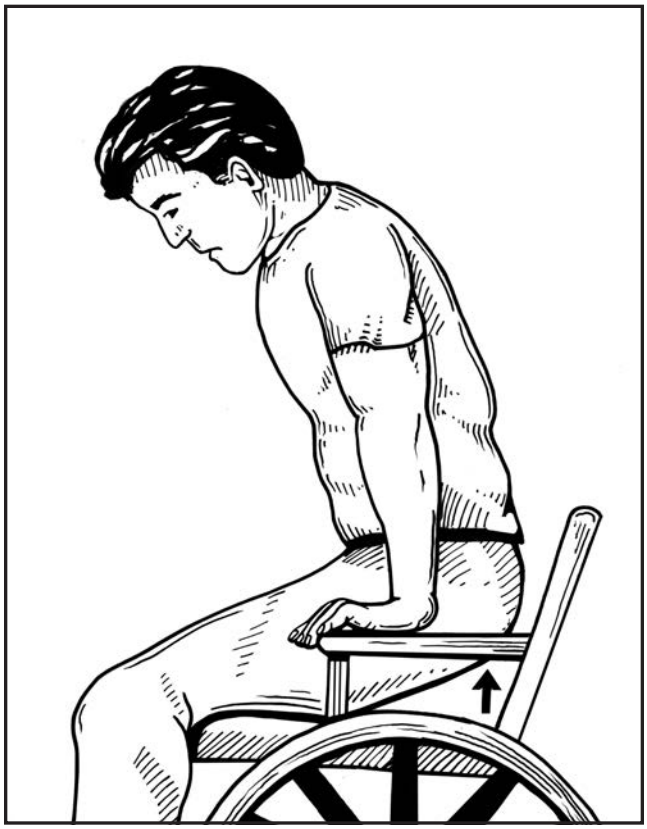


Figure 15 - Pressure Area Ischia Likely to Break Down While Sitting Up

Signs of Skin Problems

If you notice any of these signs, you may have a skin sore or the beginning of a skin sore:

- Red, dark or shiny areas
- Any change in color of skin
- Bruises
- Blisters
- Any opening in the skin
- Swelling
- Raised areas
- Hardened areas
- Warm areas felt near a red, dark, raised or hardened area
- Rashes

Early Treatment of Skin Problems

What to do for a red or dark area, warm, raised or hardened area, bruises, or any color change:

- Keep off the area by padding or by staying in bed if needed.
- Decrease time between turns.
- Inspect your skin more often than twice a day.
- If the area opens, call your doctor.
- Find out what caused the problem and keep it from happening again.

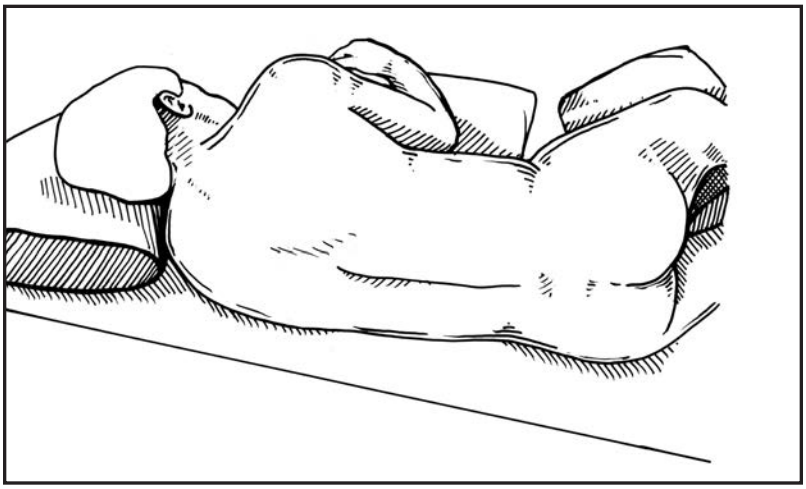


Figure 16 - Skin Problems (Red Area)

Remember!

You can prevent the reddened or darkened area from becoming a skin sore. You must keep all pressure off the area until the color returns to normal.

What to do for an open area:

- Call your doctor about the sore right away.
- Stay off the area, even if it means staying in bed.
- Clean with soap and water only.
- Apply antibacterial ointment. (You can purchase at a drug store.)
- Cover with a dry, clean dressing.
- Wash the area and change the dressing 2 times a day. Use a small amount of tape to hold dressing in place.
- Do your skin inspections more often.

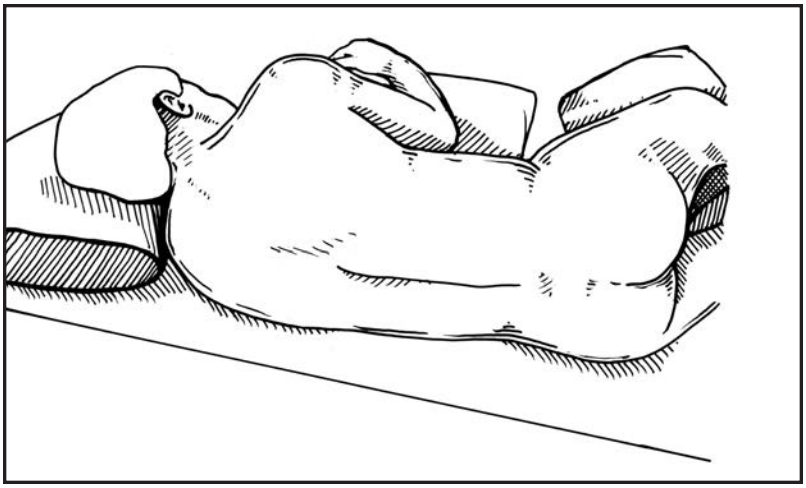


Figure 17 - Skin Problems (Open Area)

What to do for a blister or burn:

- Put cool water on the burn, right away, for 20 minutes.
- Leave blister alone. Do not break it.

If blister breaks open:

- Wash with soap and water.
- Apply antibacterial ointment.
- Cover it with a dry, clean dressing.
- Change the dressing twice daily.
- Keep all pressure off the area.
- Call your doctor.

What to do for a rash:

- Leave open to air.
- Wash with soap and water. Dry well.
- Do not put any medicines on it unless your doctor has told you to.
- Call your doctor.
- Remember, a light dusting of cornstarch based powder helps prevent moisture build-up.

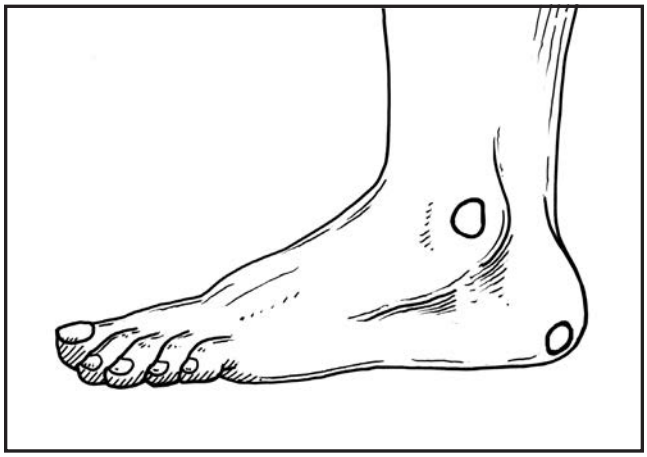


Figure 18 - Skin Problems (Blisters)

Your Skin Care Program

A good skin program will keep you from getting skin sores.

Prevention is the Key!

Your skin program should include:

1. Scheduled weight shifts when you are sitting at least every 30 minutes.
2. Skin checks at least twice a day in the morning before you get out of bed, and in the evening soon after you get back into bed.
3. A turn schedule when you are in bed.
4. Correct padding and positioning to protect bony areas.
5. Early treatment of all skin problems.
6. Wearing the right shoes.

7. Doing good foot care.
8. Wearing the right clothing. Wear clothes that allow the air to circulate and are not too tight.
9. Padding between bony areas when you have bad spasms.
10. Special care of your skin during car travel. Use a cushion in the car seat and do weight shifts.
11. Safe transfers.
12. Avoiding heat sources that may burn your skin.
13. Checking your wheelchair cushion for wear and tear.
14. Sitting in the chair correctly.
15. May use cornstarch-based powder to keep skin dry. Dry cracks and creases well after bathing.
16. Cover the skin on your buttocks with Vaseline if diarrhea or urine leakage is a problem.This keeps the stool or urine off the skin.

Scheduled Weight Shifts

1. Do weight shifts whenever you are sitting up in bed.
2. If you're not sitting in your wheelchair, transfer your cushion to your seat.
3. While sitting in a wheelchair, relieve pressure with the weight shift schedule you learned in your rehabilitation program. Weight shifts are done every 30 minutes. Each weight shift must last at least 60 seconds (one full minute) to relieve pressure.

KEY POINT: If in a manual wheelchair, you should always remember to lock the wheels on your chair and have the caster wheels forward before doing a weight shift.

Weight shifts are important because the weight of your body above the hips increases the pressure on the skin over the buttocks. The bony areas on the buttocks are called the ischia or sitting bones. Relieve pressure by the following weight shift methods:

1. Leaning side to side relieves pressure over one ischium (sitting bone) at a time. Do each side for 60 seconds. You must lean over far enough to relieve the pressure on your bottom. (Figure 19)

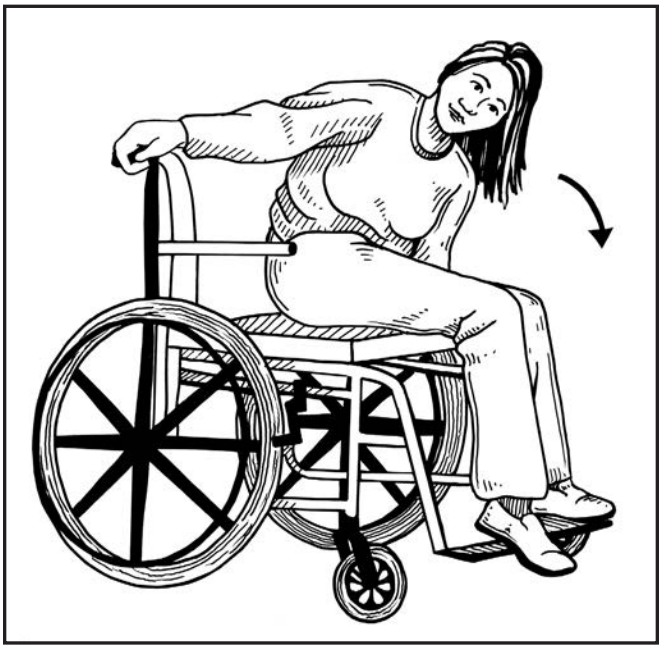


Figure 19 - Side to Side Weight Shift

2. Push-ups relieve pressure on both ischia (sitting bones) at one time. Do this weight shift for 60 seconds. (Figure 20)

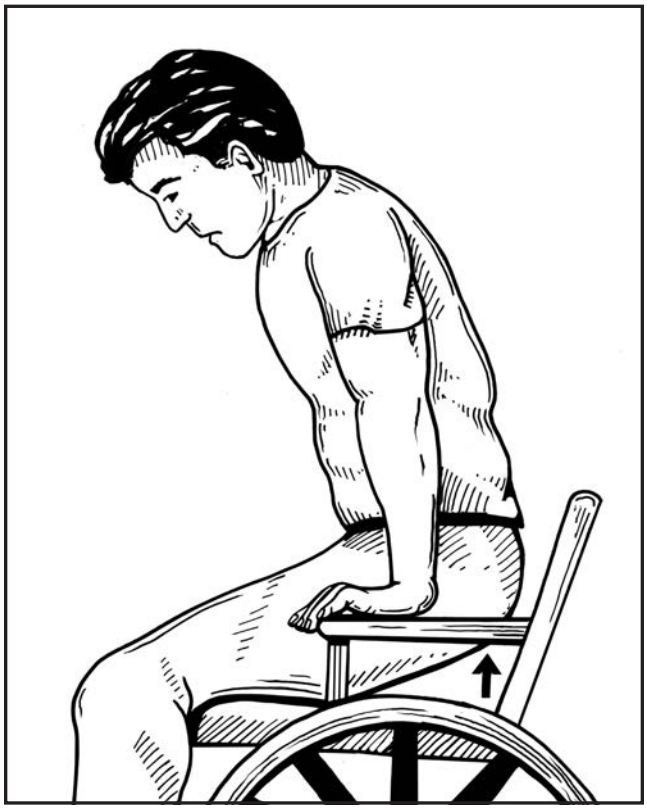


Figure 20 - Push Up Weight Shift

3. Recline or tilt the back of the chair - with recline weight shifts, make sure your leg rests are raised up so you are in a lying position. This relieves pressure on both ischia (sitting bones) at one time. This method is used with a reclining wheelchair. Do this weight shift for 60 seconds. (Figure 21)

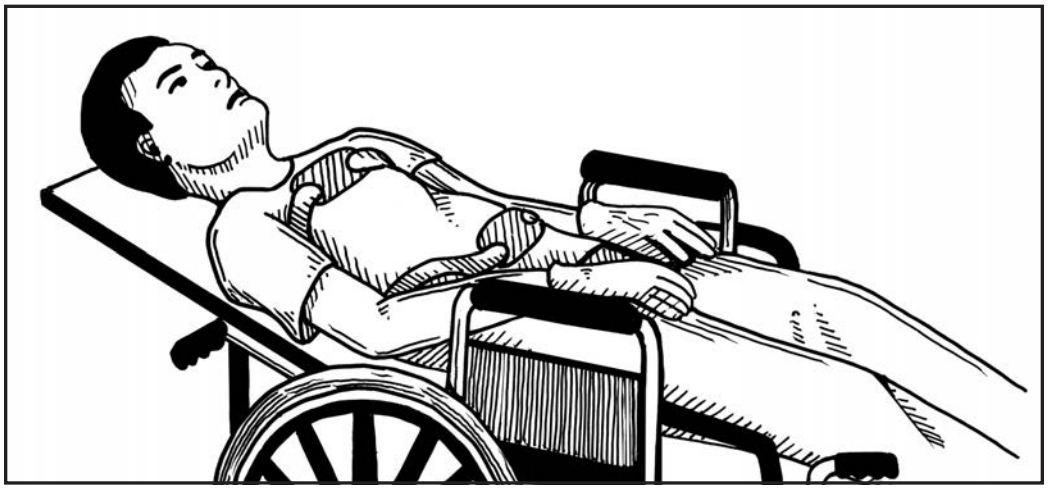


Figure 21 - Reclining Weight Shift

4. Forward lean weight shift relieves pressure on both ischia (sitting bones) at one time. Make sure you are clearing your buttocks off the chair. Do this weight shift for 60 seconds.

Skin Checks

Remember, because of the injury to the spinal cord, the nerves in your skin cannot send a message to the brain to let you know when your skin is in trouble. For this reason, daily inspection of your skin is a very important part of your skin program. By looking at your skin every day, problems will be caught before they become serious. Checking your skin is your responsibility! You should check your whole body at least twice a day, paying special attention to bony areas. This is done every morning when you dress and every evening when you undress. If you do not get out of bed, you should still check it in the morning and again in the evening. If you have an accident (burn, cut, bruise), check your skin as soon as possible. Remember to check skin problem areas more than twice a day.

How to do a skin check:

Supplies Needed:

Mirror – either long-handled mirror or larger short handled plastic mirror. (Figure 22)

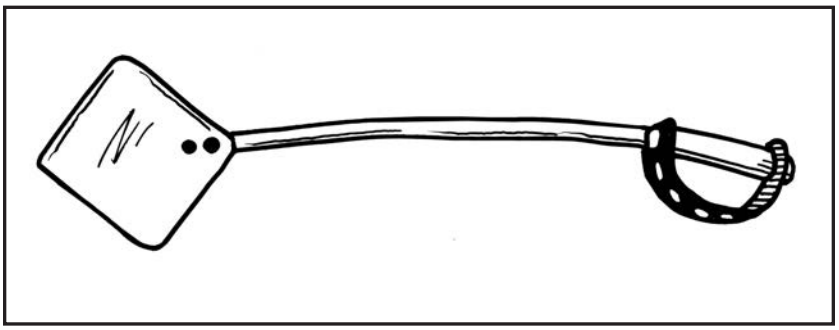


Figure 22 - Skin Mirror

1. If help is needed, have a person ready to hold the mirror to help you look at your skin. This person will also need to feel your skin for warm, raised hardened areas.
2. Start with the front part of your body. Begin at the head and end with the toes.
3. Look for redness, any color change, bruises, scratches, blisters, rashes, scabs, cuts or pimples. Check the groin area and buttocks crack for any rash or moisture. If dark skinned, look for darkened or shiny areas.
4. Feel over bony areas for swelling, raised, warm or hardened areas.
5. Move on to the backside after you have completed the front part of your body. Begin at the head and end with the toes.
6. Repeat step 3.
7. Repeat step 4.

KEY POINT:

1. Check your skin more often if you are increasing sitting or lying times.
2. Check your skin after a fall or accident to any area with decreased or loss of feeling.
3. Check known problem areas more than twice daily.
4. Call your doctor for help if you have any:
- open areas
- darkened or black areas
- burns
- blister

Turn Schedule

During the night or while you are in bed, stay on the turn schedule that was set in your rehabilitation program. You will be able to tolerate a turn schedule from 2 to 6 hours, from side to back to side.

If you are able to lay prone (on your stomach), you may stay in that position up to 8 hours with the proper padding.

Skin tolerance is the amount of time a person can lie or sit in the same position without a change in skin color.

It is important for you to know how to change these times at home. Your schedule might be interrupted by illness or change of equipment.

Skin tolerance is affected by: 1) newness of injury, 2) type of wheelchair, 3) wheelchair cushion, 4) mattress, 5) state of health, 6) type of skin and 7) age.

To increase your turning times, follow these rules:

1. Increase the amount of time you lie in one position by only 30 minutes every week.
2. Only continue to increase the time you lie in one position if your skin remains free of red or dark areas.
3. Do your skin checks by looking and feeling your skin more than two times a day.
4. Evaluate the new turn schedule each week.
5. If you have a newly healed skin area, start with 10 to 15 minute time increases.

Correct Padding and Positioning

Positioning on your back:

- Support your head with a pillow.
- Place a foam pad under ankles so the heels do not touch the bed.
- Use padding to keep the feet from pressing against a firm foot board.
- Bridging may be used to pad off the sacrum if needed. Check pads often.

Remember, if you develop a skin problem, it is best to stay off the area completely until it heals. If you need to be on your back for a short period of time and have a sacral sore, bridge the sacrum. Foam pads above and below the sacral sore will take pressure off the area.

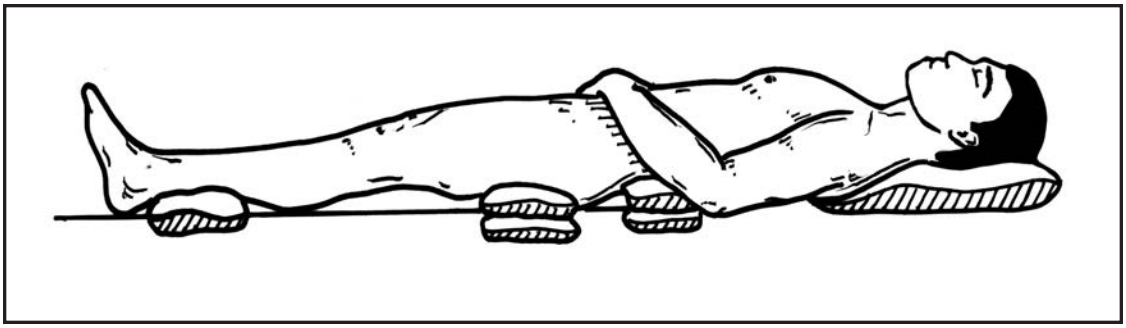


Figure 23

Positioning on the side

- Support your head with a pillow.
- Place a pillow behind your back for support.
- Place a pillow lengthwise between your legs. Note: Do not let your knees or legs rest on top of each other. Your ankles should not touch.
- Place a pillow between your ankles and between the bed and ankle.
- Do not let the bottom of your feet rest against the footboard. Bridging can be used to get pressure off the trochanter (side lying bone), side hip bone, side of the knee and ankle.

Positioning on the stomach (prone)

Lying prone is very important for three reasons:

1. Proning allows you and your family to have a restful night of of sleep. No turning through the night is necessary. You can lay prone up to 8 hours.
2. Proning straightens the hips and prevents tightness in the hips and knees, reducing spasms.
3. Proning gives the skin you sit on a break.

Positioning on your stomach

(See Figure 25)

- Support your head with a regular pillow under the forehead and chin.
- Place 2 or more pillows under the chest and thighs (this frees your hips from pressure).

