UC DAVIS HEALTH | Department of Physical Medicine and Rehabilitation

Spinal Cord Injury Manual

MPEC date of approval 9/2025

Acknowledgements

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The information from this manual has been adapted from information of rehabilitation centers, the Academy of Spinal Cord Injury Professionals, The American Spinal Injury Association, and the Model Systems network.

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Disclosure

This manual includes references to specific brands or products for illustrative and educational purposes. We do not receive any financial compensation from these companies and do not formally endorse any specific brand or product. All examples are included to support learning and should not be interpreted as commercial endorsements.

Introduction

This manual is a valuable tool to help you understand what has happened to your body and what to expect while you transition from the hospital to when you go home.

This manual contains a great deal of information on every aspect of your care. It will serve as a workbook while you are in the hospital and a reference manual when you go home. Each section will help you learn how to take care of yourself and to teach others to help you, if necessary. Your nurses, doctors, and therapists will guide your study of these topics and provide other learning materials to meet your specific needs.

Before you go home, you will be expected to show that you have the knowledge and skills you need to stay healthy and be as independent as possible. If there is anything you do not understand, ask someone, or look it up in the manual to get your questions answered. Our goal is for you to leave the hospital well informed and ready to manage your care successfully at home.

For more information and other resources, please read on. Of note, we have several “QR Codes” in this manual. They will look like patterned black boxes. To access the research, open any smart device (e.g., phone or tablet) camera and point it at the box. A link should appear that you can select.

As a demonstration, scan this QR code with your phone. It will take you to our website which has a lot of information and resources:

The SCI Rehabilitation Program

What Is Rehabilitation?

"Rehabilitation" means "restoring ability". The overall goal of the rehabilitation program is to enable you to maintain your health and to be as independent as possible once you leave the hospital. Because of your injury, you may need to learn some new ways of doing things.

To help you reach this goal, a professional rehabilitation team, which includes doctors, nurses, therapists, social workers/case managers, and psychologists, will provide:

- Medical diagnosis and treatment of your injury
- Knowledge and training you need to take care of yourself
- Counseling, support, and referrals to other agencies

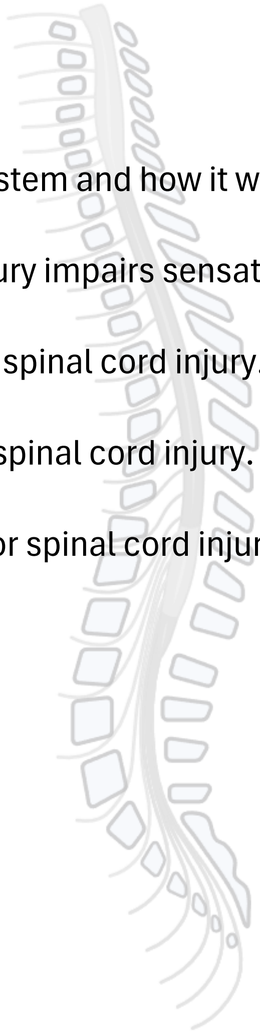
Family Conference

During your hospital stay, the staff will hold a meeting with you and your family. They will discuss your condition with you and explain your rehabilitation program. You and your family will have a chance to ask questions and express your concerns at that time. Concerns and questions can be answered throughout your stay, but this acts as a formal venue for discussion. The case manager will contact you and your family to schedule this meeting.

Individualized Program

Soon after you come to UC Davis Rehabilitation Hospital (UCDRH), you and the staff will set some specific goals for you to work toward during your hospital stay. There will be physical tasks you need to practice and facts you need to learn. As you reach each goal, it will be recorded in your chart. Setting clear, realistic goals and reaching them will help you see that you are making progress in the gradual process of rehabilitation.

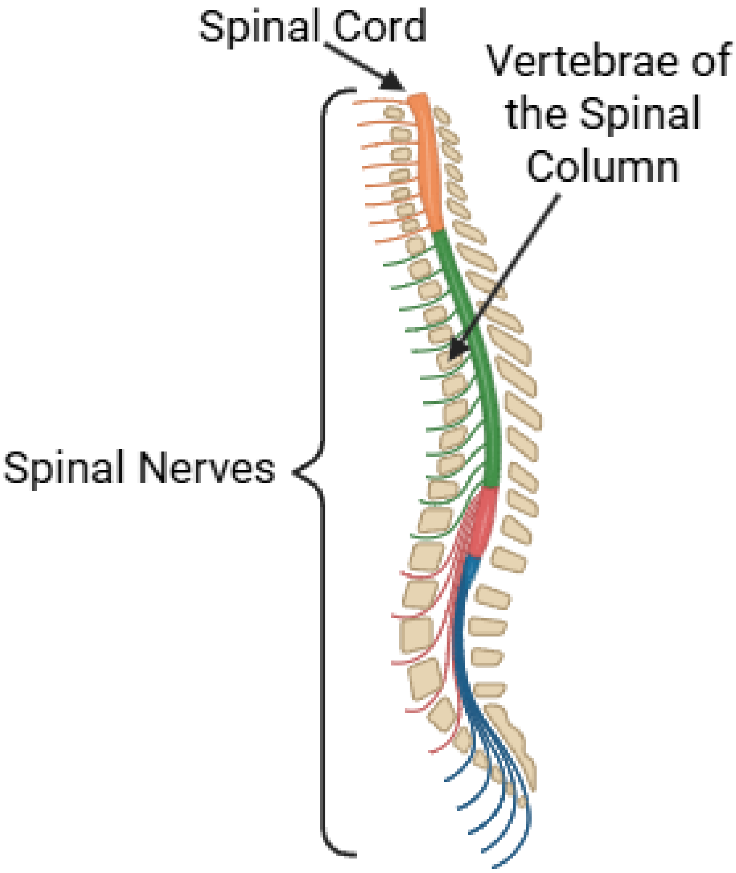
CHAPTER 1:
The Nervous System
and
Spinal Cord Injury



In this section you will learn:

- About the nervous system and how it works.
- Why a spinal cord injury impairs sensation and movement.
- The different kinds of spinal cord injury.
- About recovery after spinal cord injury.
- Current treatments for spinal cord injury.

The Nervous System and How It Works



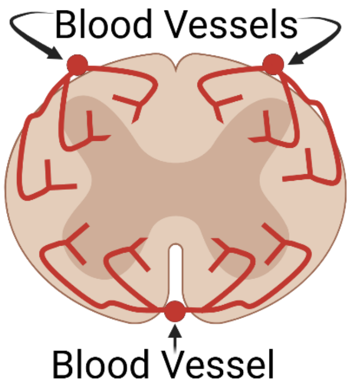
The nervous system is made of the brain, spinal cord, and the peripheral nerves. Together they form a vast network of millions of nerve cells (neurons) which act as a communication system throughout the body.

The spinal cord is a bundle of nerve fibers, which go from the brain down through the spinal column, connecting the brain with the rest of the nerves in the body. It is like a central telephone cable, in the sense that messages going between the brain and the peripheral nerves must pass through the spinal cord on the way.

The spinal column, or backbone, is composed of bones called vertebrae. It has four sections, which correspond to the normal curves of the spine: The neck (cervical), chest (thoracic), waist (lumbar) and lower back (sacral) areas. The peripheral nerves, which branch out from the spinal cord, are also named for these sections.

There are seven cervical vertebrae and eight cervical spinal nerves. There are 12 thoracic vertebrae (these have ribs attached) and 12 pairs of thoracic nerves. There are five lumbar vertebrae and nerve pairs. The five sacral vertebrae are fused into one bone called the sacrum, and there are five corresponding sacral nerve pairs.

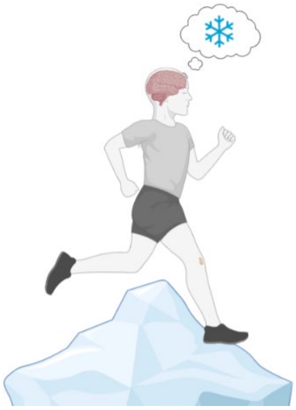
The Spinal Cord



The spinal cord is a very delicate, Jell-O-like tissue protected by the hard, bony spinal column. There are blood vessels on either side, which provide it with nutrients and oxygen. Every tiny blood vessels extend from these major vessels into the center of the cord so that all the nerves have a blood supply.

Kinds of Nerves

There are many kinds of nerves, which do different jobs. To understand your spinal cord injury (SCI), you should know about these.



SENSORY nerves enable you to feel. These nerves start in the skin and other organs of the body and carry messages to the brain. The brain interprets these messages as SENSATIONS such as pressure, pain, hot and cold. For instance, the brain gets a message: “My feet are cold!” when you walk on ice.

MOTOR nerves make it possible for you to move. When you decide to move, the message flows from your brain through the motor nerves to your muscles. For example, your arm reaches out and brings food to your mouth.

Some nerves work automatically, without you being aware of them. For example, if you are in a cool room, the nervous system acts like a thermostat, telling your blood vessels to tighten up, which helps keep more heat inside your body. This may happen before you even notice that you feel cool. This automatic part is called the *autonomic nervous system*.

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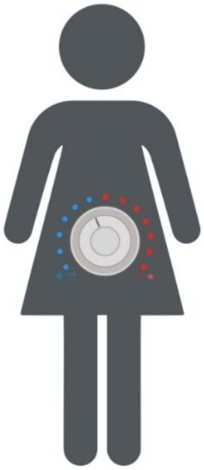
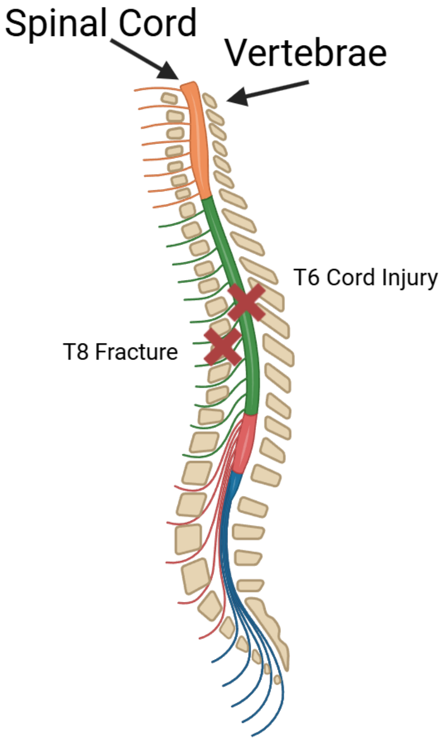


The sensory, motor and autonomic nerves, along with the brain, regulate everything that goes on in your body, including the many autonomic activities you are not aware of, such as blood pressure, temperature and digestion.

