



VA



U.S. Department of Veterans Affairs
Veterans Health Administration

SPINAL CORD INJURY & DISORDER VETERAN EDUCATION BOOK



**Michael Bilirakis VA Spinal Cord Injury Center
James A. Haley Veterans' Hospital & Clinics
13000 Bruce B. Downs Blvd.
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*Approved by Veteran & Family Health Education Committee
2020 #47*

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Revised 2020
Editor: Diana Weinel, MS RN VHA-CM

This handbook was prepared by the Spinal Cord Injury (SCI) Team to help you and your family members become familiar with the aspects of spinal cord injury. It covers many of the things that you will learn while you are in the hospital. Your nurses, therapists, and other members of the team will help you identify specific parts of the book to review. As problems or questions occur, this book may also provide some of the needed information. Of course, your rehabilitation team is available as a resource, too.

We hope this handbook will give you some understanding of spinal cord injury and will serve as a reference for you, your family and friends after your discharge.



Welcome to the Michael Bilirakis VA Spinal Cord Injury Center!

We are a Center with a rehabilitation focus. Our overall goal is to help you help yourself. The things you learn here will help you stay healthy and active for the rest of your life. Our rehabilitation program is an active one. You will find yourself busy with the many activities of the day. Each day may include personal hygiene activities, several therapies, medical appointments, group classes and time out for meals. You will be expected to take an active role in learning and doing the things necessary to live a normal life. We will encourage you to be self-reliant.

Rehabilitation is a learning process. It is learning to do old jobs in new ways. Each success in therapy is put into use on the ward by encouraging self-care. There is no substitute for practice. Rehabilitation is not just your therapy sessions. You are expected to practice your self-care skills on the nursing unit. Your rehabilitation is 24 hours a day, 7 days a week. You have come to a place where you work. You are not worked on!

Rehabilitation is also the process of decreasing dependency. You will develop to the greatest extent possible those abilities you need for functioning. Our goal is to do everything possible to assist you in returning to your community. As soon as you are medically able, you can request passes for time with family and friends. Away from the security and dependency of the hospital, you will find new meaning in your role with your family. You and your family will also be able to practice skills needed after discharge.

Welcome to our Center. May you experience many successes during your rehabilitation process and a healthy and fulfilling life after your discharge.

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VETERAN & FAMILY EDUCATION

Learning is a key part of your rehabilitation process. You, your family, and your caregiver will receive much information during your hospital stay. This information may come in varied forms.

- You will receive written material, such as this handbook
- You may watch a video on a certain topic
- You will observe or actually do a treatment
- You will talk with your rehab team members
- You will attend group classes or a workshop

All of these are options for learning.

Your rehab team members are willing to provide any teaching you need. Your nurses and therapists will teach you skills such as dressing, eating, and hygiene. You will be expected to do these skills during your rehab. The more you do them, the better you perform. If you are not able to perform self-care because of your injury, we will teach your caregiver. Your caregiver will perform your care several times during rehab.

You are expected to attend scheduled education classes during your rehabilitation. These classes present important information to help you stay healthy when you go home. Information shared during interaction among class attendees is especially valuable. Family members are welcome to attend the classes.

You, your family, and your caregivers are welcome to obtain written materials, view videos, take part in computer assisted learning or practice skills related to your care in the Center. The Spinal Cord Injury Patient Education Coordinator can help you locate other resources, as needed.

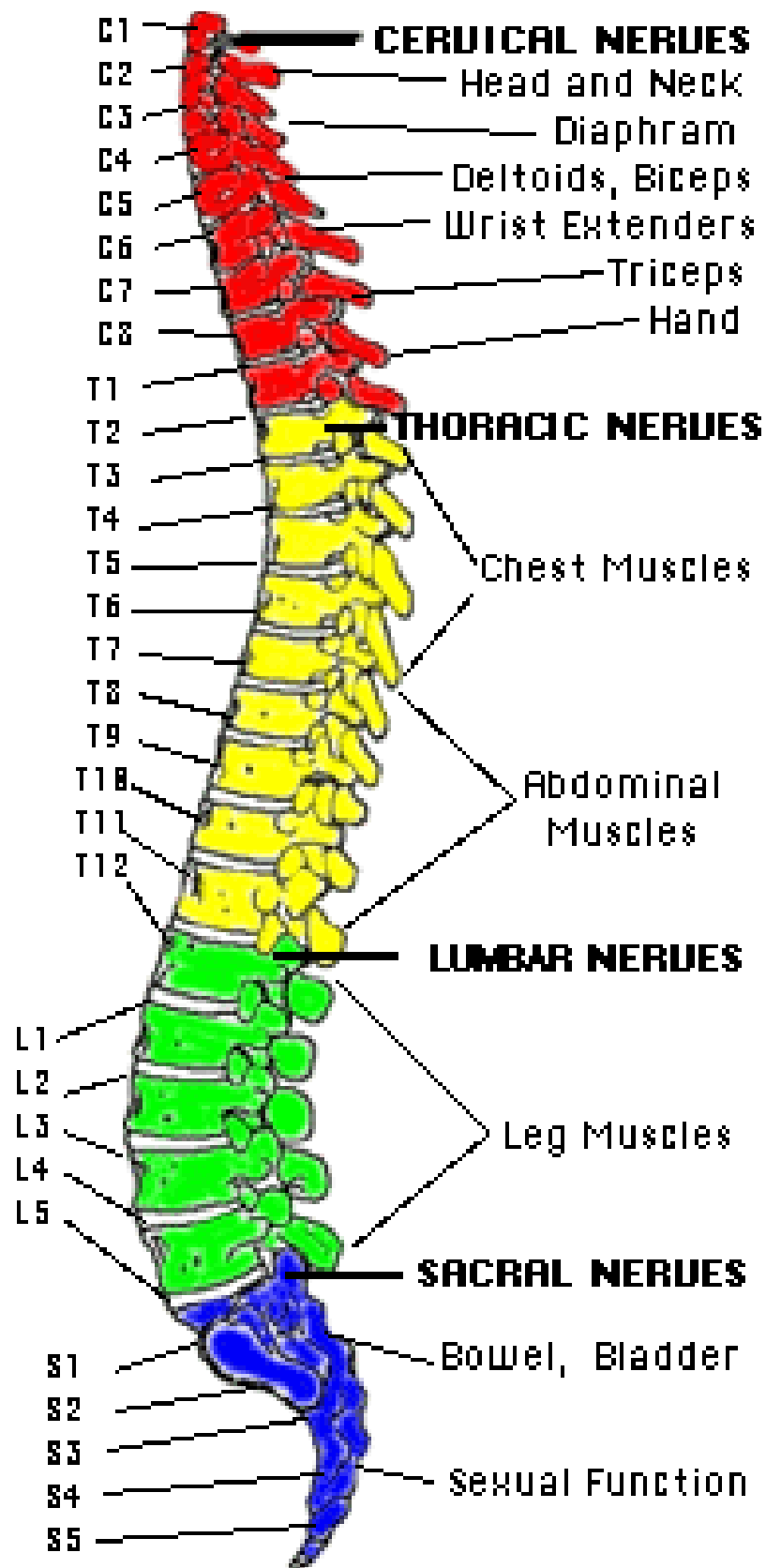
Be active in getting all the facts you need to make informed choices. The choices you make will affect your future health. Take advantage of the resources you have available here. Ask questions and be active in your learning.

OVERVIEW OF SPINAL CORD INJURY

The spinal cord is an oval-shaped tube about as wide as your little finger. It starts at the base of your brain and goes down to the lower part of your back. It is made of bundles of nerve fibers, like a telephone wire, which connect the brain to muscles, skin and the organs inside the body. The spinal cord carries messages from the brain to tell a muscle when, how far and how fast to move. Messages such as temperature, pain, touch, and location are carried from the body to the brain. The brain also controls the normal function of the organs inside your body such as the bowel and bladder. An injured spinal cord is like a broken telephone wire. The brain and body parts on each end are fine, but the connection between them does not work.

The spinal cord is a very delicate organ. Bones called vertebrae protect it. There are 33 vertebrae stacked on top of each other. Between each vertebra is a disk that is made of spongy material (like a cushion). This acts like a shock absorber does on your car. Each vertebra has a hole in it. When they are stacked up they become a hard boney tunnel through which the spinal cord passes. The vertebrae have different names depending on their location. They are:

- Cervical
- Thoracic
- Lumbar
- Sacral
- Coccyx



Each vertebra and spinal nerve branching out is numbered and labeled by its location. There are 7 cervical vertebrae and 8 cervical spinal nerves located in your neck. There are 12 thoracic vertebrae and 12 spinal nerves located in your chest area. There are 5 lumbar vertebrae and 5 spinal nerves located in your lower back. The sacral section has 5 pairs of spinal nerves coming out through holes in it. The very tip of the spine is the coccyx bone.

Spinal cord injuries (SCI) are identified as either **paraplegia** or **tetraplegia** (quadriplegia). Persons with paraplegia are not able to move the lower parts of their body. Someone with tetraplegia has lost movement in both the upper and lower parts of the body. SCI affects each person in a different way. This is because the spinal cord is not damaged in exactly the same way for each person.

A numbering system is used to describe the level of injury. It is named for the lowest level of the spinal cord which functions the way it did before your injury. For example, “C-5” means that your spinal cord from the 5th cervical nerve and **above** still functions the way it did before your injury. The nerves below that level are affected. Those nerves involve shoulder, arm, trunk, and leg muscles function. “T-10” means that your spinal cord from the 10th thoracic level near the lower back and above is intact. The affected nerves below that level involve your belly and leg muscle function.

Your injury can be further described as **complete** or **incomplete**. A complete injury is when there is no movement and no feeling below your spinal cord injury level. If you have some feeling or voluntary movement below your injury, you have an incomplete injury. This is because there is only partial damage to your spinal cord.

Right after the injury, the spinal cord stops working completely for a period of time that may last days, weeks or months. This is called “spinal shock”. During this period, all the movements below the level of your injury are absent. The return of reflexes below the level of injury marks the end of spinal shock. Your doctor will describe your level of injury to you after spinal shock.

The spinal cord may be damaged due to trauma or disease. Injury such a fracture of the vertebrae can cause tearing or pressure on the cord. Stab wounds or gunshot wounds can damage the spinal cord without breaking vertebrae. Paralysis may occur in parts of the body that are supplied by nerves leaving the cord below the level of injury. Damage to the spinal cord can affect your movement, feeling, and sensations as well as bodily functions, such as control of your bowel and bladder.

Functional Goals

Functional goals are what you should be able to do based on your particular level of injury. The goals are grounded in research and expert opinion related to expected outcomes of persons with SCI at one year after injury. The functional goals outlined in the following chart are typical of return after a complete spinal cord injury. These goals suggest outcomes for your rehab. Of course, factors such as your type of SCI and other health related issues can affect your outcome. Your rehab team will discuss your expected goals with you in more detail.



Possible Functional Goals Following Spinal Cord Injury

Level of Injury	Active Motion	Possible Functions
C1 - C2	Facial muscles intact	Chin or breath control of wheelchair and environmental control unit (bed, call light, phone, lights, TV, etc.)
C3	Neck motion	Chin or breath control of wheelchair and environmental control unit
C4	Shoulder shrug	Chin or breath control of wheelchair and environmental control unit
C5	Weak shoulder motion & elbow flexion	May feed self and perform some hygiene activities using adaptive equipment Arm drive control wheelchair
C6	Shoulder, biceps and wrist extension	Performs most eating, grooming, & upper extremity bathing & dressing tasks Assists with toileting May be independent with transfers Power or modified manual wheelchair
C7	Triceps and finger extension	Independent with eating, grooming, dressing, transfers and bladder care May need assistance with bowel care and some lower extremity dressing. Manual wheelchair
C8	Finger & thumb weakness	Independent with eating, grooming, dressing, toileting, and transfers May need some assistance with bowel care and lower extremity dressing. Manual wheelchair
T1 – T9	Weak chest & abdominal muscles	Independent with eating, grooming, dressing, toileting, and transfers Manual wheelchair, may stand with brace

T10 – L1	Chest and abdominal muscles, Trunk stability	Independent with eating, grooming, dressing, toileting, and transfers Manual wheelchair, may walk short distances with brace & walker
L2 – L5	Trunk & hip movement. Weakness in knees	Independent with eating, grooming, dressing, toileting, and transfers May walk with brace & cane, manual wheelchair for long distances
Sacral	Weakness in ankle & foot	Independent with eating, grooming, dressing, & toileting Able to walk

.

PSYCHOSOCIAL ISSUES

What lies behind us and what lies before us are tiny matters compared to what lies within us. Ralph Waldo Emerson

Overview

A spinal cord injury is a major life change. It takes time to adjust and the process is different for everyone. You may have lots of questions and concerns. How will my life change? How will I get around? What will therapy be like? What will others think of me?

Emotional responses like sadness can happen. You may feel sad or grieve the changes in how you do things and how you will live your life. Life roles and responsibilities often change after an injury, and the grieving can continue for months and even years.

It is normal and healthy to have all different kinds of emotions. Sometimes emotions grow into strong and upsetting feelings. This can make it hard to finish things that you started or hard to feel joy from things that you like. The process of adjustment can help you. You can start to feel better when you adapt to changes, learn important self-care skills, engage in activities that will help you to get back to your community, and rebuild a life that is filled with purpose.

Living with Spinal Cord Injury

To live with a spinal cord injury means learning new skills or new ways of doing things. These skills will help you be more independent and to get back

into your community. It can be helpful to know about the experiences of other people.

Common Emotional Responses

- Emotions happen in response to the physical changes and changes in physical functioning. You may feel sad, worried, scared, angry, confused, or even out of control. These reactions are normal and may be different for each person or different for the same person at different times.
- Many people feel a sense of loss or grief about the changes in their bodies. You may feel sad at times or angry about what has happened. These feelings often decrease on their own as you gain confidence in handling the changes. You can also feel better when you have a chance to express your emotions to others.
- You may notice that you have less control over your body and your environment. You may also have more difficulty handling frustration. This can happen with basic tasks or with tasks you could manage on your own before but now require help from another person.
- There are many new experiences for people after spinal cord injury. You may need to re-learn things that you easily did before without thinking about it. The future may seem less clear with all the sudden changes and new experiences. You may feel overwhelmed and anxious at times. This

may occur even if you never thought of yourself as being an anxious person before.

- Some people struggled with depression or anxiety before the spinal cord injury. The stress after an injury can make this even more noticeable.

Other Changes After Injury

- Some people experience clinical depression. Clinical depression is intense sadness that does not go away. There can also be a feeling of hopelessness. Other symptoms are loss of interest or enjoyment in your usual activities, social withdrawal, poor concentration, reduced energy, and sleep and appetite problems. People with clinical depression may have frequent thoughts of self-blame or experience low self-esteem. There may also be thoughts of death or even suicide. If you experience clinical depression, it is important to know that clinical depression is treatable. Talk with your psychologist. Your psychologist can tell you more about evidence-based options to relieve these symptoms.
- You may be preoccupied with the thought, “Why did this happen to me?” This is a common question for people trying to make sense of their situation. For some people, a spinal cord injury can challenge religious beliefs or spiritual perspectives. However, most people find that their religious or spiritual backgrounds are a significant source of positive support.

- Changes in thinking or difficulty with thinking clearly can happen for different reasons after the injury. Sometimes the reason is related to a traumatic brain injury or pain. Sometimes the reason is medication side effects, problems with sleep, or the hospital environment. Changes in thinking, remembering information, and paying attention should be reported to your team. Thinking difficulties can get in the way of your rehabilitation.
- Most people adjust well to the changes after spinal cord injury. They continue to participate in activities that are meaningful and enjoyable to them. Finding a “fighting spirit” and the ability to overcome challenges or setbacks can be a helpful coping strategy. Also, it is important to stay connected to your support networks such as family, friends, faith, or other groups in your community. Positive supports can help you find your sense of purpose and to achieve your goals.

Inpatient Rehabilitation at the Hospital

The inpatient rehabilitation stay after a spinal cord injury is often the longest amount of time anyone will spend in a hospital. Some things will be different while you are in the hospital compared to when you are in your home environment.

- The inpatient acute rehabilitation setting usually includes a lot of structure. For example, therapies and groups are at scheduled times. Activities like getting ready for the day, eating meals, and going to bed

also usually have set times. This structure, along with your hard work in therapy and other activities, help you make progress toward your rehabilitation goals. Moving through the rehabilitation day can lead to feeling tired with low energy by the end of the day. Keeping your scheduled activities each day will help your energy improve over time.

- Rehabilitation has a lot to do with learning. You will learn how to accomplish old tasks in new ways. You will learn how to use new equipment. With the heavy emphasis on learning, it may help you to think of this as a “school” environment, where there is a lot to remember and even more to practice. And like school, rehearsal and practice are vital to learning.
- The psychologist is a member of your rehabilitation team. Your psychologist is here to help you learn to deal with many of the physical, psychological, and social changes you are experiencing. A psychologist can offer support and assistance by providing education about your injury, teaching you new skills to manage emotional reactions, reviewing how to appropriately ask others for help, and setting short and long-term goals. A psychologist can also help you use your supportive resources such as family, friends, church, and other support groups.

Coping Strategies

Adjusting to life after a spinal cord injury is an ongoing process. These changes can be stressful. Coping refers to the things that people do to reduce the negative impact of stress and increase overall well-being. The following

are examples of some strategies that can be helpful during the adjustment process. Talk with your psychologist to learn how to use these strategies and to learn other skills.

- Keep track of your goals and your progress towards goals
- Identify your strengths and make the most of your strengths
- Get support from your social network
- Practice effective problem solving
- Practice healthy self-care behaviors related to sleep, nutrition, and activity
- Use effective communication to work with your treatment team
- Refrain from using things that seem helpful in the moment but can be harmful down the road, such as alcohol or drugs
- Consider formal assistance from providers, such as psychology service, psychiatric medication evaluation and management, chaplain service, and substance use related resources

It is important to know when to seek immediate mental health attention. If symptoms are so severe that you begin to have thoughts of wanting to hurt yourself and/or someone else, it is important to seek immediate assistance. Keep in mind that after discharge, you can access assistance by a trained professional 24 hours a day at the *Veterans Crisis Line (1-800-273-TALK)*. Confidential chat is available at *VeteransCrisisLine.net* or you can text *Veterans Crisis Line* staff at 838255.

SKIN CARE

Your skin is the largest organ in your body. It covers and protects your whole body. Your skin serves important functions for you. The three major functions are to:

- Protect
- Sense or feel
- Adjust your body's temperature and fluid content

Your skin acts like a shield, protecting you against germs, dirt, objects such as pebbles, and the ultraviolet rays of the sun.

The nerve endings in your skin send messages to your brain through the spinal cord. These messages give you the feelings of heat, cold, pain, and touch.

Your skin also helps in keeping the right amount of water in your body as well as keeping your body temperature stable. Sweat glands produce water; this changes the water content of your body. When the sweat evaporates, it helps to keep your body temperature stable.

These functions may be different after a spinal cord injury. For example, you may not be able to feel touch, pain, or temperature below the level of your injury. This means that you may not be able to detect those signs that used to warn you of possible skin problems. In addition, the skin below your level of spinal cord injury may become more fragile and can be injured very easily. You will need to focus on your skin more than you did before your injury.

Nutrition

Protein in your diet is vital to maintain healthy skin. Protein comes from such foods as meat, beans, milk, and eggs. Vitamins, minerals, and fluids are also important in keeping your skin healthy. The key to getting good nutrition is to eat a well-balanced diet with a variety of foods. (Refer to the chapter on nutrition for more information.)

Skin Hygiene

You must keep your skin clean and dry. Damp and moist skin is a prime place for skin breakdown to occur. You must pay special attention to areas with body creases, such as your groin and buttocks. Wash and dry these areas very well each day. Your feet also need special care. Inspect them daily for cracks, calluses, red areas, and long toenails. Soak your feet in warm water, and gently remove hardened skin with a washcloth. After rinsing, dry your feet well; even dry between your toes. Keep your toenails short. Cut your toenails straight across. Massage your feet with cream or skin oil to keep the skin soft.