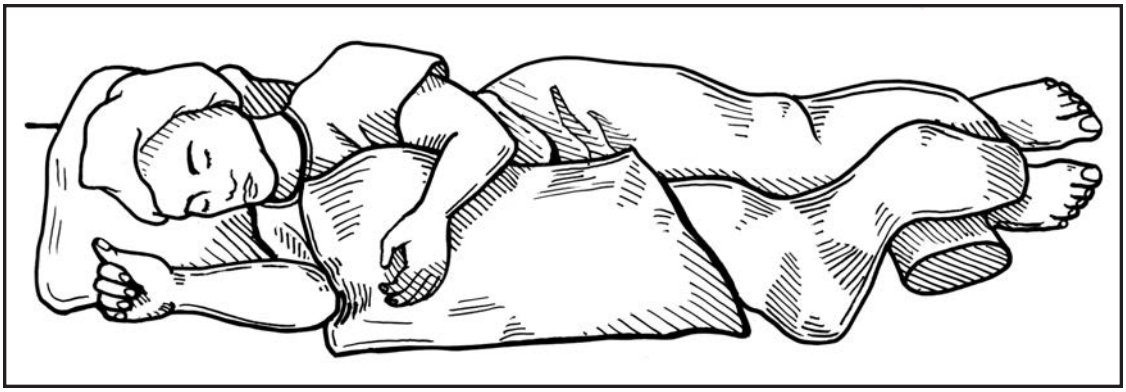


Figure 24 - Padding - Side

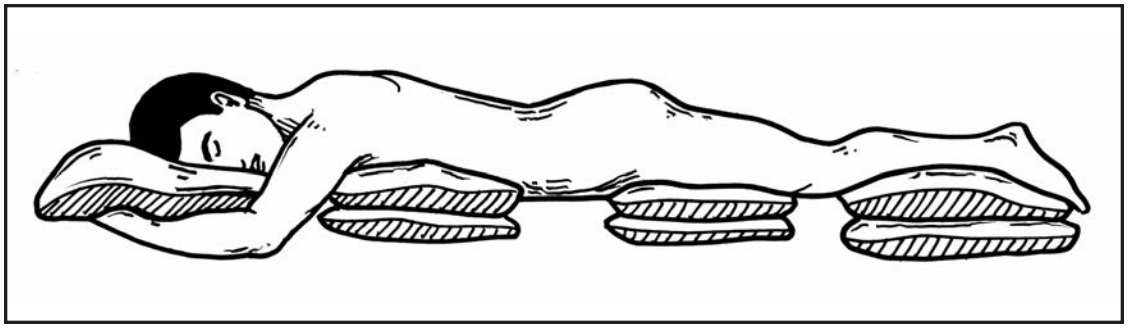


Figure 25 - Padding - Prone

- Place 2 or more pillows below the knees (this frees the knees from pressure).
- Support feet with pillows or pads to protect the top of the feet and toes.
- If you have bad spasms, place a pillow between the knees so they do not rub together.

KEY POINT:

- No two skin surfaces should rest together.
- Bridging may be used to relieve pressure on bony areas and wounds. Bridging is a method of padding with foam pads and pillows. Correct bridging supports the body so bony areas have no pressure. Bridging can be used when lying on your back, side or stomach (prone)

Special Skin Concerns

Shoes

- Wear shoes 1 to 1 1/2 sizes bigger than usual. Bigger shoes are needed because your feet may swell and need more room than before your spinal cord injury.
- Slowly increase the amount of time you wear new shoes. Here is how:

  1. Wear new shoes for 30 minutes the first time. When you take them off, check for red or dark areas on the feet and ankles.
  2. If you did not notice any signs of skin problems after 30 minutes, you may begin wearing the shoes for 1 hour.
  3. If there are no problems wearing the shoes for 1 hour, you can add 1 hour each day until you reach 5 hours. Make sure to check your feet each time you add 1 hour.
  4. If the skin on your feet tolerate new shoes for 5 hours, you can wear the shoes all day.
  5. Adjust footrest height for every pair of shoes.
  6. If you're unable to wear shoes, place a pillow or pad under your feet in the wheelchair.

Remember to check your feet every morning and evening with your regular skin checks. If you get a pink or dark area on your feet, you should:

1. Decrease the amount of time you wear shoes.
2. See if you need a bigger size shoe.
3. If redness does not go away, stop wearing your shoes until redness disappears.

Foot Care

- Open areas, calluses and toenails (if not cut correctly) can lead to skin sores. Carefully inspect your feet every day when you check your skin. Wash and dry your feet every day, paying special attention to drying between the toes.
- Cut toenails straight across.
- Keep toenails clean.
- Check for ingrown toenails (Ingrown toenails may cause autonomic dysreflexia and infection.)
- Puffy or reddened areas around the edge of the nail may be a sign of an ingrown toenail.
- Use vinegar soaks to remove calluses on hands and feet.

Clothes

- Be sure clothes are not too tight.
- Be careful of zippers, buttons and snaps that may cause pressure.
- Dress for outdoor temperature when going outside.
- Wash new jeans or any stiff clothing before wearing.
- Do not wear tight hose or tight socks.
- Wear natural fiber clothing such as cotton or wool which help to absorb moisture and allow air to get to your skin.
- 100% cotton underwear may absorb moisture.
- Wear pants without bulky seams or pockets.

Spasms

- Protect your body parts from rubbing together by using correct padding in your bed and wheelchair. Place a pillow between your knees if you have leg spasms. Do safe transfers.

Car Travel

- Continue to do your weight shifts in the car.
- Always sit on your wheelchair cushion when in the car unless you have a special car cushion made for traveling.
- Wear shoes to prevent burning your feet on the floorboard of the car.

Transfers

- Be careful when doing transfers.
- Do not drag or scrape your bottom when moving in and out of your wheelchair. Especially watch out for the wheelchair tire.
- Wear some type of clothing over your bottom when using a sliding board or use a pillowcase to cover the board when bare bottomed.
- Lift your body as much as possible when you transfer.
- Always wear shoes while in the wheelchair to prevent bumping your toes, especially when transferring.

Heat Sources

Heat sources can be dangerous to your skin. Be careful with:

Hot Foods and Drinks

- Spills can burn.
- Do not carry hot drinks between your legs.
- Do not put hot plates on your legs or your lap.

Fireplaces and Portable Heaters

- Feet and legs should be at least 6 feet away from the heat.
- Check feet, shins and knees regularly to be sure they are not too hot.
- Check objects touching your body (such as the footrests) to make sure they are not heating up.

Ovens and Stoves

- Have an area available to always place hot pots and pans.
- Watch out for pot handles.
- Be careful of shirt sleeves when cooking.
- Try to have an area in the kitchen that you can reach easily in the wheelchair.

Cigarettes

- Do not smoke in bed, as you may fall asleep.
- Do not hold an ashtray on your legs or lap; heat may go through and burn you. Cigarettes can burn fingers that may have decreased feeling.

Hot Water Bottles and Heating Pads

- Do not use hot water bottles or heating pads over areas that do not have sensation.

Floorboards of Cars or Vans

- When traveling, always protect your feet by wearing shoes or placing a pillow between your feet and on the floor of the car.

Metal Footrest on your Wheelchair

- Protect the bottoms of your feet from footrests which may have been heated by the sun.

Hot Water from Bath or Shower

- Always test the water temperature before using on body parts with little or no sensation.
- Turn on cold water first, then gradually add hot water. Turn off hot water first.

Hot Water Pipes

- Take care to avoid resting feet and legs against exposed pipes under sinks.
- Cover water pipes with insulating foam.

Arm Rests on the Wheelchair

- Protect hands, arms and elbows from too hot arm rests.

Checking your Wheelchair Cushion

- Check your wheelchair cushion at least once a week when you wash the cover.
- Roho cushions (a cushion with air) should be checked daily.
- Follow the directions your physical therapist gave you in your rehabilitation program on how to care for the cushion and what to look for when checking your cushion.
- Replace the cushion according to the directions given to you by your physical therapist.

Sitting Correctly in your Wheelchair

- Slouching and poor posture causes pressure in areas which normally do not get pressure
- Footrests should be adjusted so that your thighs are level.
- Crossing your legs can cut off circulation and increase pressure on your skin.

Good Hygiene

- Take a bath every day using soap and water.
- Take care to wash and dry well around the genitals, buttocks, fingers and toes.
- Bathing is a good time to check your skin too.
- Use lotion or bath oil to prevent dryness.

Eat a Healthy Diet

- See Digestive System Section to learn more about Nutrition.
- A multivitamin taken daily is helpful.

Summary

The skin is the body's largest organ and is responsible for protecting you from things like infections and harmful rays of the sun.

The skin also helps to control body temerature and allows you to feel things like pain, touch, pressure, temperature and body position.

With injury to the spinal cord, there will be some changes in the ability of the skin to protect the body. Two important changes are loss of feeling below the injury and loss of temperature regulation.

Because of the loss of feeling and movement, you will need to learn how to protect your skin from problems like pressure sores, burns, bumps and bruises. Care must be taken to prevent overheating and from being too cold. The skin care program that you learned at Shepherd will help you avoid problems, but you must take care of your skin every day.

Important key points to remember about your skin care program:

- Do weight shifts every 30 minutes for one minute.
- Take care of your wheelchair cushion.
- Inspect your skin every morning and every night.
- Know what you are looking for when checking your skin (red areas, bumps, bruises, dark spots, warm, hard places, scratches, cuts, pimples and rashes).
- Know what to do for each type of skin problem. Rule #1: always stay off the problem area.
- Stick to your turn schedule at night. Sleep prone if possible.
- Keep your skin clean.
- Exercise, eat a healthy diet, drink 6 to 8 glasses of water a day and get plenty of rest.
- Wear clothing that allows air to circulate (cotton, other natural fibers).
- Do not cut off blood flow with too tight clothes, stockings, belts or shoes.
- Perform good foot care.

Most importantly, take care of problems early before they become serious. If you are not sure what to do for a skin problem, do not wait. Call your doctor.

What You Have Learned About the Skin

1. Where does the sensation change in your body?
2. Do you have a skin sore?
   If so, where?
3. How often do you do a weight shift?
4. What are your turn times?
5. When will you do skin checks?
6. Who is responsible for your skin care?
7. What is the first thing you will do if you find a skin sore?

The Respiratory System

5 **CHAPTER CONTENTS**

What You Will Learn In This Section

After reading this section you will be able to:

1. Name the parts of the respiratory system.
2. Describe how the lungs works before and after a spinal cord injury.
3. Name the main muscle of breathing.
4. List the causes, signs, treatment and prevention of pneumonia.

New Words

Abdominal Muscles
Muscles located in the front part of the body near the stomach. They help you cough and sneeze.

Alveoli
Tiny air sacs in the lungs.

Assisted Cough
A method used to help someone with respiratory muscle weakness to cough up secretions from the lungs.

Breathing
Air going in an out of the lungs.

Bronchitis
An irritation and/or infection of the bronchial tubes. The bronchial tubes are part of the airway to the lungs.

Carbon Dioxide
A gas that is a waste product of breathing.

Clapping
A method of tapping on the chest to help loosen thick secretions in the lungs.

Congestion
A feeling of fullness or stuffiness in the nose or chest.

Diaphragm
The main muscle of breathing located under the rib cage.

Incentive Spirometer
A device used to strengthen the muscles for breathing.

Infection
Germs entering a part of the body, possibly causing illness. The main symptom is a fever.

Intercostal Muscles
Muscles to help you breathe out. They are located between the ribs.

Lung Secretions
Fluids produced in the lungs, also called sputum, mucous and phlegm.

Oxygen
A gas found in the air that all living things need to survive.

Pneumonia
An infection in the lungs.

Postural Drainage
A method of positioning the body to help drain secretions from the lungs.

Rattle
An abnormal vibration caused by too many secretions in the lungs; can be felt by placing hands on the chest.

Respiration
The process of getting oxygen into the body and removing carbon dioxide from the body. This happens with each breath.

Ribs
The bones surrounding the chest.

Trachea
A tube also called the windpipe. Air travels into and out of the lungs through the trachea.

The Parts of the Respiratory System

To better understand the importance of preventing respiratory problems, here are a few facts about the respiratory system. The respiratory system includes the nose, trachea, bronchi, lungs, heart, diaphragm, and intercostal, abdominal, and neck muscles.

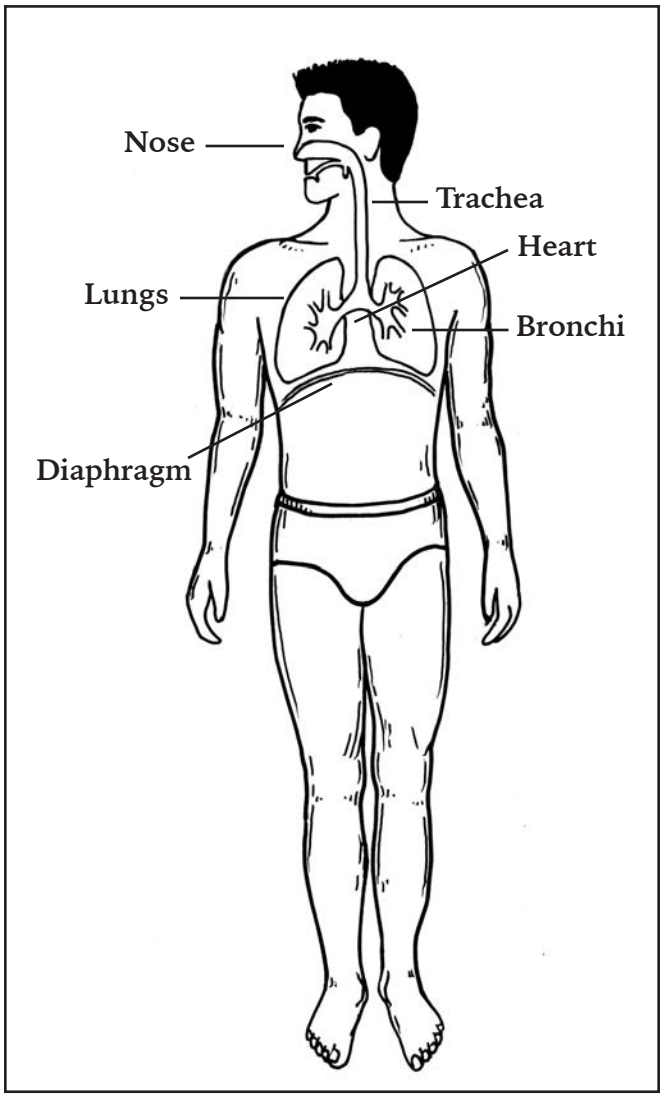


Figure 1

Nose

- It cleans the air we breathe by filtering dust and dirt from the air.
- It warms the air.
- It humidifies the air.

Trachea (Windpipe)

- The tube leading from the throat to the lungs.

Bronchial Tubes

- The two branches leading from the trachea to the lungs.

Heart

- The heart pumps blood to all parts of the body.

Lungs

- There are 2 lungs, one on each side of the chest.
- Oxygen is taken into the lungs and passes to the blood through tiny air sacs called alveoli.

Diaphragm

- The diaphragm is located under the rib cage and is the main muscle used while inhaling or breathing in. It does not help you to breathe out.
- It is the muscle that separates the chest from the abdomen.
- The diaphragm connects to the spinal cord at C3, C4, C5.

Neck Muscles

- These muscles can be used to help breathing when the main breathing muscles are weak or not able to work.

Rib Muscles (Intercostal Muscles)

- These muscles are located between each rib.
- They are the muscles used to help you breathe in or out.
- These muscles connect to the spinal cord at T1 - T6.

Stomach Muscles (Abdominal Muscles)

- These muscles are used to help you cough and sneeze.
- These muscles connect to the spinal cord at T6 - T12.

How the Respiratory System Works Before A Spinal Cord Injury

Air is taken in through the nose or mouth. Air contains oxygen which all living things need to survive. When you take a breath, air filled with oxygen moves down a tube in the throat called the trachea (windpipe). Air then moves from the trachea to the bronchi and into the lungs. The body has two lungs, one on each side of the chest. The lungs contain millions of tiny air sacs called alveoli that take in the oxygen and transfer it to the blood vessels. The blood vessels then carry oxygen to all parts of the body. Waste products such as carbon dioxide are removed from the body as you breathe out.

Breathing is controlled by special centers in the brain. Breathing messages or signals are sent from the brain, down the spinal cord and out to the nerves. The nerves carry messages to the breathing muscles, causing them to move. This moves air into and out of the lungs.

The diaphragm is the main muscle to help you breathe in air. The abdominal and intercostal muscles are the main muscles which help you breathe out air with force. For example, a cough, sneeze, or laugh requires you to use force to breathe out air.

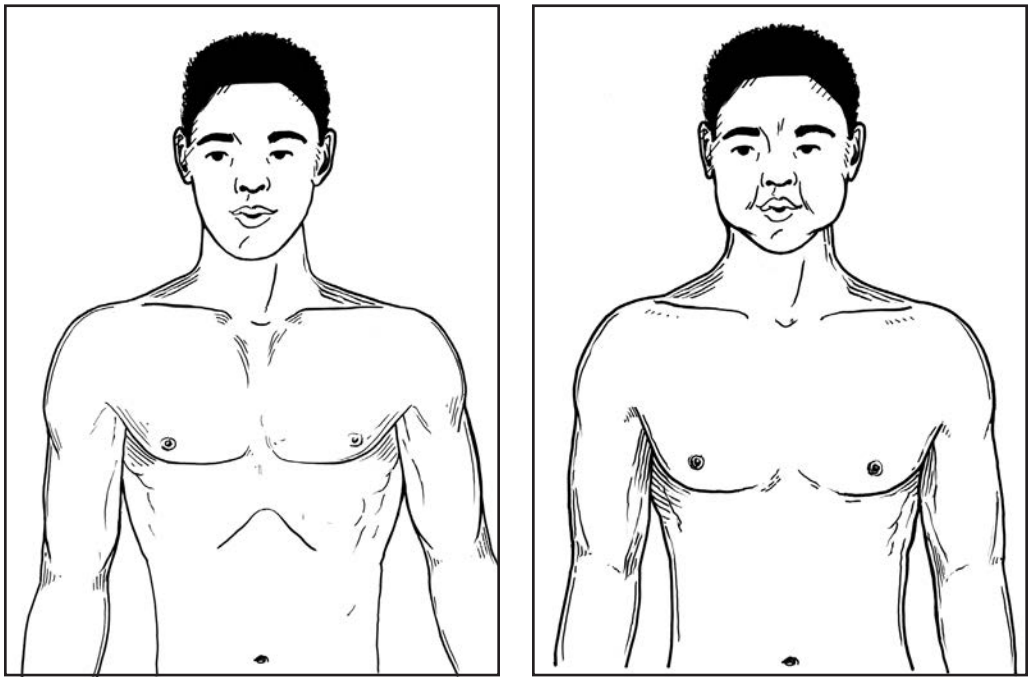


Figure 2 - Breathing In and Breathing Out

How the Respiratory System Works After A Spinal Cord Injury

How much your spinal cord injury changes your breathing depends on the level and extent of injury. The higher the injury level, the greater the change in breathing. Changes in breathing occur because messages or signals to the muscles of breathing are partially or totally blocked by the spinal cord injury.

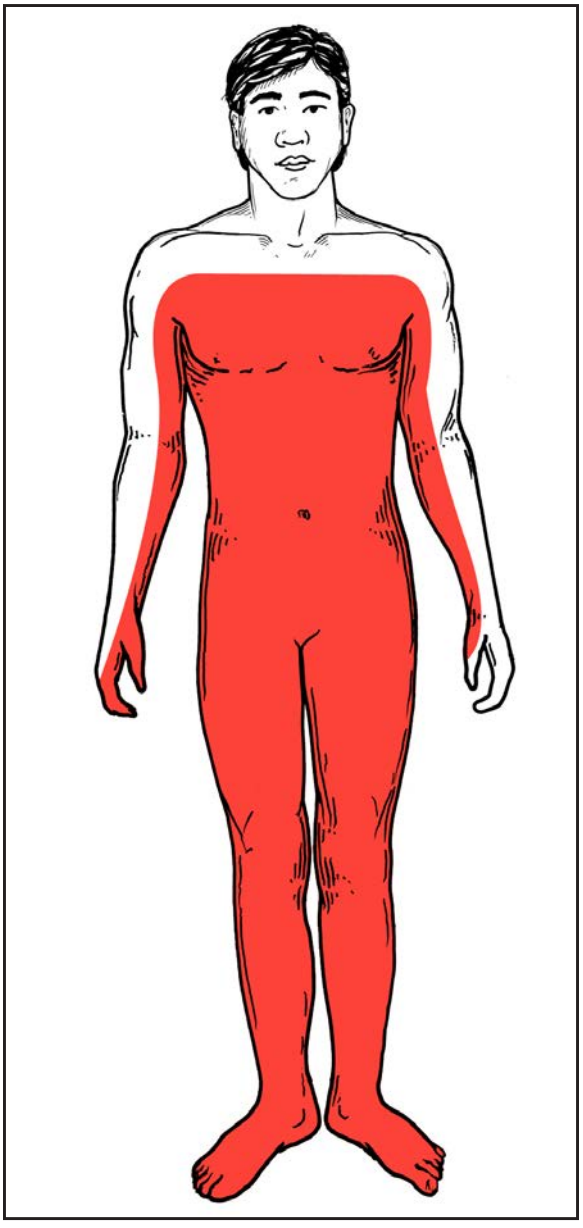


Figure 3 - C3

How Injury Levels Affect Breathing with A Complete Spinal Cord Injury

Above C3

The diaphragm does not work at all. Cannot cough or sneeze.

C3, 4, 5, 6, 7, & 8

Partial function of the diaphragm (C3, 4, 5). Intercostals (rib muscles) don't work. Abdominal muscles don't work. Cannot cough or sneeze well.

T1 - T6

Diaphragm works well. Intercostals don't work well. Abdominal muscles don't work. Cough or sneeze is weakened.