The Double Nature of Spinal Cord Injury



When there is a SCI, two different types of injury can occur. The bones of the spinal column (vertebrae) might be broken, crushed, or pushed out of place. This is a "bony injury". Surgery may be needed to repair it; you may have to wear a brace or collar to hold you still and allow the bones time to heal. After a few weeks or months, the bones will mend themselves and you will no longer need the brace.

During the injury, the spinal cord itself may also be damaged. It is rarely actually broken or cut. The reason this type of injury can be so serious is that once nerve tissue in the cord is destroyed, it cannot grow back. Unlike bone, spinal nerve tissue does not repair itself, and doctors have not yet been able to repair it. Nerve messages cannot travel over or around the damaged area. The feeling and the movement will be missing from the areas of the body which the damaged nerves controlled. This will include part or all the nerves and muscles at and below the level of injury.

The Different Types of SCI

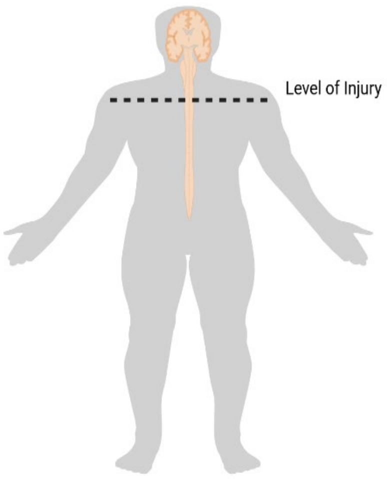
There are many kinds of SCI. These depend on where the cord is injured and how much of the cord is affected at that level. Different spinal nerves serve different parts of the body, so the effects of your injury will depend on which nerves are damaged.

The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI)

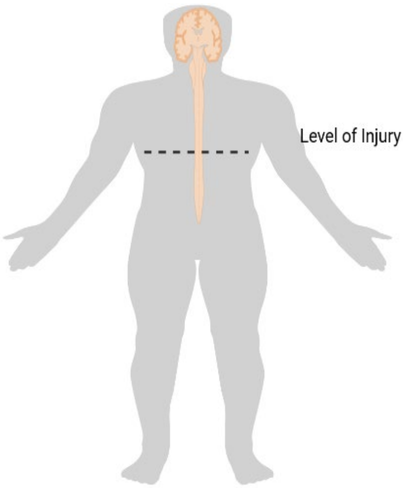
This is the exam performed on everyone who gets a SCI. It helps us determine the level below which feeling (sensation) and movement (motor function) are impaired— known as your "level of injury." Additionally, it allows us to assess the extent (severity) of damage to your spinal cord—known as the "Completeness" for which there is an ASIA Impairment Scale grade. With this information we can better understand your injury so that we can plan for your rehabilitation and medical management.

Level of Injury

In speaking of a SCI, we talk about the "level of injury". This means that everything at and above this location is "normal." Everything below has been changed because of the injury. Of note, the bony and neurological level of injury may differ- so even if your fractures were in one place, the neurological level could be in another though they are often close.



Tetraplegia



Paraplegia

Tetraplegia. ("Tetra" means "four") refers to an injury where all four limbs will be affected. *Paraplegia* ("para means "to one side of") refers to an injury that impacts the legs only.

Complete or Incomplete

If an injury is *complete*, this means that signals from the brain are not getting to the end of your spinal cord. An *incomplete* injury means only part of the cord was damaged, and there may be varying degrees of connection between your brain and the bottom of the spinal cord.

ASIA Impairment Scale (AIS)

Doctors use a system called the ASIA Impairment Scale to quickly identify different degrees of injury based on the ISNCSCI.

ASIA Class	**Degree of Injury**
A	Complete: No motor or sensory function is present at the lowest part of your spinal cord (the anus).
B	Sensory Incomplete: Sensory but not motor function is preserved in the lowest part of your spinal cord. There may be some motor function below your level, but it is limited.
C	Motor Incomplete: Motor function is preserved below the neurological level, but more than half are not strong enough to lift against gravity.
D	Motor Incomplete: Motor function is preserved below the neurological level, and more than half of them are strong enough to lift against gravity.
E	Normal: The tested sensation and muscle movements have returned to normal. There may still be some abnormalities, but they are not part of the ISNCSCI.

About Recovery After SCI

Right after a SCI, it is hard to know how much recovery you will have. However, for most people, the greatest recovery occurs within the first 6 months to 1 year after injury. There is a full physical exam that will be completed with you called the International Standards Neurological Classification of SCI (ISNCSCI), discussed above, that helps us to give you more information on your individual prognosis. Keep in mind, every individual has their own, unique recovery. The prognosis we discuss is based on what others have experienced, but no two people recover the same.

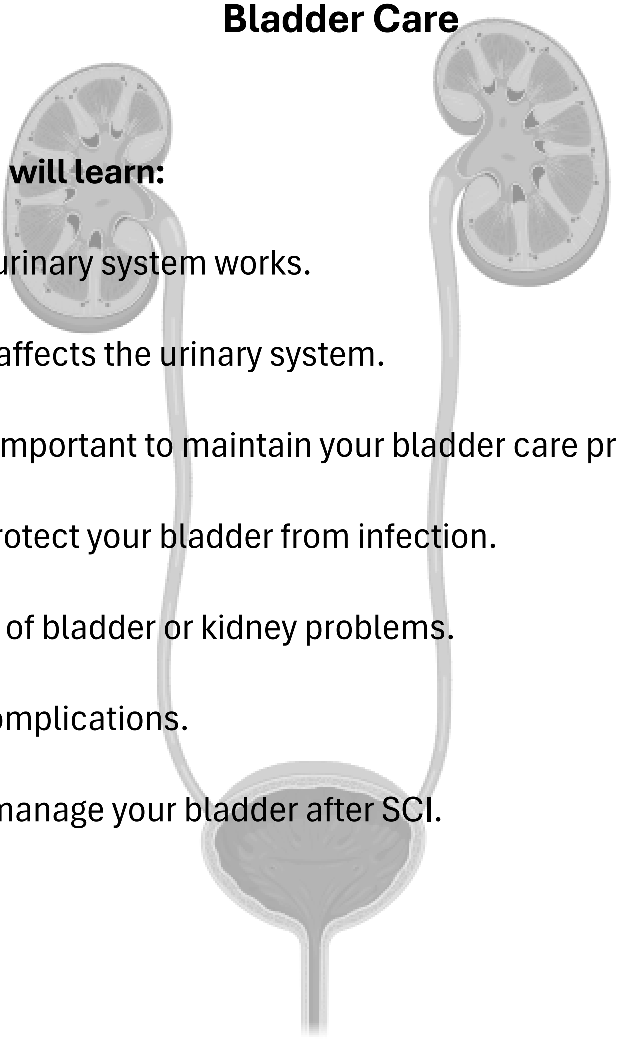
You may have surgery to stabilize the broken bones and reduce pressure on the spinal cord. A brace may be used to immobilize your spine and protect your spinal cord from further injury while the bones heal. The doctors will monitor your healing with x-rays and neurological evaluations. Therapies to keep your body flexible, strong and healthy will also allow for the greatest possible return of function.

So far, doctors have no technique for restoring spinal nerve tissue once it is destroyed. Research is being done in this area, and some promising results have been achieved with laboratory animals.

There are many factors which determine the outcome of a SCI. Some are under our control and some are not. Our philosophy is to do everything we can to ensure the greatest possible recovery. At the same time, we feel it is important to prepare for worst, and hope for the best. By learning to cope with the effects of your injury, you are not giving up hope. On the contrary, you are giving yourself and your body the best chance for recovery by maintaining your health and a good attitude about life.

For more information about general SCI, use this QR Code:

CHAPTER 2:
Bladder Care



In this section you will learn:

- How the urinary system works.
- How SCI affects the urinary system.
- Why it is important to maintain your bladder care program.
- How to protect your bladder from infection.
- The signs of bladder or kidney problems.
- Kidney complications.
- Ways to manage your bladder after SCI.

How The Urinary System Works

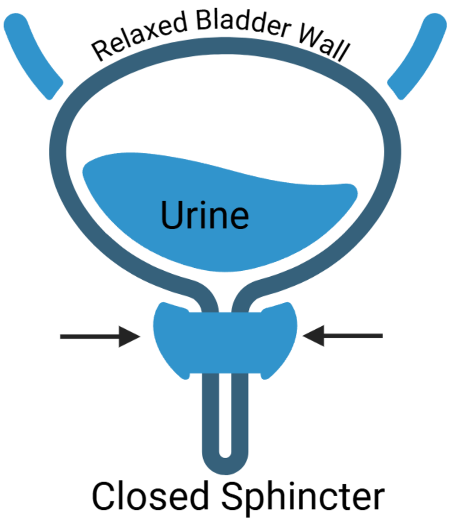
The urinary system is made up of the kidneys, ureters, bladder, sphincters, and urethra. It filters waste products from the blood and removes them from the body in the form of urine.

The kidneys are filters, which draw waste from the blood and form the urine. The ureters are narrow tubes, which drain the urine from the kidneys into the bladder. The bladder is a balloon-type muscular sac where the urine is stored until it is expelled from the body during urination. The urethra is a tube leading from the bladder to the outside of your body. There is a donut-shaped muscle called a sphincter at the opening of the urethra, which keeps the urine from leaking out of the bladder.

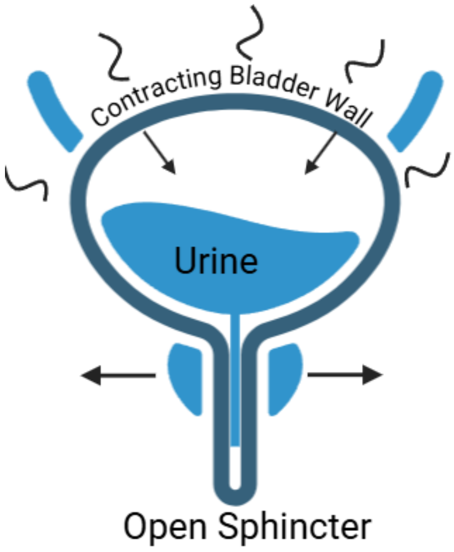
The Process of Urination

In order for you to empty your bladder (urinate), the bladder needs to contract, and the sphincter needs to open at the same time. Autonomic nerves control the contraction of the bladder. The closing or opening of the sphincter is controlled by voluntary (motor) nerves. Normally, you have voluntary control over the sphincter, so you can hold in the urine until you get to the bathroom.

Bladder at Rest



Normal Urination



The Effects of SCI on the Urinary System

After SCI, most people lose control of urination. This is because the nerve messages between the brain and the bladder are interrupted at the level of injury.