Skin Inspection

Use a mirror to check your skin frequently. Check your skin at least twice per day. One of those times can be during bathing. Look carefully at areas that are bony (knees, elbows, hips, buttocks), your groin, under your arms and breast, and between your toes. If you are a male who wears an external urinary catheter, check your penis for skin breakdown.

When you inspect your skin, look for changes in color such as redness. Look for scrapes, blisters, rashes, or wrinkles. If you find red or broken areas, keep your weight off those areas until they heal. After discharge your caregiver can help you check your skin if you cannot do it yourself.

Pressure Injuries

Pressure injuries are a major problem among persons with spinal cord injuries. This is because of partial or total loss of feeling and decreased movement. Skin cells must have a good blood supply to stay healthy. If the blood supply is stopped, the cells will die and pressure injuries will develop. Your weight pushes your bones against the blood vessels, and the blood supply is reduced. The pressure can be from sitting too long in your wheelchair or from lying in bed too long without moving. Over a period of time, the skin cells will die, and your skin starts to break down. This skin breakdown is the beginning of a pressure injury.

Pressure Relief

Change your position often. This will take the pressure off a bony area. It is very important to allow blood to get to the skin cells to prevent pressure injuries. Changing your position often is the key to preventing pressure injuries.

There are several methods that you can use to relieve pressure.

In Your Wheelchair:

Relieve pressure using one of these methods at least **every 15 minutes**.

- Push down on your arm rests and raises your buttocks off the seat.
- Shift your weight by leaning from one side to the other.
- Bend forward with your head down. Be sure your lap belt is in place.
- Lock the wheels and tilt the chair backwards so that the handles rest on a bed or another chair to relieve sitting pressure. Get your therapist or nurse to show you how to do this if you have a manual wheelchair.
- Use the tilt feature if you have a power wheelchair with that feature.
- Always use your wheelchair cushion.

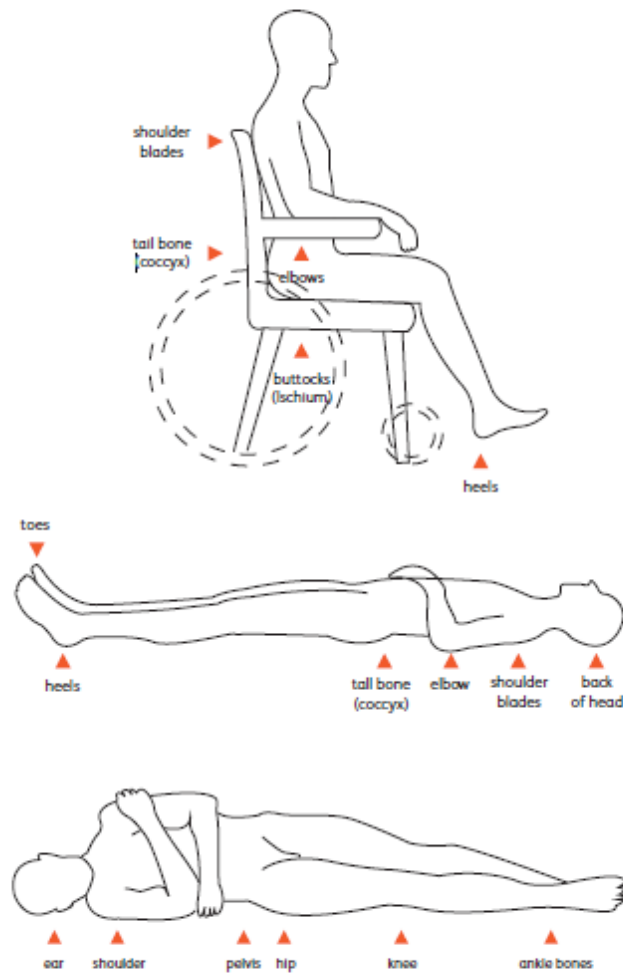
In Bed:

- Turn from one side to your back every 2 hours.
- Do not rest directly on your hip bone when lying on your side. A 30-degree side-lying position is best.



- If you can lie on your stomach, you can stay in that position longer. Keep a close watch on your knees and elbows for skin breakdowns. You may need pillows under your chest, thighs, and between your knees and feet to help you lie on your stomach comfortably.
- If you have a wound, do not lay on it until it has healed.

These are the common pressure areas when sitting and lying in bed:



Clothing and Shoes

Be sure your clothes and shoes fit. Do not wear tight clothes, nylon underwear, or clothes with heavy seams. Watch out for heavy double seams and rivets especially in jeans. You may want to take the pockets off the back of your jeans (you can sew them on the legs if you like). Avoid wearing nylon

sweatpants in the summer. Nylon keeps moisture close to the skin, damp skin is easy to injure. Most persons with a spinal cord injury do not wear underwear. This is your own choice. You will have to decide what works best for you.

Be sure your urinary drainage bag is covered. You can request covers from your nurse if you are not wearing long pants. Your shoes should not be too tight or too large. Often your feet will swell by the end of the day. You may need to wear shoes one size larger than what you wore before you were injured. Wear shoes when you are using your wheelchair. Bare feet, “bunny boots”, or just socks do not provide protection to your feet and toes.

Friction during Transfers

Be sure to lift your body during transfers instead of sliding. When using a transfer board, be sure to wear clothes or cover the board with a towel or pillowcase. You will not transfer smoothly with bare skin on the transfer board. The two most common areas that are most likely to break down from friction during transfers are your buttocks and your heels.

Protection from Burns

Your skin may become more sensitive to heat. Beware of hot dishes from the microwave. **Do not** put hot drinks between your legs. Watch out for things like hot car seats, space heaters, fireplaces, and hot bath water.

What to do if you see signs of skin breakdown

- If you notice a red spot, keep your weight off the area, and check the spot in an hour. If it has not gone away, you must stay off it until the skin color is normal.
- Keep pressure off the area. Depending on where the breakdown is, you may not be able to sit in your wheelchair. Instead, you may have to remain in bed until the skin looks normal. Be sure to change your position while in bed, so you don't get skin breakdown on other parts of your body.
- If your skin has actually broken (cracks, cuts, etc.), keep the area clean and dry. Stay off the area and tell your doctor or nurse right away.
- The best way to heal a beginning pressure injury is to remove all pressure from the area.
 - Keep an eye on the rest of your skin when you do this, so you do not breakdown in other places as you try to heal one area.

Pressure Injuries

Causes

Pressure injuries are usually the result of pressure on your skin for a long time or extra pressure on your skin. This pressure cuts off the blood supply to your skin. The skin then dies and soon breaks down. Any part of your

skin can break down. The areas where the pressure is greatest are over your bones: your tail bone, heels, hips, ankles, ischial bones (where you sit). These areas are at greater risk for skin break down.

Stages of Pressure Injuries

Pressure injuries are described by stages.

Stage 1

The skin is not broken. The skin is red, and it may feel hot to touch. There may be swelling, change in temperature, or firmness at the site of the injury. The redness does not go away. If you press the area, you will not see blanching. (Skin turning white with pressure, and then quickly turning red when finger is removed).

Stage 2

You will notice a break in the surface of your skin (a cut, crack, tear, etc.). This is a partial thickness loss of skin. You may also notice a blistering and swelling over the area.

Stage 3

The skin breakdown is now deeper than the surface; the next layer of the skin is also damaged. This is a full thickness loss of skin. Breakdown goes to the subcutaneous tissue.

Stage 4

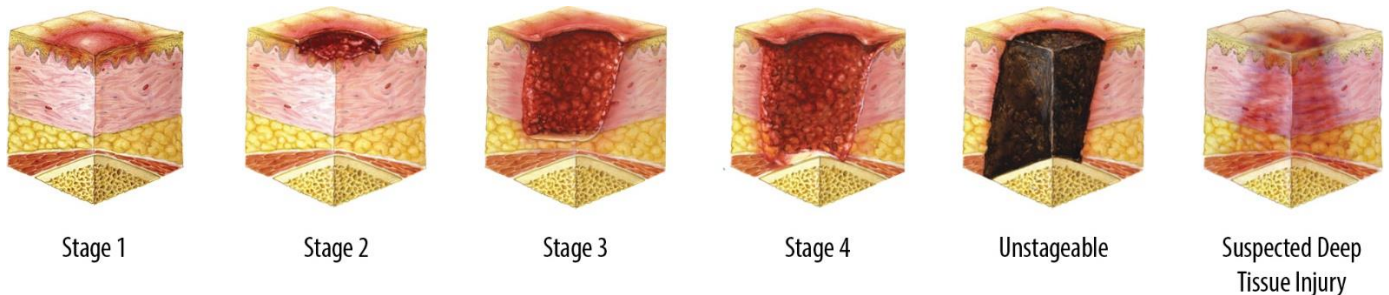
The wound is deeper; it may go down into the muscle and bone. This injury has full thickness loss of skin and tissue loss. This is the worst stage of pressure injuries. All the tissue between the bone and the skin may be damaged. There could be infection in the bone. The wound may look small or have a very small opening at the skin surface, but there may be a deep infected hole underneath. This deep cavity, which you cannot see from the outside, is called “undermining.”

Not Stageable

The skin has a thick black hard area, or the wound base is covered by slough or dead tissue. This area is dead skin.

Deep Tissue Pressure Injury (DPI)

The skin is intact with deep red, purple, or maroon discoloration or blood blister(s)



Prevention

You must learn ways to avoid pressure injuries. It is best to never get a pressure ulcer.

- Inspect your skin on a routine basis so if you do start to develop a pressure injury it does not progress to the next stage. Focus on the bony parts of your body.
- Change your position often to relieve pressure. In your wheelchair, lift your buttocks off the seat, shift your weight from side to side, or lean forward every 15 minutes to relieve pressure. In bed, turn every 2 hours. If you can, lie on your stomach at night to sleep.

Treatment

If you do get a pressure injury you can help with the healing process.

- Keep your weight and pressure off the area. This is very important; it will not heal if there is pressure on it.
- You need plenty of oxygen for the new cells to grow. The nicotine from smoking causes blood vessels to get smaller, so less oxygen gets to the cells. If you don't smoke more oxygen can get to the area.
- Nutrients in the blood will help the new cells to grow. Doing range of motion exercises can increase the blood flow to the area.

- Eat a healthy diet. High protein foods and a well-balanced diet will help your wound heal faster.
- Keep the area around the pressure injury clean and dry.
- There are different methods to treat pressure injury. You must follow the instructions given to you by your doctor and nurse.
- A deep pressure injury may need surgery to help it heal. Your doctor may bring in other doctors to assist in this.

BOWEL MANAGEMENT

After a spinal cord injury, your intestines may slow down or not work at all. You may not be able to make your bowels move the way you did before you were injured. You may not be able to feel when you have to have a bowel movement. Bowel movements that happen when you don't expect them can be embarrassing. ***Constipation*** or ***Diarrhea*** can become serious problems. It is very important for you to set up a bowel training program.

Bowel Training Program

A bowel training program helps your body have a bowel movement on a regular basis. You may no longer have voluntary control over your bowel movements and may need manual bowel care. The important thing to remember is the schedule – it should be set and seldom varied. Random bowel care causes bowel movements to be irregular. If you never know when your bowels may move, it makes planning activities difficult. The fear and embarrassment of having an accident may keep you from going out.

The usual routine for bowel care is Monday – Wednesday – Friday or Tuesday – Thursday – Saturday in the morning or evening. With some people it may be necessary to use a every three days, every other day, or even a daily schedule. Your routine will depend on such things as:

- your preference
- your lifestyle
- your habits
- type of spinal cord injury or disorder
- type and amount of food eaten

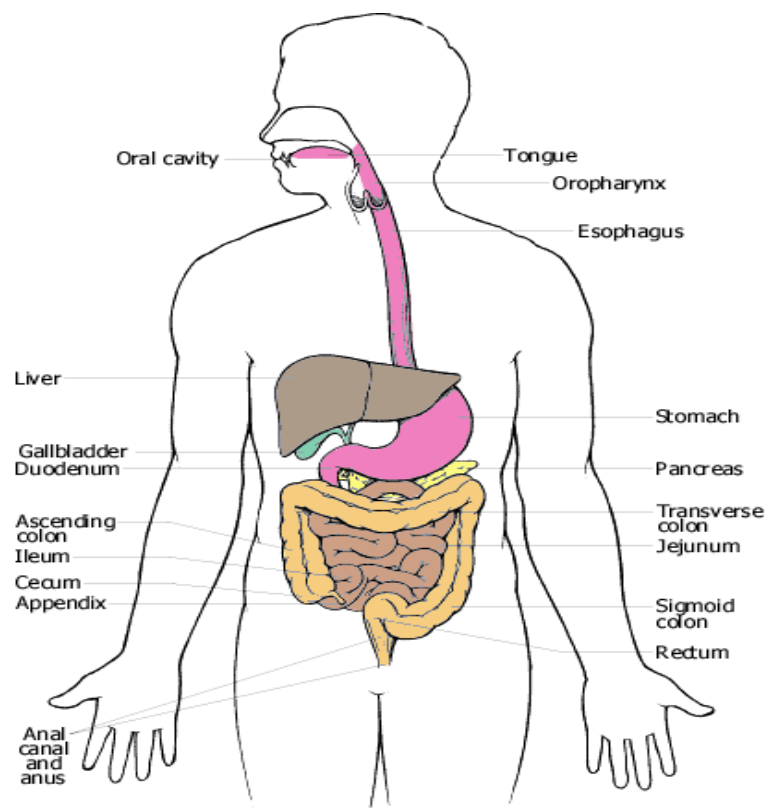
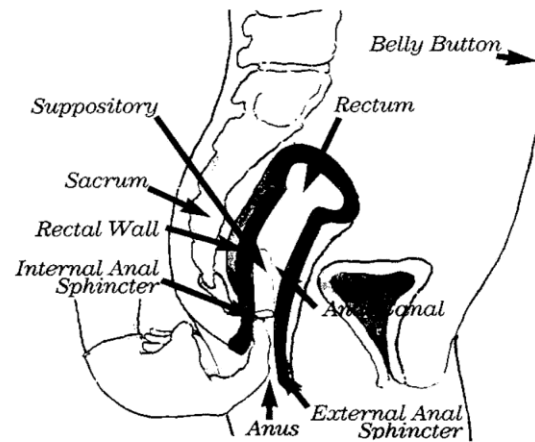
Your rehab team will start you with an every day bowel care program and progress to a schedule that works for you. Most people have a Monday-Wednesday-Friday early morning schedule. Your bowel training will begin while you are in bed. When you can sit up, you will have your bowel care while sitting in a shower chair or on a raised toilet seat. The sitting position is the best position for passage of the stool or feces. Sitting helps bowel care proceed a little faster. We suggest you use the sitting position as soon as possible.

You will be taught to do your own bowel care. If you are physically unable to do your own bowel care, you will learn how your bowel care is to be done so you can direct others. The person who will be caring for you will be taught how to do your bowel care. That person will perform your bowel care several times before you are discharged. If you are able to do your own bowel care, you will do your own bowel care during your rehab. This will help you become skilled in performing the task.

How the bowel works

The bowel is part of the intestine. When you eat, the food moves from the mouth to the stomach and then to the intestines. In the intestines, the body absorbs fluids and nutrients from the food. The remaining solid waste collects in the large intestine or bowel. As the bowel fills, the muscle at the end of the bowel (anal sphincter) relaxes. This lets the intestine muscles push the stool out the rectum. Before your SCI you could tell when the anal sphincter was ready to relax, and you could tighten it until you got to the toilet. Now, you may not be able tell when the urge is there. You may not be

able to tighten the anal sphincter. Can you have a regular routine and avoid accidents? Yes - with a bowel program.



Your Bowel Program

A bowel program includes the following –

- Proper diet and fluid intake
- Medicines
- Regular manual bowel care

Proper diet and fluid intake are important to good bowel care. Foods high in fiber or roughage – vegetables, fruits, and salads are needed. You can change the amount of fiber you eat based on the texture of the stool. More fiber yields a softer stool, less fiber yields a firmer stool. Juices and fresh fruits increase the activity of the bowel. Drink enough liquids to keep the stool from getting hard and dry. You want your stool to be formed and soft. Avoid foods that give you diarrhea or very loose stools. Some people find that eating a lot of spicy and greasy foods gives them diarrhea.

Your doctor may order medicine to help keep your stool soft. Stool softeners (docusate sodium, docusate with senna) may be used. Your bowel care may include a suppository or mini-enema.

Regular enemas are never used for normal bowel training. Repeated use of enemas can stretch the bowel, causing the bowel to lose its muscle tone. Certain tests and x-rays may require an enema preparation. A regular enema is used for those events.

Your bowel care should be done on a regular schedule to prevent accidents. Drink a cup of hot liquid such as tea or coffee 30 minutes before your bowel care. This will help get things started. Get your supplies ready. The best position for bowel care is sitting in a bowel chair or on the toilet. Gravity helps with emptying the bowel. If you are not able to sit, lay on your left side in bed. This helps the stool move into the lower bowel so it can be removed.

Use digital stimulation (continuous or intermittent) if you have a reflexic bowel. A spinal cord injury above the sacral segments of the spinal cord produces a reflexic bowel in which the reflex connection between the colon and spinal cord remains intact. Digital stimulation will trigger the reflex to help evacuate the stool.

Use manual evacuation if you have areflexic bowel. A spinal cord injury below the sacral segments produces areflexic bowel in which defecation caused by a reflex does not occur.

Digital Stimulation:

1. **Remove stool** from the rectal area with a gloved finger. This will make sure that your suppository or mini-enema will make contact with the lining of the rectal wall.
2. **Insert** the suppository (glycerin, Magic Bullet®, Enemez®, mini enema, etc.). Allow about 10 – 15 minutes for the suppository to melt.
3. **Digitize** the anal sphincter (ring of muscle). Insert a gloved well-lubricated finger into the rectum. Aim the finger toward the belly button and follow the wall of the bowel. Massage the rectum slowly

with a semicircular motion. It often takes about 20 seconds, but no longer than 1 minute unless instructed otherwise. This stimulates the sacral segments of the spinal cord to produce reflex stool movement. (Digital stimulation is done in a semicircular motion toward the spine to prevent injury to the prostate gland that lies in front of the rectum). Repeat digital stimulation every 5-10 minutes until no stool comes out. Internals greater than 10 minutes between digital stimulations can slow stool movement and prolong complete evacuation.

Manual Evacuation:

1. **Remove stool** from the rectal area with a gloved finger. This will make sure that your suppository or mini-enema will make contact with the lining of the bowel.
2. **Insert** the suppository (glycerin, Magic Bullet®, Enemex®, mini enema, etc.). Allow about 10 – 15 minutes for it to melt.
3. **Insert** gloved well-lubricated finger gently into rectum stretching anal sphincter.
4. **Manually remove** stool from rectal area.
5. **Massage abdomen** up the ascending colon (right side) across the transverse colon and down the descending colon (left side) to aid in stool movement.
6. **After 5 minutes, check rectum** to ensure evacuation is complete.

Helpful Hints to Remember

- Do your bowel care on your regular scheduled day and time.
- Even if you have diarrhea, do your bowel care. You may have hard stool that is not moving down. (Signs of impaction – swollen hard stomach, sweating with chills and nausea, constant liquid stool, possible headache). If you have diarrhea and are not impacted, do not use the suppository.
- Be aware of your results. Know the color, texture or consistency (hard or soft), and amount of your bowel movement. Even if you have a high injury and cannot do your own care, you need to know what's going on.
- Massage your abdomen if you can. This helps move stool along quicker.
- Do not do digital stimulation when it is not the regular scheduled bowel care day and time. If an accident occurs, clean yourself up but do not check for more stool. (**EXCEPTION**: If you are in dysreflexia and a distended bladder is not the cause, check for stool and remove if present. See the Autonomic Dysreflexia section of this book for further explanation.) Any other unnecessary digital stimulation will confuse your body and accidents may occur more often.
- Persons with a new spinal cord injury take longer to evacuate their bowel. As you learn how to do bowel care and train your bowel it will take less time. The goal is for bowel care to take about an hour to complete.