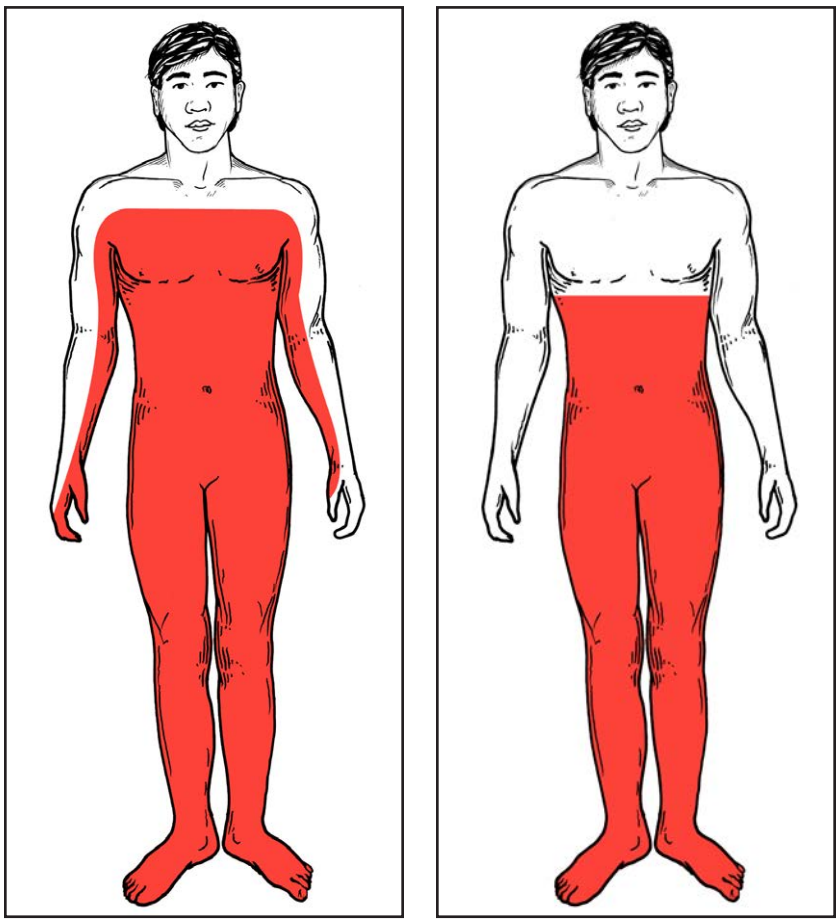
T6 - T12

Diaphragm works well. Intercostals work well. Abdominal muscles don't work as well. Cough or sneeze is weakened.

L1 - L5 & S1 - S4

All respiratory muscles work well.

Remember: If you have an incomplete spinal cord injury, this may not be true for you.



Figures 4 and 5

KEY POINT: Spinal cord injury affects everything from the injury down. This means if the diaphragm is affected, so are the intercostaland abdominal muscles. You cannot breathe in as well and cannot cough well.

Changes in breathing are noticed when you cannot take a deep breath, cough hard, giggle or sneeze. Coughing and sneezing help to clear mucous out of the lungs, keeping the lungs healthy. When the lungs are healthy, there is less chance of getting an infection. If the tiny air sacs (alveoli) in the lungs become clogged with mucous, not enough oxygen can get into the lungs. If oxygen cannot get into the air sacs, then oxygen cannot get to the blood or body.

Common Respiratory Problems

Increased mucous in the lungs can lead to congestion and infection.

Respiratory Infection

How to Tell When You Are Congested:

- Increased mucous in lungs.
- Coughing up thick mucous.
- Any change in the color of your mucous; yellow, green or red.
- Shortness of breath.
- Fever.
- Cough.
- Stuffy nose.
- Rattles are felt by placing the hands on the four parts of the chest when breathing (above each breast and at the bottom of the ribs).

What to do if you have congestion:

Congestion in the lungs can lead to respiratory infections such as colds, pneumonia, bronchitis or collapsing of the tiny air sacs in the lungs.

Should you have lung congestion, there are several helpful things you can do:

- Drink more liquids, ideally 6-8 glasses of water. Drinking plenty of water helps to thin secretions, making it easier to cough them up.
- Do not drink caffeine or alcohol.
- Turn more often. For example, if you now turn every 6 hours, turn every 2 hours. This helps move the secretions and prevents them from gathering in one part of the lungs. When you are no longer congested, go back to regular turn times.
- Check your temperature. A fever could mean you have pneumonia. If your temperature is 101° F or greater, call the doctor right away.

- If you smoke, please consider quitting. If you decide not to quit, cut down and smoke a lighter brand. If you choose to smoke, do not smoke with others. Smoke by yourself and you will usually smoke less. Smoke irritates your lungs and causes more secretions (mucous). People who smoke will have more respiratory infections.
- Use assisted coughing.
- Use your Incentive Spirometer (exercise breathing machine) at least four times each day while you are congested. See page 14 for instructions on how to use your Incentive Spirometer.
- Use postural drainage. See page 14 for instructions on how to do postural drainage.
- Clapping. See page 16 for instructions on clapping.
- Get OUT OF BED unless the doctor orders bed rest. Move about and change your position frequently.
- Take Tylenol or Advil for elevated temperature.

Pneumonia Kills!

Pneumonia is caused by irritation to the lungs. Irritation is usually caused by germs or by a virus. Pneumonia is very dangerous to someone with a spinal cord injury. In fact:

More people with spinal cord injuries die from pneumonia than from any other cause!

How to Prevent Pneumonia

1. The number one rule to prevent pneumonia is KEEP MOVING. If you stay in bed or do not move around, the mucous in your lungs can harden and block off parts of your lungs.

2. Dring 6-8 glasses of water each day.

3. Ask your doctor about getting the flu and pneumonia shots. They can help prevent certain kinds of pneumonia caused by viruses.

REMEMBER: it is a lot easier to prevent pneumonia than cure it.

Don't get caught by pneumonia!

How to be Assist Coughed

Assisted coughing is a method to assist someone with either a weak diaphragm, intercostal and/or abdominal muscles to cough up secretions to clear the lungs. There are several ways to perform this procedure.

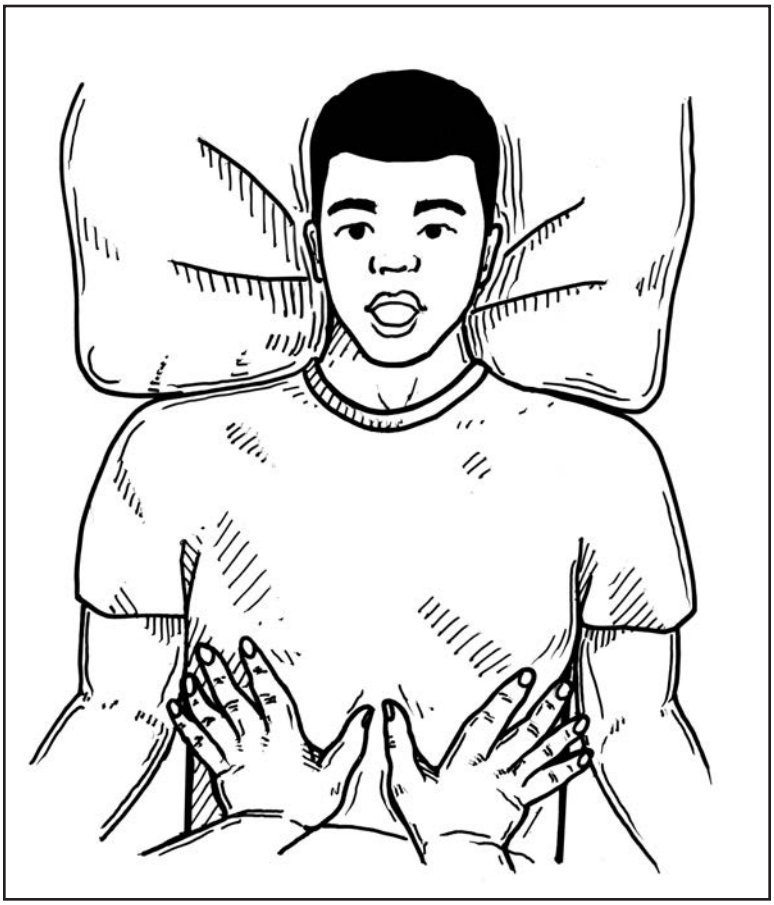


Figure 6 - Assisted Cough in Bed

The first step is to recognize the fact that you need help coughing. Some ways to find out:

1. You may try to cough.
2. You may hear congestion when you breathe.
3. You may feel the mucous in your chest. If this occurs, then you need to tell someone to assist cough you.

Assist coughing is a way of helping a spinal cord injured person to cough and clear the lungs. The idea is to imitate the muscles that normally help us to cough.

Usually, persons with a complete spinal cord injury above T-10 will need to be assisted with their coughing.

The person who helps you should place the palms of both hands on your abdo-men, with your belly button between their thumbs and their hands spread wide.

Figure 7 - Assisted Cough in Chair

- Take 2 or 3 deep breaths. Each time you breathe out, blow ALL of your air out while the person helps you by pushing and holding in and up.

- Take another deep breath in. This time, try to cough while the person gives another firm push inward and upward under your rib cage. You may need to repeat this several times.

- DO NOT let the person place the hands on your ribs because it could bruise your chest or break your ribs. Only a person who has had special training should press on your chest.

- If you should have abdominal pain or chest injury, ask your nurse or doctor if assisted coughing could be of danger to you. Always look at the mucous that you cough out for signs of infection. Yellow = infection, green = severe infection.

KEY POINT: How to assist cough a person: The person should be lying flat, if possible. If not, this can be done sitting up, though not as well.

1. Locate the person's belly button.
2. Place your thumbs together with the belly button in the middle of them. Spread your fingers wide to make a butterfly.
3. Tell the person to take a deep breath in and that you will help them push it back out. As they exhale, use firm, steady pressure to push in and up. Be sure to use smooth motion.
4. After 2 or 3 efforts, have the person take a deep breath and say, "cough!" At the same time, push in and up and hold until the person needs to take another breath. Then get ready to do it again.
5. Have the person cough as hard as possible during assist coughing. You may have to let the person rest if tired.
6. Repeat as often as needed.

REMEMBER: Always have tissue ready or something to spit into.

1. Keep your fingers spread wide.
2. Do NOT press on the person's ribs.
3. Remember to hold pressure IN and UP when coughing the person.
4. Remember to hold pressure IN as long as the person is coughing. Do not let up until the person starts to breath IN.

* If it hurts the person to be assist coughed or if there is an injury of the stomach or if the person vomits, call the doctor.

How to Use the Incentive Spirometer

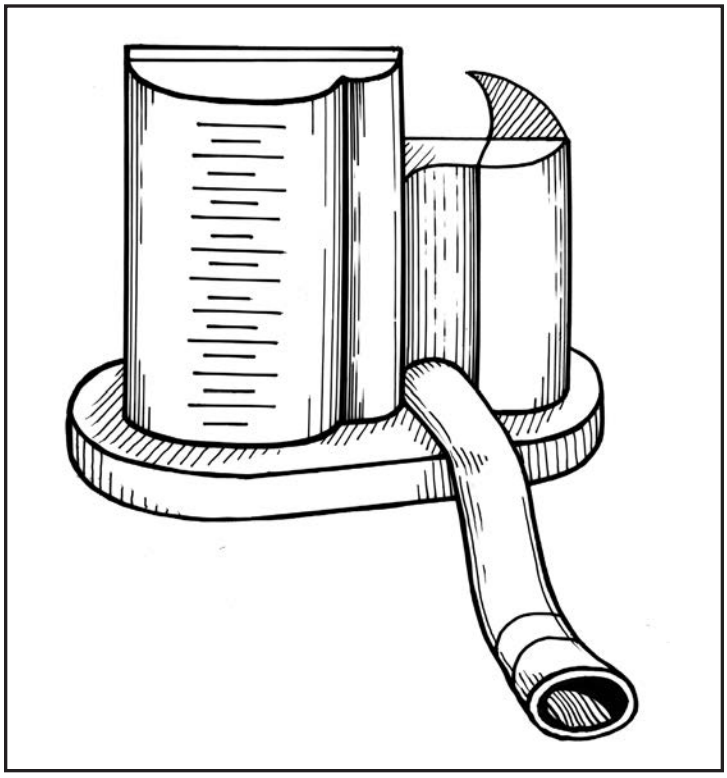


Figure 8 - Incentive Spirometer

The Incentive Spirometer is a breathing device that helps exercise your lungs by making you take deep breaths. This device also helps to make your breathing muscles stronger so they work better and help to clear lung secretions. The Incentive Spirometer is used by people who have an injury from C3 to T8. Here is how to use your Incentive Spirometer:

- Place mouthpiece in mouth.
- Take in the deepest breath you can through the mouthpiece and hold it in for 3 seconds, then let it out. DO NOT EXHALE INTO THE MOUTHPIECE.
- Try to reach the goal set for you by your respiratory therapist. DO NOT GET DISCOURAGED if you can't make it. Do the best you can!
- Try to sit up to do the treatments.
- Repeat for 10 breaths.
- This exercise should be done twice a day, once in the morning and once at night.
- Deep breathing is one of the easiest ways to help keep the lungs clear. Remember to take a few deep breaths every hour.

KEY POINT: Try to sit up to do both treatments. This exercise must be performed on a regular basis to strengthen muscles of breathing.

How to Do Postural Drainage

This is a method for clearing the lungs by changing your posture (position). This allows gravity to drain mucous to the top of the lungs, where it can be removed. This should not be done if it affects your heart rate or makes breathing harder.

The person checking should:

- Feel the chest for rattles to see where the mucous is located.
- Position correctly to drain the lungs.
- A person should stay in each position for five to ten minutes to allow the lungs time to drain.

If there is ever a question about placing a person in a certain position, ASK THE DOCTOR FIRST! Positions for Postural Drainage:

- To drain the lungs in the lower back, the person should lie face down (prone) with the hips propped up with pillows (about 18 to 20 inches). (See Figure 9)

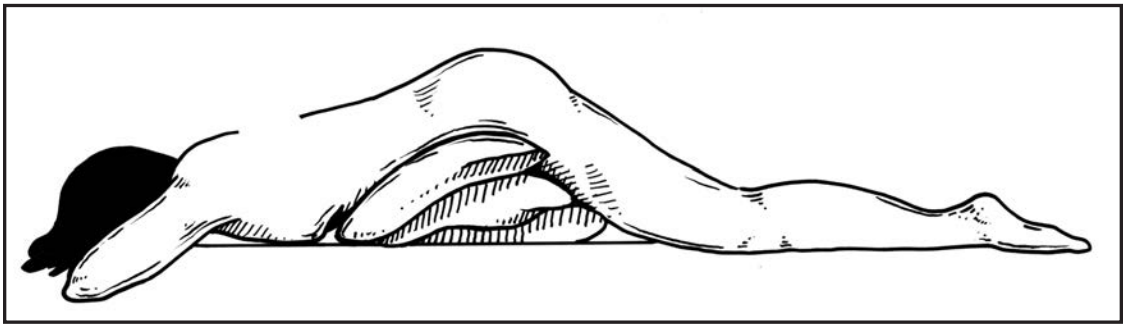


Figure 9 - Position for Postural Drainage

- To drain the bottom front parts of the lungs, the person should be on his/her back with the hips propped up with pillows (about 18 to 20 inches). (See Figure 10)

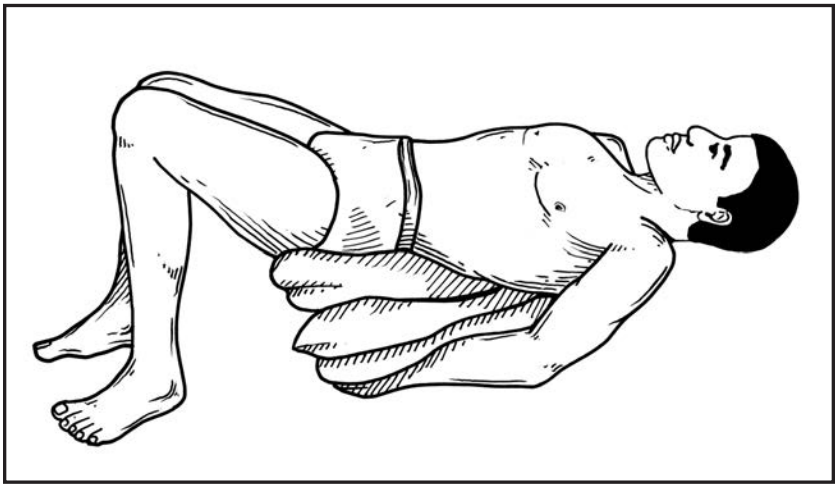


Figure 10 - Position for Postural Drainage

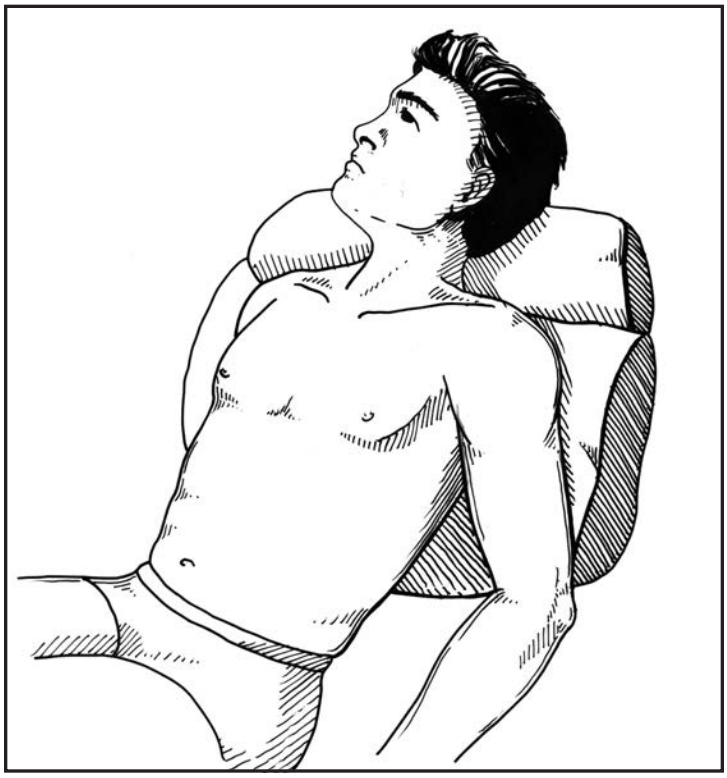


Figure 11 - Position for Postural Drainage

- To drain the upper lungs in the front, the person should be sitting up and leaning back slightly. (See Figure 11)
- To drain the upper lungs in the back, the person should be sitting up and leaning forward slightly. (See Figure 12a)

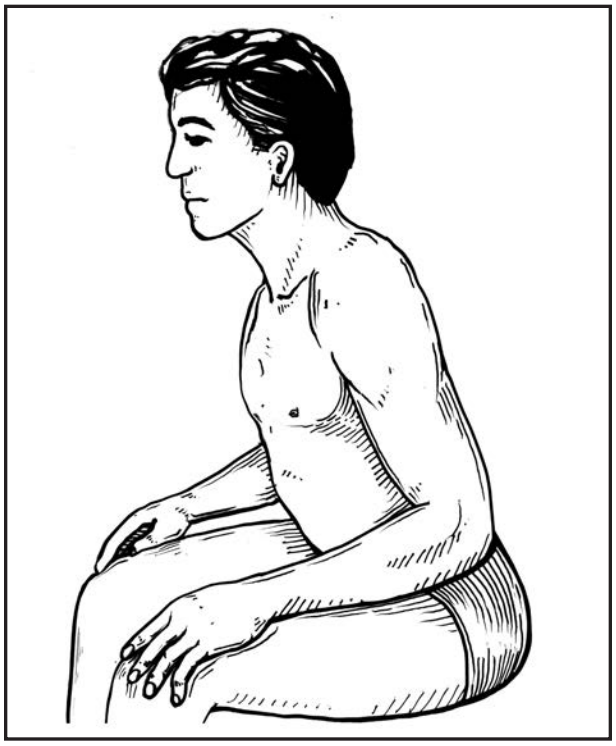


Figure 12a - Postural Drainage

- To drain the bottom side part of the right lung, lay on your left side with the bed flat.

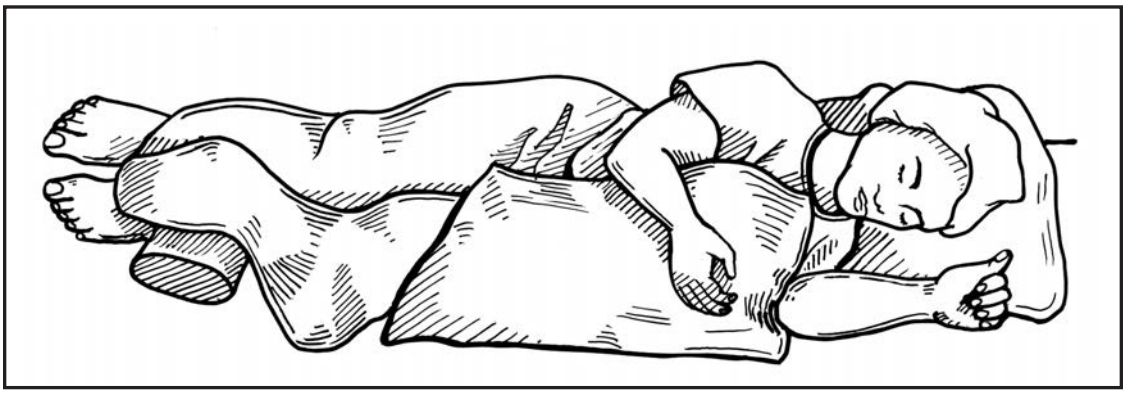


Figure 12b - Drainage

- To drain the bottom side part of the left lung, lay on your right side with the bed flat.