You may or may not be able to tell when your bladder is full, and you may or may not be able to control the sphincter, which holds the urine. Your bladder may become flaccid, which means it loses its ability to contract and expel urine on its own, or it may become spastic, contracting automatically when it is full. The sphincter may become relaxed, allowing urine to leak out continuously; or it may become spastic, preventing urine from being expelled when the bladder is full.

As you can see, there are several factors, which determine how much control you will have over urination. After SCI, a bladder care program is usually needed to be sure the bladder is emptied completely at regular intervals to avoid uncontrolled wetting and infection.

Management of Your Urinary System

Your doctors will prescribe a “Bladder Program” that will be used to manage how you pee. Your nurses will do your bladder care at first. Later, they will teach you how to do it or teach others to help you. As your nervous system recovers, your bladder may change, and your program may change with it.

By the time you go home, you or the person who will be providing your care will be taught how to do your bladder care and to prepare the equipment you will need at home.

The Importance of Maintaining Your Bladder Program

Kidney problems are common after SCI, and they can be serious. In the past, it was the number one cause of death in people with SCI. Now, we have bladder programs and tests to monitor the health of your bladder/kidneys.

Benefits of a bladder program:

1) Regular emptying prevents your bladder from becoming too full. A full bladder increases the risk of infection.
2) Regular bladder emptying reduces your risk of leaking or peeing when you do not want to. This protects your skin and minimizes the chances of having an accident in public.

Long term, your doctor will monitor your bladder/kidney health with an ultrasound at least once a year. They will also have you see a urologist who can do a urodynamic study. The ultrasound is a non-invasive way to check kidney health that can be done quickly and easily. Urodynamic studies (UDS) are more invasive but give us the most understanding of what is going on in your bladder. It consists of a doctor (often a urologist) filling up your bladder with saline (salt water) and measuring the pressure in your bladder. It helps the medical team to understand if your bladder is too active, if you can tell that your bladder is full, if you can empty your bladder, and what is going on in your body when your bladder is full.

How To Keep Your Urinary System Healthy

Drink Fluids and Eat Well

Taking in enough fluid (2-3 liters/day) is an important part of your bladder program. Water helps to keep your blood pressure up (blood pressure must be above a certain level in order for your kidneys to work), dilute your urine so you are less likely to form stones, and helps to flush the system to reduce the chance of infection. It is recommended to drink fluids regularly throughout the day rather than a lot a few times. Most people reduce what they drink or stop after dinner to minimize urine collection while they sleep. You can monitor your intake using the “Bladder Journal” (Appendix 1).

Maintain Good Hygiene

Keep your body and all your equipment very clean. This will help keep germs and infections out of the bladder. Especially when you use a catheter, you need to use “clean technique,” a procedure that reduces the number of germs that enter the bladder. Germs are invisible, but they can do a lot of damage. You may need to learn to think in stricter terms about cleanliness than would usually be necessary.

Signs Of Bladder Infection*

1. Dark, cloudy, or bloody urine
2. Strong or foul odor
3. Smaller amounts of urine than usual
4. Fever, nausea, vomiting
5. Pain, burning, or urgency if you have sensation.
6. Leaking of urine between catheterizations

Signs Of Kidney Disease

1. Pain in mid-back region if there is sensation.
2. Unusual swelling of feet, legs, or hands
3. Dark circles around eyes, or dark tinge of skin

Other Signs to Watch For

1. Grit or particles inside the catheter or drainage tubes
2. Unusual difficulty inserting catheter.
3. Decreased stream or dribbling (if you urinate without a catheter)
4. Worsening spasticity or pain

You should notify your doctor immediately if any of these signs appear. See the section on "Complications" (page 57) for more about kidney and bladder problems.

***Keep in mind that these changes do not definitively mean there is an infection.**

Kidney Problems

The kidneys are delicate and complicated organs which do several important jobs. Most important, they filter poisonous waste products and excess water from the blood and remove them from the body as urine. They also produce substances needed for blood building and control the amount of some minerals and vitamins in the body.

In the past, kidney disease was the leading causes of death among people with SCI. This is no longer true because bladder care and monitoring have improved. But immobility, catheterizations, low blood pressure and kidney stones can all be hard on your kidneys. You need to check routinely for early signs of problems. Early in your recovery, you will need a complete examination and evaluation of your kidneys, ureters and bladder by a doctor who specializes in this area of the body (Urologist).

Following is a description of some common kidney problems; their signs and symptoms and the measures you can take to prevent them. If you suspect you have a kidney or bladder disorder, contact your medical team immediately.

Renal Calculi (Kidney Stones) and Bladder Stones

After SCI, “stones” may form in your kidneys or bladder if too many minerals become concentrated in the urine. The stones increase your infection risk, can cause pain, spasms, or autonomic dysreflexia (AD- page 57) as they are passed; or they can block the flow of urine, causing pressure and damage to the delicate filtering system of the kidneys. Having a foley or suprapubic catheter increases your risk of stones so your urologist may want to use a camera to look inside. Drinking plenty of fluids will help reduce the chance of stones forming.

Urinary Tract Infections (UTIs)

Infections are often the result of urine being in the bladder for too long. That is why we keep a close eye on your bladder volumes and ensure regular emptying. UTIs should not be something that happens all the time. Work with your doctor if this is a problem so that you can figure out why and prevent it from happening.

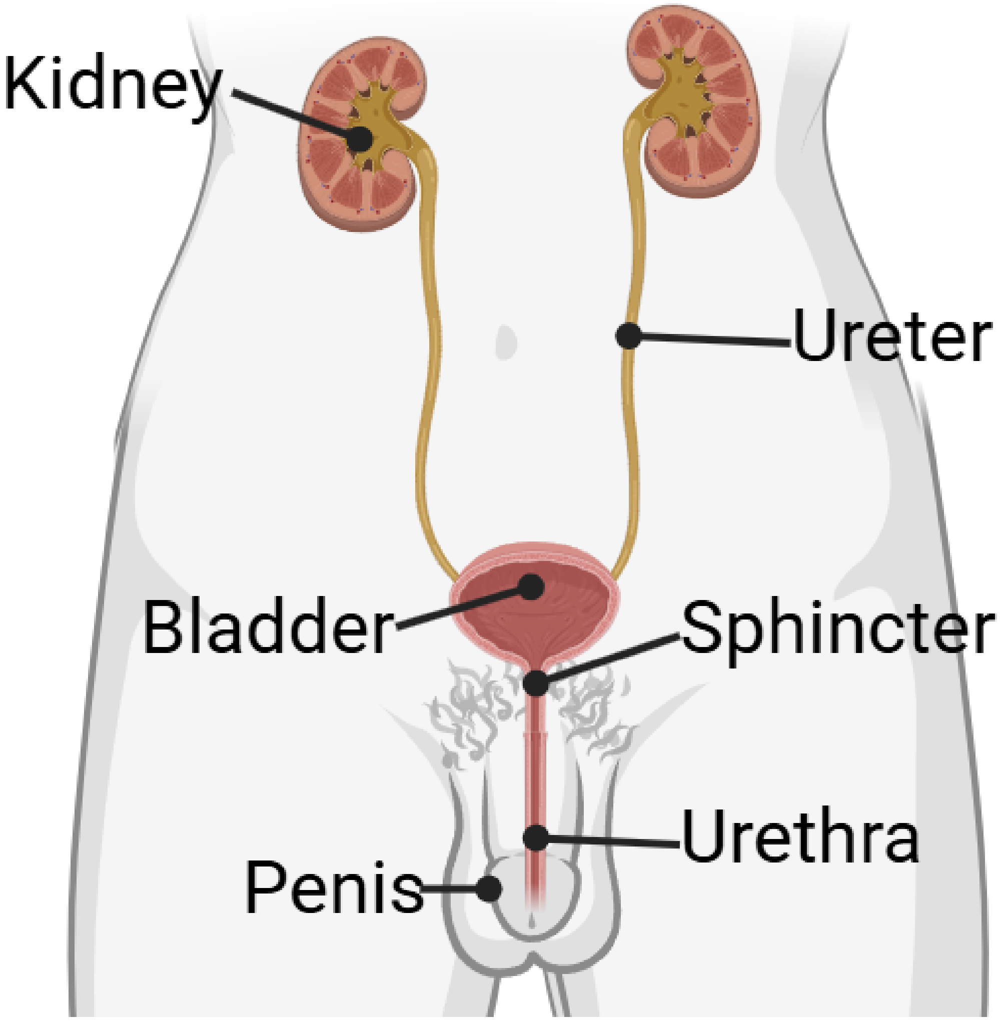
To prevent infection, you should always use careful clean technique when you catheterize and keep your equipment very clean. Drink plenty of fluids and take any medications, which are ordered to reduce bacteria (germs) in the bladder. Infections in the bladder or kidneys are treated with antibiotics. Be sure to report any symptoms to your doctor and follow treatment orders fully. In particular, it is important to take all the medication ordered, not to stop taking it when your symptoms disappear.

Ways To Manage Your Bladder After SCI

Below are the most common ways to manage your urine after SCI. There are other options but are less common so we are not going into detail here. They can be discussed with your doctor if needed.

1) Intermittent Catheterization
   This requires you or a caregiver to put a catheter into your urethra every few hours to drain the urine in your bladder.
   a. Pro: there is nothing attached to you, there are no tubes in your penis/vagina, low infection risk (when done correctly).
   b. Con: you or someone must remember to do it every few hours (including overnight), must be more careful of fluid intake.
2) Transurethral Urethral Catheter (Foley)
   There is a tube in your urethra that constantly drains urine. You or a caregiver must be able to empty the bag, and you must get it changed every 4 weeks.
   a. Pro: constant drain so you do not have to worry about stopping what you are doing or worrying about how much you drink.
   b. Con: You must go to doctor office (typically) to have it changed, something is always in your penis/vagina (can interfere with sexual activity), big infection risk if not taken care of appropriately, higher risk of developing bladder stones.
3) Suprapubic Catheter
   A surgically placed catheter that drains urine directly from your bladder. You or a caregiver must be able to empty the bag, and you must get it changed every 4 weeks.
   a. Pro: it constantly drains so you do not have to worry about fluid or stopping what you are doing, can be changed by you/caregiver, there is nothing in your penis/vagina.
   b. Con: it is a surgical procedure (which requires anesthesia and must be performed by a urologist), there is an infection risk if not well taken care of, there is a risk for stones.
4) External Urethral Catheter (Condom Cath)
   Only appropriate for a certain subset of people with SCI. Wear a condom like sheath over penis to drain urine.
   a. Pro: do not worry about fluids and constant drainage, can be removed for sex or other activities.
   b. Con: only available for men, can cause skin damage, can fall off/twist and cause accidents.