After you go home, you may want to change the time of day you do your bowel care to fit with your lifestyle. This will not be a problem as long as you

change it to a set schedule and time. Remember, a regular schedule keeps your bowels trained and helps to prevent accidents.

Possible Bowel Problems

Constipation and Impaction

Constipation is a condition in which stool does not pass as often or as completely as usual. Poor diet, not enough fluid intake, not enough activity, or side effects of some medications often cause it. The longer the stool stays in the bowel, the harder and drier it gets.

Impaction is the result of large amounts of hard stool plugging the rectum. Frequently there may be loose stool oozing out. This means that only liquid is passing around the impacted stool and coming out. The causes are the same as constipation. Remove the stool manually. You may have to use an enema. Be aware that autonomic dysreflexia may occur. Your bowel care program may have to be adjusted to prevent impaction from occurring again.

Diarrhea

Diarrhea is passing watery loose stools. This may cause unplanned bowel movements and accidents. The causes of diarrhea include poor dietary habits, certain medicines, overuse of laxatives or stool softeners or some illness such as the flu. To resolve this, you must correct the problem. (If you are impacted, you may be passing only liquid stool. Check your rectum to make sure you are not impacted.)

Excessive Gas

Gas is common in persons with a spinal cord injury. It is often made worse by lying in bed for a long time, swallowing air while eating, improper diet, and eating gas forming foods such as onions, cabbage or cucumbers. To reduce this problem, try to determine the cause and make changes in your diet. Activity or exercise can help move gas through your system in small amounts.

BLADDER MANAGEMENT

Urinary System

The urinary system is made of the following parts:

Kidneys – There are two kidneys, one on each side of your back just below your rib cage. As blood flows through your kidneys they remove some of the waste products from the blood. The waste products are removed from the body as urine.

Ureters – There are two ureters. They are tubes that connect each kidney to the bladder. Urine flows down from the kidneys into the ureters to your bladder.

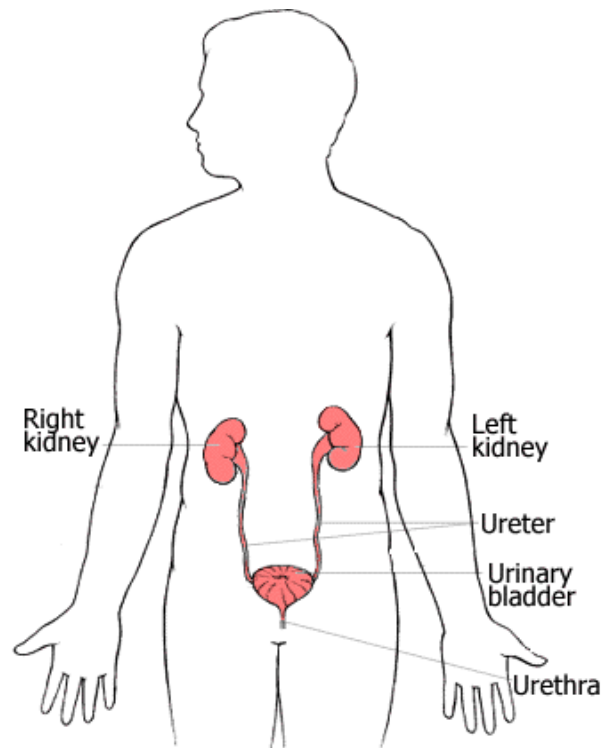
Bladder – This is the muscle that stores urine until you go to the bathroom to get rid of it. Similar to a balloon, it stretches when full and shrinks when empty. Before you were injured, when your bladder was full, a message was sent to your brain to let you know that you needed to empty your bladder. In persons with a SCI, this message doesn't get through to the brain.

Urethra – This is a tube that carries urine from the bladder and out of your body when you urinate.

Sphincter – These are special muscles in the urethra that keep urine in the bladder. Before you were injured, you controlled when you urinated by tightening or loosening the sphincter. Depending on where your spinal cord

is injured, this sphincter may be tight or loose. This may determine if you will leak or dribble urine.

Valve – A valve is located where the ureters connect to the bladder. It keeps the urine from going back up to the kidneys. If the valve can't work properly, the urine flows back to the kidneys. This is called reflux.



How the bladder works

When the bladder is full of urine, the nerves in the bladder send messages up the spinal cord to the brain. If you are not near a bathroom, the brain sends a message down the spinal cord to the sphincter to tighten. This holds the urine back until you reach a bathroom. When you get to a bathroom, the

brain sends a message down the spinal cord for the sphincter to relax. Urine then flows out of the urethra and the bladder is emptied.

In persons with a spinal cord injury, the bladder often loses its ability to function normally. There has been damage to the nerves that carry messages to and from the brain about bladder function. You may not be aware that your bladder is full. You may not be able to tighten or relax your sphincter. The normal bladder empties itself completely during urination. After a spinal cord injury, this may not be true. Some urine may come out, but your bladder may not empty all the way. Sometimes urine does not come out at all. It is very important to make sure the bladder does not become too full.

The term “neurogenic bladder” is often used in spinal cord injury. There are two main bladder types in persons with a spinal cord injury: spastic and flaccid. Each type depends on the location of the injury on the spinal cord.

Spastic Bladder

In this type, the bladder muscle tightens, and it may or may not cause urine to flow from the bladder. This type of bladder is usually found in a spinal cord injury above the T12 level.

Flaccid Bladder

In this type, the bladder muscle has lost all the ability to contract or squeeze the urine out. Therefore, urine collects in the bladder and the bladder stretches. Urine comes out if you push down with your abdominal muscles, or if you apply manual pressure over the bladder (such as in bending forward

at the waist). This type of bladder is usually found in a spinal cord injury at the T12 level and below.

It is difficult to know what kind of bladder you have without doing testing to find out. Just because your level of injury falls above or below T12 does not mean that you have a spastic or flaccid bladder. A test called **urodynamics** will tell what pressure your bladder has when it fills with urine and what pressures your bladder has if you are able to pass urine out of your bladder. This test will also show what your bladder looks like. The test is needed to decide the best way to manage your bladder. The important information we get from the study is the bladder pressure. The higher the bladder pressure the more chance there is for damage to the kidneys. Unfortunately, most people who are paralyzed are not able to tell how high their bladder pressure is. Without the urodynamics test and annual physical exams, kidney damage may go unnoticed until it is too late to correct.

Your bladder care will depend on the type of bladder you have and the results of the bladder testing your doctor orders. You will be taught how to manage your bladder in order to prevent problems.

Bladder Training Program

During the first few weeks immediately after your injury, you will probably have an indwelling catheter (foley catheter) in your bladder to drain urine. As soon as possible, you will have this catheter removed. Most people start a program that will take the urine out of your bladder several times a day. This is called intermittent catheterization (IC or “cathing”).

During the training period, your doctor may order you to drink only a certain amount of fluids. This is so your bladder does not become too full or distended. Your doctor may also order urodynamic tests, to find out how well your kidneys, bladder muscles and sphincters are working. Bladder problems are often a major problem in persons with a spinal cord injury or disorder. It is important that you do everything you can to promote a healthy urinary system. Depending on your level of injury, you or your caregiver may be taught to do catheterizations. Adaptive equipment can be used if you have limited hand function.

External Catheter (External Urinary Device, EUD, condom cath)

An external catheter is used to collect urine if you pass urine from the bladder between catheterizations or if you don't need an indwelling catheter. It keeps you dry and prevents irritation of the genital area from urine. There are many brand names and sizes and many methods of putting on an external. Don't be discouraged until you have tried several. External catheters are not an option for females.

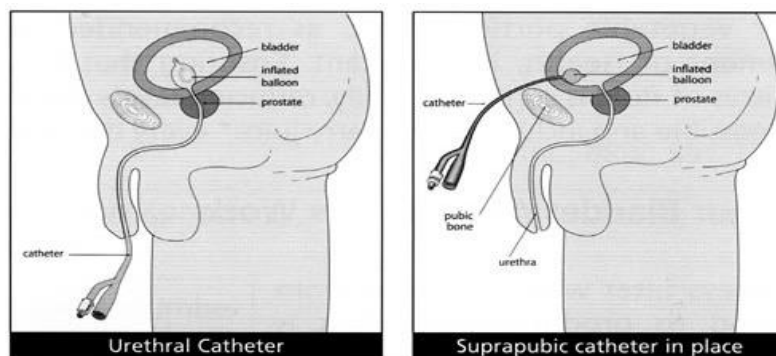
Procedure for Applying External Urinary Devices (EUD)

- 1) Shave or cut public hair if necessary.
- 2) Wash the penis with soap and water.
- 3) Dry penis thoroughly. Make sure the penis is completely dry.
- 4) Apply skin prep to the penis. It protects the skin and helps the EUD stick. Let it dry until it is "sticky" before putting on the EUD.

- 5) Apply the EUD according to the instructions on the package or given by your nurse.
- 6) Connect the EUD to a bedside drainage bag if you are in bed or on a prone cart or connect the EUD to a leg bag if you are in your wheelchair.
- 7) Cover your drainage bag so others do not see the drainage.
- 8) Check your EUD often to make sure it is not twisted.

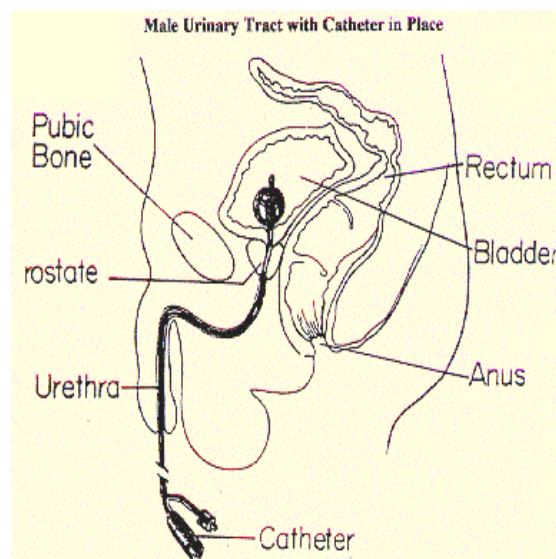
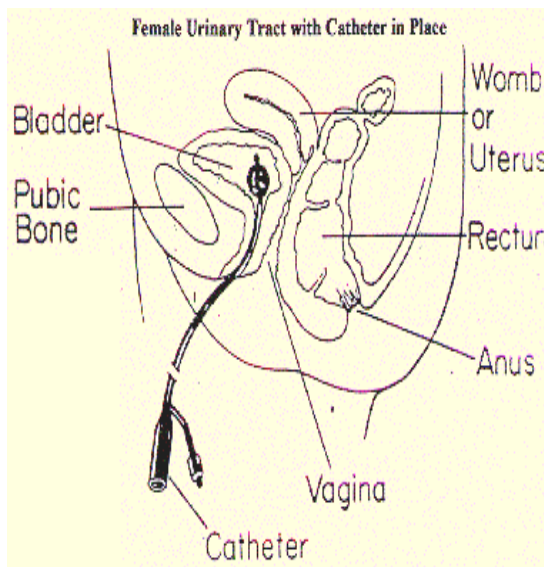
Suprapubic Urinary Catheter

A suprapubic catheter is an indwelling catheter that is placed directly into the bladder through the abdomen. The catheter is inserted above the pubic bone. The catheter drains into a leg bag. A suprapubic catheter may be considered if you have an indwelling urinary catheter and intermittent catheterization is not an option. The risk of urinary tract infection is less with a suprapubic catheter than an indwelling urinary catheter. The insertion site (opening on the abdomen) and the tube must be cleaned at least daily with soap and water. You can wear a simple dressing over the site. Empty your leg bag when it is $\frac{1}{2}$ to $\frac{2}{3}$ full.



Intermittent Catheterization

“Intermittent” means “periodic, at intervals”, and “catheterization” is a procedure to empty your bladder. With intermittent catheterization, your bladder is emptied at regular intervals (every 4 hours is the usual starting point). A tube (catheter) is put into the bladder, draining out the urine that is in the bladder. This is called catheterization or a cath. The catheter is then removed until another 4 hours have passed. If you pass urine or leak between caths, then the time between caths may be shortened. This will depend on the results of the urodynamics test and the amount of urine left in the bladder. Males can deal with leaking by using an external urinary device. Intermittent catheterization is an ideal method for females to use if there is no leakage between catheterizations. For the female, there is a special short female catheter that can be ordered. If the female leaks urine, then the best method of bladder drainage would be an indwelling catheter or suprapubic catheter.



Stimulation of the bladder by taping on the abdomen, scratching the thigh, or pulling the pubic hair can sometimes help you urinate. This should be done before catheterization if your bladder is the spastic type. The urine drainage bag should be emptied, and the amount of urine recorded before this stimulation. After you void, record that amount of urine. The urine obtained from the catheterization after voiding is known as the post-void residual (PVR). The number of caths may be changed if the PVR is low and bladder pressure is low from the urodynamic testing.

Intermittent Catheterization at Home

While you are in the hospital you will use a sterile cath kit. This is because there is more chance of infection in the hospital than in your own home. You will not have to use the sterile cath kit when you are on pass or after you are discharged from the hospital. If you are on intermittent catheterizations, you may use a technique called clean cath when you are not in the hospital. (See procedure).

After discharge you will be given one catheter for each cath. For example: If you do 4 caths per day, you will receive 120 catheters per month.

After your discharge you may want to adjust your cath schedule to your lifestyle. You may be able to cath when you get up in the morning, again around lunchtime, then in the late afternoon, and finally before you go to bed. If you limit your fluids in the evening, you may be able to sleep through the night without cathing. You will want to gauge your caths so you will not have over 500 ml (about a half of quart of fluid) at any one cath.

You may have to cath while you are sitting up. If so, you will want to either transfer to the toilet (if you are able) or slide your hips forward in the chair to straighten out the angle to pass the catheter. If you sit straight up in the chair to pass the catheter, there is a chance that the catheter will meet resistance as it goes under the pubic bone. The catheter may not follow the natural curve in the urethra and might go straight and put a hole in the urethra. This is called a *false passage*. The catheter will follow this false passage and you will not be able to drain your bladder. If this occurs you will need an indwelling catheter.

Procedure for Clean Self-Catheterization –At Home

Equipment:

Straight catheter #14F
Lubricating gel
Providone iodine prep swab
Urinal (optional)

Procedure

1. Wash hands with soap and water
2. Clean head of penis with iodine swab. Women should clean outside parts of vagina.
3. Open lubricating gel and catheter.
4. Spread gel on catheter.
5. Catheterize self. Insert catheter until urine flows. Allow urine to flow into urinal or toilet. Push on bladder to make sure all urine is out of bladder.
6. Remove catheter.
7. Discard catheter.

Key Points

To be as clean as possible.

Use water soluble gel.

Helps catheter pass and prevent trauma to the urethra.

If you are sitting up, remember to slide forward in the chair to help prevent damage to the urethra.

While on *Pass* it is important to do your caths at the same times you do them in the hospital. It is important that the bladder does not become too full (distended).

Urinary Tract Infections (UTI)

A urinary tract infection (UTI) is one of the most common problems for persons with a spinal cord injury. Because of your neurogenic bladder, you will need catheterization at some point. The urinary catheter is a common source of bacteria entering the bladder and causing infection. It is very important for you to learn how to prevent UTIs and to recognize the signs and symptoms.

Preventing UTIs

The most important prevention is to use a sterile or clean technique if you are on intermittent catheterization.

If you are not on intermittent cath, drink plenty of fluids (such as water, apple and cranberry juice) to flush your kidneys and prevent bacteria from collecting in your bladder and growing.

It is also important to have urinary check-ups as recommended by your doctor. This will help to detect problems that you may not be aware of due to your spinal cord injury or disorder.

Signs and Symptoms

Most people with spinal cord injury will not be able to feel the common sensations caused by a UTI, such as urgency to urinate and burning sensations when urinating. The following list gives other signs and symptoms. You may have one or any combination of these symptoms:

- Fever (elevated temperature)

- Cloudy urine
- Blood in urine
- Foul-smelling urine
- Sweating and/or chills
- Increase in bladder spasms
- Increase in muscle spasms
- Back discomfort
- Feeling lousy

What you should do if you have a UTI:

Sometimes the symptoms may be so mild that you may not notice them. It is very important to get medical help as soon as you notice any of the UTI symptoms. You must follow your doctor's advice and take your medication. An untreated UTI can progress to kidney infections and serious blood infections.

Urinary Stones

Frequent infections of the urinary tract or stagnant urine may cause stone formation. These stones may block the flow of urine, like a large rock in a narrow creek. Stones can be formed in any location in your urinary tract and can become a source of infection. Stones present in the bladder may also cause dysreflexia.

Signs and Symptoms:

Symptoms may vary depending on the size of the stone. Here are some of the signs and symptoms that might be present:

- Pain in lower back or lower abdomen. The pain may spread to your groin.
- Nausea or Vomiting
- Blood in your urine

What You Should Do:

If you have any of the above symptoms, drink plenty of fluids. Check your urine for stones. Sometimes the stones are small enough to pass out of your body and appear in the urine like sand.

Call your doctor. Your doctor may order special tests to determine the location of the stone. Some stones can be crushed during a procedure using special sound waves (lithotripsy).

RESPIRATORY CARE

Basic Respiratory Function

The respiratory system consists of:

- Two lungs
- Windpipe (trachea)
- Air sacs (alveoli)

The trachea branches into smaller airways. At the end of the airways are the **alveoli**. Surrounding each alveolus is a net of capillaries (small blood vessels) that carry blood to and from the air sacs. The sac and capillaries are like a basketball inside a basketball net.

When a person inhales, several sets of muscles expand both lungs. The expanding lungs draw in air that contains oxygen (O₂) and water vapor. Air travels through all the airways until it reaches the alveoli. Once the air is inside the alveoli, gas exchange occurs. This means that oxygen passes from the alveoli into the capillaries that surround them. At the same time carbon dioxide (CO₂) travels from the blood in the capillaries into the alveoli. When a person exhales, the air with the CO₂ flows from the lungs out of the nose and mouth.

During breathing, also known as **ventilation**, air travels to and from the alveoli several times per minute. It is very important for all the alveoli in the lung to be kept healthy.

There are a lot of these tiny alveoli in each lung. A big part of keeping your lungs healthy involves making sure these air sacs stay open and gets air. When there is a problem with the lungs, it often means that air cannot get into and out of the alveoli as easily or as often as it once did. Secretions, mucus plugs, and collapse of the air sacs are some problems that can affect the lungs. These problems can make it difficult or impossible to breathe normally.

Breathing Basics

The main muscle that helps you to inhale is the diaphragm. The diaphragm does about 70% of the work of bringing air into the lung. This muscle is shaped like a dome with the lungs “floating” on top of the dome. The intestines, stomach, and liver are under the dome. The diaphragm divides the chest cavity on top from the abdominal cavity on the bottom.

Between each rib there are intercostal muscles, which help to expand the chest. Expanding the chest helps expand the lungs. Other muscles, called accessory muscles, are found around the neck and back. Their job is to expand the upper chest. These muscle groups help pull air into the lungs during inhalation.

The muscles in your abdomen help you exhale air from the lungs. They also help you to cough hard. Loss of muscle function in the abdomen can make it hard for you to cough with a lot of force. This may set the stage for lung problems that can be fatal.

Spinal Cord Injury and Breathing

Breathing signals travel from the brain or brain stem to the spinal cord. The spinal cord sends the signals to the diaphragm, intercostal muscles, accessory muscles, and abdominal muscles. When a spinal cord injury occurs, the signals cannot pass from brain to spinal cord and out to muscles.

The effect that a spinal cord injury has on your ability to breathe depends on the level of injury and how much of the spinal cord is injured. With higher levels of injury, there is more loss of breathing function. There is also a greater chance for breathing problems. Persons with *complete* injuries of the spinal cord usually have more problems breathing than those with *incomplete* injuries.