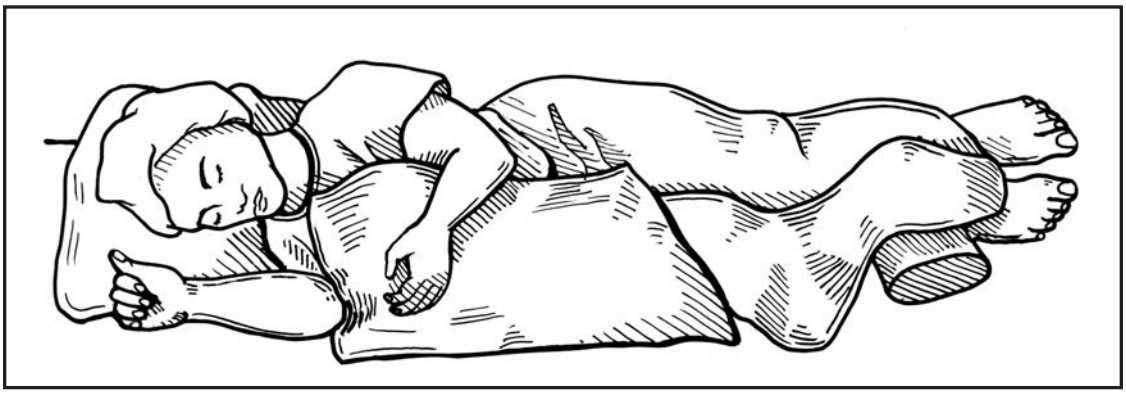


Figure 12c - Drainage

Clapping

Clapping is used to loosen the mucous by shaking it loose. This is used after the person is already in the proper POSTURAL DRAINAGE position. This will also move secretions from the air sacs in the lungs into the larger airways where they can be coughed up or suctioned.

Here's How:

The hands are held in a "cup" shape formed by the fingers and the thumb. The congested part of the lung is then "clapped" gently for 3 to 5 minutes. This is done in a smooth rhythm. Stop while the person is coughing. (See Figure 13)

Do Not Clap on the Spine, Kidneys, Lower Part of Back on Each Side, Breasts or Stomach!

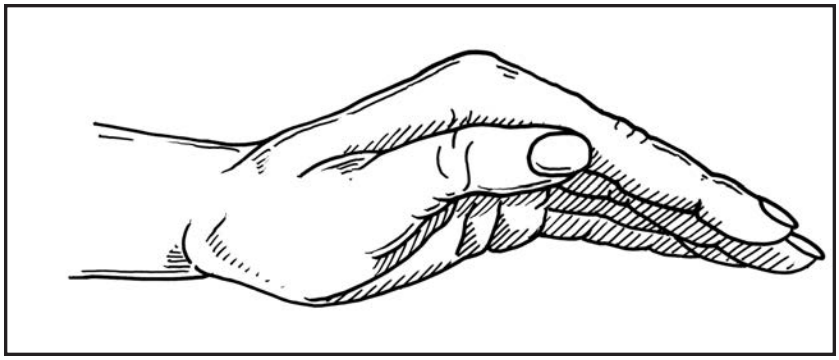


Figure 13 - Clapping Hand Position

Refer to the following positions and "Clap" over the following areas:

POSITION 1: From below the shoulder blade to about three inches above the bottom of the ribs - NOT over the backbone or kidneys. (See Figure 14)

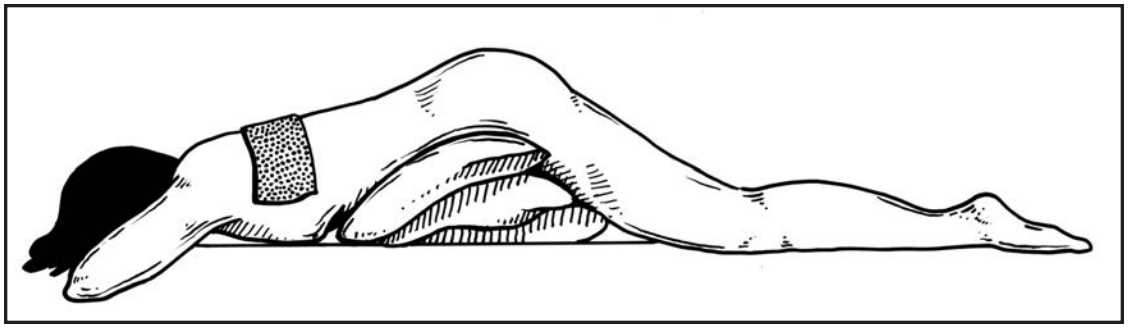


Figure 14 - Clapping Position

POSITION 2: From below the nipple line to the bottom of the ribs - NOT over the stomach. (See Figure 15)

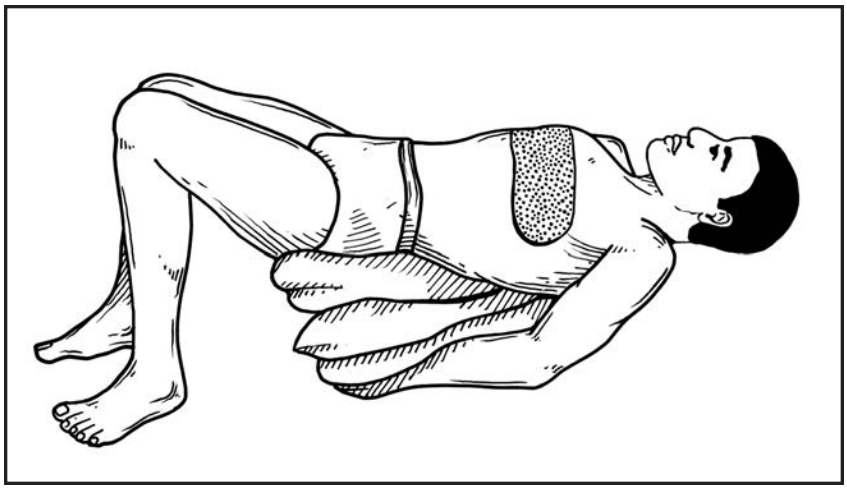


Figure 15 - Clapping Position

POSITION 3: Directly under the collarbone. (See Figure 16)

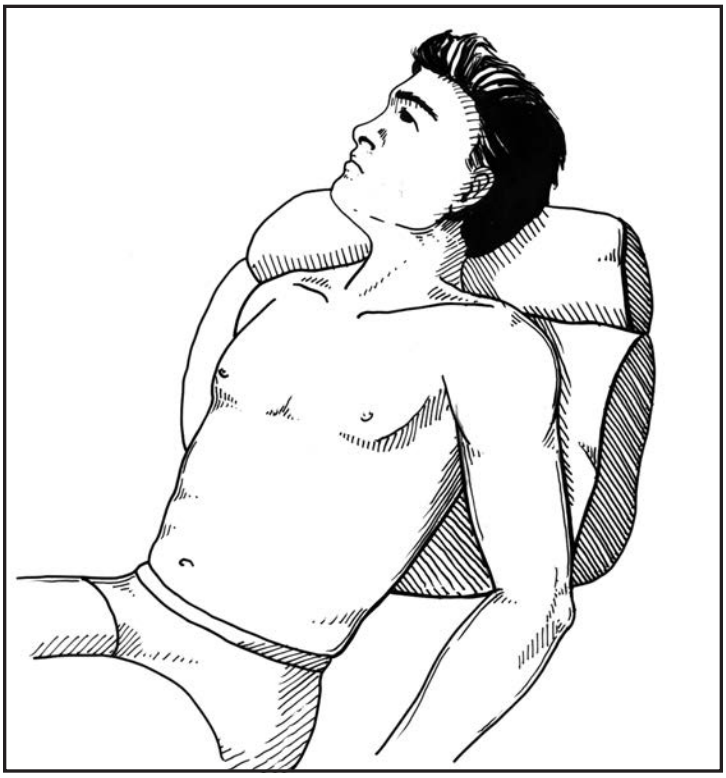


Figure 16 - Clapping Position

KEY POINT: If you have questions about any of these methods, call your doctor. If you need medical help, go to the nearest emergency room or call your doctor. Call 911 or the emergency phone number in your area if you need help right away.

* Caregivers should consider taking a CPR training class in their neighborhood.

What to Do If A Person Is Choking

1. Ask the person, "ARE YOU CHOKING?"
2. If the person is choking, ask, 'CAN YOU SPEAK?"

If the person can speak:

a. Assisst cough the person.
b. If the person is sitting up and the assist cough does not work, the person must lie down.

Reclining Chair

Lower the head of the chair and support it so that it does not tip over when performing assisted cough.

Rigid Back Chair

Go behind the chair, tip it backwards and CAREFULLY lower person to the floor.

If the person cannot speak:

a. Let him/her know you are going to help.
b. Attempt the Heimlich Maneuver. If this does not work sitting up, the person needs to be moved out of the wheelchair and laid on the floor.
c. Straddle the person's thighs and place the heel of one hand just above the belly button. Place the heel of the other hand directly on top of the first and lock the fingers.
d. Press into the person's stomach with quick upward thrusts.
e. If the object choking the person does not come out, have someone call 911.
f. If no one is available and the person becomes unconscious, STOP, CALL 911, then CONTINUE until the paramedics arrive or begin CPR.

How to Call An Ambulance

Always have the number for your ambulance service programmed in all phones and leave the number by your landline.

Tell the person on the phone:

- Who you are.
- What the problem is.
- What you have done to help.
- Where you are:
    1. The address.
    2. The nearest cross street.
    3. The part of the house you are in.
- The phone number from which you are calling.
- Do not hang up until the ambulance company knows all they need to know.

If you are calling an ambulance for a spinal cord injured person, be sure to tell them about the injury when you call.

Prevention of Respiratory Problems

1. KEEP MOVING! If you don't, pneumonia could catch you!

2. GET OUT OF BED unless the doctor orders you to stay there.

3. DRINK PLENTY OF FLUIDS, 6-8 glasses per day.

4. INCREASE TURN TIMES WHILE CONGESTED up to every 2 hours. When the congestion gets better, GET BACK ON YOUR REGULAR SCHEDULE!

5. Have someone ASSIST COUGH you when needed.

6. Have someone do POSTURAL DRAINAGE AND CLAPPING when needed.

7. Take Tylenol or Advil for increased temperature.

When To Call the Doctor

1. If the mucous turns yellow or green.
2. If the amount of mucous increases.
3. If you have a temperature of 101 degrees or greater that will not go away with aspirin, Tylenol or Advil.
4. If you stay congested when you've tried everything you know to do.

Other Common Sense Things To Do

1. Avoid close contact with a person with a cold or the flu.
2. If you smoke, **PLEASE** try to quit. If you won't quit, smoke lighter brands. **DON'T** allow people to smoke in the room with you. Most people do not smoke as much if they have to smoke alone.
3. Dress for the weather, but always carry a light jacket in case you get cold.
4. Eat a well balanced diet. This helps keep resistance up and helps prevent infection.
5. Ask your doctor about getting a flu and pneumonia shot.

DON'T LET PNEUMONIA CATCH YOU!!!

Summary

We breathe about 12 times a minute or 720 times an hour. When you take a breath, air filled with oxygen is taken into the lungs. The lungs contain air sacs called alveoli. It is in the alveoli that oxygen is taken into the body and carbon dioxide is removed.

Breathing is controlled by special centers in the brain. Signals are sent from the brain to the spinal cord and out nerves which cause the diapragm to move. This draws air into the lungs. Abdominal and intercostal (rib) muscles assist in exhaling air from the lungs and in coughing or sneezing.

The level of spinal cord injury will affect the ability of the respiratory muscles and how they work. The higher the level of injury, the more respiratory muscle function will be lost. This loss of function can cause the lungs to become congested and infected. It is important to know what respiratory changes you have and how to keep your lungs healthy.

If your level of injury is T12 or above, there is some loss of respiratory muscle function.

What You Have Learned About the Respiratory System?

1. What parts of your respiratory system are affected by your spinal cord injury?
2. Have you had changes in breathing since your spinal cord injury?
3. What should you do to prevent a lung infection?

Special Concerns

6 **CHAPTER CONTENTS**

What You Will Learn In This Section

After reading this section you will be able to:

1. Describe problems which frequently occur following a spinal cord injury.
2. List the causes, signs, treatment, and prevention of these problems.

New Words

Cervical
The neck area, where eight cervical nerves carry messages for movement and feeling to the arms, the hands, the fingers and the diaphragm.

Dehydration
A serious condition occurring when water (fluid) level in the body is low.

Deep Vein Thrombosis (D.V.T.)
A blood clot which occurs in the legs or arms.

Dysreflexia
A serious condition in which the body overreacts to a painful stimulus and causes the blood pressure to rise (also called Autonomic Hyperreflexia, Autonomic Dysreflexia, or Hyperreflexia).

Heterotopic Ossification (H.O.)
An abnormal growth of bone in a joint.

Joints
A place in the body where two bones come together (example: elbow, knee, hip).

Muscle Tone
The springing action of a muscle. Firmness or tightness of a muscle.

Paraplegia
Paralysis of the legs.

Tetraplegia
Paralysis of the arms and legs.

TED Hose
Name brand elastic stockings worn on the legs to improve blood flow.

Body Temperature Control

Body temperature is controlled by a heat regulation center in the brain. If your spinal cord injury is T6 or above, you may have changes in temperature control.

This is because after a spinal cord injury, messages about being hot or cold cannot get past the spinal cord injury to reach the brain. Before injury to the spinal cord, when you were cold, your body would shiver to warm you. When you were too hot, your body would sweat to cool you.This process kept your body temperature normal.

When messages about being hot or cold cannot reach your brain because of your spinal cord injury, you will not sweat or shiver below the point of injury. This makes it hard for your body to control its temperature. As a result, your body may get too hot or too cold.

Overheating (Increased Body Temperature)

Causes:

- Staying in the sun or outside on a hot day for too long.
- Using too many blankets.
- Using a pool, bath, shower or hot tub that is too warm.

How to tell if your body is overheating:

You may feel

- very tired or weak
- dizzy
- faint
- thirsty

You may have

- headache
- cramps
- upset stomach
- flushed face
- elevated temperature

What to do if your body is overheated:

- Drink plenty of cool liquids (especially water)
- Sponge or mist your body with cool water.
- Remove any heavy or dark clothing
- Stay in a cool place, near a fan
- Take your temperature. If it is higher than 100° F, call the doctor.

KEY POINT: Tetraplegics and paraplegics injured above T6 may have a heat stroke if they get too overheated.

How to prevent your body temperature from becoming too high:

- Avoid being in direct sun or very hot weather for more than 15 to 20 minutes at a time.
- Stay in a cool or shady spot if you stay outside a long time.
- Spray your body with cool mist from a water spray bottle.
- Wear sunscreen to avoid sunburn.
- Do not drink beverages with alcohol as alcohol increases loss of body fluids.
- Drink plenty of water when out in the heat.
- Wear a hat or sun visor.
- Wear light colored, loose fitting clothing. Cotton fabrics will let air circulate.
- Avoid very active exercise in hot weather.

Lowered Body Temperature

Causes:

- Not dressing warmly enough in the cold.
- Staying in the cold too long.

How to tell if your body is too cold:

- Shivering above the level of injury.
- Pale or white hands, fingers, toes, lips and face.
- Take your temperature. If it is below 97.6° F, you are getting too cold.

What to do if you are too cold:

- Drink warm liquids like coffee, tea, and hot chocolate.
- Cover up with warm blankets.
- Move to a warm place. Remember, do not get your hands or feet too close to a space heater or fire; you may burn areas of skin.
- Dress in layers.
- Keep skin dry.

How to prevent your body temperature from becoming too low:

- Avoid being in cold temperatures for long periods of time.
- Check your skin for frostbite every hour if outside for a long time.
- Wear a sweater, coat, hat, and gloves when out in cold weather.
- Dress in layers.
- Do not drink beverages with alcohol because alcohol will make you feel warmer than you are.

Swelling

People with a spinal cord injury can have problems with swelling. Swelling is most common in the feet and ankles. Swelling occurs when extra fluid collects in the body tissues.

Causes:

- Loss of muscle tone.
- Loss of muscle movement.
- Decreased blood in the feet and legs.

What to do if you have swelling:

- When in bed, raise your legs and feet on 2 to 3 pillows. Be sure to position and pad yourself to prevent skin problems.
- When out of bed, raise your legs for 30 minutes several times a day. You may do this by raising the footrest of your wheelchair or by propping your feet and legs up on a chair or stool. Be sure to pad your feet, heels and ankles to prevent skin problems.

How to prevent swelling:

- Your doctor may order TED hose for you to wear. TED hose help to prevent swelling. When wearing TED hose, be sure to check your feet and ankles for any skin problems. Wear your TED hose at all times until your doctor tells you to not wear them. You may remove your TED hose twice a day for 30 minutes.

*Call your doctor quickly if any of the following occurs:

a. Swelling does not go away after being in bed all day.
b. The area becomes red and warm.
c. The swelling is in one leg or one foot only.

***KEY POINT:** This could mean that you have a D.V.T.

Fainting & Dizziness

Fainting or dizziness is caused by a sudden drop in blood pressure. This happens most often when you sit up quickly. It can also occur when getting up after being in bed for a few days.

A drop in blood pressure is caused by the slowing of blood flow and changes in the nervous system as a result of spinal cord injury. People with high cervical injuries have the most problems with fainting and dizziness.

What to do for dizziness:

- Have someone tip your chair backwards to lower your head and raise your feet. If you are in a reclining wheelchair, the back of the chair should be lowered and the footrest raised.
- If you are able to walk, lie down. All of the above things help to raise your blood pressure by getting the blood flow back to the brain.

How to prevent dizziness:

- Sit up slowly. Try propping up your upper body on a few pillows for about 15 minutes, then sit up.
- Wear TED hose if your doctor has ordered them.
- Wear an abdominal binder if your doctor has ordered it.

Blood Clots - Deep Vein Thrombosis (D.V.T.)

You are more likely to get a blood clot after a spinal cord injury because of decreased muscle movement, decreased blood flow in the legs and other changes in the cardiovascular system. The chance of having a blood clot is greatest right after injury. It is less common after a person begins getting out of bed and exercising.

Causes:

- Poor blood flow in the legs.
- Decreased muscle tone.
- Decreased exercise.
- Not able to move legs.

How to tell if you have D.V.T.:

- One arm or leg more swollen than the other
- Redness, swelling, tightness, hot or warm areas in the legs or arms
- More spasms than usual.
- Low fever (99° F to 101° F) with no other signs of infection.

What to do if you think you have D.V.T.:

- Call the doctor if you have any of the symptoms of D.V.T. This is a very serious problem.
- Stay in bed.
- Keep the leg straight.
- Do not bend that knee.
- Do not massage or rub the area.
- Do not exercise.
- Do not put foam pads or pillows under the knee area.

What you can do to help prevent D.V.T.:

- Get out of bed every day.
- Stay as active as possible.
- Do range of motion exercises daily.
- Wear TED hose if they have been ordered by your doctor.
- Drink 6 - 8 glasses of water daily.
- Before getting up in the morning, check your legs for signs of D.V.T.
- Stop smoking in order to improve circulation. If you are unable to stop, talk to your doctor for help to stop smoking.
- Don't strain during a bowel movement.
- Don't wear tight-fitting items like garters, girdles, tight jeans, tight socks or knee high pantyhose.

Heterotopic Ossification (H.O.)

Heterotopic Ossification (H.O.) is a buildup of new bone around joints in the body. This new bone continues to grow and causes decreased range of motion in that joint. About twenty percent of persons with a spinal cord injury have H.O.

H.O. usually occurs in the first year after injury and can affect the knees, elbows, and shoulders but is most commonly found in the hip joint. The cause of H.O. is unknown.

How to tell if you may have H.O.:

- Redness of a joint.
- Stiffness of a joint or decreased movement in joints.
- Swelling of a joint and in the arm or leg near the joint.
- Fever.
- Pain or discomfort.

What to do if you think you have H.O.:

Call the doctor right away if any of these signs occurs.

How to prevent H.O.:

Your doctor may have you take medicine to prevent new bone growth.

Spasms

Before spinal cord injury, a normal function of the spinal cord is reflex activity. There are protective reflexes which help to keep you from hurting yourself. For example:

1. A painful pressure is placed on the skin or muscle.
2. This pressure causes signals to be sent out from the nerves in the area.
3. These signals travel to the spinal cord and then to the brain.
4. As the signal reaches the spinal cord, it makes a loop.
5. A signal is sent back to the muscle telling it to move or jerk away from the discomfort.

The brain also plays a role in controlling your protective reflexes. Control centers in the brain send signals down the spinal cord to the muscles. These signals limit the reflex action to a single controlled movement.

After a spinal cord injury, reflex centers in the spinal cord are still present if your spinal cord injury is T12 or above. People with spinal cord injuries between T12 and L2 may or may not have spasms. Signals from the control center in the brain cannot get past the injury level in the spinal cord to limit and control the movement.

Here is what happens:

1. There is pressure on the skin or muscle. This is usually something that causes pain or discomfort. A light touch can also cause a spasm to begin.
2. These signals travel to the spinal cord. The signal cannot be sent past the injured part of the spinal cord to get to the brain.
3. The signal makes a loop through the spinal cord.
4. Then a message is sent back down to the muscle, telling it to move or jerk away from the pressure.
5. The signal from the control center in the brain cannot get past the block in the spinal cord to limit or control the jerking movement.
6. This is called a spasm.
7. The spasm will stop when the muscle gets tired or when the signals get weak.