Male Urinary System



Intermittent Catheterization Procedure
Using Clean Technique

Male Genitalia Clean Technique Self-Catheterization

Supplies Needed:

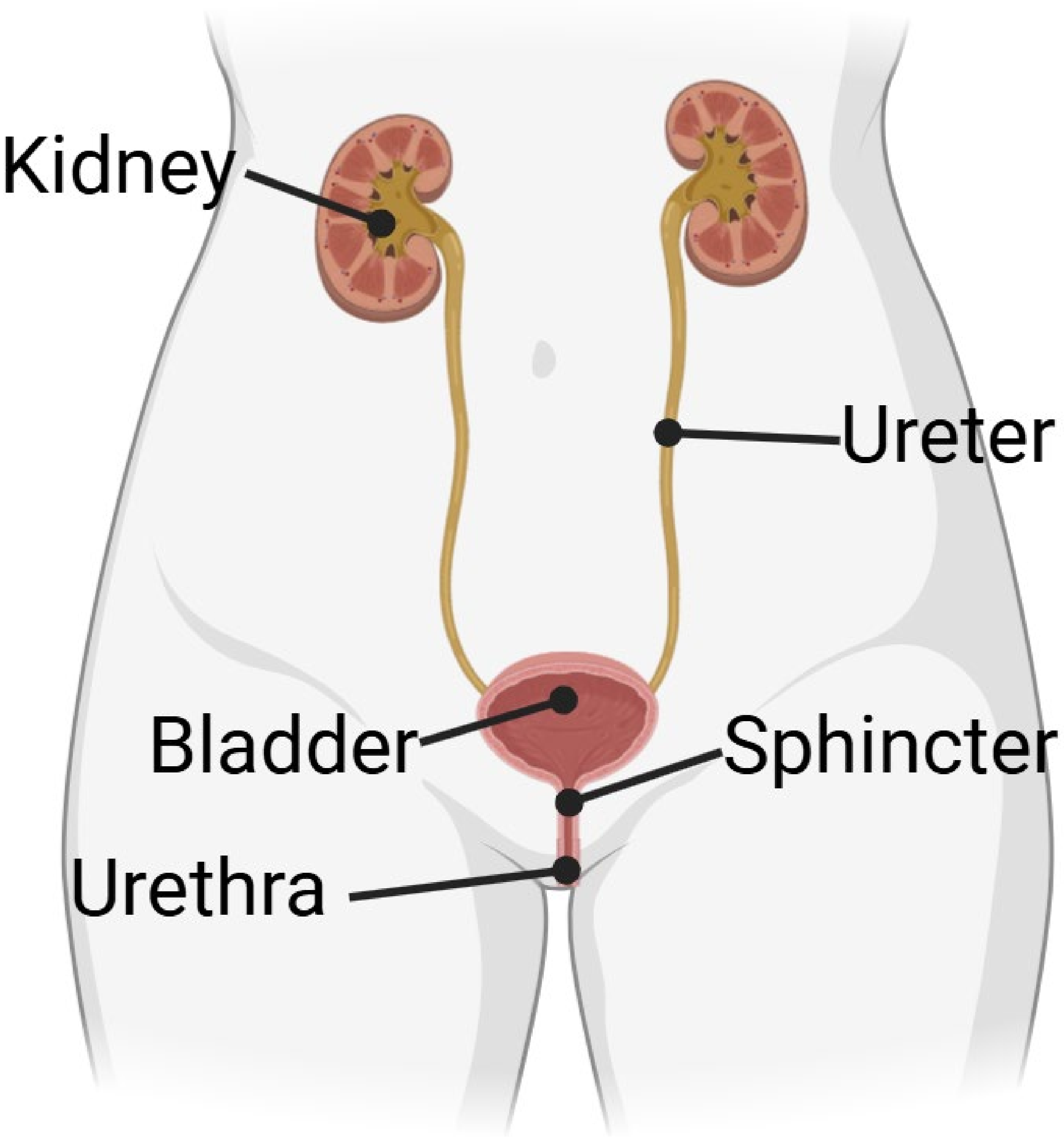
1. Urethral catheter (12-14 Fr.)
2. Water soluble lubricant (e.g., K-Y Jelly)
3. Receptacle for urine
4. Wet wipes suitable for perineal hygiene
5. Hand sanitizer/Soap and water

What To Do:

1. Sit up
2. Clean hands with soap and water or hand sanitizer. Open catheter containers and/or lubricant packages and place nearby.
3. Clean penis with a wet wipe.
4. Clean hands again.
5. Lubricate catheter and hold in dominant hand. Hold penis in non-dominant hand. Insert catheter into urethral opening of penis until urine starts to flow. Avoid touching the end of the catheter that is inserted in your penis to avoid infection.
6. When urine stops flowing, adjust your catheter to ensure emptying.
7. Pinch off or bend the catheter to keep any urine from going back into the bladder.
8. Dispose of catheter.
9. Measure urine and observe color, odor, and amount. Empty contents of urinal in toilet and wash hands.

How to video:

Female Urinary System



Intermittent Catheterization Procedure
Using Clean Technique

Female Genitalia Clean Technique Self-Catheterization

Supplies Needed:

1. Urethral catheter (12-14 Fr.)
2. Water soluble lubricant (e.g., K-Y Jelly)
3. Receptacle for urine
4. Wet wipes suitable for perineal hygiene
5. Mirror (when first learning to do procedure)
6. Hand sanitizer/Hand soap

If Done in Bed:

1. Clean hands. Open catheter containers and/or lubricant packages and place nearby.
2. Sit in a slightly reclined position with your back against the wall, headboard of the bed, or wheelchair. Position your legs in frog legged or ring sit, and position mirror to see your urethral opening.
3. Clean vaginal and urethral opening, wiping from top to bottom with a wet wipe suitable for perineal hygiene.
4. Position urinal within reach to receive urine.
5. Clean your hands again.
6. Lubricate catheter, hold in dominant, and place the end of the catheter into urine receptacle. Avoid touching the end of the catheter that is inserted in your urethra to avoid infection.
7. With index and middle finger of non-dominant hand (make a peace sign or number 2 sign with fingers), retract labia firmly enough to see, or feel urethral opening.
8. Insert catheter, aiming upwards into urethral opening until urine flow begins. Insert a bit further.
9. When urine stops flowing, reposition to ensure complete emptying.
10. Pinch off or bend catheter to keep any urine from going back into bladder.
11.Remove catheter and dispose.
12. Measure urine and observe color, odor, and amount. Empty urine in toilet and wash hands.

How to video:

Transurethral (Foley) & Suprapubic (SP) Catheters:

Always use the size catheter that was prescribed for you. Your catheter should be changed once a month by a home health nurse or at your return appointment to the clinic. Every day, during your routine care, rub the outside of your catheter between your fingers to see if it feels gritty inside. If it does, the catheter should be changed. Also, watch the characteristics of your urine. See that urine is draining well through your catheter. If it does not flow freely through the catheter, change the catheter immediately. Unless you have been training, do not flush a clogged catheter to try and get it unplugged. This would force the material into your bladder, which could cause damage.

The urine drainage system should be opened only to empty or change the drainage bag. These bags should be emptied before becoming full and it is recommended to perform when halfway filled. Leg bags connected to indwelling catheters need to be changed every day to a new bag. The bedside drainage bag needs to be changed to a new bag once a week. When not in use, the bedside drainage bag should be kept in a clean, dry area.

Condom Catheters:

The condom catheter should be removed daily for skin inspection and cleaning as follows:

1. Clean the shaft and meatus of the penis with soap and water, dry thoroughly.
2. Unroll the condom catheter over the penis. Press behind the head of the penis to seal.
3. Leave about 1/8-inch slack at the connecting end.
4. Connect the adaptor to the tubing and attach to a urine receptacle. If you ambulate or use a wheelchair, you may choose to use a leg bag.
5. Leg bags, bedside urine drainage bags, and extension tubing are not discarded daily. Generally, these can all be used for two weeks. The bag and tubing should be cleansed and rinsed daily using a vinegar solution (1/4 cup white vinegar to one quart water for 45 minutes). As above, empty the bag before it is completed filled.

It is particularly important to have a follow-up appointment at least yearly. This is the only way to assess your urinary tract to make sure it is functioning properly.

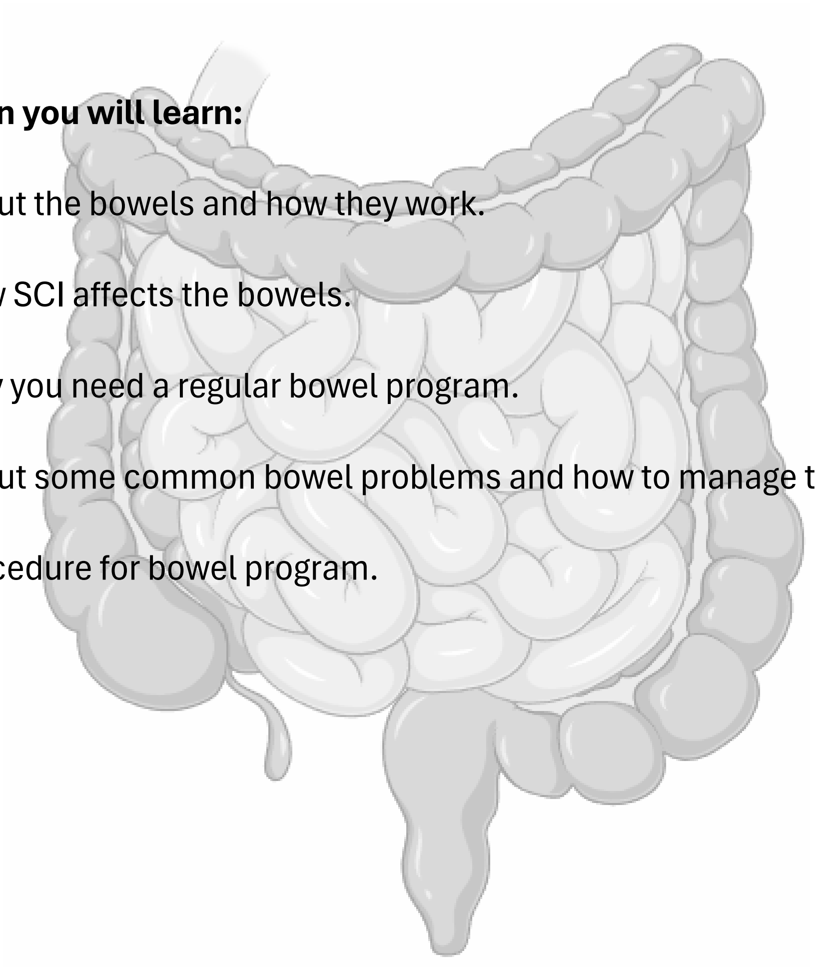
For more information about bladder health after SCI use these QR Codes:

Bladder information:

Bladder information:

UTIs:

CHAPTER 3:
Bowel Care



In this section you will learn:

- About the bowels and how they work.
- How SCI affects the bowels.
- Why you need a regular bowel program.
- About some common bowel problems and how to manage them.
- Procedure for bowel program.