Our SCI Center can treat patients with spinal cord injury who cannot breathe as well as they should. Mechanical ventilators can help with breathing function. Medicines can make the airways wider. Special devices can be used to help get the secretions out. Using a special head-down position also helps move secretions out of the lungs.

Persons with a *complete* injury at spinal cord level C-3 or higher often lose all breathing function and need to use a mechanical ventilator. Some patients with an *incomplete* injury at C-3 may be able to breathe without a mechanical ventilator or may require a mechanical ventilator only at night during periods of sleep.

The goal for patients in the Ventilator Unit is to decrease their dependence on a ventilator as much as possible. We use a respiratory rehabilitation and

ventilator weaning protocol to help patients meet this goal. The protocol is based on scientific research and guides the care we provide.

Ventilators used at the SCI Center:



Pulmonary Problems

Loss of muscle function related to breathing decreases lung capacity. This sets the stage for breathing problems no matter what your level of injury is or the degree of completeness. The risk of problems is highest in persons with complete tetraplegia. Mucus plugs can develop in the airways. The alveoli can collapse (atelectasis). Symptoms of lung problems include:

- increased chest congestion,
- fever
- shortness of breath
- heaviness in the chest
- increased heart rate
- decreased voice

If these lung symptoms are present, call your doctor right away. Lung problems must be treated quickly and completely to prevent pneumonia. Pneumonia is the leading cause of death for all persons with SCI regardless of the level of injury or the time since the initial injury.

Preventing Pulmonary Problems

Pulmonary problems are most likely to develop within the first 12 months after a spinal cord injury. The following steps are important during the period of rehabilitation.

- If you have a tracheostomy and are on a ventilator, have your lung secretions suctioned as often as needed.
- If you are on a ventilator or have thick secretions, increase your intake of water. You may also need a device to increase the moisture in air that goes into your lungs.
- If you have bronchoconstriction (narrow breathing airways) you may need medicine to open the airways.
- Sometimes you may be placed in a head-down position (Trendelenburg). This will help remove secretions from your lungs, improve the delivery of aerosolized medicines to your lungs and increase the size of collapsed air sacs. Your lungs may also be inflated while in this position to help reverse collapse of alveoli.
- If you cannot cough, you may need tracheal suctioning, quad cough assistance or use of a cough assist device. Your caregivers will be taught

how to perform tracheal suctioning and quad cough assistance. Your caregivers will learn how to use the cough assist device if you will be going home with one.

- You should be vaccinated against pneumococcal pneumonia. You should get the influenza vaccine each year.
- At home keep a bag valve mask (Ambu® bag) and portable suction machine near you. Be sure your caregivers know how to use them.

Keeping Your Lungs Healthy

You need to adopt a life-long plan to decrease the risk of breathing problems. Follow these steps for healthy lungs.

- Exercise. Regardless of your level of injury or time since injury you should perform exercises for your breathing muscles. Be as active as you can. Even persons with high tetraplegia and on a ventilator can often perform exercises. These exercises can help them to “breathe” for a short time in case they are disconnected from the ventilator. A respiratory exercise program can be designed for you while you are a patient at the SCI Center.
- Get enough sleep each day. Rest and sleep are as important as exercise to get the desired results from training. Persons with weak breathing muscles may be at high risk for developing sleep apnea. Symptoms of sleep apnea include:
 - snoring

- daytime sleepiness
- waking up often during the night
- problems with memory or concentration
- waking up tired or with a headache

If sleep apnea is suspected, your doctor will order special tests to see if you have it.

- Cough often. Mechanical or manual assistance may be required. An abdominal binder can be used to help you to cough.
- Drink water. Adequate water intake helps keep secretions loose, making them easier to cough out.
- Eat a healthy diet and manage your weight. Over time persons with SCI tend to gain body fat and loose body protein. Excess fat can limit your ability to breathe without a ventilator. Normal protein levels are needed to maintain the muscle strength required for breathing. Breathing problems are much more likely when patients are underweight or overweight.
- You must turn regularly in bed to decrease the risks of congestion, atelectasis, and pneumonia.
- Sit up in your wheelchair daily. This will help to move secretions and may improve your cough.
- Maintain good posture with mechanical aids if needed.

- Stop smoking. Smoking increases congestion in the lungs, destroys lung tissue, makes it harder to get rid of secretions, and increases the chances of getting pneumonia or bronchitis.
- Have a health exam every year. You should get a chest x-ray and pulmonary function tests during your yearly visit.
- Stay informed. Be aware of your condition and how things are going. Talk to your healthcare team members about how you are doing.

NUTRITIONAL HEALTH

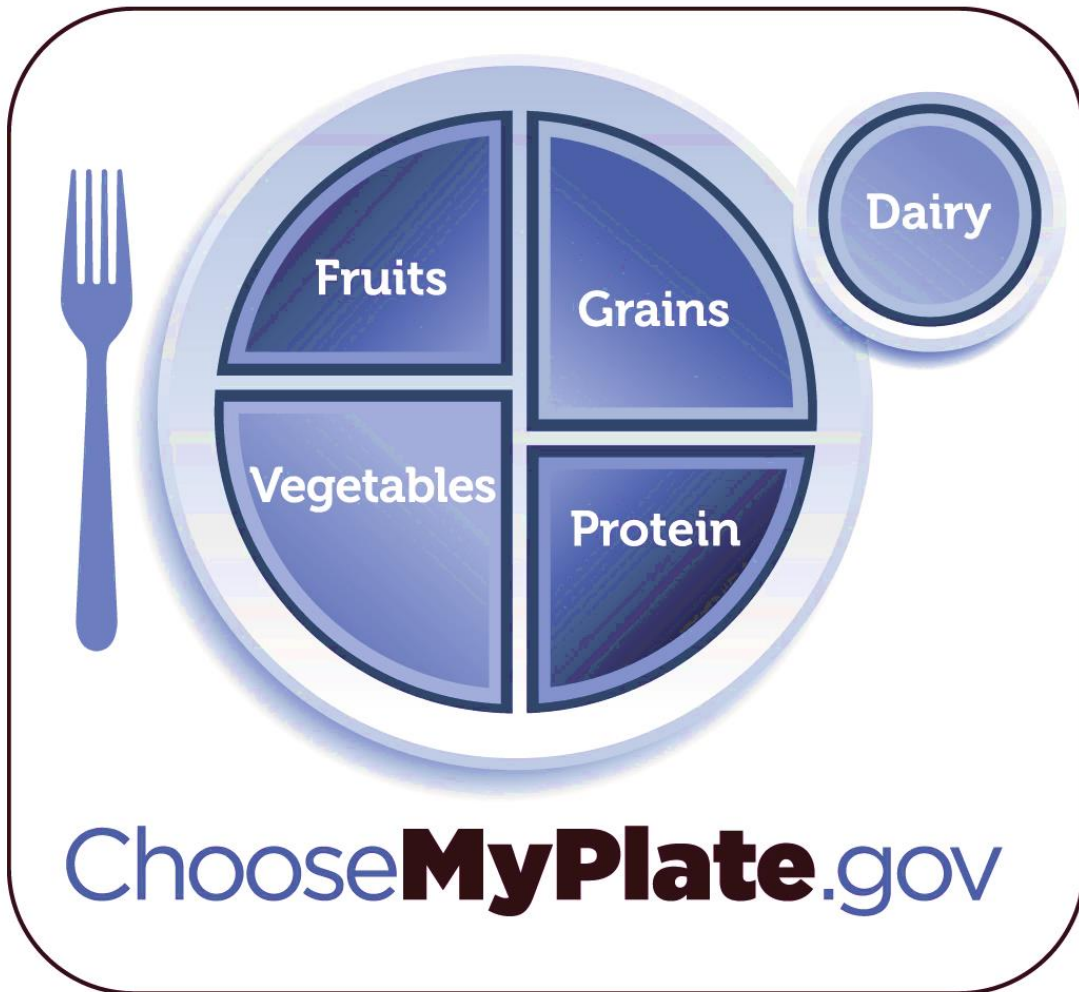
Good nutrition is important. Nutrition affects many aspects of your health. It affects your physical health by preventing disease, fatigue and damage to bones and organs. It helps you resist infection, maintain healthy skin, promote regular bowel function, and maintain your desired weight. It affects your emotional health by keeping you feeling good and keeping your mind sharp. This is why it is vital to get varied foods into your diet. As a person with a spinal cord injury, nutrition is an important part of your total treatment program. Good nutrition will help you feel great and help prevent many problems.

There are six main nutrients which come from basic food groups. These six basic nutrients are:

- 1) carbohydrates
- 2) protein
- 3) fat
- 4) water
- 5) vitamins
- 6) minerals

The food groups which provide the above nutrients are grains, fruits, vegetables, protein, dairy, and fats, oils & sweets.

A Guide to Daily Food Choices



ChooseMyPlate gives a visual picture of the proper amounts of each group of food in the daily diet. Choosing varied foods from each group will provide most of the nutrients you need. Try to spread your daily intake over at least three separate meals per day. This way, your body can properly digest the food and make the most use of it.

Grains:

Eat at least 3 ounces of whole grain bread, cereal, crackers, rice, or pasta every day. They provide fiber, a variety of B vitamins, other trace nutrients and some protein. Complex carbohydrates such as pasta, rice, beans, **whole grain breads and cereals** have greater nutritional value than other forms of carbohydrates like sugar. Some vegetables including potatoes, corn and peas can be considered a part of this food group because they are starches.

Fiber (the portion of complex carbohydrates that is not digested) is important in controlling bowel function. Fiber attracts water and softens the stool, making it bulkier. This helps the stool to pass through the intestinal tract easily and quickly. A diet that lacks fiber may lead to constipation. A high fiber diet may also help keep cholesterol down and prevent other diseases. Increase your fiber slowly to avoid constipation. Start with 15 grams of fiber and slowly increase your intake to 30 grams of fiber a day. Look for breads and cereals with 3 or more grams of fiber per serving listed on the label. When eating a high fiber diet, make sure you drink enough fluids.

1 serving or portion =

- 1 slice bread (1oz.)
- 1 cup dry cereal
- 1/2 cup pasta
- 1/2 cup rice
- 1/2 English muffin
- 1/2 cup cooked cereal or grits
- 1/2 hamburger bun

Fruits & Vegetables:

Most fruits and vegetables are low-fat sources of complex carbohydrates, protein, vitamins and minerals. They also provide fiber. Foods high in vitamin A, such as apricots, cantaloupes, carrots, sweet potatoes and spinach, are needed for normal growth, to maintain healthy skin, to help fight infection and to prevent night blindness. Vitamin C, also called ascorbic acid, is needed to keep the gums healthy, promote wound and fracture healing and resist infection. Good sources of vitamin C are citrus fruits, cantaloupes, strawberries, tomatoes, cabbage, broccoli and green peppers. Folic acid, found in orange juice and green leafy vegetables, is also key. It helps promote cell division and protein synthesis, which is central for tissue growth and repair. Choose a variety of colors to get the most types of vitamins. A good rule is to have at least one fruit and/or vegetable with each meal and snack.

1 serving or portion =

- 1/2 cup raw, canned or cooked fruit
- 1 medium apple, pear, orange, or banana
- 1/2 cup cooked or raw vegetables
- 3/4 cup fruit or vegetable juice

Protein:

The protein group consists of meat, poultry, fish, dry beans, eggs and nuts. These foods are a good source of protein, fat, B vitamins (thiamin, riboflavin, niacin, B6, B12, folic acid, and iron. You may get tired easily if you don't get

enough iron. Iron is needed to build red blood cells, which is very important for oxygen transport throughout the body. The B vitamins help with proper function of nerves and muscles. They also aid digestion and are needed for keeping healthy skin and eyes. They also play a central role in the release of energy (calories) from food. Certain cooked, dried peas and beans are clustered in this group because of their protein content. One serving of these would be a 1/2 cup.

1 serving or portion =

- cooked lean meat
- 1 egg
- 2 to 3 oz. cooked lean fish or poultry
- 2 tablespoons peanut butter

A special word about **protein** - Protein is used for the growth and repair of tissue, and to help the body fight infection. An increased amount of protein is needed when the body is under stress, or when the body is breaking down body proteins faster than it is building them. Severe injuries (such as new spinal cord injuries), surgery, pressure sores, burns, or high fever will greatly speed up tissue breakdown. A high protein diet will help rebuild what is lost and will help heal and prevent pressure ulcers. If you have a pressure ulcer, your protein needs will be increased. If you feel a protein supplement would be helpful, please ask your dietitian about your protein needs.

Dairy Group:

This group includes milk, yogurt, and cheeses. The foods in this group all provide protein, calcium, vitamin D and other nutrients. Some foods contain a higher fat content, so try to use low fat options. Milk is very good source for calcium, vitamins A & D (fortified milk), and zinc. If you don't or can't drink milk, choose lactose free products or other calcium sources.

1 serving or portion =

- 1 1/2 - 2 oz. hard cheese
- 1 cup of milk (skim & 1%)
- 1/2 cup of ice cream, ice milk or frozen yogurt
- 1/2 cup of cottage cheese
- 1 cup of yogurt

Fats, Oils & Sweets:

This group includes foods such as margarine, butter, cakes, pies, cooking oils and other high-fat or high-sugar items. While some fat in the diet is needed, certain types of fat are more desirable. Mono- and polyunsaturated fats and omega-3 fatty acids (found in vegetable oils, nuts, avocados) and omega-6 fatty acids (found in seeds, fish) are more helpful to the heart than saturated fat. Saturated fat would be limited or avoided if possible. Food labels now provide the grams of saturated fat content in the product. Cholesterol is only contained in animal products, so choose vegetable-based oils and margarines to avoid cholesterol. Butter comes from milk, an animal product, so it does contain cholesterol.

1 serving or portion =

- teaspoon butter or margarine
- 1 1/2 teaspoon mayonnaise

As mentioned before, complex carbohydrate foods are better for you than simple carbohydrate foods. Simple carbohydrate foods, such as table sugar, syrup, candies, cakes and honey, provide calories, but little else in the way of nutrition. High-sugar foods, even the low-fat ones, provide excess calories. Excess calories may turn into excess fat. Limit the high-sugar foods to help control calorie intake. The foods below provide some nutrients, but the fat content is high. These foods should be used sparingly.

- candy bar
- soda
- cake
- chips



Fluids:

How much fluid is enough? Drink two to three quarts (8 to 12 cups) of water or other liquids every day. These fluids help keep your body from drying out (dehydration). Fluids also act as a wash, keeping your kidneys and bladder flushed, and helping to prevent stones from forming. If you are on the intermittent catheterization program, you must drink the amount allowed by your fluid limit. Gelatin, ice cream and frozen ices, as well as drinks, soup, juice and water count toward the fluid amount allowed. Fluids taken in excess may cause bladder problems if urine fills the bladder beyond what it can hold. To avoid problems, follow your prescribed fluid limit.

Fluid intake should be spread out throughout the day. In warm weather you may need to increase your fluid intake to make up for the water lost through sweating and maintain normal body temperature. You can help prevent urinary tract infections and constipation through proper fluid intake.

You can see that each food group “specializes” in certain nutrients. This is why it is crucial to get varied foods into your diet. As a person with a spinal cord injury or disorder, nutrition is a vital part of your total treatment program. Good nutrition will help you feel great and help prevent many problems

Vitamin Supplements

A good, well-balanced diet provides all the vitamins you need unless you have a medical problem for which your doctor has prescribed a supplement.

Weight Control

Controlling your weight will keep you looking and feeling healthy and will enable you to move around easily. During the weeks following your spinal cord injury you will lose weight. This is due to loss of lean muscle mass and the stresses of any medical issues you may have (surgeries, pressure ulcers, etc.). During rehab your dietitian can help you attain your ideal body weight. Ideal body weight for a person with a spinal cord injury is less than someone without a spinal cord injury. (See the chart on page 61.)

It is important to maintain your ideal body weight after rehab. Many people with a spinal cord injury gain excess weight in the first years after rehab. This can make transfers hard, decrease mobility and increase the risk of pressure sores. Beware of crash diets, magic pills or potions advertised to make it easy to lose weight without dieting. Crash diets can be dangerous. They are too severe and usually do not provide enough nutrients. They can also deplete muscle (instead of fat) as the source of weight loss. The best way to reduce weight is to eat fewer calories than you use in energy. Gradual weight loss will last longer than quick weight loss. Avoid losing more than two pounds per week.

Some people will require more calories than others, while some people will require fewer calories. People who are very active need more calories. To decide how many calories you will need, speak with your dietitian. If you just want to lose a few pounds, follow *ChooseMyPlate* to be certain that your diet is nutritionally well balanced. Control your portion sizes and limit the

amount of concentrated sweets, fats, alcohol, desserts, sugar, margarine, fried foods and fatty meats in your diet.

Ideal Weight:

Use the SCI Weight Scale on page 71 as a guide for recommended weight ranges. If you are unable to weigh yourself at home, you can judge your weight gain or loss by the fit of your clothes. Have you moved your belt buckle over a notch? Did you buy a larger (or smaller) size the last time you shopped for clothes? We will weigh you during rehab and during your annual exam.

Special Diets:

If you are on a special diet because of a medical condition or have more than a few pounds to gain or lose, **speak with a dietitian** for help in planning a weight control program.

Calcium and Kidney Stones

Many patients with a spinal cord injury are concerned about calcium and kidney stones. As a result, dairy products such as milk and cheese are often left out of the diet to help lower blood calcium levels and prevent stones from forming. *This practice has no basis in fact.* High blood calcium levels are not caused by the food you eat. The high levels are caused by 1) not being able to move around or 2) by the natural process of calcium leaving the bone in an attempt to heal a bony injury or break. If you leave milk out of your

diet, it cuts down on your protein, vitamin and mineral intake. It also makes it harder for you to meet the Recommended Daily Intake (RDI) for calcium.

The most common kidney stones contain oxalate (a food substance) that can be managed by limiting some foods such as: chocolate, tea (higher amounts with increased brewing time), spinach and nuts. Helpful foods to include are calcium fortified orange juice and low sodium foods. Water must be included. See your dietitian for other diet changes needed.

SCI Weight Scale

Height	Paraplegia	Tetraplegia
5'1	97-102	92-97
5'2	103-108	98-103
5'3	109-114	104-109
5'4	115-120	110-115
5'5	121-126	116-121
5'6	127-132	122-127
5'7	133-138	128-133
5'8	139-144	134-139
5'9	145-150	140-145
5'10	151-156	146-151
5'11	157-162	152-157
6'	163-168	158-163
6'1	169-174	164-169
6'2	175-180	170-175
6'3	181-186	176-181
6'4	187-192	182-187
6'5	193-198	188-193

COMMON MEDICAL CONCERNS

Autonomic Dysreflexia (AD)

Autonomic dysreflexia is a complication that may occur in persons with spinal cord injury above thoracic level six (T-6). Autonomic dysreflexia can be mild or it can be a life-threatening medical emergency. For this reason, it is very important for you to be able to identify this complication as soon as it occurs, know what causes it, what to do to correct it, and how to prevent it.

Causes

Autonomic dysreflexia is your body's over-reaction to some kind of irritation or "trigger." Before your spinal cord injury, this trigger would have signaled pain or discomfort to you. Because of your spinal cord injury, your body can't respond properly. Instead your blood pressure goes up quickly.

Listed below are some of the possible and most common causes of autonomic dysreflexia:

- Full or distended bladder
- Stool impaction (severe constipation)
- Infection of bladder
- Bladder stones
- Pressure injuries
- Burns (including sunburn)
- Ingrown toenails
- Tight clothes or shoes
- Pressure on the testicles
- Too hot and too cold temperature
- Menstrual cramps

There are cases where autonomic dysreflexia is caused by something that is not uncomfortable or painful. An example might be sexual activity. This is uncommon, but possible.

Signs and Symptoms

You may experience a few of the following signs and symptoms or all of them.