What to do if you have spasms:

- Take the medicine the doctor orders to reduce spasms. (See list of medicines at the end of this section.)
- Keep body temperature at a normal level.
- Perform passive range of motion exercises every day.
- Prevent skin sores, bladder infections and other infections. (Sores and infections increase spasms.)

KEY POINT: A certain amount of spasms can be helpful with body movement. Spasms also help maintain muscle tone and improve blood flow to the muscles below the level of injury.

Severe spasms can lead to joint stiffness or pressure sores. An increase in spasms may be telling you that something is wrong and should be reported to your doctor.

Dysreflexia

Dysreflexia is a serious conditon. It is a reaction of the body caused by nerve signals trying to get to the brain. A spinal cord injury blocks the signals trying to get to the brain. This condition can happen if your spinal cord injury is T6 or above. Dysreflexia is an emergency situation.

When your bladder, bowels or skin are in trouble, they send signals to your spinal cord and a reflex begins. This reflex causes the blood vessels below your injury level to tighten. This makes it harder for the blood to pump through the blood vessels and causes the blood pressure to rise.

Your brain tries to send a message to the blood vessels to open up. These messages cannot get past the spinal cord injury. Therefore, your blood pressure keeps rising. A very high uncontrolled blood pressure can cause a stroke, heart attack or death. The blood vessels above your injury level open up and get larger to try to balance what is happening below the level of injury.

Causes:

- Your bladder or bowel when they are too full.
- Bowel program when done too long or too hard.
- Pressure on your skin.
- Pressure sores.
- Ingrown toenails.
- Bladder infections.

How to tell when you have dysreflexia:

The signs are:

- A severe pounding headache that gets worse.
- High blood pressure. You should know your normal blood pressure.
- Red blotches above the level of injury (face, neck, arms).
- Sweating above the level of injury.
- Goose bumps above the level of injury.
- Stuffy nose.

What to do if you have dysreflexia:

KEY POINT: It is important to do these in the order in which they are written.

1. Sit up if you are not already doing so (this helps to lower your blood pressure).
2. Remove or loosen tight clothing, such as your binder, TED hose, socks and shoes.
3. Do an I.C. If you have a foley or suprapubic catheter, check tubing for kinks. Change the catheter if the urine passage is blocked. If you use a condom, be sure the condom or condom strap is not too tight.
4. Do your bowel program. You may need to insert a numbing ointment like Nupercainal, Dibucaine or Xylocaine gel into the rectum. If doing a bowel program and dysreflexia occurs:
   - Stop the bowel program
   - Sit up if not already doing so.
   - Insert a local numbing lubricant like Nuprcainal, Dibucaine or Xylocaine gel into the rectum. (See the Bowel chapter of this book if needed.)
   - If signs of dysreflexia go away, resume bowel program.
   - If signs of dysreflexia continue or get worse, stop and call 911 or the emergency number in your area.
5. Check your skin and toes for ingrown toenails.
6. If there is no relief, go to the nearest emergency room right away or call 911 or the emergency number in your area. Have the Shepherd Center Personal Care Manual handy when you go to the emergency room and your Dysreflexia Emergency Card (see how to create a card later in this section).
7. If dysreflexia will not go away, and your blood pressure remains very high, medication will have to be given to lower the blood pressure.

How to prevent dysreflexia:

- Empty your bladder on schedule.
- Empty your bowel on schedule.
- Stay free of bladder infections.
- Know the signs of a bladder infection and notify your doctor if they occur.
- Stay free of constipation or impactions.
- Keep pressure off the skin.
- Prevent skin sores.
- Do good foot care and clip toenails straight across to prevent ingrown toenails.
- Stay free of all other infections.

Dysreflexia Emergency Card

Create a card similar to this below and carry it with you at all times.

Shepherd Center

Dysreflexia
Emergency Card

While waiting for an ambulance to arrive:

1. Keep the pt in a seated, upright position.
2. Loosen any tight clothing.
3. Stay with the pt until help arrives.
4. Give this card to the emergency medical technician (EMT).
5. Trained persons empty the bladder and bowel.
6. Medical personnel consider giving a high blood pressure controlling medication.

Card Front

Home Address

Phone #

In case of emergency, please notify

at

Card Back

Card Inside

What You Have Learned About Problems That May Occur After A Spinal Cord Injury

1. Have you had any of the complications discussed in this section? If so, which ones?

2. What signs did you have?

3. What did you do to treat the problem?

4. How can you prevent the problem from happening again?

Sexuality

7 CHAPTER CONTENTS

What You Will Learn In This Section

After reading this section you will be able to:

1. Define Sexuality.
2. Identify the parts of the female and male reproductive system.
3. List sexual options to consider after spinal cord injury.

New Words

Anus
The opening at the end of the bowel where stool comes out of the body.

Artificial Insemination
A process by which a physician uses a tube to put healthy sperm into the uterus so a woman may become pregnant.

Cervix
The neck of the uterus (womb) that protrudes into the back of the vagina.

Clitoris
One of the sexual organs in the female genitals which makes sex enjoyable.

Disability
Physical or mental changes which affect the way you do certain jobs and activities.

Dysreflexia
A serious condition in which the body overreacts and causes the blood pressure to rise. (Also called Autonomic Hyperreflexia, Autonomic Dysreflexia or Hyperreflexia.)

Ejaculate
To discharge or release sperm.

Emotion
The way you express feelings about an issue or person. Being sad, happy, excited and/or angry.

Erection
The process of the penis changing from being soft to hard.

Erection Aid
A device or medication that enables a man to achieve an erection for intercourse.

Erogenous Zones
Areas of the body that, when touched, give you sexual pleasure.

Fertilize
To join sperm and egg.

Genitals
The reproductive organs of males and females which can be seen.

Intercourse
Sexual relations involving the penis going into the vagina.

I.U.D.
Intrauterine device. A small metal or plastic object that is placed into the uterus of the female to prevent pregnancy.

Menopause
The time in a woman's life when menstrual periods stop and when pregnancies are no longer possible.

Menstrual Period
A discharge of tissue, blood and secretions from the uterus.

Orgasm
Intense, usually pleasurable release of sexual energy.

Penile Implant
A device inserted into a penis to make it erect (hard).

Penis
The male organ which has three main functions: to pass sperm into a female in order to have a baby; to obtain sexual pleasure; and to allow a male to urinate.

Prostaglandin
A natural body substance found in many different body organs.

Prostate Gland
A gland that provides 50% of the protective fluid (semen) for sperm.

Psychotherapist
A person who helps with personal feelings and provides supportive care. One who gives you the chance to express grief and concerns.

Reproductive System
The male and female systems which work together to produce children.

Scrotum
The sac that holds the testes.

Spermicide
Foam or cream that kills sperm.

Testes
The place where the sperm and testosterone are produced in a man.

Urethra
The tube leading from the bladder to the outside of the body.

Uterus
The female organ that holds a growing unborn baby and from which the menstrual fluid comes.

Vagina
Often called the "birth canal." The canal from the uterus to the outside of the female body.

What Is Sexuality?

Sexuality includes physical, emotional, intellectual and social characteristics of a person's personality. Sexual intercourse or other types of sexual acts are only one part of sexuality. This leaves many other ways to express your sexuality.

How can I have positive sexual expression?

The basic way to have healthy and positive sexual expression includes understanding how to:

- Listen
- Communicate your feelings, thoughts and desires.
- Express yourself sexually in a positive, healthy way.
- Practice expressing yourself.
- Experience sexual pleasure without having erections and orgasms.
- Use all of your senses, including sight, hearing, smell and taste, as well as touch.

What is good communication?

Good communication includes the ability to talk with your partner about:

- Your needs.
- Your likes.
- Your dislikes.
- Your disabilities.
- Your anger.

Good communication also includes listening to your partner when he or she expresses the same desires and emotions to you.

What can good comunication do?

- Prevent misunderstandings between you and your partner.
- Help you prepare for sexual relations.

Where can I learn good communication skills?

While at Shepherd Center, your counselor or psychologist can help. Continued counseling after leaving Shepherd Center may also help in learning these skills.

KEY POINT: Good communication skills are an important part of sexual therapy.

What are erogenous zones?

There are many areas of the body that when touched will give you sexual pleasure. These sexy spots are called erogenous zones. Finding these zones with your partner can increase sexual pleasure and communication. Many areas can increase sexual pleasure, including your ears, neck, armpits, nose, arms, nipples, eyelids, cheeks, lips and cervix.

The Female Reproductive System

A woman's reproductive system includes the clitoris, vagina, uterus, fallopian tubes, ovaries and breasts. These parts work together to allow a woman to enjoy sexual intercourse and to have children. (See Figures 1 & 2).

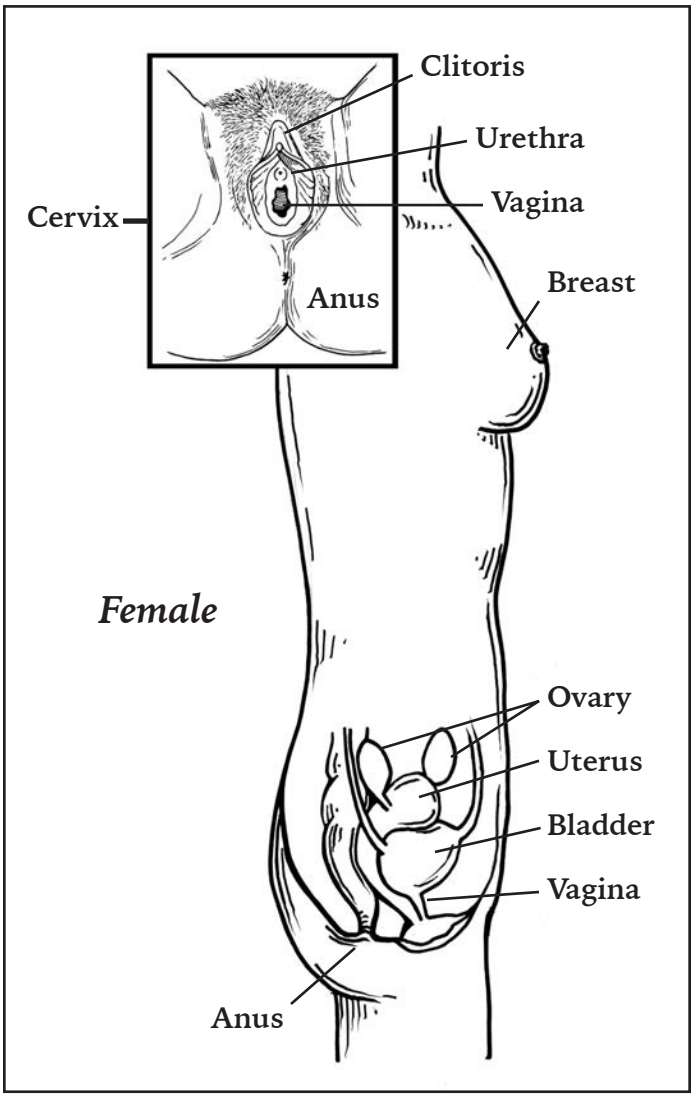


Figure 1 and 2 (inset)

The Clitoris

- The clitoris is above the urethra.
- This is the part with the most feeling of sexual pleasure for most women.

The Vagina

- The opening of the vagina is located between the urethra and anus.
- It is a muscular tube that stretches open when a penis is inserted during sexual intercourse.
- If a woman is pregnant and has a natural birth, the baby passes out of the woman through the vagina.
- This is why the vagina is called the birth canal.

The Uterus

- The uterus is located in the lower abdomen or pelvis.
- The uterus, or womb, is a muscular organ which provides a safe place for a growing unborn baby. The uterus stretches larger as a baby grows. The section of the uterus that protrudes into the vagina is called the cervix.

The Fallopian Tubes

- The fallopian tubes carry an egg from the ovaries to the uterus.
- Women usually have two fallopian tubes.
- This is also the area where an egg is fertilized by sperm.
- The fallopian tubes keep the fertilized egg warm and moist as it travels to the uterus.

Ovaries

- There is one ovary located on each side of the uterus.
- The ovaries are two almond-shaped organs where the eggs develop.
- Normally, at least one egg is released into the fallopian tubes each month to be fertilized.
- When a woman is in her mid-forties to early fifties, no more eggs mature. This is a part of the process called menopause.
- The ovaries are also responsible for producing the sex hormone testosterone. Testerone is important for producing sexual drive in women.

The Breasts

- The breasts' function is to provide a newborn baby with nutrition. They are also an area of sexual pleasure.

Questions About Female Sexuality After Spinal Cord Injury

What sexual changes must a female consider after a spinal cord injury?

Four areas need to be considered:

- Bladder elimination
- Fertility
- Lubrication
- Orgasm

How is fertility affected?

The ability to become pregnant and give birth is usually not affected by a spinal cord injury. A female may miss some menstrual periods after a spinal cord injury. Some may miss up to six periods and others may miss none at all. The menstrual cycle almost always returns to normal. It is important to remember that you can become pregnant even if you miss a period. Use birth control if you do not want to become pregnant.

If I want to become pregnant, is there anything I need to know first?

Choose a doctor who is familiar with spinal cord injury and pregnancy. Or, find a doctor who is open to learning about the special needs of a pregnant woman with a spinal cord injury. It is important to get a physical exam to check your overall health. Your bladder and kidneys will need to be watched closely while you are pregnant.

Are there any problems I might have with pregnancy because of my spinal cord injury?

Some woman who are injured at T6 and above may have symptoms of dysreflexia. (See Special Concerns Section.) Special precautions need to be taken during labor to prevent dysreflexia.

- The opening to the womb may be thin and result in an early delivery. However, most women with a spinal cord injury have a normal delivery.
- If your injury is above T10, you may not experience labor pains. Some women wear a piece of equipment at night that tells them when labor is beginning. Discuss all of your concerns with the doctor before you are pregnant or soon after your become pregnant.

If I do not want to become pregnant, what is the safest method of birth control?

The best choice to prevent pregnancy is a combination of methods. Condoms used with spermicide foam or a diaphragm used with spermicide cream are two methods to use. Birth control pills may increase your risk of blood clots. I.U.D.s are dangerous because if they are not in the right place, you will not know it. Some women choose to have surgery to prevent pregnancy. Patches and injections are other options to consider.

Will I still have orgasm after spinal cord injury?

Many women with spinal cord injury have an orgasmic response to stimulation of their cervix (see Figure 2). A nerve connects the cervix directly to the brain. Even women with no sensation may be able to achieve orgasm.

How does a spinal cord injury affect lubrication?

Spinal cord injury usually de-creases the body's ability to produce lubrication. This is easily fixed by using a water based lubricant like Astroglide or K-Y Jelly. Do not use lubricants that have oil in them. The lubricant should be applied while touching and every three minutes during any sexual activity. This includes touch other than oral sex.

KEY POINT: Remember, always use a lubricant unless your sex therapist or doctor tells you it is not required.

What should be done about my bladder program before having sex?

- If you have an indwelling catheter, coat it with a lot of K-Y Jelly and tape it to your abdomen before having sexual activity.
- If you do I.C.s, always empty your bladder before and after having sexual intercourse.

KEY POINT: If good hygiene is practiced and the bladder is emptied, having sex does not increase the chance of getting a bladder infection.

The Male Reproductive System

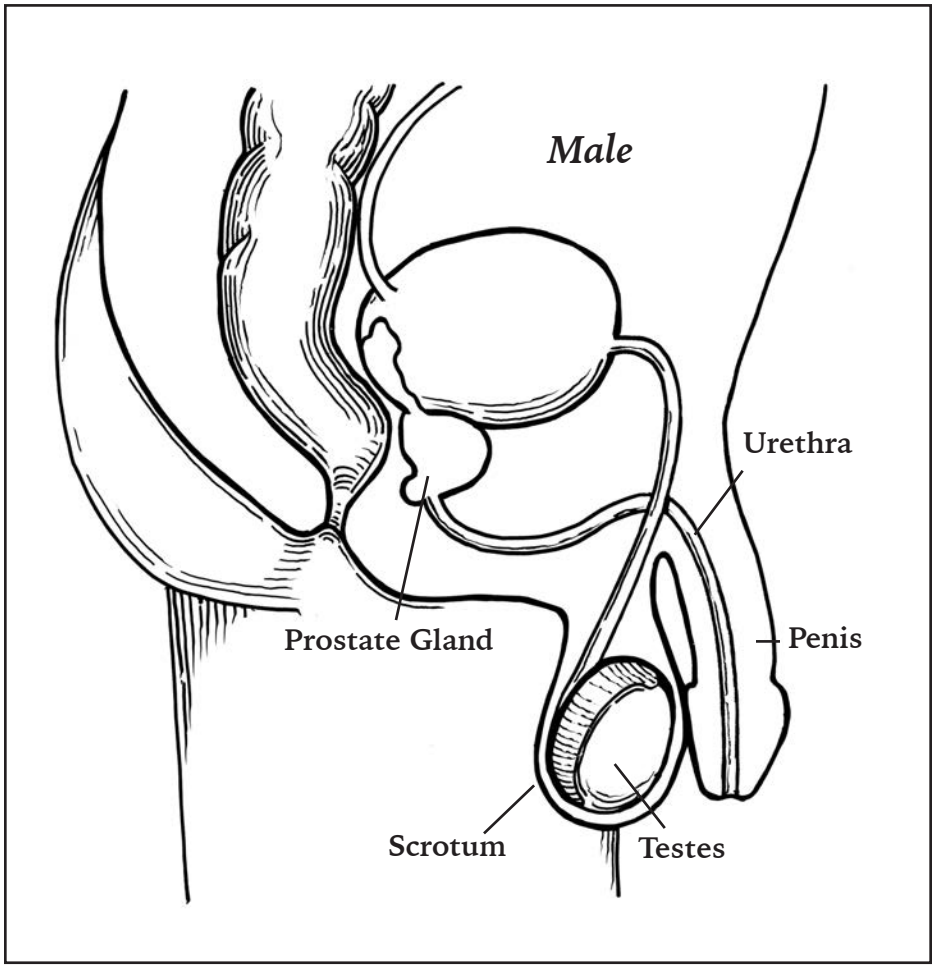


Figure 3

A man's reproductive system includes the penis, testes, scrotum and prostate gland. These parts all have a role in sexual pleasure and allowing a man to father a child. (See Figure 3.)

The Penis

- The penis plays a part in both the urinary system and the reproductive system.
- Urine is passed out of the body through the penis.
- A major purpose of the penis is to pass sperm into the vagina during sexual intercourse so sperm can swim to the fallopian tubes and an egg can be fertilized, resulting in pregnancy.

The Scrotum

- The scrotum is a sac that houses the testes and keeps the temperature lower than body temperature.
- The scrotum is very sensitive to touch, pressure and temperature, and protects the testes from harm.

The Testes

- The testes are oval shaped organs contained in the scrotum.
- The testes are where sperm is produced. The sex hormone testos-terone is also produced in the testes. The production of this hormone is not affected by a spinal cord injury.

The Prostate Gland

- The prostate gland is located below the bladder.
- The prostate gland provides a thin, milky fluid that sperm swim in for protection and nourishment.

The Breasts

- The breasts in men are sensitive to touch and can be an area of sexual pleasure.

Questions About Male Sexuality After A Spinal Cord Injury

What sexual changes must a male consider after a spinal cord injury?

There are five areas that need to be considered:

- Fertility
- Erection
- Ejaculation
- Orgasm
- Bladder elimination.

How is fertility affected?

In the past, most men with spinal cord injuries were unable to ejaculate. Now ejaculation can occur with procedures like Electroejaculation and Vibrastimulation. With these techniques, the male may ejaculate sperm so that it can be placed in the woman by a doctor (artificial insemination). This is successful in about 30% of males with spinal cord injuries. Spinal cord injury does make the sperm slower and less effective, making it more difficult to father children.

Erections

First, it is important to know that there are two kinds of erections.

1. Psychogenic – This erection is a result of the brain thinking about something sexual.

2. Reflexogenic – This erection is the result of direct stimulation of the penis. This is not control-led by the brain. A full bowel and bladder sometimes cause this type of erection.

How do erections change?

If a male has a complete spinal cord injury above L2, he will not be able to have a psychogenic erection. How-ever, the desire and excitement in the brain remains the same as before injury. Most males with spinal cord injury are able to have a reflexogenic erection. It can happen at any time, even when you have no interest in having intercourse. This type of erection may not remain hard long enough or be firm enough to complete sexual intercourse. If your injury is below L2, neither type of erection may occur.

Is there anything I can do to overcome problems with erection?

There are several things you can do to have erections. Several types of oral medication have been approved for use by men with and without spinal cord injuries. While success for men with spinal cord injury is not universal, it is still useful for many men.

The Osbon Erecaid is a vacuum pressure device that draws blood into the penis. This usually causes an erection that lasts for 30 minutes so that you can have sexual intercourse. This device can be used many times in one day. The Osbon Erecaid is used outside of the body so no surgery is needed. It is also one of the least expensive ways to overcome an erection problem.

There are several types of penile implants for men with spinal cord injury that are inserted with surgery. They are called penile prostheses. Penile implants must be used with caution.

Some spinal cord injured patients get injections into the penis to have erections. A small pellet can also be inserted into the urethra. This product, called Muse, has helped some men attain erections.

You should discuss these treatment options with a urologist. This kind of doctor handles issues related to erections and having children after the injury.

Will I ejaculate?

Ejaculation is usually impaired in men with a spinal cord injury. Some-times the sperm back up into the bladder. Ejaculation may be very weak or stop altogether.

Will I still have orgasm after spinal cord injury?

As with females, the ability to have orgasm depends on the amount of sensation below the navel. Again, you most likely will continue to experience all pleasure leading up to and following orgasm. The more erogenous zones used, the greater the ability for pleasure.