The Bowels and How They Work

The bowels, or large intestines, are part of a long tube called the digestive tract, which extends from your mouth to your anus. This tube digests food and turns it into fuel for your body. Some parts of the food are not digested. These solid waste products are stored in the bowel until they are expelled from the body as “stool”, “poop”, or “feces”.

The walls of the bowel are made of muscles, which contract and relax automatically, pushing the stool down and out. The rectum is the lowest section of the bowel, where the stool collects until you are ready to move your bowels. The anus is the opening where the stool comes out. It has a donut-shaped muscle called the rectal sphincter, which, you tighten and relax in order to control your bowel movements.

How The Bowels Move

The process of a bowel movement is normally controlled by automatic reflexes via the autonomic nervous system and by voluntary muscles. Automatic wave-like movements of the bowel wall (called peristalsis) move the stool down toward the rectum at regular intervals. When some stool has collected in the rectum, you feel the need to go to the bathroom. Once on the toilet, you voluntarily relax the sphincter, push down with your abdominal muscles, and the stool comes out.

How SCI Affects the Bowels

After SCI, the speed of peristalsis slows down. It takes 3 times longer for food to get from your mouth to poop than before your injury. Also, part or all of your voluntary control over your bowels may be lost. The sensation in your rectum may be impaired, so you may not know when the stool is there. Even if you have sensation, you may not be able to control your sphincter, so you cannot hold in the stool, or let it out when you want to.

Where your injury is (the level) will impact the changes to your sphincter. If your neurological level of injury is above T12 (as described by your doctor), you will probably have a “spastic” (tight) sphincter. The sphincter will be tight, and poop will just come out when there is too much to hold back. If your injury is below T12, you will probably have a “flaccid” (loose) sphincter. The sphincter will be relaxed and as soon as poop arrives, it will come out because the sphincter cannot hold it back. The level is not exact, so we will do a physical exam to help determine how your bowels are affected.

The Importance of Your Bowel Program

A bowel program is simply a plan for emptying your bowels at the same time with regular frequency so that you prevent bowel problems and maintain control over your bowel movements. Our goal is that you have a regular bowel program to avoid having accidents (incontinence) and severe constipation (impaction). We want to empower you so that you can live your life without worrying about there being problems if you are out and about.

When To Do the Bowel Program

Timing is very important. The best time to do a bowel program is one half hour after a large meal. Eating causes the bowel to become more active, with increased peristalsis and often an urge to move the bowels. It is your body's way of helping to empty the tank when new food comes in. This is called the gastro-colic reflex.

If you have flaccid sphincter, you will need to check your bowel after every meal. This will avoid accidents and clear the rectum so that stool will keep moving down and out. Some people also do a bowel check before bedtime.

If you have a spastic sphincter, you will start with a daily program (though this may change over time). Whether to do your bowel program in the morning or evening is a decision you will make based on several factors:

- Did you have a regular bowel movements before your injury?
- What is your schedule?
- Do you need assistance with the program?
- How long does your bowel program take?

Once you establish a suitable time, do your program at the same time (within 30 minutes) every day. It may take up to several weeks to achieve regularity; once the program is well established, you should not have bowel movements at other times. If after a trial period you find it is not working, or you want to change because your schedule changes, it can be done but it may take a while to make the transition. You should expect and prepare for possible accidents until the new schedule is well established. While working through this, you can use the bowel tracker (Appendix 2). If you need more copies, please ask the nursing staff for more or find them on our website.

Common Bowel Problems

Constipation

Constipation is difficulty moving your bowels because of hard, dry stool. It can cause many problems, such as muscle spasms, headaches, trouble sleeping, grouchiness, poor appetite, nausea, vomiting, hemorrhoids, or even autonomic dysreflexia (AD- see page 57). If allowed to persist, constipation can become impacted, in which a hard mass of stool gets stuck in the bowel and cannot be removed by normal means.

Measures to prevent or treat constipation:

1. Take adequate fluids and eat a well-balanced diet with plenty of fiber (~15g per day). Whole grains, fruits, and vegetables have the most fiber.
2. Avoid or limit foods, which tend to “bind” the bowels, such as apples, cheese, popcorn, and refined grains such as white rice or white bread.
3. Follow a regular bowel program and make sure your bowels empty as completely as possible. Take medications as prescribed by your physician.
4. Be aware of how often your bowels move and do not allow more than two days to go by without a movement. Contact your doctor if this happens.

Diarrhea

When the stool is loose, elimination at unplanned times is more likely. Diarrhea can be caused by medical problems, food indiscretions, overuse of laxatives/stool softeners, antibiotics, x-ray procedures requiring bowel preps, constipation, and psychological factors.

Measures to prevent or treat diarrhea:

1. Find cause of medical problems and treat them.
2. Keep checking your diet.
3. Readjust medications or bowel training program, as necessary.

Hemorrhoids

Hemorrhoids are swollen blood vessels surrounding the anus. You may or may not be able to see them, depending on whether they are inside or outside the sphincter. Hemorrhoids are usually caused by hard stool irritating the anus or by rough handling of the delicate anal tissue. If you do not have feeling in your anal area, the first sign of a hemorrhoid may be bright red blood in your stool or in the toilet. If you or your helper notices a swelling of the rectum or a bloody stool, you should take measures to reduce the irritation and to prevent further damage.

Measures to prevent or reduce hemorrhoids:

1. Keep the stool soft.
2. Use plenty of lubricant during your bowel program and handle the anal area gently. Keep fingernails trim and smooth; replace rough or broken anal stimulators.
3. If you do have hemorrhoids, ask your physician or nurse about using one of the over-the-counter ointments at the pharmacy.
4. If there is a lot of bleeding, tell your physician. You may need medical treatment.

Bowel Training Program

Supplies Needed:

1. Suppository
2. Water soluble lubricant
3. Gloves
4. Hand sanitizer/soap
5. Mirror as needed (when first learning to do procedure)

UMN/Reflexive Bowel Procedure:

1. Position yourself for suppository insertion.
    a. If you have quick results you may start on the commode, if not then start by laying on your left side in bed.
2. Clean your hands with hand sanitizer.
3. Put disposable gloves on.
4. Lubricate your gloved index finger and insert your finger into the rectum to check for stool. If there is some stool, remove all you can with your finger. Change gloves as needed.
5. Open package to suppository and apply lubricant to the suppository.
6. Insert the suppository into the rectum, pointed end first. Push the suppository high into the rectum, and ensure it touches the rectal wall. If the suppository is not inserted high enough the suppository may fall out and you will have to repeat this process.
7. Wait for 20 minutes for the rectum to absorb the suppository.
8. If you are not already on the padded commode or padded toilet seat, transfer to the appropriate toilet seat.
9. Complete digital stimulation- Move your finger in a circular motion against the rectal wall for 1-2 minutes and remove your finger.
    a. Wait for 5-10 minutes to allow your rectum to release the stool.
    b. Repeat this technique every 5-10 minutes until the rectum is empty, there is mucosal discharge, or has been completed 3 times.
10. Remove and discard gloves. You may put new gloves on if desired.
11. Cleanse the anal area, discard the waste, and wash your hands.

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Helpful Hints:

1. Drink something hot to stimulate bowels to move 20 minutes before
2. Keep a closed plastic bag handy to deposit waste.
3. Whenever possible, you should be in the upright position because peristaltic activity is greater, and gravity is more assistive to stool expulsion. In general, spending time upright or standing can speed up your bowel program.

Lower Motor Neuron/Areflexive Bowel Procedure (Manual Disimpaction):

1. Transfer to a commode or toilet.
2. Put disposable gloves on.
3. Lubricate your gloved index finger and insert the gloved finger into the rectum.
4. Gently remove the stool with your finger. Bearing down may also assist with self-evacuation of the stool.
5. When you have removed all the stool, remove, and dispose of your gloves.
6. If you desire, you may apply new gloves.
7. Cleanse the anal area, discard the waste, and wash your hands.

Helpful Hints:

1. See the hints listed above
2. Ensure nails are cut short to prevent injury to your rectal wall.
3. The bowel program will be most successful if completed at the same time of day and using the same method that is recommended by your health care team.
4. Complete a weight shift if sitting on the commode or toilet for longer than 30 minutes.
5. Padded commodes or padded toileting seats are recommended to avoid skin breakdown.

Equipment

A toilet should be used if you can transfer to and balance on it. When back support is needed and there is no water tank that can be used as a backrest, a removable padded backrest attached to the toilet or permanent backrest attached to the wall can be used. A safety belt should be used, if necessary, for additional stability. A handrail at the left or right side of the toilet helps with grasp to maintain balance. A raised toilet seat can be added if the seat is too low. If the toilet seat is too high, a footstool should be used to rest the feet on to promote comfort and good balance. A portable commode can be substituted for a toilet.

See the occupational therapy chapter (chapter 10) below for more details on equipment.

Medications

Suppositories

Insertion of a suppository is intended to initiate reflexes that stimulate peristalsis of the lower colon and rectum with resulting relaxation of the external and sphincter muscles. There are many types including glycerin, bisacodyl, or magic bullet. The type used will be a discussion between you and your care team.

Enemas

Similar to the suppository, an enema is intended to initiate reflexes that stimulate peristalsis of the lower colon and rectum with resulting relaxation of the external and sphincter muscles. Since you squeeze liquid with an enema, it can cause more distension to get a faster response. There are many types including Enemeez and fleet. The type used will be a discussion between you and your care team.