- Severe, throbbing or pounding headache.
- High blood pressure. An increase of 20 to 40 mm Hg higher than usual is serious. Normal pressure for a person with tetraplegia or high paraplegia is 90/60.
- Blurred vision. You may also see spots in front of your eyes.
- Slow heart rate or a fast heart rate. As your brain responds to high blood pressure your heart rate may decrease, but a few minutes later your heart rate may increase to above normal.
- Goosebumps.
- Sweating, mainly in the face, neck and shoulders
- Flushing or redness of the skin above the level of the injury
- Nasal stuffiness
- Anxiety or jitters

Autonomic dysreflexia is considered to be a medical emergency.

If not treated, the high blood pressure can cause a stroke, heart failure, or retinal detachment (eyes).

What You Should Do If You Have Any Signs and Symptoms of AD

1. Sit up, if you are lying down. This will help bring your blood pressure down. Take your blood pressure if you haven't already done so.
2. If you are wearing an abdominal binder or (TED) elastic stockings, remove them. Loosen or take off any tight clothing or shoes.
3. Check your bladder.
 - Make sure your indwelling catheter is draining and not kinked.
 - Catheterize if you do not have an indwelling catheter. Empty your bladder slowly. If you empty your bladder too fast, you may cause it to go into spasm, which can cause your blood pressure to go up again.
4. Check your rectum for stool. If there is stool in your rectum and your blood pressure is still high, take the medicine your doctor ordered for autonomic dysreflexia. When your blood pressure is normal, gently remove the stool. Before removing the stool, you may need to put xylocaine jelly on the anus and wait five minutes for the medicine to work. This will prevent stimulation to the area, which could cause your blood pressure to go up again.
5. Look for any skin problems, such as cuts, bruises, sores, or insect bites.
6. If your symptoms continue after taking the above measures or your blood pressure is more than 150 systolic you will need to take your autonomic dysreflexia medicine if you haven't taken it yet

7. If your symptoms still do not decrease you will need medical treatment to treat your blood pressure. Get to the Emergency Room immediately.
8. You must tell the medical personnel that you have a spinal cord injury and your problem is autonomic dysreflexia. Show them your *Autonomic Dysreflexia* card. Be sure you receive your card before you are leave the hospital.

Ways to Help Prevent Autonomic Dysreflexia

- Know the causes of autonomic dysreflexia.
- Know your usual symptoms of autonomic dysreflexia.
- Make sure your bladder drainage system is working well
- Keep a regular bowel care schedule and avoid constipation.
- Avoid wearing tight clothing or tight shoes.
- When you are in your wheelchair, do not put pressure on your testicles.
- Avoid exposure to too much heat or cold.

Deep Vein Thrombosis (DVT)

Thromboembolism or blood clot is a leading cause of death and illness in persons with a spinal cord injury. Before your injury the action of your muscles tightening and relaxing helped to keep your blood moving. Now, your blood travels more slowly. Blood tends to clot when it does not move at

a steady pace. Blood clots begin in the veins, often those veins in the legs. This is called a deep vein thrombosis (DVT). The blood clots can block the blood from getting through your veins. Blood clots can break free and may travel to other parts of your body. When a DVT breaks free it is called a thromboembolus. It may travel to the lungs and cause serious breathing problems.

Prevention

- Be as physically active as you can. Turn often in bed and get up in the wheelchair as much as you can. Do passive or active range of motion exercises.
- Never briskly massage or rub your legs. You may gently apply lotion for dry skin.
- Drink as much fluid as you are allowed
- Wear your elastic support stockings (TED hose)
- Stop smoking. Nicotine slows blood flow
- Avoid tight leg bag straps, girdles, tight pants, and knee-high boots
- Continue taking any medicines your doctor ordered to help prevent DVT

Signs of Blood Clot in your leg

- One calf or thigh feels warmer than the other. It may be red.
- One calf or thigh is more swollen than the other
- Pain or tenderness over the area if you have sensation
- The area may feel hardened
- Increase in spasms

What You Should Do

- 1) If you notice these signs, stay in bed.
- 2) Keep your legs at the level of your heart.
- 3) Tell your doctor or nurse.

Diabetes Prevention

Persons with spinal cord injury (SCI) are more likely to get diabetes than those without SCI. Diabetes keeps your body from turning food into energy. It can cause problems with your eyes, kidneys, nerves, and feet. It can also hurt your heart and blood vessels. It is important to take steps to prevent getting diabetes.

Ways to Help Prevent Diabetes

- Eat a healthy diet
- Maintain your correct weight
- Stay as active as you can.

Edema

Persons with SCI may have swelling or edema, mainly in the lower legs and feet. This occurs when extra fluid collects under the skin. You may notice the edema after you have been sitting for a while.

Ways to Reduce Edema

- Wear support hose
- Limit your salt intake
- Elevate your feet above the level of your heart

Heterotopic Ossification

For unknown reasons, extra bone sometimes forms around a joint or in a tendon or muscle. It most often occurs at the hips, but the shoulders, knees, elbows, and fingers can be affected also. This extra bone growth is called heterotopic ossification or H.O.

Signs of Heterotopic Ossification

- Warm enlarged area around a joint
- Decreased movement of the extremity at the joint
- One leg bigger than the other one

The bone growth can be seen on x-ray or bone scan about 4 to 10 weeks after the process begins.

Treatment

There is no known method to prevent ossification, or to stop the process once it begins. In time, the bone growth stops on its own. Passive exercises are necessary to maintain range of motion even when H.O. is present. Some studies indicate that the severity of H.O. is less when certain medicines such as anti-inflammatory agents and etidronate disodium (Didronel®) are used.

Surgery may be the choice of treatment to remove the bone growth, but can be linked with bleeding problems, infection and recurrence.

Osteoporosis

Throughout our lives our bones break down and rebuild over and over again. In the process, several vital minerals - chiefly calcium - are lost and then replaced. Sometimes the breaking down process happens faster than the building up process. This net loss of minerals causes bones to become brittle or osteoporotic. These bones are at risk for fracture. Fractures can happen for almost no reason - during range of motion, after a minor fall, even after a bad spasm. Hip bones (femurs) and leg bones (tibias) are often affected.

How does that relate to SCI?

Osteoporosis occurs in almost everyone who ages. For nondisabled persons, women who have gone through menopause have more problems with osteoporosis than men do.

Some risks for osteoporosis for persons with spinal cord injury are similar to those in nondisabled people:

- Female
- Early menopause
- Small, thin frame
- Light-skinned or fair-haired
- Smoking
- Too little vitamin D
- Too little calcium in diet
- Too much alcohol or caffeine use

- Very high fiber or protein diet
- Long-term use of steroid medications
- Family history of osteoporosis

SCI itself seems to pose extra risks. Osteoporosis and inactivity go hand in hand. Soon after an SCI injury, bones begin to lose minerals and become less dense. We know that muscle traction and bearing weight on bones helps keep them strong. For persons with an SCI other factors such as metabolic, hormonal, and neural function also play a part. As a result, the hips, knees and legs of persons with spinal cord injury are at most risk for osteoporosis and possible fracture.

What can you do?

There are some things you can do to help to reduce the process of bone loss:

- Take part in physical activity – mainly weight-bearing or resistance exercises.
- Eat more foods that have calcium and Vitamin D – dairy products, fish and green leafy vegetables. You should have at least 1200 mg of calcium and 400 IU of Vitamin D each day.
- Quit smoking, if you are a smoker. Smoking speeds up bone loss.
- Limit alcohol intake. Alcohol can speed up bone loss.

Pain

It is common for persons with a SCI to experience pain. For most people the pain is temporary and mild. The pain can be in areas where there is normal feeling. The pain can also be in areas where there is little or no feeling. This is called neuropathic pain. You may have severe pain at times and no pain at other times. Things like the weather, being tired or upset, bowel or bladder problems, and skin problems can affect your pain.

It is important to talk with your doctor about your pain. Together you can identify what kind of pain you have and what might be causing it.

There are different kinds of pain and many causes.

- *Muscle, joint, or bone pain* is often from overuse, overstretching, or spasms. Common areas for this pain are the shoulder, low back, neck, and hands. This pain is usually made worse by movement. Resting the affected body area, heat or cold therapy, massage, and analgesic medicine can help.
- *Nerve pain* is caused by pressure, irritation or stretching of a nerve. An example is wrist pain caused by carpal tunnel syndrome. Splints, pads, positioning aids, and some medicines can help with this pain.
- *Internal organ or visceral pain* affects organs such as your stomach, intestines, or bladder. Often the pain is the result of overstretching. An example is constipation. This type of pain can also occur when blood flow is stopped (heart attack) or when there is inflammation or

infection (appendicitis). Usually this type of pain is new and often gets worse fast. It is important to get prompt treatment.

- *Spinal cord pain or neuropathic pain* is caused by injury to the spinal cord. For some people the pain is a very sensitive area around the body at the level of the SCI. There may be tingling or burning or an unpleasant feeling when the area is touched. Other people may have burning or tingling feelings in their feet. Still others may have brief shock feelings in the legs. Different treatments can make the pain less. Stretching, exercise, relaxation techniques, acupuncture and medicines can help. Social and leisure activities can help distract you from the pain. Talk with your doctor about managing this type of pain.

Spasticity

Spasticity is an involuntary movement of your legs or your arms. You have no control of these movements. These muscle spasms do **not** mean your voluntary movements will return. Spasticity usually begins six weeks to three months after the spinal cord injury.

Cause

Following a spinal cord injury, the nerve pathways between the brain and some reflexes are no longer intact. Stimulation below the level of the spinal cord injury causes the reflex response. In time, some muscle cells can develop an increased response to the reflex. For example, touching or suddenly moving the legs may cause an oversized reflex contraction of your

muscles that you cannot control. A common type of reflex muscle contraction is a rigid straightening of the knees and pointing of the toes. Low level injuries such as T-12 to L-1 usually have fewer spasms. The higher the injury, the more likely spasms will occur.

Advantages of Spasticity

Mild spasticity can actually be used to your advantage.

- Helps maintain muscle tone and bone strength.
- Increases blood flow to the area.
- Can be triggered to assist in dressing your lower extremities or in transfers from bed to chair.
- Can cause a penile erection in males.
- Alerts you to problems or an irritating stimulus below your level of injury.

You can learn some ways to trigger spasticity and use it to your advantage. For example, pinching your legs may cause the lower legs to spasm. This can aid in dressing your lower extremities. Rubbing your abdominal skin or thighs may cause your bladder to spasm and help empty it.

You will gradually learn what causes your spasticity, and how to use it to your advantage.

An increase in spasticity may occur if there is any unusual or irritating stimulus below the level of your spinal cord injury. A few examples are:

- Pressure injury
- Over distended bowel or bladder
- Body too cold or too hot

- Urinary tract infection or urinary stones
- Broken bone (fracture)

Be aware of any increase in spasticity and look for the cause.

Problems with Spasticity

- Too much spasticity can cause skin breakdown from scraping or hitting against solid objects during a spasm. For example, your legs could spasm and hit the bed rail and become bruised. When in your wheelchair, be sure you wear shoes to protect your feet in the event of a spasm.
- Spasticity can also cause pain and cramps and can interfere with your sleep as well as your ability to work. It can also interfere with activities of daily living, such as eating.
- Spasticity can affect your safety. A strong spasm may cause you to fall from your wheelchair or bed. Use a seat belt when you are in your wheelchair.
- Spasticity may cause contractures (shortening of muscles). Contractures limit the movement of your joints and may make it impossible to straighten the affected leg or arm. This would affect how you position yourself in bed and your wheelchair.

Treatment

If spasticity is interfering with sleep or other functions, here are some things that can help.

- Perform range of motion exercises each day. Sometimes these exercises can be done while you are being bathed.
- Avoid the things that you find trigger your spasms, such as certain body positions.
- Medicines, such as baclofen, can decrease spasticity. However, none will eliminate spasticity completely. Talk with your doctor about this option.

Temperature Control

After a spinal cord injury your body may not be able to control its temperature as it did before your injury. A person with a spinal cord injury at T-6 or above can lose the ability to shiver to conserve heat and can lose the ability to sweat to reduce heat. The body will tend to assume the temperature of the environment around it.

You may find that you are often cold and like to have a blanket or wear a long-sleeved shirt. You may enjoy sitting in the sun to get warm. However, your body may not sweat, and you may become overheated. This puts you at risk for heat stroke. Be aware of your body during warm weather. You may want to take your temperature before covering up with a blanket to be sure you do not have a fever. These are some signs that your body is getting hot:

- Muscle spasms
- Weakness
- Nausea
- Lightheadedness, faintness

- Headache
- Rapid pulse
- Red or flushed skin
- Heavy sweating in face, neck, shoulders

If you feel that you are overheating, come indoors as soon as possible and apply cool moist compresses to your neck, groin and underarms. Drink a cool beverage.

Here are some things to help prevent overheating when outdoors:

- Wear lightweight and “breathable” clothing. Avoid nylon garments.
- Wear a broad-brim hat.
- Use a water spray bottle in hot weather to cool your body.
- Drink fluids.
- Avoid alcohol. It can dehydrate you.

PHYSICAL REHABILITATION

Physical Therapy and Occupational Therapy

Introduction

The goal of physical therapy and occupational therapy is to help you get as independent as possible. Each therapy will provide a specialized program geared toward your level of spinal cord injury. Physical therapy will focus on exercise for functional strength and mobility. Occupational therapy will focus on training for activities of daily living (dressing, shaving, feeding, transfers, etc.). At the time of your discharge, you and your family or caregiver will be skilled in all components of your care. You will also have your adaptive equipment including your wheelchair and wheelchair cushion.

Range of Motion (Joint Flexibility)

One of your goals of therapy will be to maintain or improve the flexibility of your arms and legs through range of motion (ROM) exercises. These exercises help to:

- Prevent muscle tightness of the tendons and muscles around the joints that can interfere with movement
- Reduce pain
- Allow for better personal hygiene
- Decrease spasticity (involuntary movement)

If you are able to do the ROM exercises by yourself, you will be taught self ROM. If an attendant or caregiver will assist you with your exercises, they will learn how to do ROM on you. Each movement should be performed ten times, slowly and gently, before going to another movement.

It is important to observe the following guidelines to prevent injury:

- When the body part or joint being moved cannot go any further, that is a signal to stop.
- When there is pain, go no further. This does not mean not to move the part, but rather that it should only be moved to the point of pain.
- When doing the exercises, always have your arm or leg lifted slightly to prevent it from rubbing against the sheets (which could cause skin breakdown).
- Notify your doctor if pain increases to the point that it limits your activities of daily living.

Muscle Strengthening

A spinal cord injury can cause permanent damage to the nerves that cause muscle movement. This may result in paralysis or severe muscle weakness. To be able to perform everyday activities, you will need to strengthen your weakened muscles.

You will start a muscle strengthening program while you are in the hospital. Functional exercises, such as pushing your wheelchair, transfers, and self-care tasks are included as part of the strengthening program.

You will need to continue the program at home after you are discharged. Your therapist will work with you to design a home program to meet your specific needs.

Activities of Daily Living

Your occupational therapist will help you learn to perform activities of daily living based on your level of injury. Daily tasks can include:

- Dressing
- Shaving
- Grooming
- Bathing
- Toileting
- Transferring
- Eating

You may need to use special equipment to help you do tasks by yourself. The equipment can be tailored to your needs and you can practice using it during therapy sessions. You are expected to use your new skills on the unit to perform these daily tasks yourself. This will help you become more skillful.

Your occupational therapist can also help you learn different ways to perform other activities such as:

- Cooking
- Laundry
- Money management
- Cleaning
- Grocery shopping
- Home management

You will practice these skills in the hospital setting and during community outings. This practice will help you prepare for your discharge home.

The occupational therapist may conduct a home or work environment assessment. This will help determine what home or workplace modifications would best increase your function and independence. Your team will work together to help address these needs.



THERAPEUTIC RECREATION & LEISURE SKILLS

Recreation and leisure are important aspects of your life. After your SCI you may feel that you can't take part in your favorite sports and hobbies. Many sports and hobbies can be adapted for persons with SCI. The Therapeutic Recreation Program addresses ways you can pursue your leisure interests. The Therapeutic Recreation Therapist will work with you during rehabilitation to improve your ability to function independently. You will be evaluated to determine your individual needs and interests. You and your therapist will then decide which programs will best meet your needs.

General Program Goals:

- Improve physical abilities including physical endurance, balance, fine and gross motor coordination, flexibility, mobility, and range of motion.
- Promote self-reliance necessary for independent living.
- Increase quality of life by exploring a variety of leisure pursuits.
- Manage stress through activities that promote relaxation and concentration.
- Increase social skills by taking part in social activities in the hospital and in the community.
- Use adaptive equipment to pursue past and present leisure interests.

- Identify community resources that can be used after discharge to pursue leisure activities.
- Actively pursue leisure activities in the community setting.

Programs Available

Craft/Art Program:

Offers options to take part in crafts such as ceramics, leather, stained glass, pottery, drawing, woodworking, copper tooling, and a variety of craft kits. The promotes creative self-expression which helps with relaxation, overall physical rehabilitation, communication, socialization, and management of chronic pain. Consults to Creative Arts Therapy may be ordered by your doctor.

Adapted Sports Program:

Gives you the chance to explore selected wheelchair sports such as softball, power soccer, obstacle course, bowling, table tennis, air rifle, sailing, basketball, and more. This program introduces you to adapted sports as an inpatient and encourages your activity after discharge.

Leisure Education Program:

Provides information to develop and maintain an appropriate leisure lifestyle. Helps you explore the benefits of taking part in recreation, i.e., physical, social, emotional, psychological, etc.

Group Activity Program (GAP):

Promotes participation in social activities at the hospital and in the community such as dinner outings and local events. Allows you to practice wheelchair skills in a group setting.

Music Therapy:

Can help you develop socially appropriate behaviors and interpersonal skills, cognitive skills related to daily functioning, communication skills, and successful and safe self-expression. This therapy can improve mood and affective states leading to overall quality of life.

Games and Bedside Activities:

Encourages you to take part in leisure activities and use adapted equipment to continue to pursue your leisure interests. Learn new skills, increase physical endurance, maintain current functional level, and maintain active participation in leisure interests. A variety of table games, outdoor activities and movies are available. These include video games, table games, cards, social visits, craft kits, videos, table tennis, golf, and gardening.

Community Re-integration

As you progress in your rehab you will have scheduled trips or outings into the community. The purpose of these trips is to address issues of transition from hospital to home, accessibility in public places, money management, self-image, socialization, and functional independence. This program uses the community as a classroom to teach newly injured spinal cord Veterans

the skills needed to successfully adapt to the challenge of life with a physical limitation. You will practice newly learned skills in the “real world”. This guides your overall rehab treatment.

You and the Recreation Therapist will plan the trips. You and the therapist will select the date, time, place, mode of transportation (public or private), goals, accessibility issues, etc. You will work with the Recreation Therapist to obtain the information you need. You will use such things as newspapers, telephone books, guides, internet, as well as state and local services for the disabled.

You will help organize your personal and medical needs prior to going out into the community. You will practice problem solving skills to improve physical, social, and leisure independence in the community setting. Following the trip, you and your therapist will discuss the trip and any problems that may have occurred regarding safety and mobility. This will help you identify areas that may need more attention during your rehab.

Additional hospital resources include:

Library Service – Provides book holders, various magnifiers, talking books, books on tape. Call ext. 6571 for more information

GetWell Network – Provides movies, educational videos, and internet access through your bedside monitor.

Veteran Service Organizations (VSO) – Provide social visits and comfort/personal items such as blankets, toothpaste, razors, etc.

MEDICATIONS

Persons with a spinal cord injury often need to take medications. This chapter lists some of the medications commonly used for persons with a spinal cord injury. Different types of ailments sometimes require different types of medications. You might need other medications that are not listed here.

Each person reacts differently to any given medication. Many medications have side effects. Discuss these with your doctor and pharmacist. Your spinal cord injury can also have an effect on how the medication reacts. Putting more than one medication into your body may produce some unexpected and unpleasant results. Do not let anyone else use your medications, and do not use medications prescribed for someone else.