What should be done about my bladder program before having sex?

- If you do I.C.s or reflex void, always empty your bladder before and after having sexual intercourse.

KEY POINT: If good hygiene is practiced and the bladder is emptied, having sex will not increase the chance of getting a bladder infection.

This may not answer all your questions about sexuality. You may have many more questions. Feel free to ask your counselor, or psychologist any questions you may have about sex.

KEY POINT: Whenever possible, it is important and helpful to include the partner in sex therapy.

Summary

Being able to express yourself sexually after a spinal cord injury takes practice. Good communication becomes very important. Knowledge of the body's sexual function is also important so that children may be produced, marriages and relationships can grow and problems can be prevented.

All senses should be used to provide sexual pleasure. Finding the erogenous zones (sexy spots) with your partner can increase sexual pleasure and communication. Remembering that sexuality includes more than sexual intercourse is most important to be able to remain a sexually happier person.

What You Have Learned About Sexuality

1. What four things are included in sexuality?
2. What are your erogenous zones?
3. What type of lubricant should be used for sexual intercourse?
4. What should be done to the bladder before and after sexual intercourse?
5. What kind of doctor do you want to talk to about problems with erections or having children after the injury?

Medications

8 CHAPTER CONTENTS

What You Will Learn In This Section

After reading this section you will be able to:

1. Describe how to use the medicine information sheet and medicine card.
2. List the medicines you take and when to take them.
3. Explain how to take each medicine the doctor orders.
4. List the side effects of all the medicines you take.

New Words

Antacid
Medicine taken for an upset stomach.

Antibiotics
Medicine that kills the germs which cause infections.

Expiration Date
The date a medicine becomes too old to take.

Laxative
A medicine to make the bowels move.

Pharmacist
A person who fills the medicine prescription the doctor gives you. A pharmacist also answers questions about medicines.

Pharmacy
An area located in many drug stores and hospitals where prescriptions for medicine are filled.

Prescription
Written directions to the pharmacist from the doctor about a medicine.

Prescribed Medicine
Medicine which must be ordered by a doctor.

Tetanus
A disease that causes spasms and pain, especially of the jaw.

Tranquilizer
A medicine that reduces anxiety and tension.

The Pharmacy

When you leave Shepherd Center, you will most likely be taking medicine that your doctor prescribes. To avoid problems, it is important to know about the medicines you take.

Shepherd Center has a pharmacy which assists you and your family to understand each medicine prescribed. The pharmacy gives you medicine information sheets and medicine cards to help you learn about the medicine you take.

The Medicine Informaton Sheet

The medicine information sheet provides the answers to the following questions:

- Why am I taking the medicine?
- When should I take the medicine?
- How shall I take the medicine?
- Are there any special instructions to follow while taking the medicine?
- What should I do if I forget to take the medicine?
- Are there any side effects that the medicine may cause?
- Are there any food or drugs that do not mix with the medicine?

During discharge counseling before you go home, the pharmacist gives you information sheets on each medicine you take. After discharge, drug information sheets are available from the pharmacy.

Here is an example of the information contained on the medicine sheet for Lioresal:

Lioresal

Common Name: Baclofen

Why is this medicine prescribed?

Lioresal is used for patients with a spinal cord injury for treatment of spasms.

When should it be taken?

Your doctor determines how often you should take Lioresal. Follow the instructions carefully on your prescription label and ask your pharmacist to explain any part that you do not understand.

How should it be taken?

Lioresal comes as tablets to be taken by mouth. Your prescription label tells you how much to take at each dose. Your doctor may change the amount of Lioresal you take until he finds the dose that is best for you.

What should I do IF I FORGET a dose?

Take the missed dose as soon as you remember it. Take any remaining doses for that day at evenly spaced times. DO NOT take a double dose to make up for the missed one.

What SIDE EFFECTS can this drug cause? What can I do about them?

Dizziness, weakness, confusion, headache, difficulty sleeping, nausea or large amount of urine: contact the doctor, but DO NOT stop taking Lioresal until the doctor tells you to.

What OTHER PRECAUTIONS should I follow while taking Lioresal?

While you are taking Lioresal, stay in touch with your doctor. DO NOT allow anyone else to take this medicine. Keep out of reach of children.

The Medicine Schedule

A medicine schedule is available to you from the pharmacy to help you keep a record of the medicine you take during a weekend pass.

The medicine schedule reminds you:

- what medicine to take.
- when to take it.
- how to take it.

After you are discharged from Shepherd Center, keep the schedule with your medicines. Remember to bring the schedule to all Outpatient Department visits. This helps to keep the schedule up to date.

Here is an example of a medicine schedule:

Patient Name: John Doe														
	Time													
	6a	8a	9a	10a	12n	1p	2p	4p	5p	6p	8p	9p	10p	12mn
Medication														
Geocillin 382mg 2 tablets, 4 times a day	X	X	X	X										
Coumadin 2.5mg 1 tablet at nigh					X									
Lioresal 10mg 2 tablets, 3 times a day	X				X X									

Family Training

During discharge counseling, you meet with the pharmacist. The pharmacist discusses general information to remember. Here are some key tips:

1. Always follow the doctor's directions and the label directions.

2. Do not take more or less of any medicine. **Only take what is prescribed.**

3. Take the complete number of doses ordered.

4. It is important to take all the doses of an antibiotic to prevent an infection from returning. Keep taking the antibiotic even if you feel better.

5. Do not take any medicine all at once unless instructed to do so by the doctor.

6. Ask the pharmacist to put the name of the medicine, the strength and the expiration date on the label of each medicine.

7. Be familiar with all information on the medicine sheet.

8. If you miss a dose, do not double up the next dose.

9. Some medicines are taken with food to prevent an upset stomach. Take these medicines after a meal or small snack.

10. Other medicines are taken on an empty stomach. Take these medicines with water, not with juice or milk.

11. Remember, the medicines are only for you and can be harmful if someone else takes them. Do not let anyone else take your medicine.

12. Store medicine in the container it comes in.

13. Keep all medicine out of the reach of children.

14. Do not save medicine to use later for other problems.

15. Check with the pharmacist before you mix other drugs or alcohol with the medicine you take.

16. If you live in Georgia and your child should accidentally take your medicine or if you accidently take too much, call the **Georgia Poison Center at 1-(800)-282-5846**. Keep this number by the phone, especially if you have small children.

17. If you have private insurance, and if you wish, Shepherd Center's pharmacy will provide a one-month supply of medicine after discharge. The Shepherd Center Apothecary accepts Medicaid for prescriptions and supplies.

18. It is important to decide which pharmacy you will use after you go home. When a medicine needs refilling, call the outpatient nurse with your pharmacy phone number and the name of the medicine. The medicine order is called to your local pharmacy by 5 p.m. that day.

19. When you visit Shepherd Center or if you live nearby, you are welcome to use the Shepherd Center Apothecary.

What to Know About Getting

Your Medicines For a Weekend Pass

- Talk to your case manager by Wednesday before the weekend you plan to go on your pass.
- Inform your nurse if you plan to leave before 4 p.m. Friday.
- Pick up your medicines at the inpatient pharmacy by 6:00 p.m. on Friday. You will get a two-day supply of medicine and one extra dose.

Medicine Side Effects

Sometimes unexpected changes happen when you take medicine. These changes are called side effects. Many times they go away as your body gets used to the medicine. Other side effects can be dangerous and require that you call the doctor. The doctor may tell you to stop taking the medicine.

Taking certain medicines together may cause unwanted side effects. You should always tell the doctor, nurse or pharmacist about all medicines you take. This includes medicines such as aspirin, Maalox, laxatives and cold medicines.

KEY POINT: If you have a headache or fever when you are home, check with your doctor before taking aspirin. Tylenol, Panadol, etc. are usually the best choices because aspirin will thin your blood and does not mix well with many medicines.

The following are some common medicines prescribed at Shepherd Center. Notice which medicines should not be taken together and helpful hints to make the drugs work the best for you.

Lioresal – May cause drowsiness or dizziness. Do not take with alcohol, beer or wine.*

Septra-DS or Bactrim-DS – Take 30 minutes before a meal with a large glass of water.

Motrin or Rufen – Take with milk or meals.

Ditropan – May cause dry mouth, drowsiness or dizziness. Use hard candy or gum to relieve dry mouth. Do not take with alcohol, beer or wine.*

Elavil – May cause drowsiness and dry mouth. Use hard candy or gum to relieve dry mouth. Do not use alcohol, beer or wine.*

Keflex – Do not take with milk or meals.

Colace or Surfak – Drink a large glass of water with each dose.

Probanthine – Take 30 minutes before meals and at bedtime. May cause dry mouth. Use hard candy or gum to relieve dry mouth.

Zantac – Do not take antacids at the same time you take Zantac. Take antacids two hours before or after taking Zantac.

Aspirin or Bufferin – Take with milk, meals or with a large glass of water.

Carafate – Take on an empty stomach at least one hour before or two hours after meals and at bedtime. Do not take antacids 30 minutes before or after taking Carafate.

Didronel – Must take on an empty stomach at least two hours before meals and must take with fruit juice or water. If your stomach gets upset, divide the dose and take at two different times.

Tegretol – Take with food or milk.

Tylenol – Take with a large glass of water and on an empty stomach for faster results.

Tofranil – May cause drowsiness or dizziness. Do not take with alcohol, beer or wine.*

Dantrium – May cause drowsiness or dizziness. Do not take with alcohol, beer or wine.*

** Alcohol includes any liquid medications containing alcohol such as Nyquil, Suda-fed, Robitussin, and Benadryl syrups.*

KEY POINT: If you are taking any of the following medicines, you must have a blood test done: Dantrium, Tegretol or Coumadin. You will not be given a refill of these medicines if you do not have your blood test done. These blood tests are done to make sure you are taking the right amount of medicine.

Summary

Medicine plays an important role in changing the way your body works. Medicine can be helpful or dangerous! This section increases your understand-ing of how to take medicine properly. Not all medicine is taken the same way. Shepherd Center's inpatient pharmacy provides individual medicine sheets to help you understand about each medicine. Medicine schedules will remind you what time to take each medicine. Family training prepares you and your family for medicines for weekend passes and taking medicines after discharge.

There are many medicines that do not mix with food and other medicine. Most medicines should not be taken with alcohol, beer or wine.

Remember, taking medicine is serious and should be done carefully. If you have any questions, contact the Outpatient Department or the Pharmacy.

What You Have Learned About Taking Medicine

1. What does the medicine information sheet tell you about the medicine being taken?

2. What does the medicine schedule help you remember about your medicine?

3. Keep taking an antibiotic medicine even if you feel better.
   T or F

4. Can you drink alcohol while taking most medicine?
   Yes or No

Emotional Adjustment After Spinal Cord Injury

9 CHAPTER CONTENTS

What You Will Learn In This Section

After reading this section you will be able to:

1. List the psychological services offered at Shepherd Center.
2. List the common false beliefs about disability.
3. List ways to increase adaptation (adjustment) to a spinal cord injury.

New Words

Able-bodied
Having a sound, strong body without disabilities.

Adaptation
Adjusting to changed conditions. For example: a spinal cord injury.

Alcoholics Anonymous (AA)
A 12-step program designed to help people who have trouble with alcohol.

Chaplain
A person who provides spiritual support.

Counseling
Professional guidance in dealing with problems.

Disabilities
Physical or mental problems which change the ability to do certain jobs and activities.

Frustration
A deep sense of disappointment and insecurity.

Grieving
A process involving many different feelings (such as sadness and anger) related to the loss of a loved one or one's own physical abilities, and life changes.

Motivation
A strong desire or drive to accomplish something.

Peer Supporter
A former patient who volunteers to come in and answer patient questions.

Psychologist
A person who helps people manage feelings and problems. A psychologist also provides practical skills on how to deal with the changes brought on by spinal cord injury.

Psychotherapy
A way of coping with problems by discussing them with a psychologist/counselor who helps to identify the problem, suggests ways of dealing with the problem, and offers support in this process.

Rehabilitation
To return individuals to the highest level of function possible with the level of injury.

Emotional Concerns

It takes a long time to deal with the feelings and changes that result from a spinal cord injury. Sometimes you may feel sad, angry, confused, scared, lonely or out of control. You may also discover strengths that you did not know you had , grow more confident in yourself as you learn new skills, and develop new interests and abilities. Relationships with family and friends are tested and may change. You may feel overwhelmed and try to act like nothing has changed. Everyone copes with these feelings in different ways. With time and support from family and friends, as well as a counselor or psychologist from Shepherd, you will begin to adjust to your spinal cord injury and set new goals for your future.

Seeing a psychologist/counselor does not mean that you are crazy or adapting poorly.

In fact, all patients at Shepherd are seen by a psychologist and/or counselor because rehabilitation includes both the body and the mind. A psychologist and a counselor help by giving information about things like:

- How to adapt to changes in your body.
- How to adjust to lifestyle changes resulting from spinal cord injury.
- How to understand the grieving process as it relates to your physical losses and resulting life changes.
- How to manage your many feelings, especially about your spinal cord injury.
- How to cope with anxiety and depression that may be interfering with your rehabilitation.
- How to deal with drug and alcohol problems.
- How to deal with chronic pain.
- How to deal with parenting.
- How to deal with sexuality after your spinal cord injury.
- How to manage stress.
- How to set new goals for yourself and your life.

Counseling Key Classes will help you to express your feelings with others who are going through similar experiences. The class also provides education on many possible ways to cope with your injury. Peer supporters will meet with you to discuss how they have coped with spinal cord injury and found satisfying lives for themselves. Peer support meetings are held on a regular basis to provide education and support. You can continue to attend these meetings after you are discharged.

Family Issues

Family members have many of the same feelings as the person who is injured. Shock, anger, hope, sadness and anxiety are all feelings that family members may experience. There are no right or wrong feelings. At first, it may be difficult for family members to show their feelings to you. They may be concerned that doing this could depress you. However, once you feel able, you can let your family know that it is all right to talk with you about their concerns, questions and feelings. Being open with your own concerns and feelings will set a great example.

No one ever "gets over" a spinal cord injury, but as the months and years go by, adjustment occurs. The best way to make a healthy adjustment is to keep an open mind during your rehabilitation. Taking advantage of all the therapeutic opportunities, talking about your feelings and concerns, and meeting other people with both new injuries and old injuries are all key behaviors that will lead to healthy adjustment.

How to Cope

While everyone deals with stress and change differently, there are key things you can do to increase your chance of success in coping emotionally. Most of these come from breaking down false beliefs that you, your family and friends have related to disability. These false beliefs include:

1. "I need to be depressed for awhile before I work on my rehabilitation goals."

Depression is not a requirement after you've had a spinal cord injury. However, sometimes depression can occur as you struggle to cope with the many changes resulting from a spinal cord injury. Your psychologist/counselor can help you tell if you are depressed.

2. "If only I had a lower injury or if it was more incomplete, life would be better."

The ability to change and cope depends on your personality. A person with an incomplete injury often has the most emotional difficulty because the injury is less obvious. A person may feel guilty for doing so much better while others have a higher level or a more complete injury.

3. "I already know how to adapt."

While many people have great strengths and family support during rehabilitation, no one is fully prepared for either the changes or the challenges. In many ways, rehabilitation many ways, rehabilitation is like school. People can be very smart without schooling, but education helps teach them things they may not have experienced in life. A few of the topics you may discuss with a psychologist/counselor include communicating with family and friends, lifestyle changes, dating, parenting, and job interviewing.

4. "My spinal cord injury will cause divorce."

Spinal cord injury will cause divorce only if you and your spouse let it. The divorce rate is the same for people with and without disabilities. People get divorced for hundreds of reasons, usually concerning communication. You will have to be better at communication after a spinal cord injury. You need to be able to communicate your needs, thoughts and feelings.

5. "There is a time when adaptation is over."

There are many stresses connected to a spinal cord injury. At first, you may worry about surviving your injury. You may then worry about doing well in rehabilitation. Later, you may worry about finances or career choices. You will continue to learn and adapt during your life. Adaptation is a life-long process.

6. "I am the only one affected by my spinal cord injury."

The disability is a shared experience. You, your family, friends and employer all need to learn to deal with this change in their lives. Family members need to learn when to help and when not to help. Their issues may be different from yours. Their issues may deal with such things as fear, change in responsibilities and guilt. Open communication will help everyone to know how those concerned are feeling.

7. "I will not use drugs again or I will not drink again."

Many times, alcohol and/or other drugs are involved in the circumstances during which spinal cord injuries occur. Often, people believe that their alcohol/drug habits will change following such a catastrophic event. Even if your intention is to stop, "guts" alone rarely works with habits like alcohol and drugs. The people with the most success are the ones who not only use their motivation to quit but also use help such as Alcoholics Anonymous and counseling. Often, people say they will do this after leaving the hospital. But, the best time is while you're in the hospital.

What Is Normal Adaptation?

Normal adaptation involves:

- Having a wide range of feelings without getting stuck in one feeling. These include sadness, frustration, denial, anger, happiness, boredom, and excitement.

- Realizing that you control your moods. You do things to make yourself feel worse and feel better. For example, being around people can decrease your depression.

- Knowing what you do not know. Asking for help and knowing where to get help are learned skills. Building a support system through your family, hobbies, friends, church, peer support or counseling is important in the prevention of bigger problems.

- Addressing the permanence of the injury. This does not mean giving up hope or liking the fact that you are paralyzed. It means realizing that this is the way life is right now and finding ways to enjoy it. You have to live life as it is today. Wishing the accident never happened is a normal feeling. Hoping for a cure is a normal feeling. Stopping your life because of your wish to change the past or to wait for your preinjury life to return unchanged can often lead to depression.

- Fitting the disability into how you see yourself. This means that instead of the disability being an "outside" factor to become frustrated over, it becomes one of many ways you can describe yourself. For example, you may describe yourself as a tall, good-looking, balding male with a C-5 spinal cord injury. This does not mean that it is abnormal to dream or fantasize about being able-bodied, just as it is not abnormal for people to dream about being pro football players. So long as it does not stop you from living your life, it is just part of being human.

Coping with Pain

Pain or unusual physical feelings are common in people with spinal cord injury. About two-thirds of patients report chronic pain in areas of their body below their injury level. Often these feelings are described as burning, tingling or feeling like "pins and needles" in their buttocks or legs.

This chronic pain is very different from acute pain. Acute pain is short-term pain that happens after an event, like burning your hand on a stove or breaking your arm. It is a signal of danger, telling you that something is wrong and that you should do something to correct it. Chronic pain "hurts" as much, but does not mean that something is wrong that can be corrected easily. Pain can still occur in paralyzed parts of your body or even in missing limbs because pain is a learned process. That is to say, your brain interprets sensations from your body and calls it pain. After spinal cord injury, the brain can "misinterpret" nerve messages in the spinal cord or in damaged nerves as "pain". There is no specific "cure" for the pain in certain areas because even though the pain might feel like it is in one area of the body, it might start in another. In fact, the skills that you normally would use in coping with acute pain, like taking pain killers, focusing on your pain in order to understand more about it, and decreasing your activity level, may make chronic pain worse. While in many cases, treatment cannot remove chronic pain, it can decrease the suffering that results from lack of knowledge and poor ways of coping. After the doctor has determined a lack of acute problems that could be causing the pain, the following steps can be taken to decrease the effect of the pain in your life:

1. Temperature often affects people with pain in the lower extremities following spinal cord injury. Taking care to provide warmth and circulation to your legs can often help decrease problems.

2. Stop smoking. Nicotine decreases circulation in your legs and acts in the same way lower temperatures do in increasing pain.

3. Decrease alcohol. Alcohol and other drugs decrease your body's own ability to tolerate pain, and research has shown that people who use a lot of alcohol or drugs have a lower tolerance for pain - even many months after stopping their use.

4. Keep a pain diary for one week. Rate your pain on a 1 - 10 scale (1= none, 10 = severe) every hour you are awake for one week, describing your activity at the time of each rating. At the end of the week review it and see if the increase or decrease of pain coincided with changes in activity level, bowel or bladder care, emotions, exercise, etc.

5. Take care of yourself. Eating right, getting plenty of rest, exercising and recreation are all important in pain control. Most people find that they limit their socializing due to their pain, but this only makes the pain worse. The pain is now controlling their lives. Increasing your activity level, knowing your limits and building in rest times decreases pain problems.

6. Stop letting it control your life. Often, people let the pain take over their lives and make it a topic of conversation with everyone they meet, making it hard for people to want to stay around them. Try to look at ways you unconsciously let people know you are in pain (wincing, gripping the painful area). See if you can tolerate more

pain without making people aware of it. Try to tolerate pain by imagining another cause for your pain. For example, imagine that your shoulder pain is an injury from the last minute touchdown that won a football game. Pain in your legs could be imagined as the pain after a good physical therapy workout. The more positive the fantasy, the more the pain will be tolerated.

7. Watch for depression. Your mood can greatly affect your ability to cope with pain. Learn how to deal with your emotions and how to relax to help you with pain relief.

8. Reduce or do not use "pain killers" unless prescribed by your doctor. Drugs used for treating acute pain or sleeping problems only increase chronic pain problems. They interfere with your body's own ability to deal with pain.

9. See if positioning affects your pain. If you feel less pain in certain positions, you may need an evaluation to determine if you are developing posture problems because of the way you sit. Perhaps you are having problems with body mechanics.

10. Low dose medicines prescribed by your doctor often aid in pain relief. These medicines are non- addictive and are not called "pain killers" - that is to say, they are not used for acute pain, but are good for chronic pain problems. Other pain management techniques are effective in helping with pain control, such as: TENS, bio-feed-back, relaxation, and hypnosis.