Oral Agents

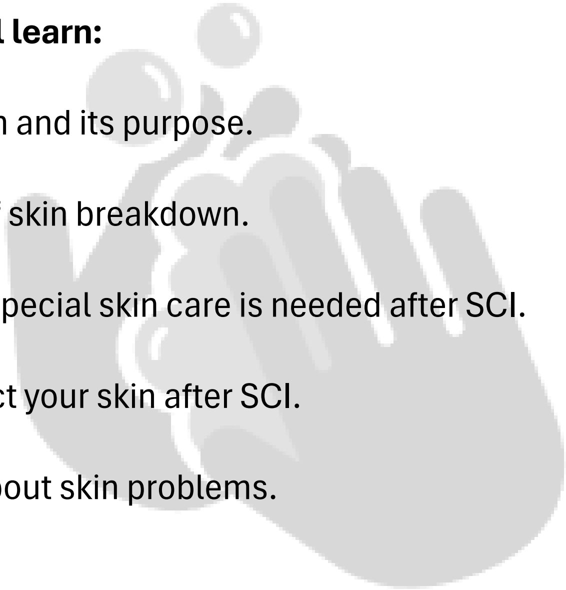
While enemas and suppositories move things from below, oral medications help to move the poop through your colon to get to the rectum. MiraLAX helps to soften stool and move it along by pulling water into your colon. Senna helps peristalsis be more effective since things have slowed down after SCI. This usually prevents the acute symptoms of this autonomic response. While there are other medications, these are the most common.

For more information on bowel function after SCI use these QR Codes:

CHAPTER 4:
Skin Care

In this section you will learn:

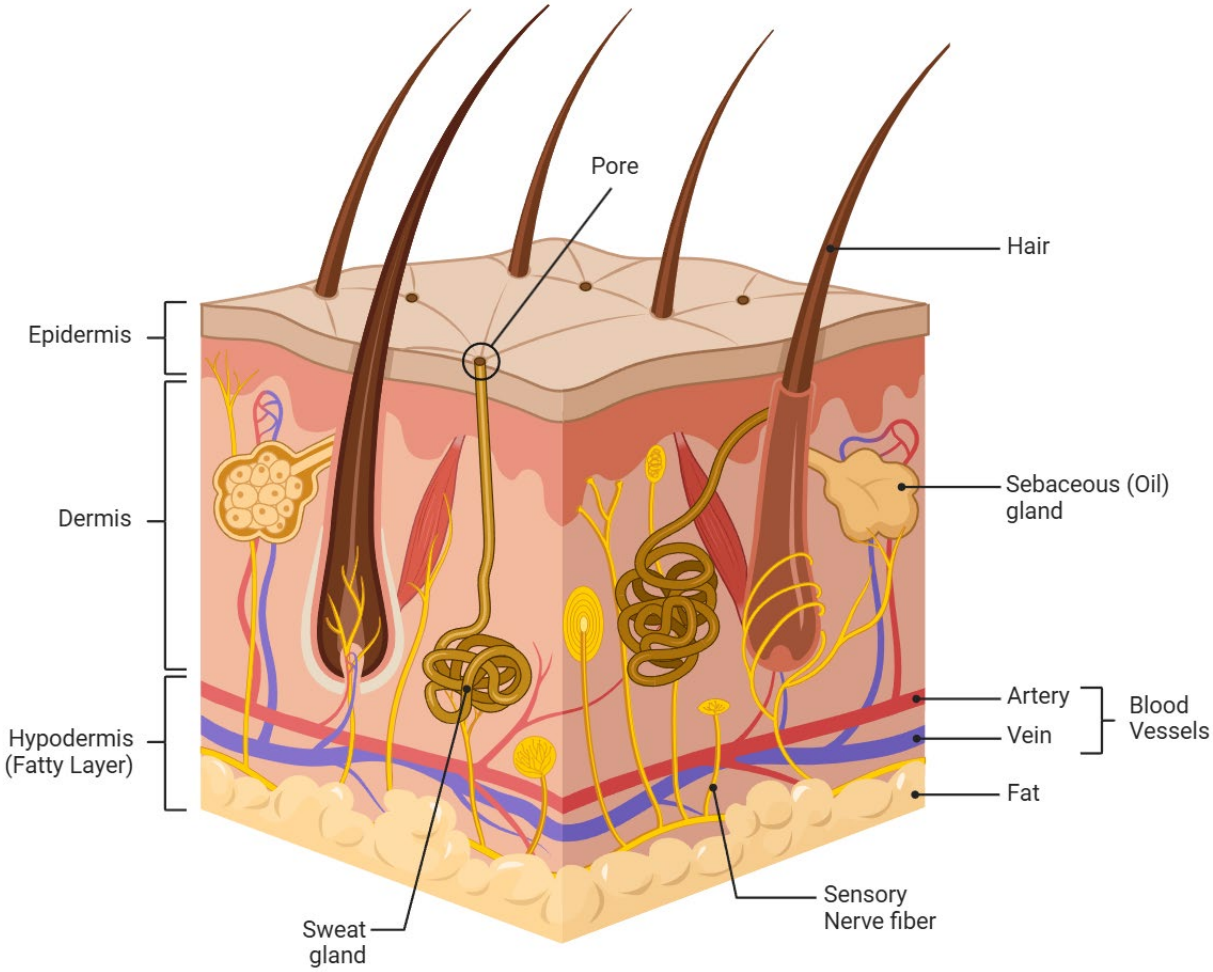
- About the skin and its purpose.
- The causes of skin breakdown.
- The reasons special skin care is needed after SCI.
- How to protect your skin after SCI.
- What to do about skin problems.



What Is Skin?

The skin is an organ of several layers, which covers your whole body, keeping germs out and important substances in. By sweating, it also helps to get waste products out of the body and to regulate your temperature. Normally, keeping your skin clean is all you must do to keep it healthy. After SCI, skin care becomes an especially important part of your daily program.

A network of blood vessels provides nutrients and oxygen to make new skin cells. As surface cells dry up and flake away, new cells replace them.



The Effects of SCI on the Skin

After a SCI, you may have decreased or absent sensation (feeling) below the level of your injury. This increases the risk of injury to your skin. For example, you may not feel if the bath water is too hot or if a sharp object is poking you. Your skin may become injured or burned without you knowing it. Because you move less, your skin will get more pressure in some areas than it did before. Constant pressure can damage your skin and cause pressure injuries (sometimes called bed sores).

Normally, your skin is constantly rebuilding itself and shedding its outer layers. After SCI, there is a reduced blood supply to the surface, and the skin does not rebuild itself quite as well as before. Your skin will become thinner and more delicate. Thin skin can be more easily injured and will heal more slowly.

Causes of Skin Problems After SCI

Pressure is the most common cause of skin problems after SCI. Pressure cuts off the blood supply to the skin. Without fresh blood, the tissue dies within hours. The damage often starts under the surface, appearing as a reddened or bruised area. Soon after, a blister forms as the layers of skin separate. An opening (“pressure injury”) eventually develops on the surface. This open area can get infected. Any infection is dangerous and can cause serious problems if not treated.

There are other dangers to your skin as well. Friction from tight clothing, sheets, or wheelchair wheels can cause scrapes or blisters. Wetness from perspiration or incontinence increases friction and is a breeding ground for germs. Heat from bath water, fireplaces, car vents, hot water bottles, or sun can burn you without feeling it. Exposure to cold or the draft from an open-air vent can cause frostbite. If your sensation is impaired, you need to be aware of such possible dangers and avoid them.

The Importance of Special Skin Care After SCI

It is especially important that you learn to protect your skin and to treat any injury right away. Any opening in the skin, regardless of cause, can get infected. This can be life threatening if not treated promptly. If you do not take care of a wound, you may end up needing surgery to repair it; this is time consuming and expensive. A deep wound almost always leaves a large, disfiguring scar, which is not as strong and healthy as normal skin; this increases the chances of more sores.

Fortunately, these problems can be prevented if you do good skin care every day. If you make your skin care a daily habit, as automatic as eating and sleeping, you will be able to avoid one of the most serious health problems associated with SCI.

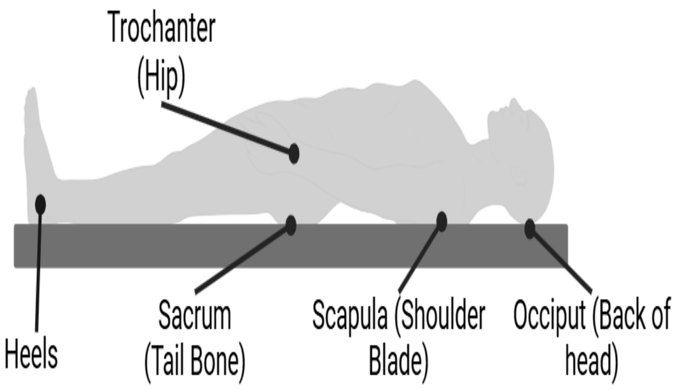
Three Steps to Healthy Skin

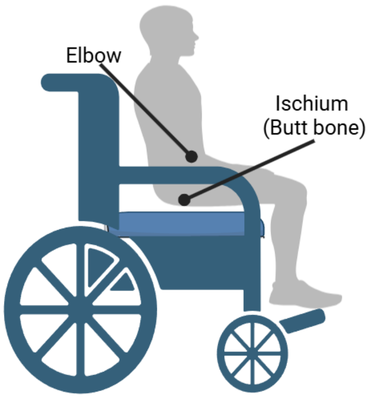
1. Relieve Pressure -Weight shifts, good posture, good positioning, and padding.
2. Eat Well - Weight control, vitamins, proteins, and fluids.
3. Daily Skin Care and Observation- Look at skin daily to catch problems early.

Pressure Relief

You MUST give your skin a chance to breathe and renew its blood supply at regular times throughout the day and night. You will be taught how to do "weight shifts" in your wheelchair so you can stay in the chair all day. When in bed, a turning schedule and careful positioning will also help protect your skin.

This illustration shows the points on your body where pressure injuries are most likely to occur:





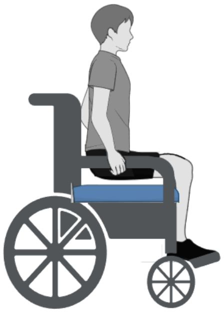
Weight Shifts

There are several ways to do weight shifts. Which way you do it (and how often) will depend on your level of injury, type of wheelchair, and how much pressure your skin can tolerate. There is more pressure on your bony prominences of your bottom when you are sitting in your wheelchair (see image above). Because of this, you must relieve pressure for at least 1 minute every 20-30 minutes while seated. Your therapist will show you which weight shift method is best for you.

Examples of Weight Shifts

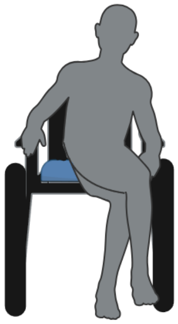
Weight bearing relief may be accomplished in the following ways:

Shoulder depression or trunk elevation



Bending forward while in the sitting position

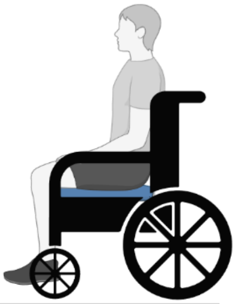
Shifting your weight from side to side while in your wheelchair



Having your chair tilted or leaned backwards.