Be responsible! Once you leave the hospital, you will manage your own medications. To get the most benefit with the least problems, you should know the following about each of your medications:

- Reason to take the medication
- Name of the medication
- Dose (amount you need to take)
- Times to take the medication
- What the medication looks like
- Whether or not to take the medication with food and/or other medications
- Storage requirements (refrigerator, etc.)
- Beneficial effects
- Possible side effects and what to do if they occur

- Possible interactions with other medications

Ask your pharmacist, physician, or nurse for the answers to these questions and be sure you understand the answers. Keep in mind that medications may have more than one name. In the list of medications in this chapter, the generic name is first, with the trade name in parenthesis.

Medications Commonly Used by Persons with SCI

Bladder Symptoms

- Oxybutynin (Ditropan®)

Decreases bladder spasms; may cause dry mouth or constipation

- Tamsulosin (Flomax®)

May cause low blood pressure when sitting up or standing

Blood Pressure Control

- Nitroglycerin ointment (Nitro-Bid® Paste) and hydralazine

Lowers high blood pressure due to autonomic dysreflexia (common with spinal cord injuries above the 6th thoracic vertebrae)

- Midodrine

Increases low blood pressure due to sitting up (orthostatic hypotension)

Bowel Regulation

- Bisacodyl (Dulcolax[®], Enemeez[®])

Stimulant laxative

- Milk of Magnesia (MOM), magnesium citrate

Osmotic laxative

- Polyethylene glycol (MiraLAX[®])

Saline laxative

- Psyllium (Metamucil[®])

Bulk providing laxative; slow onset of action

- Docusate plus senna

Stool softener plus stimulant laxative

Spasticity

- Baclofen (Lioresal[®])
- Tizanidine (Zanaflex[®])
- Dantrolene

Decreases spasms, increases range of motion. Do not abruptly change your dose or stop taking baclofen since hallucinations or seizures could occur.

Talk with your doctor about slowly decreasing the dose.

- Diazepam (Valium®)

Decreases hyperactive reflexes; may cause drowsiness, confusion, and fatigue. Do not drink alcohol if you take diazepam.

- There are other medications used for muscle spasms. These muscle spasm medications work in the brain and with the signals traveling from the brain to the muscles in the arms and legs. These signals may be decreased or absent in persons with spinal cord injury.

Infections

Infections are treated with antibiotics. The antibiotic is selected based on the results of a culture and sensitivity test from a sample of the infected substance such as urine or blood.

Drug Interactions

Medications you buy without a prescription (OTC or over-the-counter) and herbal products may produce unwanted reactions in a spinal cord injured person. These reactions can include constipation, urinary retention and increased blood pressure. Some OTC and herbal products when taken with prescription medications can cause unsafe interactions. For example, combining aspirin with warfarin (Coumadin®) can increase your chance of bleeding problems. Please check with your pharmacist or doctor before taking any herbal products or any medications that are not prescribed for you.

Food can sometimes slow down or help the absorption of medication. Some medications can cause stomach upset. Follow the instructions you were given on whether to take your medication with food or without food. Some foods can interfere with how a medication works. Dairy products, antacids, and iron supplements can block the absorption of certain medications. Your pharmacist, doctor, or nurse will tell you if you need to avoid certain foods.



SEXUALITY

Sexuality is your expression of yourself as whatever gender with which you identify. It can be shown in interactions, body image, grooming, clothing, hobbies, & interests. It is also expressed through physical and emotional closeness. Most people think of sexual activity as physical intimacy.

Holding hands, hugging, and kissing are also ways to express physical closeness. Sharing private thoughts and feelings, connecting with and trusting another are examples of emotional closeness. You will discover that over time your natural feelings of sexuality will return as your self-confidence and self-worth increase.

When it comes to sexuality or fertility issues, you cannot assume anything. Your sexual life may be different after a spinal cord injury, but it is still possible to have a satisfying sex life. Sexual counseling and education are important parts of your rehabilitation. It is important both while you are in the hospital and once you return home. Information and counseling are available to you and your partner on an inpatient and outpatient basis.

Many individuals with SCI, especially in the months after an injury, have personal questions and concerns that can be difficult to ask and talk about. This can include topics such as relationships, adaptive equipment, erectile dysfunction and fertility. Staff members are aware that these are very sensitive issues for you to bring up and will handle them with sensitivity and respect. This SCI Center has a team approach to sexual education and counseling. Team members realize the importance of specific education related to sexual functioning. General education on sexuality is provided as part of your rehabilitation education. Additional one to one sessions can be

arranged with team members if desired. You can talk with any team member with whom you feel most comfortable. Staff members can explain how your spinal cord injury can affect your sexual functioning and answer your questions.

Verbal communication is an important key – both your ability to talk about your concerns to staff and your ability to share information with your partner.

Effects of SCI on Sexuality

A spinal cord injury can alter function and sensation related to sexuality. These changes depend on the level and severity of your injury. It usually takes some time to find out how much sexual function will return. Be patient.

Even though some function may be gone or reduced, your sex drive usually remains strong. Sexual activities can be satisfying when you know how to use the abilities you have. There are different things you and your partner can do. Some persons with SCI find that areas above the level of injury are more sensitive and use these sensations for sexual pleasure. You may want to experiment and discover new ways of pleasuring each other. You can explore new positions, adaptive devices, fantasies, or whatever you and your partner find satisfying.

Men

Many men with SCI are able to have erections. In general, if the injury is incomplete or if the injury is an upper level injury, there is a better chance for an erection. There are two types of erections:

Reflexogenic erections

These result from direct stimulation of the genitals. It is involuntary and can occur without sexual thoughts. Men with upper level spinal cord injury tend to have this type of erection. Usually, if the S2 – S4 spinal cord pathways are not damaged, a man can have these reflex erections.

Psychogenic erections

These result from sexual thoughts or seeing or hearing something arousing. Signals from the brain are sent down the spinal cord to the T10 – L2 level where they trigger an erection. Men with low level incomplete injuries tend to have this type of erection.

Sometimes men with SCI cannot maintain an erection long enough for sexual activity. There are treatments that can be used for this. Your doctor or the urology nurse practitioner can give you detailed information on your options.

Women

Some women with SCI have decreased vaginal lubrication. Lubrication is a response to something sexually stimulating or arousing. It permits easier vaginal penetration. If the nerve signals from the brain to the genital area

are blocked, lubrication is reduced. Most women with SCI are able to experience orgasm. It may take longer or feel different than prior to injury.

Fertility

Men with SCI may have a difficult time getting their partner pregnant. They may not be able to ejaculate, or they may have retrograde ejaculation. Retrograde ejaculation is when the semen fluid goes back up into the bladder instead of coming out of the penis. There are several options for men to father a child. Talk with your doctor about fertility options that would be appropriate for you.

Women with SCI can become pregnant and deliver full-term babies. When you begin to consider pregnancy, talk with your SCI doctor and your OB doctor. They can help you plan and manage the changes your pregnancy will have on your body. They can also address issues related how your spinal cord injury may affect your labor and delivery.

Getting more information

For concerns and questions requiring more specific information, talk to one of your team members. The team member you choose will depend on what your concerns are and the rapport you have with them. Team members know about different aspects of sexuality and SCI. For example,

- the nurses can give you information on anatomy and how your specific injury affects sexual function
- the social worker or psychologist can discuss concerns and questions related to body image, self-esteem and relationship issues.
- the therapists can help you with positioning and adaptive devices
- the urology physician's assistant can provide training on treatment options such as the vacuum erection device and penile injections
- the doctor or urology physician's assistant can provide information on medicine to promote erections

If a team member does not know the answer to your question, another team member will be suggested.

You are not required to discuss sexual issues if you do not want to. You may not yet be ready to talk about them while you are a patient. You can talk to a team member when you are ready, even when you come back to the hospital as an outpatient.

We encourage you to get the information you need so that you can make informed decisions about how to express your sexuality after a spinal cord injury. You can also look in other places to find more information to consider in private. You may find the following resources helpful.

Books & Articles related to Sexuality and SCI

Enabling Romance: A Guide to Love, Sex, & Relationships for People with Disabilities by E. Klein & K. Kroll 1992

Male Fertility Following Spinal Cord Injury: A Guide for Patients by Nancy Brackett, Emad Ibrahim, & Charles Lynne 2011

Pregnancy and Women with Spinal Cord Injury by Amie McLain, Taylor Massengill, & Phil Klebine 2015

Regain that Feeling: Secrets to Sexual Self-Discovery: People Living with SCI by Mitchell Tepper 2015

Sexuality After Spinal Cord Injury: Answers to Your Questions by Stanley H. Ducharme and Kathleen M. Gill 1997

Sexuality and Spinal Cord Injury by Sylvia E. McDonald, Willa M. Lloyd, Donna Murphy, & Margaret G. Russert 1993

The Ultimate Guide to Sex and Disability, 2nd ed by M. Kaufman, C. Silverberg, & F. Odette 2007

Queers on Wheels: The Essential Guide for the Physically Disabled GLBTQ Community by Eva Sweeney 2004

The Sexual Lives of Lesbian, Gay, and Bisexual People with Disabilities: Psychological Perspectives in Journal of NSRC- March 2007, Vol. 4, No. 1, Pages 15-26 <http://link.springer.com/article/10.1525%2Fsrsp.2007.4.1.15>

Top Ten Issues to Discuss With Your Healthcare Provider by Gay & Lesbian Medical Association at

<http://www.glma.org/index.cfm?fuseaction=Page.viewPage&pageId=947&grandparentID=534&parentID=938&nodeID=1>

Websites

www.sexualhealth.com

www.stanleyducharme.com

www.sexualityanddisability.org

www.scifertility.com

www.siecus.org

www.facingdisability.com

Videos

Intimacy and Sexuality after SCI: A panel discussion

<http://event.netbriefings.com/event/mssci/Archives/Reg/>

Communication in Dating & Relationships after SCI (TED talk)

<https://www.youtube.com/watch?v=7PwvGfs6Pok>

Conversations from the Bedroom: Sex after SCI

<https://www.youtube.com/watch?v=J8HXncBbg3E>

Sex and Paralysis Video Series

http://www.drmitchelltepper.com/sex_and_paralysis_video_series

Sexual Positions for Men with SCI

<https://www.youtube.com/watch?v=HatRXFL1TxQ>

Solutions for Erectile Dysfunction

<https://www.youtube.com/watch?v=ZIQtKtsjDQY>

<https://www.youtube.com/watch?v=vOFJXgNCBr8>

Sex and Fertility after a Spinal Cord Injury

<http://www.facingdisability.com/expert-topics/sex-and-fertility-after-sci>

DRIVER'S TRAINING

The Driver's Training Program supports eligible Veterans in owning and safely operating modified or adapted motor vehicles. It is designed to meet the needs of each Veteran accepted for re-training; and if needed, to help them obtain a Florida Operator's License. If you will not be driving, the program can help you select the equipment needed for you to travel in a vehicle as a passenger.

Being able to travel in a vehicle is a very important part of rehabilitation. It will permit you to be active in your community after discharge. The driving instructor can help you with selecting the equipment for your vehicle. You may need such things as adaptive controls, power lifts, and tie-downs. The instructor can also discuss financial assistance programs for converting your vehicle.

The Driver's Training Program:

- Evaluation – The driving instructor will review your medical history. We will assess your physical abilities such as strength, range of motion, and vision. We will also assess your reaction time and thinking skills. This determines how safe it is for you to drive. We will discuss any special adaptive equipment you will need on a vehicle.

- Preparation for Instruction Permit - You must present a social security number or birth certificate. There may be classroom teaching to review road signs, driving rules and defensive driving. You will take the written test of the Florida traffic laws.
- Driving phase - We will teach you the tasks needed to drive an adaptive vehicle. You will learn how to start and stop, back up, make turns, turnabout, and park. You will have the experience of residential, city, highway, and complex driving.
- Driver's license - The driving instructor will take you for your driver's license road test.

If you have not completed your driver's training program before you are discharged, you can complete the program as an outpatient.

VOCATIONAL REHABILITATION

Have you started to ask yourself: “How will I be able to return to work”? “What kind of job can I do, now that I’m in a wheelchair”? Or, “I’m just worried about trying to support my family”. You may feel that since your injury, you have lost what you thought were your only skills for earning a living. Well, don’t shortchange yourself! You still have many job skills that most of us take for granted.

The Vocational Counselor will help you become aware of those skills. The counselor will assist you in finding the proper training to help you to meet your job needs. Your counselor will contact you during your rehabilitation.

Counseling and Testing

We provide counseling and testing to assess your skills and interests and help you decide on a plan for going back to work. We can assist you with getting training for work. If you need to get more education, we can help you find the proper school. There are many agencies in your area, such as the Chapter 31 VA Vocational Rehabilitation Office and State Vocational Rehabilitation Office that can help you with school and training. We can provide coaching for job search activities. We can also help you find volunteer opportunities and ways to stay active around your home.

Still in Doubt?

If you are still undecided about returning to work or school, you can get help when you are ready. Your counselor is there for you and can continue the process after you are discharged from the hospital.

Your future is up to you. If you decide you need help or just want to talk about what is there for you in the job market, call your counselor.



ATTENDANT CARE

What is an Attendant?

An attendant is a person who is qualified by experience or training to help you with your daily care. Specific tasks may include bowel care, bladder care, bathing, feeding, preparing meals, household shopping, and driving. The attendant agrees to perform the tasks in exchange for salary or wages. Hiring an attendant is a business arrangement in which salary or wages are paid regularly for performing a detailed list of tasks.

How to Find an Attendant

Before you begin your search, assess your needs: what do you want your attendant to do? The Needs Work Sheet on the following page can help you do this. This work sheet includes things that you may need done for you (e.g. bathing, dressing, feeding, medication, exercise, bowel and bladder care, transfers) and any other needs you may have for daily living (e.g. shopping, errands, housecleaning).

Think about what your ideal attendant might be, how often you would like the attendant to work, and how much you can afford to pay that person. There are various ways for finding an attendant: word of mouth, newspaper ads, agencies, and bulletin boards. Former Veterans have felt that relatives and close friends should not be attendants. However, that is an individual decision. Some people are willing to work for room and board, if a suitable arrangement can be worked out.

Needs Work Sheet

Need	Frequency	Times Needed
Bathing		
Dressing		
Grooming (shaving, hair care, make-up)		
Meal preparation		
Eating		
Bowel care		
Bladder care		
Turning in bed		
Transferring		
Other personal care:		
Washing dishes		
Grocery shopping		
Turning on computer		
Making bed		

Charging wheelchair batteries		
Driving van		
Writing letters		
Answering phone		
Putting away items		
Laundry		
Housecleaning		
Childcare		
Pet care		
Other household needs:		
Pressure relief/positioning		
Medications		
Range of motion exercises		
Skin inspection		
Suctioning, respiratory care		
Other medical-related care:		

Interviewing

You may want to briefly interview prospective attendants over the phone before setting up a face-to-face meeting. This permits you to provide more information to them about the job and to determine their interest and abilities. A written form can help you collect work history and references. You can have the prospective attendant fill out the form prior to the face-to-face interview. An example of an application is on the following page.

The face-to-face interview should cover your specific needs, your daily activities and what tasks you expect the attendant to accomplish. Your needs worksheet can help you remember all your needs during the interview. You will also want to discuss what you expect from an attendant in duty hours, behavior, education, and physical ability. Consider also how comfortable you and the prospective attendant are with one another.

Before offering the job to a person, ask for references and a list of previous employers. You may consider doing a background check. Take the time to check them out!!

Application for Employment: Personal Attendant

Please print clearly

Name (last, first, middle initial) _____

Date: _____

Street Address:

City: _____ State: _____ Zip: _____

Phone number: _____ Social Security Number: _____

Education: (circle one) Less than high school High school GED

Some college College degree (Major - _____)

Currently attending school: (give name) _____

Expected graduation date: _____

On what date would you be available for work?	_____
If you are under 18 years of age, can you provide required proof of your eligibility to work?	Yes No
Do you have proof of US citizenship or immigration status?	Yes No

Are you prevented from lawfully becoming employed in this country because of your visa or immigration status?	Yes	No
Can you travel occasionally if the job requires it?	Yes	No
Have you ever been convicted of a felony? If yes, please explain:	Yes	No
Are you fully capable of performing in a reasonable manner, the activities involved in this job? (A description of the activities involved is attached.)	Yes	No
Describe any special training or skills:		

State any additional information you feel may be helpful in considering your application:

Employment

Please start with your present or last job. Include any military or volunteer work that may be job related.

Employer 1

Dates Employed: From _____ To _____

Job Title: _____ Supervisor's Name & Phone Number:

Work Performed:

Name: _____

Address:

Employer 2

Dates Employed: From _____ To _____

Job Title: _____ Supervisor's Name & Phone Number:

Work Performed:

Name: _____

Address:

Employer 3

Dates Employed: From _____ To _____

Job Title: _____ Supervisor's Name & Phone Number:

Work Performed:

Name: _____

Address:

References Name: _____ Phone #: _____ Address: _____ _____	Name: _____ _____ Phone #: _____ _____ Address: _____ _____ —
Name: _____ Phone #: _____ Address: _____ _____	Name: _____ _____ Phone #: _____ _____ Address: _____ _____

I certify that all answers given here are true and complete to the best of my knowledge. I authorize investigation of all statements contained in this application for employment as may be needed in making an employment decision.

Signature of Applicant: _____ Date: _____

Hiring

It is best to interview several people before making a decision to hire your attendant. Compare the qualities of the persons who applied for the position. Carefully consider the dependability, compatibility, driving record, and interests of your prospective attendant.

You may want to hire 2 or 3 attendants, depending on hours, vacations, etc. You might also want to consider whom you might be able to call on if your attendant cannot work (extra emergency people). Always have a back-up plan.

Your Responsibilities

Your first responsibility as an employer is to train your attendant by clearly explaining, defining, and showing how each task is to be done. Don't expect quality work if your attendant doesn't understand what is expected. A written chart is helpful for this.

Keep the communication lines open! Financial areas should be written out on paper (e.g. social security, taxes, holidays, vacation, sick days, time schedules, etc.). At the first interview, you should discuss those things that you, as an employer, would consider as reasons to fire an employee.

Keep a good working relationship with your attendant. You must be thoughtful, courteous, and praise the good work of your attendant. Sort out conflicts immediately and try to give direct, clear feedback when a problem comes up. Maintain a professional relationship with your attendant.

Your Attendant's Responsibilities

Your attendant should be dependable, on time, courteous, and responsive to your needs. Your attendant should leave personal problems at home and not bring them to work. The attendant must also remember not to discuss you, or your affairs, with anyone unless you have given permission. Verbal, physical, emotional, and sexual abuse should be reported to your local police department or adult protective services. Abuse and exploitation should be identified as reasons to fire an attendant.

Salary and Finances

The attendant's salary or wages should be discussed with your advisors or counselors (social worker, Social Security person, etc.). These people know the fair prices for hourly wages and weekly and monthly salaries. Room and board as well as other details may also affect salary levels.

You, as the employer, must keep specific financial records, (e.g., taxes, Social Security, insurance, recreation, salary paid, etc.). You must discuss and put into writing what part of the taxes must be paid by your attendant, as well as the regular deductions you must make as required by law. The Internal Revenue Service has specific rules regarding employee-employer relationships. Please ask your social worker to refer you to the proper agency to get this information. Save all receipts for your yearly (annual) income tax report.

Financial aid may be available through many federal, state, county, and local agencies. You may be eligible for a needs assessment by the Social

Security Program. After this first evaluation, assistance may be given in part or along with your own private source of funds.



HOME MODIFICATIONS

Structural Barriers

Structural barriers are things in a home or building that make it difficult or impossible for a person with an impairment to access or use areas in it. Examples of barriers are stairs, narrow doorways, and high counters. These barriers can affect how you access certain areas in your home, such as the bathroom. Sometimes structural barriers make it hard for you to get into and out of your house. They may prevent you from doing activities you want to do, such as cooking.