Pastoral Services

When to Contact a Chaplain:

There are many situations when a chaplain can be useful to you. Some examples are:

- You or your family are upset or overwhelmed by your situation;
- You or your family are losing hope and motivation for being in rehabilitation or hospitalized;
- You or your family are having difficulty with accepting medical information in light of your faith and beliefs;
- You or your family are "home-sick" for support and community of friends and family;
- You or your family are having difficulty with understanding and and making sense out of why this accident/ situation occurred;
- You or your family feel guilty or angry about the way other people have used "religion" or "God talk" to explain your situation;
- You or your family are interested in talking about Advance Directives or end of life decisions;
- You or your family would like a minister, priest or rabbi of your faith contacted.

Calling a Chaplain:

The chaplain can be reached at 404 350-7328. Please leave a message on voice mail unless your call needs immediate attention. If your call is urgent, contact the Center's Operator (dial "0") and the operator will page the chaplain for you.

In the event of a medical emergency after daytime hours, nursing staff can call the chaplain at home.

Pastoral Suggestions for Family and Friends Visiting Patients

- Always listen to the patient without offering advice.
- Talk with the patient about the accident or illness only if the patient does so.
- Treat conversation with the patient normally - talk about usual subjects of interest.
- Keep your comments simple, supportive and honest.
- Avoid statements like "if you had faith...", or "don't cry", "be strong", or "I know how you feel". These comments are not helpful.
- Offer concrete tasks to help the patient, not vague and general, i.e., "Can I bring you warmups for therapy?", "May I come by next weekend and visit?"
- Don't dwell on how an accident/illness occurred or was acquired; it really does not matter over time.
- Respect the patient's rights, privacy, schedule, beliefs and religion.

Peer Support

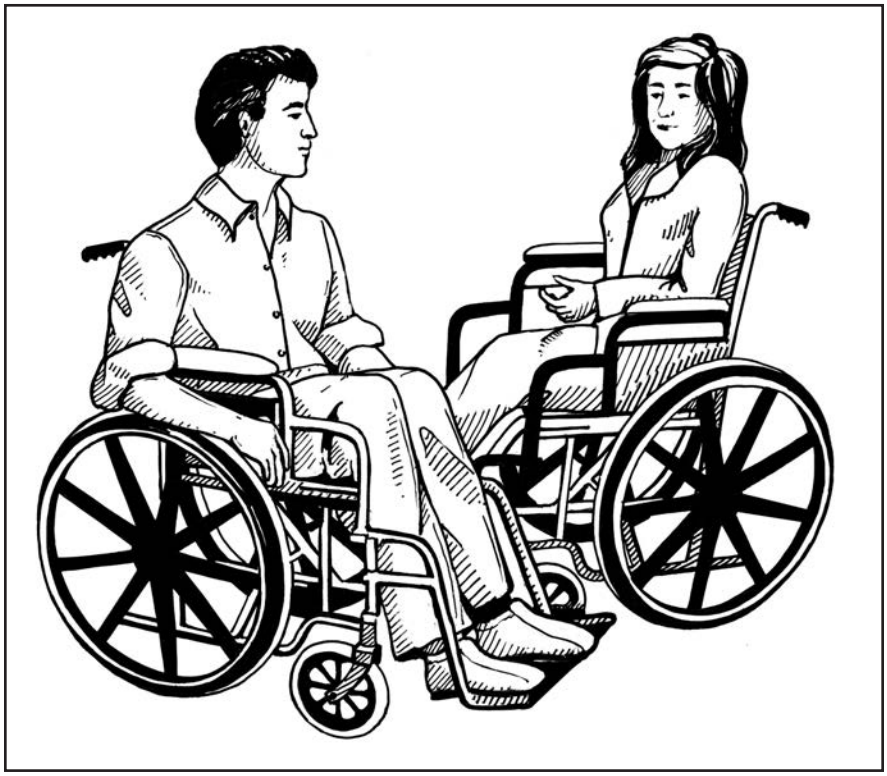


Figure 1

It often helps to talk to someone who has been there. Former Shepherd Center patients are available to offer support and information while you are at Shepherd Center and after discharge. You can talk with a peer supporter alone or in monthly group meetings. Many topics are discussed. Shepherd Center peer supporters share information, understanding and feelings on how they deal with certain experiences. Among the topics discussed are social adjustment, employment options, transportation, leisure interests and activities of daily living.

Also, as a Shepherd Center outpatient, there are many ways you can get involved in peer support.

1. Ask to be matched up with a peer supporter. Even if you are unable to come to meetings, you can still talk with an understanding peer about issues involving your spinal cord injury or disease. This is arranged through the Peer Support program.

2. Attend the Peer Support meetings at Shepherd Center. You are always welcome at these meetings.

3. Become a peer supporter. If you have been discharged from your rehabilitation program for six months or more and feel you are coping well with the changes in your life, you may want to consider this.

For more information about being a peer supporter, call the Peer Support Coordinator at 404 352-2020.

Summary

Spinal cord injury results in numerous changes and challenges which may seem overwhelming. There is help! The psychologist/counselor offers support and guidance in dealing with adjusting and adapting to a spinal cord injury. The Peer Support Program is a great way to find out what others with the same problems have done to help themselves.

What You Have Learned About Emotional Concerns and Who Can Help with Them

1. List three things a psychologist/counselor can help you with.
2. What support groups are offered to help you to deal with the feelings and changes a spinal cord injury causes?
3. Which beliefs did you have that you now know to be false?
4. List the ways you can learn to adapt to a spinal cord injury.
5. How can you contact the chaplain?
6. How can you get involved with the Peer Support program?

Alcohol and Drug Issues

10 CHAPTER CONTENTS

What You Will Learn In This Section

After reading this section you will be able to:

1. Describe the effects of alcohol use in persons with spinal cord injury.
2. Describe the effects of drug use in persons with spinal cord injury.
3. Describe self-medication and understand why it is not advisable.
4. Describe the common symptoms of alcohol or drug addiction.
5. Describe how to get help for problems you may have with alcohol or drug use.
6. Describe how caregivers can get help if a loved one has problems with alcohol or drug use.

New Words

Chemical Dependency

Using alcohol and/or drugs to satisfy a physical or emotional craving, which then causes problems for the user. Daily use is not required for it to be a problem. Signs of chemical dependency: needing more of the substance to get the desired effect; loss of interest in family life and relationships; using money for buying alcohol and/or drugs instead of necessities; legal problems caused by use; or medical problems or accidents caused by use.

Co-dependency

Not taking care of yourself in order to enable someone else to take care of their needs. It is different than freely doing something for the other person. It is more like deciding that the only way you can feel good about yourself or have an identity is to take care of another person even if it means neglecting yourself.

Dysreflexia

The body's overreaction to a full bladder that is not emptied. Symptoms can include high blood pressure, a pounding headache, blotching on your skin, or urinary leakage. If the bladder is not emptied immediately, severe medical complications including a stroke may result. It is a medical emergency.

Depression

Emotional feelings of extreme sadness, hopelessness, lack of worth, and emptiness. Loss of appetite, difficulty sleeping, exhaustion, lack of interest or desire to harm oneself can occur.

Denial

A way to reduce awareness of the fact that alcohol or drug use is causing problems. The denial can allow a person to trick himself/herself into thinking that there is "no problem".

Treatment

The process where an individual who abuses alcohol and/or drugs gets professional help to overcome the alcohol and or drug problems.

Tolerance

The ability to drink more alcohol before you feel an effect. This ability automatically increases over time and results in higher volumes of alcohol consumption because you have to drink more to get the same feeling. You are still impaired by the alcohol (reflexes and judgment) as quickly as before, you just think you are not impaired when you are. This can have dangerous consequences to you or others.

Self-Medication

It means acting like you are your own doctor. You provide the diagnosis and the treatment yourself. The only problem: you're not a doctor! Usually self-medication includes using alcohol, drugs, or other people's medication to treat your problem. It may work for a while, but eventually you have two problems: the original problem and an addiction.

Good Health and Good Decisions

That's what this section is all about. It's not about the moral or legal issues of drinking or drug use. There are other times and places to discuss that. This is about the effect of drinking or drug use on a person like you with a spinal cord injury. You decide what to do with the information, because, after all, it's your life.

Alcohol Use and Spinal Cord Injury

First let's look at the effects of alcohol use. Most people who drink enjoy it. Otherwise, they wouldn't do it. But alcohol, even in small amounts, has an effect on you. It flushes your cheeks, relaxes you, and makes you more talkative. Those are some of the good effects. What are some of the other effects of alcohol use?

Reflexes Even though you may have only a few drinks, your reflexes will become slower. You may not act or feel intoxicated, but the effects of alcohol will delay reflexes.

Judgment Ever notice how, in yourself or others, what seemed like a bad idea without alcohol could seem like a good idea with it? That is because alcohol affects your judgment. The more alcohol in your system, the worse your judgment becomes. This can lead to dangerous consequences for anyone, but especially for someone with a spinal cord injury making many decisions every day requiring safe behavior, like wheelchair mobility, transfers, and self care.

Bladder One of the biggest effects of alcohol on your system is that it makes your bladder fill up quicker. This is crucial to a person with spinal cord injury who cannot tell when their bladder is full. Failure to empty a full bladder runs the risk of dysreflexia, a serious medical condition which can be life-threatening. Dysreflexia is the body's overreaction to a full bladder that is not emptied. Symptoms can include high blood pressure, a pounding headache, blotching on your skin, or urinary leakage. If the bladder is not emptied immediately, severe medical complications including a stroke may result.

Medication Alcohol use doesn't always mix with your medications. Talk with your doctor and/or pharmacist about your medications and possible negative side effects of alcohol use. Alcohol can change the effect of medications by increasing or decreasing their effect on your system. Alcohol can also interact with some medications in harmful ways like causing a seizure. Persons who have a brain injury may be advised to avoid alcohol because it can increase the risk of seizures in someone with a brain injury.

Always talk with your doctor and/or pharmacist if you plan on consuming alcohol after you leave Shepherd or if your medications change in the future.

Drug Use and Spinal Cord Injury

There are several kinds of drug use: prescription drugs prescribed for you, street drugs and prescription drugs given to you by a family member or a friend.

Prescription drugs prescribed for you by your physician can have side effects. You should always notify your physician immediately when you have severe side effects.

Street drugs like marijuana, cocaine, methamphetamine, heroin, and LSD can have harmful effects for a person with a spinal cord injury. Let's review these:

Central nervous system Street drugs affect the central nervous system. That is how they produce their effect. A person with a spinal cord injury has a compromised central nervous system and street drugs can produce unpredictable effects. In the documentary, "J.R.'s Story" a young man takes LSD before he sees fireworks. After the drug has worn off on all of his friends, the drug is still working in his system and it starts to "run" his body, producing uncontrollable movements in his limbs and high blood pressure.

Judgment Street drugs distort reality and make you think things that are not what they seem. Since reality is an essential part of good judgment, drugs work in the same way as alcohol in making what would be a bad idea seem good.

Reflexes Street drugs distort or slow down reflexes, which can make physical activities like transfers and wheelchair mobility less safe.

Motivation Street drugs can also decrease your motivation, which can affect your desire to take good care of yourself or do well in school or participate in activities at work or with your family.

Prescription drug-sharing can be dangerous because the family member or friend who is giving you a medication they have been prescribed doesn't know your medical condition, medication, or other factors that could make taking the drug they are giving you harmful for you.

Self-medication

Self-medication is acting like you are your own doctor. You decide what you have and what you need to do about it. Only you are not a doctor!

There are a number of medical conditions in which it is tempting to try to practice self-medication. They are pain complaints, difficulty sleeping, depression, and anxiety. Some persons attempt to treat these conditions with alcohol, street drugs, or medications from family or friends. This is a mistake. The best approach is to contact your primary care physician and see what they suggest as treatment. Perhaps they will prescribe a medication, but they may know of a therapy or treatment which can make a difference for you.

Alcohol and Drug Addiction

"Do I have a problem?" is a question a person who drinks alcohol to excess or abuses drugs will eventually ask themselves. The answer depends on the situation, but there are several factors to consider in finding that answer.

Problems A simple definition of addiction is "If it causes problems, it is a problem." This means that if your use of alcohol or drugs causes health problems, relationship problems, legal problems, or work problems, it may be a problem itself.

Preoccupation If you spend a lot of time thinking about your next opportunity to drink alcohol or use drugs, your use may have become a preoccupation for you. Other signs of this problem are always needing to have alcohol or drugs available in your home and only going to restaurants or events where alcohol is available or planning your schedule around the use of drugs.

Finances If you find that your money goes to buying alcohol or drugs instead of necessities like your rent or mortgage, groceries, car payment, or other needs of you and your family, you have a problem with your use.

Legal If you find that you are willing to commit crimes to get money for your alcohol or drugs, or if you have one or more DUI arrests, you likely have a problem.

Tolerance is the ability to drink more alcohol before you feel an effect. This ability automatically increases over time and results in higher volumes of alcohol consumption because you have to drink more to get the same feeling. Building up your tolerance, for instance increasing your drinking from two drinks to five or from a six pack of beer to a twelve pack, is a sign of an increasing problem.

Family and friends may suggest to you that you are drinking or using too much or in socially inappropriate situations. You should take their concerns seriously and ask them why they think you are using too much. Their feedback could be helpful to you in identifying a problem which is difficult for you to see for yourself.

Getting Help

Help in figuring out if you have a problem with alcohol or drugs is available from your doctor, a psychologist or counselor, a local alcohol treatment center, or Alcoholics Anonymous. You may also find information on the Internet.

Once you have a suspicion that you have an addiction to alcohol or drugs, it is best to talk to your family and get their support for seeking treatment. Treatment options are:

- Counseling;
- AA meetings;
- Hospitalization;
- Day or evening treatment in a hospital or treatment center.

Helping Loved Ones Get Help

It is not easy to realize that a loved one is having difficulties dealing with alcohol or drug use. You may not want to admit that a problem exists, or if you realize that there is a problem, convincing your loved one that they need help can provoke a defensive or violent response. Often they do not want to admit a problem or they are in denial and are not even aware of how bad their problem has become.

Resources are available in your community. You may see a psychologist or a counselor who can help you deal with the effects of your loved ones use on you, and help you decide what you should do next. Sometimes you may feel sad or angry about the use. A local Al-Anon group can help you realize what you have been dealing with and possibly even how you are involved in covering up or enabling the alcohol or drug abuse. At the very least, you will feel less alone when you hear the familiar stories and insights of others in the group. They may be able to help you figure out what you need to do for yourself in response to your loved one's behavior.

Resources

1. United Way
   http://www.unitedway.org/
2. Alcoholics Anonymous
   http://www.aa.org
3. Alanon
   http://www.al-anon.alateen.org/
4. Narcotics Anonymous
   http://www.na.org/
5. International Center for Disabled Addiction Recovery Program
   http://www.icdnyc.org/content/view/19/42/

Summary

Alcohol and drugs can have a profound effect on the health of persons with spinal cord injury. Take care to make informed decisions about your behavior so that you do not place yourself at risk. Consult your doctor about health risks and about conditions you may have that require treatment. Avoid self-medication. Get help from family, friends and medical professionals if you are concerned about your alcohol or drug use.

What You Have Learned About Alcohol and Drug Issues

1. Name three effects of alcohol on persons with spinal cord injury.
2. What is self-medication and why is it a problem?
3. Name two symptoms of alcohol or drug addiction.
4. Name one resource you can call to get help with alcohol or drug problems.

Assistive Technology

11 CHAPTER CONTENTS

What You Will Learn In This Section

After reading this section you will be able to:

1. List the services Assistive Technology offers.
2. List the equipment an Assistive Technology therapist helps you obtain.
3. Describe the types of therapists who work in Assistive Technology.
4. Describe who pays for Assistive Technology equipment.

New Words

Accessibility
Creating an environment that is useable for everyone.

Activities of Daily Living (ADLs)
Any task used for self care, work or play activities. Examples include using a computer, driving, turning on a light, doing a weight shift.

Assistive Technology
Any piece of equipment that is used to increase, maintain, or improve the function of someone who has a disability.

Augmentative/Alternative Communication
Any method to replace spoken speech. This can include sign language, spelling words with a letter board, or using a talking computer. This is often called AAC, or aug.com.

Computer Access
Another way of operating a computer besides using the standard keyboard and mouse. Example: voice recognition, head mouse, using a switch (such as a sip and puff switch).

Dependent Passenger Evaluation
If you are unable to drive but will need to be transported in a wheelchair, a session call a van evaluation will be held to decide what type of vehicle, will be needed. Decisions about necessary types of equipment and/or vehicle modifications will also be made in this session.

Driving Evaluation
If you want to continue to drive, an evaluation is completed to see if that will be possible. This will include tests of your ability to operate the controls of a vehicle and determine if your vision, attention and judgment are still good enough to allow you to drive. Equipment may be recommended to help you operate the accelerator, brakes, steering and other controls.

Environmental Control System (ECS)
Equipment that is programmed to allow you to contol and use many electric appliances throughout your home. Examples: lights, telephone, TV, fan, call system.

Manufacturer
The company that makes the equipment. In some cases, this company is also the vendor.

Modifications
Any changes made to a place or to a piece of equipment to make ADLs easier for you.

OT
Occupational Therapy/Occupational Therapist.

PT
Physical Therapy/Physical

SLP
Speech Language Pathologist, also known as the Speech Therapist. The individual who works with communication skills, talking computers, or swallowing.

Vendor /Supplier
The company that sells equipment. This company also sells parts and provides service for your equipment.

Assistive Technology Services

Augmentative/Alternative Communication (AAC)

You may experience either temporary or permanent loss in your ability to speak. Possible causes include tracheotomy and ventilator tubes, weakness of the mouth muscles, or paralysis of the vocal folds. Augmentative/Alternative Communication, or AAC, can provide new ways to communicate.

Light tech methods include spelling or word boards, communication booklets, or eye gaze boards. You point or look toward words or pictures to choose activities or ask for things. Sometimes, your family and staff must point to letters, words or pictures and have you indicate yes or no to choose the message.

Low tech methods use an electrolarynx, voice amplifiers, or communication devices with tape-recorded words. You operate the electrolarynx by mouthing words and using the device to produce a "buzzing" sound to replace voice.

Amplifiers act like microphones to increase the loudness of speech. AAC devices can operate by activating keys with printed words or pictures to speak messages.

High tech systems use computers or communication devices to spell or retrieve pre-stored words and sentences. They can be operated by touch, a mouse, switches, or head pointers. Often, high tech communication systems can also operate computers and environmental control systems.

The SLP can assist if you have problems speaking.

Computer Access Clinic

Computers are a part of everyday life for people at home, school and work. If you cannot type on the keyboard, an Occupational Therapist in the Computer Access Clinic can show you new ways to access a computer. Other options for accessing a computer might be to use voice commands to perform mouse and keyboard functions or to use a headpointing device. In addition, the Occupational Therapist will look at computer programs that can help you with some of your activities of daily living, such as: balancing a checkbook, paying bills, ordering groceries, and making airline reservations.

Environment Control Systems Clinic

In the Environmental Control Systems Clinic, an Occupational Therapist will meet with you to talk about what devices will be important for you to control when you go home. The O.T. will then help you look at equip-ment that might help you with these devices. Environmental control systems (E.C.S.s) let you turn lights and appliances on and off at home or work with the use of a switch (such as a sip and puff switch) or by voice command. Some E.C.S.s are simple push-button boxes, such as a remote control. Other E.C.S.s can control many different appliances and lights throughout the house and can even answer and dial the telephone. E.C.S.s help people become more independent and safe in their home environments.

Accessibility Program

Occupational and Physical Therapists in the Assistive Technology Center are available to help with home evaluations and workplace evaluations. They will make recommendations on how to modify these envrionments to help you be more independent and safe. These modifications can be simple, such as: removing a door, adding a curtain, or rearranging furniture. Some modifi-cations can be complex, such as: widening a door frame, building a ramp, or building an addition.

Driving/Transportation

Working, going to school, shopping, running errands - transportation is an important part of daily life. Your need for transportation does not change, but the way you travel may be different. The Adapted Driving Program of the Assistive Technology Department provides driving evaluations for persons wanting to learn or return to driving. It also provides dependent passenger evaluations for persons who need advice on the appro-priate vehicle to be used for transporting a person in a wheelchair. You may be seen on both an inpatient and out-patient basis.

We provide equipment recommend-ations and training in the use of adaptive equipment. It is best to meet with the driving specialist before deciding to purchase a vehicle. There are many different types of equipment and van modifications available. It is helpful to have expert advice. We can also assist you in locating vendors in your area.

Seating and Mobility Clinic

In Seating Clinic, a therapist (either a P.T. or an O.T.) and a vendor meet with you to talk about your wheelchair needs. If your doctor agrees, a new wheelchair, a wheelchair cushion or other wheelchair parts may be ordered.

Why would you go to the Seating / Mobility Clinic?

1. New wheelchair - if your chair is worn out.
2. Fit - if you gain or lose weight, or if you change shape (because of HO or scoliosis)
3. Balance - if you are falling forward or sideways in your wheelchair
4. Mobility - if you have trouble moving your wheelchair, if you get weaker or stronger, etc.
5. Skin care - if you have trouble doing your weight shift, if your cushion is not working, if you have an open wound.

Your physician will have to approve any new equipment.