Posture

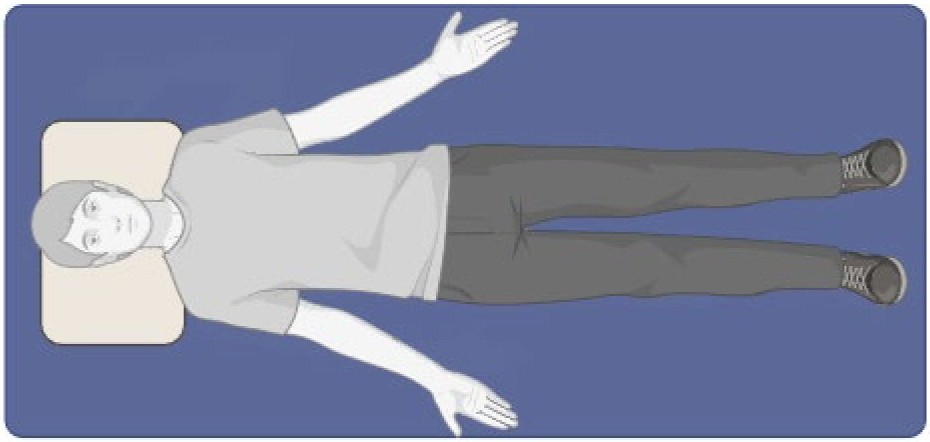
Poor Posture - When you slump in your chair, the weight of your body falls on your poorly padded sacrum, the large flat bone at the base of your spine. This is the most frequent site of pressure injuries. If you find it hard to maintain good posture, you or your helper will have to reposition you every so often.



Good Posture **-** The body weight is distributed to your ischia (sitting bones) and the fatty pads of your buttocks and thighs. This position also allows your skin to breathe more freely and avoids pressure on your internal organs.

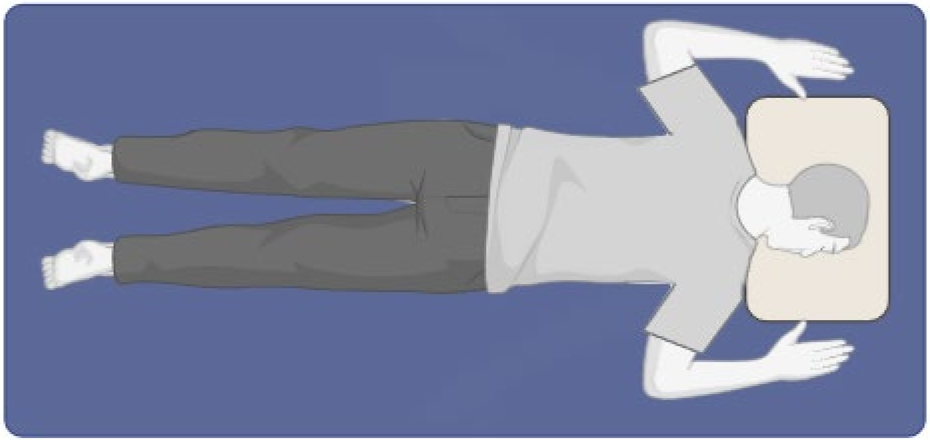
Positioning in Bed

Good positioning helps keep your body in good alignment and your joints flexible. But most important, it keeps pressure points from getting too much pressure. Since you spend so much time in your chair, it is better to stay off your back when in bed. All joints should be in their natural position and properly supported with pillows or splints. The following are examples of good positioning:



Proning

Proning means lying on your stomach. This is the best position for sleeping for several reasons. It allows you to go for several hours without turning; this means you do not have to wake up during the night to reposition yourself. Proning also can help reduce spasms and tightness in your hips and knees. It may take some practice for you to feel comfortable in this position, but careful positioning should make it possible for you to prone at least a part of each day.



Equipment

Use your wheelchair cushion whenever you are sitting, whether in your wheelchair, in the car, or on another chair. Use pillows, heel and elbow protectors, and any other devices or methods you need to reduce pressure, rubbing and irritation. There are items you can wear to protect your heels and hands depending on your needs.

Eat Well

To help your skin stay healthy and strong, eat nutritious foods with enough protein, fluids and Vitamins A, C and E. Make every effort to stay at your ideal weight. Extra weight puts more stress on your skin (and every other system). Being underweight means you have less padding and more pressure on your pressure points. See the nutrition chapter for more information (Chapter 6).

Daily Skin Care and Observation

The skin is always shedding old cells and perspiring. Wash your skin gently every day, dry thoroughly, and use lotion to soften any dry areas. Clean and dry your skin right away if it gets wet or dirty.

Toenails may become thicker and break easily due to changes in your circulation. Trim your toenails straight across and wear roomy shoes to avoid ingrown toenails. You may need to wear shoes a size larger than before injury. Inspect for cracks, scaly areas, or rash between your toes. Check your nails for breaks or red, swollen areas, which are signs of an ingrown toenail. Get treatment for an ingrown nail or any other problem right away. Such problems can cause increased spasms, autonomic dysreflexia (AD- see page 57), or even infection.

Daily Skin Check

Using a mirror or asking a caregiver for assistance, check your entire body on a regular basis. Most people do it on shower days. Look for reddened areas, cuts, scratches, blisters, rashes, pimples, or sores of any kind. If you use a condom catheter, change it at least daily and inspect the area carefully for redness or broken skin. If you find any redness or skin breakdown, leave the condom off until skin clears.

What to Do About Skin Problems

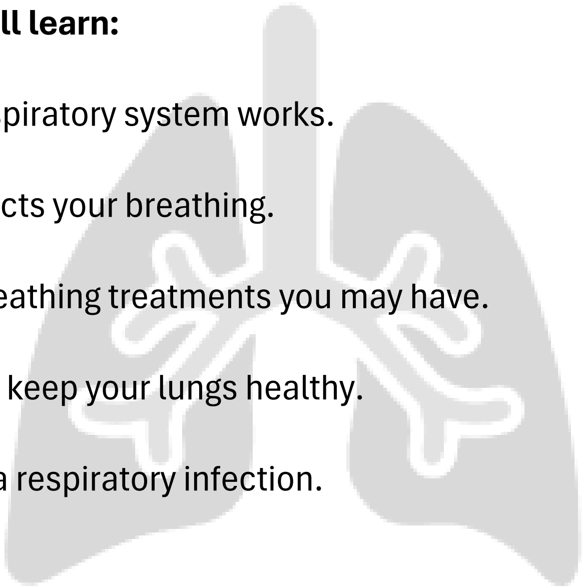
If you notice a reddened area, which does not go away after relieving the pressure, you need to give that area a chance to heal. The only way to do that is to STAY OFF THE AREA for as long as it takes to bring back its healthy, normal color. That could be a few hours or a few days. After that, measures should be taken to prevent it from happening again. You may need to do weight shifts more often, get a different type of wheelchair cushion or wear loose clothes.

You may not like the idea of reducing time in your chair, but there is a real danger that the wound will get worse, and more time will be lost. If you take one or two days when the problem is small, you can save yourself more time, money, and unhappiness in the long run. (See Chapter 8 on “Complications” for more about Pressure Injuries.)

For other skin problems, such as minor cuts, burns, pimples, blisters, or rashes, cleanse them carefully (do not pop blisters), apply a sterile dry bandage, and check daily to be sure they are healing properly. If swelling, increased redness or pus appears, or if they do not heal in a few days, tell your physician. Your slower circulation can slow down healing and your lack of sensation can keep you from feeling the pain of an infection. Even small wounds, if persistent, should be seen by a physician or nurse. Do not try to remove an ingrown toenail. See a foot doctor (podiatrist) for treatment. A rash might mean you have a drug allergy, a fungus infection, or some irritant in your environment. Talk to your physician if you get a rash.

For more information about skin, use this QR Code:

CHAPTER 5:
The Respiratory System



In this chapter you will learn:

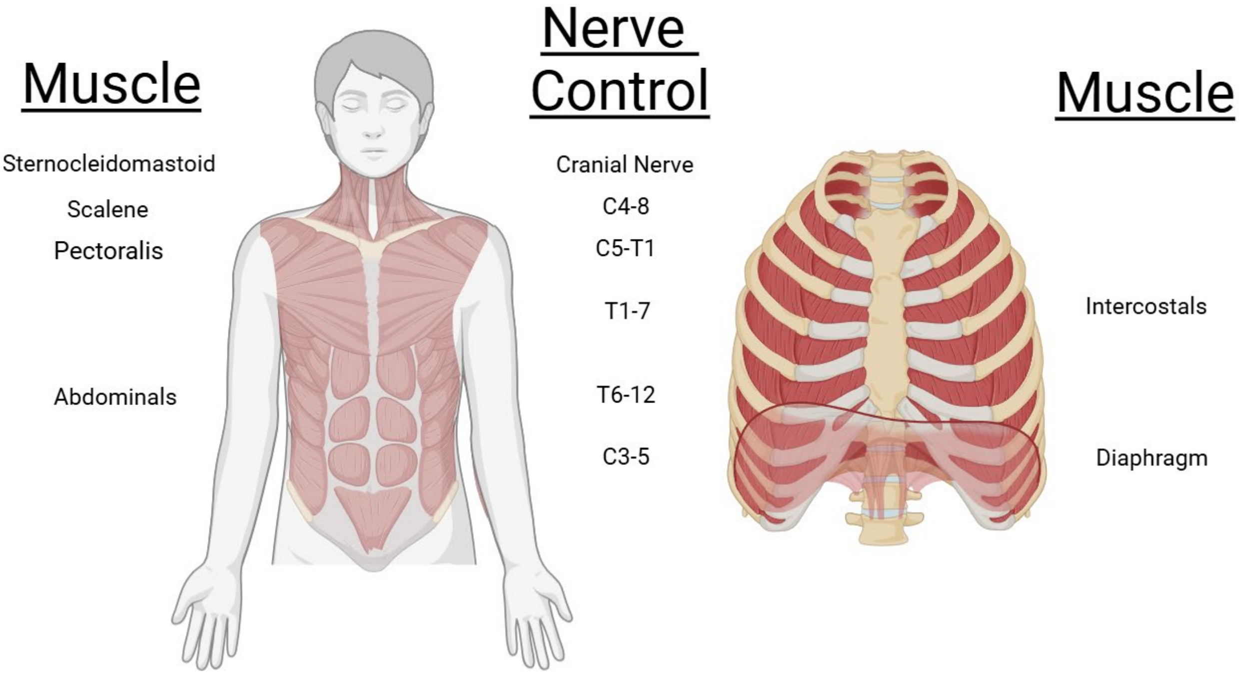
- How your respiratory system works.
- How SCI affects your breathing.
- About the breathing treatments you may have.
- How you can keep your lungs healthy.
- The signs of a respiratory infection.