Before you are discharged your home will be assessed for structural barriers. Basic access barriers should be modified before discharge. For example, a ramp may be installed so you can get in and out of your house. If you are planning to build a new home and make major changes to your home you will need to work with someone who knows about universal and accessible design. The *2010 ADA Standards for Accessible Design* are a good source of information. They can be accessed at http://www.ada.gov/2010ADASTandards_index.htm

If you will be using grant money (Home Improvement and Structural Alteration Grant – HISA) you will need approval before any work is done. Talk with your social worker or physical therapist.

Here is some basic information about home accessibility that may be useful.

Ramp for Wheelchairs

If a ramp is needed for your home, whether it is for the front door or a step inside your home, talk with your physical or occupational therapist.

- For every one inch in height needed you must have one foot of sloped ramp. For example: If you have two steps to get into your house and one step is 3” high and one is 2” high you will have a total of 5 inches. Therefore, you will need a 5 ft. ramp.
- Handrails on ramp – between 34 and 38 inches high. Handrails are mandatory on all landings and ramps 6 inches high or greater. A 2-inch curb is necessary.
- Minimum size of landing is 5 ft. X 5 ft.
- Width of ramps should be 36 inches.
- The ramp should have a non-skid surface (e.g. non-skid paint or non-skid surface material).

General Considerations

The following are some things to consider related to possible barriers within your home.

Wheelchair:

Average Adult Wheelchair Dimensions	Standard Manual	Manual with Rim Projections	Electric
Length	43"	50"	52"
Width	24" – 26"	29 1/2"	26"
Height to seat from floor	19 1/2"	19 1/2"	19 1/2"
Height to armrest from floor	29"	29"	29"
Height to push handles from floor	36"	36"	36"
Width when collapsed	11"	11"	11"

- Average turning space required by wheelchair: 5 ft x 5 ft
- Average adult reaches from a wheelchair
 - Horizontal (Forward) working reach: 43"
 - Bilateral (side to side) reach: 54"

- Height of counters and workspace: No higher than 34”
- Height of heat controls and switches: Maximum 60”
- Width of doors : Minimum 32”
- Width of halls: Minimum 36”

It is difficult to maneuver a wheelchair over scatter rugs and shag rugs. If carpets are needed, they should be short napped.

Bathroom

Some solutions to basic problems are as follows:

Sink

- A “wheel under” wall mounted sink, without cabinets underneath, mounted no higher than 34”
- Drawers located on one side of sink for toiletries, cosmetics, etc.
- Mirror placed low (just above the basin) for vision
- Long lever faucets aid with turning on the water

Toilet

- Standard toilet
- Enough room needed for a side approach transfer

- Raised padded clamp on toilet seat with splash guard removed so you can insert a suppository and clean your rectal area
- Enough room on either side of the toilet to allow a commode/shower chair to be placed over toilet (3" on each side)
- Grab bars are often necessary for safety and functional access

Tub With or Without Shower

- Enough space to move within the room to allow a side or head-on transfer
- A shower chair to equalize the height between chair and tub
- A tub stool or waterproof cushion for those who can transfer down into the tub. This can also assist in getting out of the tub
- Tub rails mounted parallel to the tub for safety
- Lift

Shower

- Shower chair for a standing-pivot transfer or a shower/commode chair
- Construction of a roll-in-shower stall at least 4' X 5', no lip on entrance and a gentle slope so water can drain off
- Faucets located at wheelchair height – 54"

Bedroom

Bed

- The bed should be placed so there is enough room on one side for easy transfer into and out of bed
- Place the bed in the middle of the room with the brakes locked. This will allow your caregiver access from both sides of the bed

Closet

- Lower the clothes rod so you can reach your clothing

Telephone or Communication Systems

Place your telephone or communication system by the bed for easy access while in bed. If you have an emergency alert system, such as Guardian Alert®, keep it within easy reach at all times.

Doors

The best height for door handles is 3 feet from the floor. Latch handles are easier to grasp than round ones. Doors into bathrooms should swing out to keep you from blocking the door when you are in the bathroom.

Drawers

Drawers with pull handles instead of knobs are the easiest to open.

SAFETY PRECAUTIONS FOR YOUR HOME

You will need to look at your home setting in a different way. There are hazards that you may not have thought about before your injury. This chapter lists some hazards you may find.

Bedroom

Hazard	Cause	Solution
Bruises, scrapes	Bed Transfers	When transferring, be careful not to bump, bruise, or scrape your skin. Wear some type of clothing or use a towel or talcum powder when using a transfer board.
Burns	Electric blankets	Do not use heating pads or electric blankets. You may not be able to feel when they get too hot.

Bathroom

Hazard	Cause	Solution
Burns	Hot water in bathtub	Adjust water temperature before bathing. Do not change temperature while bathing. A temperature control faucet could be used.

Burns	Hot water pipes under sink	Insulate pipes under the sink to prevent burning your legs.
Burns	Hair dryers, curling irons	Be careful when using. You may not feel how hot they are.
Falls	Transferring	Use grab rails that are properly installed. Drain water & dry yourself while in the tub to prevent slipping when getting out of the tub.
Pressure Sores	Bathtub, Shower, Toilet Seat	Use a cushion in the tub, a padded shower or commode seat. Check your skin after bathing or a bowel program.

Wheelchair

Hazard	Cause	Solution
Falls, bruises	Wheelchair	Keep your wheelchair in good working order. Make sure the brakes lock firmly for transfers. Wear a seat belt if needed.
Burns, frostbite	Wheelchair upholstery, metal parts	Your wheelchair upholstery and metal parts will get hot or cold in extreme weather. Wear proper clothing to protect yourself. Be cautious around fireplaces, wood burners, stoves, and radiators. Don't move so close the wheelchair gets too hot.
Falls	Reaching	If you lean too far forward, you may fall out of your wheelchair. Stay back in your wheelchair or use a "reacher". If reaching, make sure front wheels of wheelchair are aligned straight ahead.

Kitchen

Hazard	Cause	Solution
Burns	Cooking	<p>Be careful when handling hot liquids. Slide the pans—do not lift them.</p> <p>Never put hot pans in your lap to carry them. Use a wooden, not a metal tray to carry hot items.</p> <p>Insulate pipes under sink if your sink has an open area.</p>
Burns	Foods	<p>Finger foods such as pizza, French fries, or chicken can cause burns if you have little or no sensation in your hands.</p>
Burns	Stoves, Ovens, Vents	<p>Be cautious around heat. Your skin may burn more easily after your spinal cord injury than before.</p>

Car or Van

Hazard	Cause	Solution
Burns	Car Heater	Be careful of car heaters. Have someone with normal sensation check and help you determine a safe position for your legs and feet.
Burns	Steering wheel, car upholstery, metal parts	In hot weather, avoid bare skin on steering wheel, hot upholstery and on door handles, etc.

Clothes, Braces, Splints

Hazard	Cause	Solution
Pressure or abrasions	Jeans – thick seams, pockets, rivets	Check skin under seams and pockets. Remove pockets on the back of jeans. Wash new jeans with fabric softener before wearing.
Pressure areas	Keys, coins	Do not put items in pockets of pants.

Pressure areas	Braces, splints	Build up your skin tolerance to wearing braces or splints. Be sure to check your skin after removing brace.
Burns	Cigarettes	<p>Never smoke at night when lights are out.</p> <p>Be sure ashes or matches don't fall on your clothes.</p> <p>Do not put the ashtray on your lap.</p> <p>Do not let your cigarette burn too short.</p> <p>You may not be able to feel if your fingers start to burn.</p> <p>Use a cigarette holder.</p>

Ramps

Hazard	Cause	Solution
Falls	Very steep ramps	If a ramp is very steep, have someone lower you backwards to prevent falling forward out of the wheelchair.

Hot Weather

Hazard	Cause	Solution
Heat Stroke	Hot Weather	<p>Stay out of the sun during the warmest part of the day and avoid any heavy exertion.</p> <p>Increase fluid intake.</p> <p>Bathing in tepid water and turning a fan on will increase heat loss.</p> <p>Most persons with tetraplegia or high paraplegia will have trouble keeping a normal temperature in hot weather. This is because their body does not perspire below the level of injury and the body does not lose heat.</p>
Sunburn	Sun exposure	<p>Use sunscreen.</p> <p>Wear a hat.</p> <p>Limit your time in the sun.</p> <p>You may not be able to feel that you are getting a sunburn.</p>

Miscellaneous

Hazard	Cause	Solution
Fire	Burns, Smoke inhalation	<p>Know the nearest exit from each room in your house. Be sure you can access it.</p> <p>Install heat or smoke detectors throughout your home. Replace the batteries twice a year.</p> <p>Keep a fire extinguisher accessible to you and know how to use it.</p> <p>If you have a cell phone, keep it near you always in case you are trapped in a room.</p> <p>Do not smoke in bed.</p>

WHEELCHAIR MAINTENANCE

Your wheelchair is an expensive and important part of your mobility. Keep it clean and in good repair. Over time the seat area may collect crumbs and other objects. Vacuum and clean with soap and water regularly. Like your car, costly repair bills can be avoided by good maintenance habits. This section has suggestions to help keep your wheelchair working well.

Both manual and power wheelchairs will last longer if they are properly maintained. Remember to read the manual that comes with your wheelchair.

Contact the Physical Therapy Department to determine if a consult for Prosthetics has been entered for your wheelchair maintenance. This will allow the vendor to provide services to you. The consult is good for one year. A new consult is usually entered when you have your annual health exam. Be sure to have your wheelchair checked by the Kinesiotherapist (KT) when you come in for your annual health exam.

The vendor will be your contact for repairs to your wheelchair. If you have any questions about maintaining the wheelchair, contact your local vendor.

The Wheels

Always keep pneumatic tires at the proper inflation. For best results, fill the tires with no one in the chair. Under-inflated tires will not hold the chair locks firmly and the chair will be difficult to push. Replace hard rubber tires when they are worn. Never oil the wheels or bearings of a wheelchair. The oil may wash the grease out of the bearings and cause damage. When adjusting the wheel, remove the hubcap from the outer end of the axle, and then loosen the axle nut in the inside of the wheel. Tighten the axle until there is no play, but not tight enough to limit free rotation of the wheel. When done, the axle nut should be tightened. Check the tightness of the axle by spinning the wheel. If the axle is too loose, the wheel will wobble from side to side. If the axle is too tight, the wheel will stop spinning quickly. The wheel should coast slowly to a stop.

Upholstery

Upholstery screws should be checked at least once a month. These can be tightened with a screwdriver or allen wrench. It is also important to make sure that the screws and bolts are through the holes in the metal splines along the edge of the upholstery. The upholstery will tear if these are not in place. Besides cleaning with soap and water, a good leatherette product will keep the upholstery soft and pliable.

Manual Wheelchairs

Hand rims

Each hand rim should feel solid when given a tug. If it wiggles, determine which hand rim attachment is loose and tighten the bolt that holds the hand rim to the clip by using a screwdriver.

Chair Locks

If chair locks are not gripping firmly on the wheels, check the air in the pneumatic tires or the wear on solid tires. If neither of the above conditions seems to be the cause, the chair lock needs to be moved back, closer to the wheel. To do this, loosen both bolts that hold the lock to the side frame, ease the lock back on the frame tubing until it is in proper position to grip into the tire and tighten the bolts to hold the lock in place.

Casters

If your chair tends to move to the right or left when you push your wheelchair, the caster fork must be adjusted. To do this, remove the dust cap from the top of the caster stem and tighten, then tighten the stem nut so that the fork swivels freely but not wiggle up and down. Check the caster swivel by tipping the chair back and starting the caster spinning. It should swivel freely a number of times. To clean the caster axle area, remove the nut from the caster axle and pull the axle out of the axle housing. Before replacing the axle and putting the caster back on the chair, grease it and replace the felt washer that covers the bearing.

Frame

The wheelchair frame should be maintained in top condition. Foam chrome cleaner can be used to clean the rest of the frame. Fine steel wool can be used if the chair is extremely dirty. Check the frame for rust, peeling chrome and cracks. These may indicate broken welds, which should be checked by a vendor.

Armrests and Footrests

If the armrest posts become sprung so they do not easily fit into the holders, place the front post in its holder. Pull up on the armrest to spread the space between posts. When lengthening or shortening footrests, loosen the nut on the underside of the footplate or side of the footrest extension, and push down to reduce the space, moving the footrest back and forth to maneuver it up and down. Do not remove the footplate and lower tubing from the upper tubing. When correctly adjusted, you will sit in your wheelchair with thighs parallel to the ground. If your knees are propped too high, you will have increased pressure area on your ischial or sacral area. If your knees are too low, you will have increased pressure area on the back of your thighs or sacral region.

Power Wheelchairs

Some basic maintenance for power wheelchairs is the same as manual wheelchair maintenance. A power wheelchair owner should do business

with a reputable dealer. It is important to deal with someone who is reliable and skilled because care of a power chair can be complex. Only use a dealer that is certified to work specifically on the wheelchair you have.

Motors and Batteries

If the motor fails to operate, check to see that the connectors are plugged in properly and have not worked loose. The battery may be the problem if the motor seems to be running slowly. Contact your local vendor if the problem continues. You may need a new battery. Charge your batteries every night so your wheelchair is fully charged for the next day.

RESPITE CARE

What is Respite Care?

The respite care program provides a short hospital stay (13 days at a time) for Veterans with spinal cord injury or disorder to give their caregiver a rest. Discuss a date for respite with your primary care physician and the SCI Admissions Coordinator.

Why a Rest?

At times, caregivers live under a great amount of pressure. When they care for someone who needs a lot of help, they seldom find time for themselves. To be able to provide the best care, your caregivers must be able to keep themselves healthy and happy. If they do not take of themselves, they may begin to resent the time it takes to give you care. They may develop stress-related fatigue, so you may not get the attention you need. Tired caregivers are also more likely to make mistakes. Your caregivers need to do things to help prevent “burnout” from the physical and emotional stresses of the daily routine. A period of respite can help. By taking care of your caregiver, you are also benefiting.

Who Can Use This Program?

You must have a spinal cord injury or disorder, live at home and require much assistance from a caregiver. The program is not designed for those Veterans who do most of their own care or for those Veterans receiving care from a home health agency.

When Can I Use Respite Care?

An eligible Veteran can use respite care for 13 days at a time. The eligible Veteran can have two respite admissions a year. Respite admissions should not be used if you have major medical issues at the time of the admission. A very sick Veteran has priority of a regular admission over a Veteran wanting a respite admission.

How Do I Request Respite Care?

If you are interested in respite care, please contact your social worker. Do this as far in advance as possible in case there is a waiting list for respite care. The social worker will discuss your respite care stay and answer any questions you may have. After your request is made and approved in advance, the SCI Admission Coordinator will schedule your respite care stay.

Who Will Provide Care?

During your respite admission you will be assigned to the physician located on the unit of your respite stay. The respite stay rooms are located in the Spinal Cord Injury Center. The staff members on these units are trained in the care of Veterans with spinal cord injury.

COMMUNITY RESOURCES

This section lists some community resources from which you can get information or support after your discharge. These resources may be useful to you, your family, and friends as you return to your home and community. These services may be provided by state, county or local community agencies.

No recommendation of any of these organizations can be given or implied. Each agency offers different services based on the needs of the people it serves. You may have to “shop around” to find the best one for you. Your social worker may be able to help you with any questions you may have. It may be handy for you to keep a list of community resources with the agencies’ names, addresses, telephone numbers and hours.

We encourage you to advocate for yourself. When you contact an agency, be clear in stating your reason for contacting it. Make notes of all information:

- the name and title of the person you speak with
- the date
- information given, etc.

It is often best to call at the beginning of the workday. Have your own personal information ready:

- Social Security number
- VA claim number
- family contact names and telephone numbers, etc.

You may also need to have your doctors' names and the hospital's name and the telephone numbers available.

The different agencies in the community can be very busy and hard for you to contact. Don't give up! If the person you need to talk to is out, leave a message. (Don't forget to get the name and title of the person taking the message.) A personal visit by you to the agency might be helpful but find out if you need an appointment before going. Also find out if the agency is accessible to your wheelchair.

Information and Referral Services

The Information and Referral Service provides free general information over the telephone. It is confidential and private. You may ask questions without having to identify yourself. In some cases, explaining your needs can help the person assisting you get a better idea of how to help, or which agency might be better able to handle your situation. Let them know what your disability is when you discuss your specific needs.

Each county has an Information and Referral Service available to you. Look in the county listings section of your telephone book. It may be called Community Resource Guide or 211. Or ask the operator for your local number.

Housing

It is very important that you are able to move in and around your home easily without being kept from using any rooms or from leaving the house. Your family, finances, and type of impairment are important things to

consider in making decisions about where you can live. Also, consider the community services, such as accessible transportation, that are available.

Depending on the area where you live, you may find the following housing programs:

The Housing Authority

This was created in many counties and cities to help low-income individuals and families, including people who are elderly or have physical disabilities. There may be waiting list for low cost accessible housing. Contact your county or local Housing Authority office to get an application. In most cases, your name will be placed on a waiting list when your application is received and reviewed. If you find that you do not need their services, let them know so that they can remove your name from the waiting list.

Section 8 Program

This is a rental assistance program in which money is available to help eligible individuals and families in paying a portion of their monthly rent. The Section 8 Program is usually available through the county or local Housing Authority. Eligibility is based on the total amount of money you make per year. In most cases, the program uses apartments in regular apartment complexes. You may be asked to find the housing yourself and negotiate with the landlord.

Housing Assistance Organizations

There are programs in some areas that are available to help persons locate housing. Call your local information and referral agency.

VA Home Improvement or Structural Alterations (HISA)

This is a program designed to pay for some of the cost of remodeling your own home or rental. You may be eligible to receive funds for major structural changes and home improvements (i.e. ramps, bathroom modification). You will need to apply before any work is done. Contact your local VA Prosthetic Office for specific information. Your social worker can also help you. This grant can only be used once.

VA Specially Adapted Housing (SAH) for Veterans

This is a program designed to pay some of the costs in purchasing or modifying a house. Eligible Veterans with a service-connected disability that meet certain requirements may benefit from this program. Contact your VA benefits counselor at your local VA Regional Office to apply. You must do this before you buy or begin to buy land and build.

Independent Living Programs

These are programs that provide housing as well as peer counseling, advocacy, transportation, recreational activities, etc. Talk to your social worker about the Independent Living Programs in your area. You can also access information on the internet at

<https://www.helpguide.org/articles/senior-housing/independent-living-for-seniors.htm>

Other resources

You may qualify for a *state property tax exemption* if you own a house or condominium. See

[https://floridarevenue.com/property/pages/Taxpayers Exemptions.aspx](https://floridarevenue.com/property/pages/Taxpayers_Exemptions.aspx)

Contact your Property Appraiser's office for the proper forms.

Other programs include the *Energy Assistance Program* for low-income families to assist with your electricity bill and *Lifeline Assistance Program* to assist with basic telephone service. Information for these programs can be obtained from your local electric and phone companies.

Financial Assistance

Your money situation after a spinal cord injury or disorder can change dramatically. The loss of income can be very stressful and can create serious problems in the family. There are programs for persons with a financial need and a medical disability. On the other hand, a sudden influx of money from insurance or benefits can create issues related to how to manage the money. A financial planner may provide input into appropriate money management.

Federal Financial Programs

Social Security Administration has the following programs:

- a) Social Security Disability Insurance (SSDI)
- b) Supplemental Security Income (SSI)
- c) Medicare (Federal government health insurance program)
- d) Retirement and Survivors Benefits

There may be income limits and special requirements, depending on the program. Contact your Social Security Administration office as soon as possible since it could take months before you can start receiving benefits. Local Social Security offices are listed in the telephone white pages under U.S. Government.

State Assistance Programs

In Florida, contact the Department of Children and Families listed in the telephone book. In other states, contact the Department of Social Services or the Department of Human Services. Your local office can assist if you need help with the following services:

- Medicaid provides low-income persons with medical coverage for hospitalization and treatment at home: homemaker, home health aide, visiting nurse services, and transportation related to medical needs and equipment. There is often a waitlist for seniors.
- Food Stamps provide an allowance to people with low incomes to buy food. There are income limits for this program. Contact your local Food Stamp office to see if you can get this benefit.
- Temporary Aid to Needy Families (TANF) provides financial help and benefits to families with dependent children (under 18 years old). Aid may include help with purchasing food, clothing, utilities, housing and other personal needs.