Funding For Assistive Technology

It is important to follow some basic steps in order to get assistive technology services and equipment:

1. Call your case manager or insurance company to determine payment for equipment. Some insurance companies pay for more equipment than others.
2. The therapists will help you decide what equipment you need.
3. The therapists and doctor prepare a prescription and letter detailing the medical necessity for the equip- ment. These are submitted to the insurance company

Assistive Technology Services Directory

For general information on any service in the Assistive Technology Center at Shepherd Center, please call the main department number: (404) 350-7760.

For specific questions in a given area, call one of the following:

Accessibility Program (404) 350-7722
Adapted Driving Program (404) 350-7798
Augmentative Communication (404) 350-7721
Computer Access Clinic (404) 350-7715 or 350-7722
Environmental Control Clinic (404) 350-7716 or 350-7722
Seating and Mobility Clinic (404) 350-7759

Summary

Assistive Technology Services provide individual evaluations by specialized therapists who assess the need for equipment to increase, maintain or im-prove the function of someone who has a disability. This includes:

- improving communication
- everyday computer use
- environmental control systems
- home and/or workplace evaluations
- driving and/or transportation needs
- seating and mobility issues.

Information will also be provided to obtain funding for recommended equipment.

What You Have Learned About Assistive Technology

1. What do Environmental Control Systems assist you in doing?
2. Name some modifications that can be made to your environment to improve accessibility.
3. Name some reasons for going to the Seating and Mobility Clinic.
4. How would you go about getting funding for assistive technology equipment?

External Resources

12 CHAPTER CONTENTS

What You Will Learn In This Section

After reading this section you will be able to:

1. List the services the Case Management Department offers.
2. Explain how to hire and manage a Personal Care Assistant.
3. List your rights as a person with a spinal cord injury.
4. Identify your local advocacy group.
5. Explain how to obtain publications dealing with the concerns of those with spinal cord injuries.

New Words

Accessible
Something that can be used, entered or obtained by people with disabilities. For example: doors wide enough for wheelchairs, ramps in place of stairs, ramps next to stairs.

Accommodations
Something supplied for convenience or to satisfy a need.

Advocate
A supporter of a cause who speaks up in favor of the cause.

Architecture
The design of a building.

Attendant Service
A function provided by people who physically care for others by helping with personal care needs.

Case Manager
The person on the team who coordinates the rehabilitation program with the patient, team and insurance company. The case manager assists in the planning for discharge so that services and equipment are prepared for the return home.

Certified
A copy that is stamped to guarantee that it is an actual copy of the true original.

Compliance
Agreeing to a desire, demand or plan and making the changes.

Comprehension
Understanding.

Congressional District
The community you live and vote in. Each community has representatives in government.

Disability
A physical problem that changes a person's ability to do certain jobs and activities.

Discrimination
To show favor or preference to one group or person over another.

Eligible
Qualified to be chosen.

Emotional
To have strong feelings about an issue or problem. To feel sad, happy or angry.

Entitled
To have the right.

Facility
Something that is built for a certain purpose. For example: a hospital.

Financial
Concerned with money.

Home Modifications
Changes made in a home that allows one to get around more easily. For example: ramps.

Independent Living Centers
Centers that offer support groups on how to manage money, how to manage attendants, how to find funds for home modifications, etc.

Impairs
Slows ability.

Legalistic
To view from the legal standpoint.

Legislature
Lawmakers.

Medicaid
A type of health insurance available through the state government to most people with disabilities when a financial need has been documented.

Medicare
A type of health insurance available through the federal government to most people who have previously worked and who have been disabled for at least 2 years.

Neurologic Problems
Disorders in the nerves that may change the ability to think, move and feel.

Personal Assistant
A person to help with your everyday personal and medical needs; an attendant.

Precise
Exact.

Referral
Advice about where to go to get help.

Rehabilitation
The process which allows individuals to return to the highest level of function possible after injury.

Rehabiliation Team
The entire group of people working with you throughout your rehabilitation program.

Renovated
A building that is redone, made new or updated.

SSI
Supplemental Security Income.

SSDI
Social Security Disability Income.

The Case Management Department

The Case Management Department offers services to help you make plans for returning to your home and finding community resources to assist you. A case manager will meet with you regularly about financial and insurance questions. The case manager will also talk with you about scheduling family or attendant training.

Case Management Services While at Shepherd Center

When you are admitted to Shepherd Center, a case manager assists and supports you and your family with:

- coordinating your treatment
- overnight housing for family members
- financial and insurance questions
- plans for going home
- family or attendant training
- finding community resources
- discharge planning.

Community Resource Specialist

A Community Resource Specialist provides support services to Case Managers in the areas of discharge planning and community resource development, including:

- Maintaining a database of resources for home health agencies, transportation companies, long term care facilities, government agencies, and local lodging for families.
- Social Security information
- Responding to phone calls from the community at large requesting resource information.

Discharge Planning

One of the first things to do when you are admitted to Shepherd Center is to decide where you are going to live when you leave. The earlier you do this, the more time you will have to plan. Every person has different needs, so you need to work closely with your rehabilitation team to decide what those needs are. Questions to ask yourself to help figure out your needs are:

- Who will be the main caregiver to help me when I leave Shepherd Center?
- Do I need any personal care assistance other than my family?
- What home modifications are needed?
- What equipment will I need?
- What insurance coverage is available?
- What resources are available through my church? My community?
- What kind of transportation will I need?
- What are my financial needs?

Case Management Services After Discharge

After you leave Shepherd Center, case management services are available to you through the Outpatient Department. The outpatient case manager helps you in the following areas:

- Referral services to social, health, housing and welfare agencies.
- Understanding your benefits from Medicaid, Medicare, Workers' Compensation and private insurance.

Financial Concerns

Social Security

There are two types of Social Security benefits: Supplemental Security Income (SSI) and Social Security Disability Income (SSDI).

SSI

SSI pays monthly amounts to people who are determined to be disabled according to Social Security criteria. SSI is for adults and children. Whether you can get SSI depends on your income and resources. If you are married, this includes the income of your husband or wife. If you are under 18, the income and resources of your parents are considered.

When to apply: It is important to apply right away if you think you or a family member are eligible to receive SSI. SSI benefits take several months to begin. Applying early helps the case managers better plan for your discharge from the hospital.

How to apply: Apply at the Social Security office in the county and state in which you live. Call the Social Security HOTLINE at 1-800-772-1213 between the hours of 7am and 7pm Monday-Friday to start the application process. You will need the Social Security number of the applicant. Someone in your family can apply for you if you are not able.

What you need:

- Your Social Security card or record of your Social Security number.
- A certified copy of your birth certificate.
- Information about the home where you live, such as the mortgage, taxes, lease, cost of food and utilities.
- Family payroll slips, a copy of tax returns for two years, bank books, insurance policies.
- Medical records about your disability.

KEY POINT: Apply right away, even if you do not have all this information. The people at the Social Security office can help you get what is needed.

SSDI

SSDI pays monthly benefits to people who are considered to be disabled according to Social Security criteria and have paid into the Social Security system. If you qualify, monthly benefits will begin 6 months from your date of injury.

When to apply: It is important to apply right away. Applications for disability take longer to process than for other Social Security benefits. You may be eligible to receive SSI until your SSDI payments begin.

How to apply: Apply at the Social Security office in the county and state in which you live. Call the Social Security Hotline at 1-800-772-1213 between the hours of 7am and 7pm Monday-Friday to start the application process. You will need to provide your social security number. Someone in your family may apply for you if you are not able.

What you need:

- Your social security number and proof of age.
- Names, addresses and phone numbers of doctors, hospitals and clinics that have treated you and dates you were treated for your spinal cord injury.
- A summary of where you worked in the past 15 years and the kind of work you did.
- A copy of your most recent W-2 form.

- Dates of any military service.
- Dates of any marriages.
- The claim number of any other benefit you expect to receive.
- Bank books.

Medicaid and Medicare

Medicaid helps pay medical bills if you have a low income. If you receive SSI monthly payments, Medicaid is automatically provided. A Medicaid letter is mailed to you when you are approved for SSI. Give copies of all Medicaid information to your case manager immediately.

Medicare is for people over 65 years old and disabled people who receive SSDI. Social Security offices take applications for Medicare. Some of the medical insurance through Medicare requires you to pay a yearly deductible.

KEY POINT: Check with your case manager to see if you can receive Medicaid or Medicare.

Other Financial Help Needed

Food Assistance - You may be able to get food stamps, depending on your income. For information, call your local Department of Family and Children's Services. Each county has its own department, so call the local number in your county.

Heating Assistance - The Department of Family and Children's Services also has a program to help pay for heating costs. Call your local department for information.

Department of Family and Children's Services - Metro Atlanta:

Cherokee County 770/720-3610
Clayton County 770/473-2300
Cobb County 770/528-5000
Dekalb County 404/370-5251
Douglas County 770/489-3000
Fayette County 770/460-2555
Fulton County 404/657-8100
Gwinnett County 678/518-5500
Rockdale County 770/388-5025

Housing Assistance - Government housing is available through the Section 8 program. Often, there are waiting lists, so contact your local county housing authority for more information. For Metro Atlanta, call the Atlanta Housing Authority at (404) 892-4700.

Hiring and Managing A Personal Care Assistant

After a spinal cord injury, you may need help at home. Personal care assistance may be the answer to help with anything from cooking and cleaning to bowel and bladder programs. Hiring and managing an assistant can be a rewarding relationship or a frustrating experience. The following are suggestions on how to hire and manage an attendant.

How to Start

First, make a list of what you need and expect this person to do. Be prepared to show the list to any potential assistant.

Here are some questions to ask yourself to get your thinking organized.

1. What physical needs do I have (bathing, dressing, transfers, grooming, bowel and bladder programs, feeding)?
2. Do I need someone to prepare meals?
3. Do I need someone to provide transportation?
4. Do I need help with laundry?
5. Do I need housekeeping?
6. Do I need someone to take me out (shopping, school, movies)?
7. Do I have a pet that needs care?
8. Do I want someone to live in? If so, do I mind if this person has a child? How do I feel about a couple?
9. How many hours a day do I need personal care assistance?
10. Can I afford to pay someone? If so, how much?
11. Do I want someone with experience?
12. Do I mind training someone to perform my care?
13. Do I mind if the person smokes or drinks alcohol?
14. What personality traits would offend me?

Finding a Personal Care Assistant

- Local nursing agencies provide around the clock personal assistance. This may be a way to find help if you have insurance coverage or workers' compensation. Being employed by an agency means the person should be a qualified applicant. However, you still will want to screen this person yourself.

- Churches of all faiths can be a resource for finding personal assistance. Former patients have made flyers or ads and placed them on church bulletin boards and in church newsletters. Others report church attendance has provided them with contacts for personal assistance (you may meet someone who knows someone who may be interested.)

- Advertising, online or in the newspaper is a common way to find personal assistance. You may get a better response with a local or neighborhood newspaper. When writing an ad, be specific but try to keep it short. You have to screen the people who respond to the ad anyway. It may also be worth reading the "jobs wanted" section. You may find an ad there that you can respond to.

- The passing of Georgia Law Code # 42-8-22 in 1983 provides another way for finding personal assistance. This law allows non-violent lawbreakers to live in and provide care for a disabled person for up to two years at no cost to the disabled person. The assistant provides a community service in place of a prison sentence. The lawbreaker is closely supervised by the judge, lawyer and probation officer. The assistant's responsibilities may include such things as bathing, dressing, cooking, shopping, driving and housekeeping. For further information about this program, contact:

  Community Corrections Program
  State Probations Division Offices
  2 Martin Luther King Dr.
  Twin Towers East, Suite 866
  Atlanta, GA 30334
  (404) 656-6002, Fax (404) 651-6818

Here are additional ways to advertise or look for help:

- Colleges and universities, especially dormitories, sororities and fraternities
- House-mate match agencies (people with a housing need are matched with a person who has an available room)
- Rehabilitation agencies
- Homeless shelters
- High schools
- Hospitals
- Nursing homes
- Religious schools
- Volunteer organizations
- Independent Living Centers
- Your neighborhood.

Hiring

- All potential assistants should be interviewed by you. It is very important to learn everything you can about this person before hiring him or her.

- Before hiring any person, have at least two interviews. It is best to meet the person the first time in a public area, like a restaurant. It may also be helpful to have a friend or a relative present during the interview. Sometimes a second person picks up on something you do not. When screening someone on the phone, it is safest to mention only a general living area, not a specific street address, until you are positive you want the person to come to your home.

- Depending on your injury level and needs, experience in the medical field or in rehabilitation may not be necessary. Many patients are able to train new assistants to perform their care.

- Be honest with the person regarding duties, time off, salary and hours to work. If the person plans to live in, advise what is included in the arrangement.

- It is a good idea to have the person observe your care for at least one day.

- You may want to hire a person with the agreement that it is on a one-month trial basis.

- Ask about leisure interests. If your assistant is expected to go out with you, it is helpful if you have the same leisure interests.

- Pay attention to the way the person is dressed. Is the person neat and clean? Does he or she smoke?

- Ask open-ended questions. These are questions that cannot be answered with a yes or no. An example of an open-ended question is, "Tell me about yourself." You get more information this way.

- Always check the person's references or speak to a previous employer.

- Does the person have transpor-tation? This is important if you have a specific time schedule. If your assistant relies on public transportation or another person to get to work, it may cause lateness at times.

KEY POINT: If your assistant is going to be driving your van, make sure he or she has a valid driver's license. For instructions on how to get a person's driving record, call (404) 624-7442 or go to www.dds.ga.gov/

Other ways to obtain information about personal care assistance

Ask about the Personal Assistance Services video and manual in the Noble Learning Resource Center at Shepherd Center.

The Department of Rehabilitation Services (D.R.S.)

This state agency provides services to those persons who are not working because of physical, mental or emotional disability. If you qualify, the agency assigns a D.R.S. Counselor who helps you prepare for and find a job.

Services through D.R.S. may include:

- Guidance and counseling.
- Vocational evaluation and training.
- Financial planning for equipment and medical or psychological treatment.
- Job placement and follow-up.

Look in the phone book under Georgia State Government, Human Resources, Department of Rehabilitation Services, for the D.R.S. office located near you.

Client Assistance Program (C.A.P.)

This program helps answer questions and resolve complaints about D.R.S. Call the Atlanta office at (404) 373-2040. Outside Atlanta, call (800) 822-9727.

Your Legal Rights

As a person with a spinal cord injury, you have the same rights as anyone else to education, employment, accessibility and any other services paid for by United States tax dollars. There are federal and state laws that protect these rights.

KEY POINT: Pick up a disabled identification card from any place that issues driver's licenses. The card enables you to discounts on public transportation and easier ways to purchase seating for ticketed events, such as concerts and sporting events.

Georgia State Laws

8-268 Disabled persons are entitled to receive a Georgia disabled person's license plate for a motor vehicle. You must be a Georgia resident and obey laws relating to the registration, licensing and payment of fees.

91-11 Any public building renovated or constructed after July 1, 1984 must be accessible to a disabled person.

68A-1020 Any person parking, standing or stopping in a handicapped parking place without a handicap parking sticker or license plate can be fined.

Handicap parking permits are available at all places that issue driver's licenses. Applications may also be made by mail. Proof of disability is required (a signed statement by your doctor.) You must obtain a parking permit or license plate for a disabled person. Any person violating this law is fined $100 to $500.

89-17 Handicapped persons cannot be discriminated against for employment.

The above listing includes or refers to only a few laws involving the disabled person. Contact the following for information about these and other laws:

Protection and Advocacy for Individual Rights (PAIR)
(404) 885-1234
(800) 537-2329 outside Atlanta

National Groups

A person with a disability has the same rights as anyone else to education, employment, public accommodations, government facilities and services, transportation, housing and communications. There are federal laws to protect these rights. Following is a brief explanation of the Americans with Disabilities Act (ADA) and the Fair Housing Act, as well as implementation and related resources.

Americans with Disabilities Act (ADA)

This legislation provides extensive civil rights protection for persons with physical or mental impairments that substantially limit one or more major life activities. It also protects individuals from discrimination if they have a family, business, social or other rela-tionship with a person with a disability. It covers employment, state and local government services, public accom-modations, transportation, commercial facilities, and telecommunications.

How to File A Title III Complaint

Title III prohibits discrimination based on disability in public accom-modations. Private entities covered by Title III include places of lodging, establishments serving food and drink, places of exhibition or entertainment, places of public transportation, places of public display or collection, places of recreation, places of education, social service center establishments, and places of exercise or recreation. Title III also covers commercial facilities (such as warehouses, factories, and office buildings), private transportation services, and licensing and testing practices.

If you feel you or another person have been discriminated against by an entity covered by Title III, send a letter to the Department of Justice at the address below, including the following information:

- Your full name, address, and telephone number, and the name of the party discriminated against
- The name of the business, organization, or institution that you believe has discriminated.
- A description of the act or acts of discrimination, the date or dates of the discriminatory acts, and the name or names of the individuals whom you believe discriminated, and
- Other information that you believe necessary to support your complaint. Please send copies of relevant documents. Do not send original documents (retain them.)

Sign and send the letter to the address below:

Office on the Americans with Disabilities Act
Civil Rights Division
U.S. Department of Justice
P. O. Box 66738
Washington, D.C. 20035-9998.

The Office on the Americans with Disabilities Act will consider your com-plaint and inform you of its action. The office will investigate the complaint and determine whether to begin litigation.

They will not necessarily make a detemination on each complaint about whether or not there is an ADA violation. If they believe that there is a pattern or practice of discrimination, or the complaint raises an issue of general public importance, they may attempt to negotiate a settlement on behalf of the United States. They do not act as an attorney for, or representative of, the complaints.

You also have the option of filing your own case in U.S. District Court.

Small businesses have limited protection from lawsuits. Except with respect to new construction and alterations, no lawsuit can be filed concerning acts or omissions that occur before:

1. July 26, 1992, by businesses with 25 or fewer employees and gross receipts of $1,000,000 or less.
2. January 26, 1993, by businesses with 10 or fewer employees and gross receipts of $500,000 or less.

Helpful Resources, and Creditable Organizations and Websites

The American Trauma Society

Dedicated to the prevention of trauma and improvement of trauma care

www.amtrauma.org | 800-556-7890

Christopher & Dana Reeve Paralysis Resource Center

Promoting the health and wellbeing of people living with spinal cord injury, mobility impairment and paralysis by providing comprehensive information, resources and referral services

www.paralysis.org | 800-539-7309

Family Voices

Aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities

www.familyvoices.org/states | 888-835-5669

Disabled Sports USA

A network of community-based chapters offering sports rehabilitation programs to anyone with a permanent disability

www.dsusa.org/chapter.html | information@dsusa.org

National Spinal Cord Injury Association

Leading the way in maximizing the quality of life and opportunities for people with spinal cord injuries and diseases since 1948

www.spinalcord.org | 800-962-9629

NTAF

NTAF helps families address financial hardships arising from uninsured medical expenses related to catastrophic spinal cord or brain injury. Established in 1983 by medical professionals, NTAF is a 501(c)(3) nonprofit organization that provides expert fundraising guidance to patients, families and communities nationwide, while offering fiscal accountability for funds raised.

www.ntafund.org | 800-642-8399

Office of Disability Employment Policy

Federal government agency within the U.S. Department of Labor helping ensure that people with disabilities have equal employment opportunities

www.dol.gov/odep | 866-487-2365

Spinal Cord Injury Information Network

The UAB-SCIMS works to maintain and improve a cost-effective, comprehensive service delivery system for people who incur a spinal cord injury. A Model System facility must demonstrate outstanding care to individuals with spinal cord injury, from the emergency medical services to acute care in the hospital to rehabilitation.

www.spinalcord.uab.edu | 205-934-3450

Spinal Injury 101

A video series created by Shepherd Center, in partnership with American Trauma Society, National Spinal Cord Injury Association and the Christopher and Dana Reeve Foundation.

www.spinalinjury101.org

If your loved one has a dual diagnosis of both brain and spinal cord injury, you may want to access these organizations:

American Heart Association

Works to build healthier lives, free of cardiovascular diseases and stroke

www.americanheart.org | 800-242-8721

American Stroke Association

Works to build healthier lives, free of cardiovascular diseases and stroke

www.strokeassociation.org | 888-478-7653

Brain Injury Association of America

Dedicated to increasing access to quality health care and raising awareness and understanding of brain injury through advocacy, education and research

www.biausa.org | 800-444-6443

Brain Trauma Foundation

Dedicated to improving the outcome of traumatic brain injury (TBI) patients worldwide by developing best practices guidelines, conducting clinical research, and educating medical professionals and consumers

www.braintrauma.org | 212-772-0608

Summary

While you are at Shepherd Center, the case manager helps you apply for financial help, such as Social Security benefits. As you progress through the rehabilitation program, it is important that you begin to learn about other resources and how to use them. You may find that when you go back home, there will be issues to be worked out with employers or with the local government. Know what your legal rights are. Work with local officials to make changes where needed and then become a peer supporter. Share what you have learned with others!

What You Have Learned About External Resources

1. Are you eligible to receive SSI or SSDI?
2. Have you applied for SSI or SSDI?
3. Are you eligible to receive Medicaid or Medicare?
4. Have you applied for Medicaid or Medicare?
5. Will you need an attendant when you leave Shepherd Center? If so, what things will you expect that person to do for you?

PERSONAL CARE MANUAL

EDUCATION: THE KEY TO INDEPENDENCE

Developed and Created by **Shepherd Center**

Illustrations by **Eric Jablonowski**

Design by **Edward Tharp**

Shepherd Center, located in Atlanta, Ga., is a private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury or brain injury. Founded in 1975, Shepherd Center is ranked by *U.S. News & World Report* among the top 10 rehabilitation hospitals in the nation and is a 152-bed facility. For more information, visit Shepherd Center online at shepherd.org.