Veterans' Assistance Programs

Department of Veterans Affairs (Assistance Program) may provide benefits such as hospitalization, outpatient medical treatment, educational programs, pension, housing and other federal programs. A Veterans Service office is located in all VA Hospitals. There is usually an office in your hometown or city, as well. Veterans Service officers are available to

discuss eligibility and assist you with your application if you qualify for benefits. Your local Paralyzed Veterans of American (PVA) chapter can also help.

Employment

Employment provides dignity, self-worth, and money as well as a sense of personal accomplishment. You can obtain a job through federal, state, county, and local government agencies as well as in private businesses. Ask your doctor to make a referral to Vocational Rehabilitation while you are in the hospital. The vocational counselor can help you to meet your job needs or assist you in finding the proper training. The state Vocational Rehabilitation Office in your area can also help with training.

Mental Health Counseling Services and Crisis Interventions

Individual and/or family-oriented community services agencies provide mental health counseling when crises arise. If you feel you need this service, please contact your social worker or psychologist for more information. The JAHVH hospital offers several mental health support groups. There is also a toll-free Veterans Crisis Line available. The number is 1-800-273-8255. You can talk with trained VA mental health staff members. They can listen to your needs and offer crisis counseling, suicide prevention, and referral information.

Legal Aid/Rights of Disabled Citizens

Legal aid services may be available on the federal, state, county, or local level. If you need an attorney, the local Bar Association or Legal Aid can provide contacts and referral services. The internet address for the Florida Bar is <http://www.floridabar.org/>

You cannot be discriminated against in terms of your legal rights, vocational counseling, rehabilitation, education, transportation, medical/dental services, or benefits received under the Social Security Act because of your spinal cord injury or disorder.

Transportation

There may be public and/or private wheelchair transportation services in the city or town where you live. Contact the local transportation companies to find out about wheelchair transportation.

If you are traveling a long distance on public transportation, find out how accessible the vehicle is. Be sure connecting vehicles are also accessible.

If you are traveling in a private vehicle, identify the restaurants and restrooms along your route which are accessible. Most highway rest areas are accessible. If you are staying in a hotel, ask about accessibility in advance. You want to be sure your wheelchair and any equipment such as a lift can be used in the room.

Libraries

Libraries are a good resource for help in many areas. Books, e-books, audio-visual materials, pamphlets, magazines, internet sites, etc., are available on spinal cord injury or disorder. Your family or attendants may find these materials helpful for instruction or for general information.

National Library Service for the Blind and Physically Handicapped

This free program of Braille and recorded materials for blind and physically handicapped persons is administered by the National Library Service for the Blind and Physically Handicapped (NLS), Library of Congress. Anyone who is unable to read or use standard printed materials due to visual or physical limitations may receive the service.

Reading materials are sent to borrowers and returned to libraries by postage-free mail. The cassette machine is loaned free to readers for as long as the recorded materials are being borrowed. Readers with very limited mobility may request a remote-control unit. Hearing-impaired readers may be eligible for an auxiliary amplifier for use with headphones. A cassette machine designed for persons with limited manual dexterity is also available.

Contact your community library to request an application for this free service.

PREPARING FOR AN EMERGENCY

It is important that you make plans to deal with emergency situations, such as power outages and hurricanes. Temporary power outages are common during summer storms. Be prepared for a temporary power outage.

Think about your power needs for:

- Powered wheelchair batteries
- Ventilator batteries
- Environmental control units (ECUs)
- Transfer equipment
- Air beds
- Tube feeding pumps
- Suction equipment
- CPAP machine

Contact the electric company now if you depend on electricity. In the event of a power outage, you will have priority status. Your SCI Social Worker can provide a letter explaining your need for continued electricity.

If you use a ventilator, always keep your back-up battery charged. Be sure you have a bag valve mask (ambu). If you use a ventilator or CPAP and there is a “Severe Alert” security status or a Category 3 or 4 Hurricane Watch, discuss admission to the SCI Center with your SCI Social Worker.

If you use a nebulizer, keep a metered dose inhaler as a back-up.

If you use a powered wheelchair, keep it fully charged. Have your manual wheelchair ready to use.

If you have a lift for transfers, keep it fully charged.

If you have a cellular phone, keep it fully charged.

Keep a flashlight with extra batteries. Matches and candles can be fire hazards.

During hurricane season prepare for your special needs.

- Find a secure location to store important supplies and medicines.
- Have enough supplies and medicine for 2 weeks. Order supplies and medicine 2 weeks in advance.
- If you use oxygen, get back-up cylinders from the vendor.
- Have an adequate amount of stored water for drinking and hygiene needs.
- If you are on tube feedings, have a 14-day supply of tube feeding. Keep the feeding pump plugged into an electrical outlet as much as possible to keep it fully charged. Know how to provide your tube feeding without using the pump.
- Have a back-up plan if your caregiver is unable to come. If you have a home care agency, ask the agency to tell you their back-up plan.

- Pre-register with the Special Disaster Assistance County Agency in your area in advance. These shelters are staffed with nurses for emergency care and have oxygen, suction devices, & cots. You are responsible for your own care.
- Keep your vehicle's gas tank at least 1/2 full in case your need to evacuate.

Here are some resources related to preparing for emergencies that may be useful.

Disability Resources for People with Disabilities -

www.jik.com/disaster.html

Disaster Preparedness for Persons with Disabilities -

www.disability911.com

Emergency Evacuation Preparedness Guide -

http://www.cdihp.org/products.html#evac_guide

County emergency management agencies:

- Charlotte County 941-833-4000
- DeSoto County 863-993-4831
- Hernando County 352-754-4083 (Spanish guide available)
- Highlands County 239-395-1112
- Hillsborough County 813-744-5911 (Spanish guide available)
- Lake County 352-343-9420
- Lee County 239-533-0640
- Manatee County 941-749-3500
- Orlando County 321-235-5437
- Pasco County 727-847-8137 (Spanish guide available)
- Pinellas County 727-464-3800 (Spanish guide available)
- Polk County 863-534-5600 (Spanish guide available)
- FEMA 1-800-621-FEMA

Special Disaster Assistance County Agencies:

- Hillsborough County 813-307-8063
- Pasco County 727-847-8137
- Polk County 863-298-7027
- Pinellas County 727-464-3800

Supplies

A person with a spinal cord injury will need to include some additional equipment in their disaster supply kit. This list includes examples of items you may need in addition to those in the general disaster supply kit. Use this list to prepare an emergency kit to meet your needs. Keep your kit ready to use.

Items you may need in your emergency kit

Bladder management supplies

- Extra indwelling (foley) catheters
- Catheter insertion kits
- 10 ml syringe
- Urinal for emptying leg/bedside urine bags
- Extra urine collection bag
- External urinary devices (EUDs)
- Catheters to straight cath

Add meds before leaving home

Autonomic dysreflexia supplies

- Autonomic Dysreflexia (AD) information card
- Blood pressure cuff
- Lidocaine jelly
- Bladder irrigation kit
- Liter of sterile normal saline
- Nitro paste or prescribed AD medicine

Diabetic supplies

- Glucose monitor/test strips
- Insulin
- Syringes
- Alcohol wipes
- Sharps container
- Snacks

Wheelchair items

- Battery charger
- Transfer board
- Clip on holders
- Protective straps
- Cushion

Bowel management supplies

- Lubricant
- Disposable pads (chux)
- Adult diapers
- Box of disposable gloves
- Baby wipes

Wound care items

- Sterile dressings/ tape
- Ointments
- Wound cleanser
- Sterile gloves

Tube feeding supplies

- Feeding bags
- Tube feeding and water for flushing
- Split drainage sponges
- Syringes for flushing
- Pill crusher

Respiratory items

- Oxygen tank
- Oxygen mask or nasal cannulas
- Tracheal collars/sponges
- Suction catheters, gloves

Miscellaneous items

- Universal cuff, assistive feeding utensils
- Quad straws
- Bunny boots/Sheepskin pad
- Positioning pillows
- Hand sanitizer
- Other medical equipment

PERSONAL HEALTH INFORMATION RECORD

A personal health information (PHI) record is a tool to help you and your families receive ongoing quality healthcare when you need to receive care outside of the VA system. Many people carry their PHI with them already. This can be as simple as a list of medicines or a flash drive with detailed medical information.

The record should be something that you can carry easily so you can have your healthcare information ready to share at each health encounter outside of the VA system. You may need to share this information in case of an emergency or an unplanned appointment. This helps your healthcare providers to have complete and accurate information quickly.

The record can be on a paper form or other format. Use the system or tool in a format that works best for you. Some choices include:

- MyHealtheVet <https://www.myhealth.va.gov/>
- Folders or notebooks
- Index cards
- Flash drive (USB drive)
- Compact disc (CD)
- Bracelet with information

The record can include basic health information such as:

- Advance directives
- Allergies
- Emergency contact information
- Equipment and devices, vendor information
- Functional status
- Healthcare providers involved with care
- Hospital preference
- Immunization status
- Medical diagnoses/conditions
- Medications
- Surgical history

We will help you begin your PHI record using MyHealtheVet and a Personal Health Information Form. If you already have a PHI record we can help you update it.

SPINAL CORD INJURY & ADVOCACY ORGANIZATIONS

Paralyzed Veteran of America (PVA)

801 18th St. NW
Washington, D.C. 20006
1-800-424-8200

Florida Gulf Coast PVA Chapter (local chapter)
15435 N. Florida Ave.
Tampa, FL 33613
(813) 264-1111

This Veteran service organization works for improved programs in medicine and rehabilitation not only for Veterans, but also for all individuals with a spinal cord injury/disorder. They can also assist you in determining what VA benefits you may be entitled and assist you in applying for these benefits. There are 35 chapters located throughout the United States. You can locate the chapter nearest you via the www.pva.org or by calling the Washington office.

Florida Spinal Cord Injury Resource Center

(813) 844-4711
(866) 313-2949

The Resource Center is funded by a Florida state grant to provide a central location where people can find out more about spinal cord injury. A library provides access to recent SCI magazines, books, videos and reference materials. The Center also maintains a listing of SCI rehab centers, support groups, adaptive driving equipment dealers and other service providers. Their web site is www.fscirc.com

United Spinal Association

United Spinal Association
120-34 Queens Blvd. #320
Kew Gardens, NY 11415
(800) 404-2898

This organization was founded by Veterans with spinal cord injuries to help members lead full and productive lives. Formerly known as Eastern Paralyzed Veterans Association, the organization has been involved in ensuring quality health care, promoting research, advocating for civil rights and educating the public about these issues. Their web site is

<http://www.unitedspinal.org>

National Rehabilitation Information Center

8400 Corporate Dr. #500
Landover, MD 20785
(800) 346-2742

This organization is a library and information center on disability & rehabilitation. You can search for articles, reports and other documents related to rehabilitation. The website is <http://www.naric.com/>

PUBLICATIONS, WEB SITES, ETC

Some of the following magazines and web sites may interest you. They contain information on topics such as spinal cord injury, legislation, employment, equipment, recreation, research and items of general interest to persons with spinal cord injury. Some of the magazines are free; others have yearly subscription rates. Web site addresses were current at the time of printing. This listing does not imply endorsement.

Publications:

Ability Magazine

8941 Atlanta Ave.
Huntington, CA 92612
www.abilitymagazine.com

AMPlitude

11154 Huron St. #104
Northglenn, CO 80234
(303) 255-0843

Disabled Dealer of the Southeast Magazine

2391 Leisure Lake Drive
Atlanta, GA 30338
www.disableddealer.com

Florida Disabled Outdoors Association

2475 Apalachee Parkway, Suite 205
Tallahassee, FL 32301
(850) 201-2944
www.fdoa.org

Journal of Rehabilitation Research and Development

31 Hopkins Plaza
Baltimore, MD 21201
410-962-1800
<http://www.rehab.research.va.gov/jrrd/index.html>

New Mobility

120-34 Queens Blvd. Suite 320
Kew Gardens, NY 11415
(800) 404-2898 ext. 7203
www.newmobility.com

Paraplegia News

Paralyzed Veterans of America
2111 E. Highland Ave Suite 180
Phoenix, AZ 85016
(888) 888-2201, (602) 224-0500
www.pn-magazine.com

Sports 'N Spokes

2111 E. Highland Suite 180-B
Phoenix, AZ 85016
(888) 888-2201, (602) 224-0500
www.pn-magazine.com/sns

Web Sites:

AbleData

<https://abledata.acl.gov/>

AbleData provides objective information about assistive technology products and rehabilitation equipment available from domestic and international sources. ABLEDATA does not sell any products but can help you locate the companies that do.

American Academy of Pain Management

<http://www.aapainmanage.org>

The American Academy of Pain Management is the largest multidisciplinary pain society and largest physician-based pain society in the United States. Although the site is directed for physicians you can access information on pain management, programs, resources, education, outcome measures, and more.

American Academy of Physical Medical and Rehabilitation

<http://www.aapmr.org>

The American Academy of Physical Medicine and Rehabilitation serves its member physicians by advancing the field of physical medicine and rehabilitation. Education, practice guidelines, patient education, and physician locator services are offered. Sections of the site are for members only.

Americans with Disabilities Act (ADA)

(800) 514-0301

<http://www.ada.gov/>

The ADA prohibits discrimination on the basis of disability in employment, programs and services provided by state, private, and commercial facilities. This site provides information related to the ADA. There are also ADA standards for accessible design. The toll-free information line provides answers to questions about ADA.

Brain Injury Association

<http://www.biausa.org>

The Brain Injury Association (BIA) is a national non-profit organization with the mission of creating a better future through brain injury prevention, research, education and advocacy. Information for patients and families is included, especially on treatment, rehabilitation, and living with a brain injury.

Care Cure Community

<http://sci.rutgers.edu>

Features on-line messaging with over 20 forums on a wide range of topics, including pain, exercise, spasticity, sex, travel, advocacy and care giving.

Christopher Reeve Paralysis Foundation

<http://www.christopherreeve.org>

The Foundation encourages and supports research to develop effective treatments and a cure for paralysis caused by spinal cord injury and other central nervous system disorders. It also allocates a portion of its resources to grants that improve the quality of life for people with disabilities. This site provides information on current research on spinal cord injury and general information for the public.

Disability Tables

<http://www.icdi.wvu.edu/disability/tables.html>

Provided as a service of the International Center for Disability Information (ICDI) housed at West Virginia University, the disability tables supply disability statistics for the United States and the world.

Empowerment Zone

<http://www.empowermentzone.com>

An individual's personal web site which offers information, ideas, links and software related to the theme of empowerment -- helping individuals and communities achieve self-actualization and full citizenship. Topics include employment, legal issues, civil rights, accessibility, technology, health, and independent living.

Facing Disability

<http://www.facingdisability.com>

An informational and support website for persons and families facing spinal cord injuries. Site includes videos on various topics, discussion forums, and peer counseling

Florida Housing Search

<http://floridahousingsearch.org>

Sponsored by the Florida Housing Finance Corporation, this housing locator service allows you to locate housing to meet your needs. You can search for housing using a wide variety of search criteria with special mapping features and receive apartment listings that provide information about each unit. In addition, the site provides access to tools for renters such as an affordability calculator, rental checklist, and renter rights and responsibilities information.

Florida Spinal Cord Injury Resource Center

www.fscirc.com

Serves as a clearinghouse of SCI resources and information for persons with SCI in Florida. Strives to foster independence through increasing self-knowledge. Web site contains electronic version of their newsletter.

Infinitec

<http://www.infinitec.org>

Infinitec is a U.S. non-profit corporation formed to help people with disabilities and their families access life-enhancing technology services, training, assistive equipment and specialists. Information, demonstrations

of assistive technology and funding options related to technology are presented.

Institute on Independent Living

<http://www.independentliving.org>

This Swedish site offers materials, technical assistance and information on personal assistance, advocacy, access, legislation, and peer support for the disabled. Its virtual library contains documents on many aspects of independent living, including rights, sexuality, access, assistive devices, clothing, and employment from around the world.

My HealtheVet

<http://www.myhealth.va.gov/>

My HealtheVet (MHV) is the gateway to Veteran health benefits and services. It provides access to health information, links to Federal and VA benefits, a Personal Health Journal, and online VA prescription refill. Veteran registrants can view appointments, copay balances, and key portions of their VA medical records online. Veterans can also reorder their prescription refills.

National Center for Injury Prevention and Control

<http://www.cdc.gov/injury/>

A section of the Centers for Disease Control, the NCIPC contains statistics on the cost, prevalence, and prevention of disability, including TBI and SCI. Facts sheets and patient education brochures are available.

National Organization on Disability

<http://www.nod.org>

The National Organization on Disability offers programs to facilitate participation of people with disabilities in all aspects of life - employment, education, voting, religious worship and in social, recreation and community activities. Web site presents programs that promote employment opportunities and provide resources for persons with disability.

National Rehabilitation Information Center (NARIC)

<http://www.naric.com>

Funded by the National Institute on Disability and Rehabilitation Research to serve professionals and lay people who are interested in disability and rehabilitation. NARIC provides access to documents in searchable databases.

O & P Online

<http://www.oandp.com>

This site is a resource for orthotics & prosthetics information. There are links to journals, patient education, products, classifieds, and commercial stores.

Paralyzed Veterans of America

<http://www.pva.org>

This Veterans' service organization was formed following World War II to serve Veterans with spinal cord injury or disease. This site is a resource center for all such Veterans and for all Americans with a spinal cord injury or disease, as well as their families and the professional communities who serve them. Articles from *Paraplegia News* and other information of interest to the SCI person are available. Consumer guides to SCI care can be downloaded from this site.

Rehab International Guide to Drug & Alcohol Rehabilitation

25 E. 21st Street
New York, NY 10010
(877) 345-3281

<https://www.rehabinternational.com/>

This site contains basic information on drug and alcohol addiction. It discusses drug and alcohol rehabilitation and lists available rehab facilities by state and city.

Sexuality and Disability

<https://sexualityanddisability.org/>

Provides access to sexual information for a woman with a disability. Question and answer format on topics such as mechanics of having sex, intimate relationships, having children, fears/concerns and abuse.

SCI Sexuality

<https://www.sexualitysci.org/>

A series of videos on a wide variety of topics related to sexual health and fertility after a spinal cord injury.

SCI Information Network

<http://www.spinalcord.uab.edu/>

Sponsored by the University of Alabama at Birmingham, this site provides extensive educational information on SCI for patients and professionals. It also includes publications available and links to other SCI sites.

United Spinal Association

<http://www.unitedspinal.org>

Formerly Eastern Paralyzed Veterans Association. It provides information for professionals and patients on spinal cord injury, multiple sclerosis, advance directives, disability issues, clinical guidelines, and more.

VA Rehabilitation Research & Development Service

<http://www.rehab.research.va.gov/>

VA's rehabilitation presence on the Internet. The Journal of Rehabilitation Research and Development, clinical monographs, and supplements are available here.

Web Accessibility Initiative

<http://www.w3.org/WAI>

This international organization promotes usability of the Internet for people with disabilities through five primary areas of work: technology, guidelines, tools, education & outreach, and research & development. A great deal of information on making Web sites for persons with disabilities is included.

Apps:

PVA epubS

Provides access to Paralyzed Veterans of America (PVA) publications, including *Clinical Practice Guidelines* and the “Yes You Can” booklet

VA PUR

VA Pressure Ulcer Resource helps Veterans and caregivers learn about preventing and taking care of pressure ulcers.

VA Pain Coach

Provides helpful tools for tracking and managing chronic pain.

StayQuit Coach

Provides interactive tools to help users cope with urges to smoke and stay motivated.

Annie App

Provides text reminders to help motivate users to engage in healthy behaviors.

Mindfulness Coal

Learn mindfulness to reduce stress and improve emotional balance.

Mood Coach

Helps boost your mood by promoting participation in positive activities.