How Your Respiratory System Works

The respiratory (breathing) system includes the lungs and all the passages, which bring air into and out of the body. A network of blood vessels in the lungs collects oxygen from the air and distributes it throughout the body. Your body needs a constant supply of oxygen to stay alive.

There are several sets of muscles, which contract and expand the chest to make breathing and coughing possible. The diaphragm is a large muscle just below the lungs, which contracts every time you breathe in, opening the chest to draw air in. The intercostal muscles between your ribs contract when you breath to move air and stabilize the ribs. Your abdominal (stomach) muscles are also used to exhale (breathe air out), especially when you cough. Some or all of these muscles may be affected by SCI, depending on the level of your injury.

The accessory muscles in your neck and shoulders are not normally important in breathing. But a person with a high injury will use these muscles to help compensate for the loss of the main muscles described above.



How SCI Affects Breathing

If your injury is above T12, your breathing may be weakened. This chart shows the effect on your breathing of each level of injury.

Level of Injury	Muscles of Inhalation			Muscles of Exhalation		Impact on Breathing
C1	Sternocleidomastoid (Cranial Nerve)					Mechanical Ventilation
C2						
C3	Diaphragm					Most are weaned from Ventilator
C4		Scalene				
C5			Pectoralis			Shallow breathing, absent cough
C6						
C7						
C8						
T1	External Intercostal				Internal Intercostal	Reduced cough and breathing ability
T2						
T3						
T4						
T5						Weak Cough
T6				Abdominal		
T7						
T8						
T9						
T10						Slightly weak cough
T11						
T12						

A frequent problem involves the secretions (fluids), which coat the inside of the lungs and all the air passages. Normally, your daily activity and coughing keep these secretions moving up and out of the lungs. After SCI, your immobility and weakened cough may allow the secretions to build up. They tend to block the air passages and become a breeding ground for infection.

If you have a problem with secretions, you will need to learn how to do assisted coughing and/or some other ways to clear your lungs. How much of this will be necessary depends on the level of your injury and on the amount of secretions you have. Even if you do not usually need respiratory assistance, you may need it when you have a cold, flu, or COVID-19.

Assisted Cough

Assisted coughing simply means having another person help you breathe out forcefully to clear your air passages better. The person helping you stands in front of or behind you if you are sitting, or over you if you are lying down, and pushes up on your diaphragm while you cough or breathe out as hard as you can. This is done until you can bring up any extra mucus or secretions into your throat where you can spit them out or swallow them. Your nurses and therapists will be helping you learn this technique if you need it. Some situations prevent assisted cough. Your doctor will be sure to let you know if it should be avoided.

When doing an assisted cough, be sure to tell your helper:

- Avoid using an assisted cough right after eating, you might throw up!
- Avoid pushing on the ribs or the chest bone as this can injure you.
- Push only when you are breathing OUT.

Assist Cough Example: Mechanical Cough Example: Vest Example:

Mechanical Cough Assist

Sometimes it is easier and more effective to use a device for cough assist. Most commonly, mechanical insufflation-exsufflation devices are used. This device helps you cough by filling you with air and then sucking it out. The respiratory therapist and nursing staff will teach you and your caregivers how to use this.

High Frequency Chest Wall Oscillation

This machine (vest therapy) mechanically performs chest physical therapy by vibrating at a high frequency percussion. The vest vibrates the chest to loosen and thin out mucus.

Percussion and Postural Drainage

If the assisted cough does not work to loosen and bring up secretions, percussion is very helpful and effective. You are placed in a series of positions, which allow gravity to help drain the secretions. Your caregiver taps firmly on your chest with cupped hands. This loosens the secretions from the lining of the air passages. The secretions work their way up to your throat, where they can be spit out or suctioned out if you cannot cough them up yourself.

If you need this type of treatment, a respiratory therapist or nurse will teach you and your helpers how to do it. This can then be done at home whenever it is needed to keep you breathing clear. Keep in mind that this requires a lot of physical assistance, so other options may be tried before this.

How To Keep Your Lungs Healthy

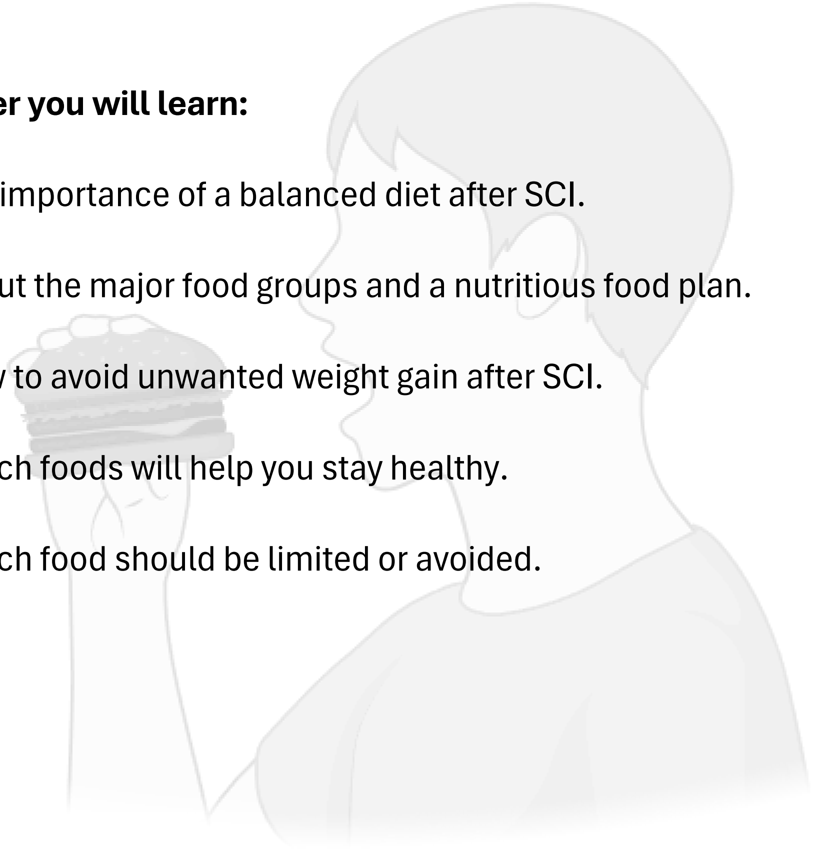
Like most diseases, respiratory infections are easier to prevent than cure. By getting into good habits, you can avoid serious illnesses such as pneumonia and improve your overall health and wellbeing.

1. Do not smoke or be around others who smoke.
2. Stay hydrated to prevent secretions from getting too thick.
3. Avoid people with respiratory illness (cough, cold, flu, COVID, etc.).
4. Stay up to date on your vaccinations including the flu, pneumonia, RSV, and COVID.
5. Move around - getting out of bed and moving can keep your lungs open.

See a doctor if you have a fever, shortness of breath, thick yellow or green secretions, or chest pain. These are signs of lung infection.

For more information on pulmonary function after SCI use these QR Codes:

CHAPTER 6:
Nutrition



In this chapter you will learn:

- The importance of a balanced diet after SCI.
- About the major food groups and a nutritious food plan.
- How to avoid unwanted weight gain after SCI.
- Which foods will help you stay healthy.
- Which food should be limited or avoided.

Food And Nutrition

Food provides you with NUTRIENTS - the substances your body needs to grow and stay healthy. Good nutrition means eating wholesome foods that provide you with all the nutrients you need and not eating too much of the foods that are useless or harmful to your health. In this section, you will learn how to choose wholesome foods to create a healthy eating plan for yourself.

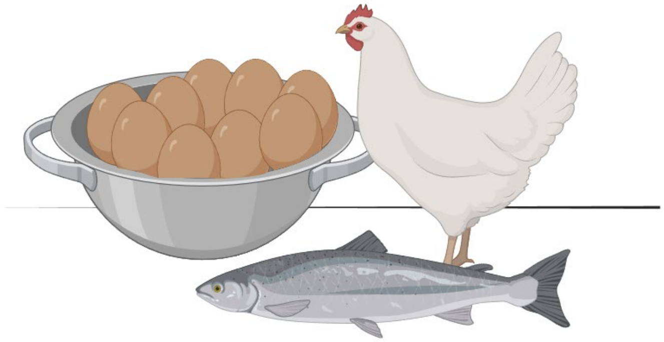
Why Study Nutrition?

Before your injury, you may not have thought much about the nutritional value of the foods you ate. But because you are not moving around as much, you are more prone to certain diseases, bowel problems and weight gain. Eating nutritious, well-balanced meals can make a big difference in whether you remain healthy or not.

The Basic Food Groups

To make it easier to choose balanced meals, nutritionists have arranged all foods into basic food groups. By eating the proper number of servings from each food group every day, you will get the right amount of all the important nutrients. The following pages will show you how many servings of each food group you should include in each day's menu. The serving size of each food is shown so you will know how much of each food you should eat. There is also an explanation of each of the food groups and what they provide.

Protein



2-3 servings* / day

Nutrients: Iron, B vitamins, zinc
Serving size: 3 ounces of meat
½ cup cooked beans
1 egg

*If you have a wound, you will need more protein to help wound healing

Lean meat, poultry, fish, eggs, beans, lentils, sprouts, nuts and seeds are all high in protein. Protein is a nutrient needed by every tissue in your body to grow and rebuild itself. Most Americans eat plenty of protein, often too much. It is best to eat a small amount every day, since unused protein breaks down into other substances, including fat and uric acid, which are harmful to your body. Also, fatty meats are high in saturated fats and cholesterol, which may contribute to heart disease and other problems. It is best to get most of your protein from skinned poultry, fish, beans, and other vegetable sources.

Starches

4 servings / day

Nutrients: Fiber, calories, B vitamins, iron
Serving size: 1 slice of bread
1 ounce of dry cereal
½ cup of cooked grain, noodles

Bread, cereal, rice, potatoes, corn, crackers, spaghetti, noodles, tortillas, and any other foods made from grain or flour are high in starch, or "complex carbohydrates." These foods give you the energy you need for movement, warmth, and internal functions. In their whole, natural state, grains also contain valuable vitamins, minerals, and fiber, which are important for good health. This is why it is recommended that you eat whole grain products instead of refined (white) products as much as possible.

Fruits and Vegetables

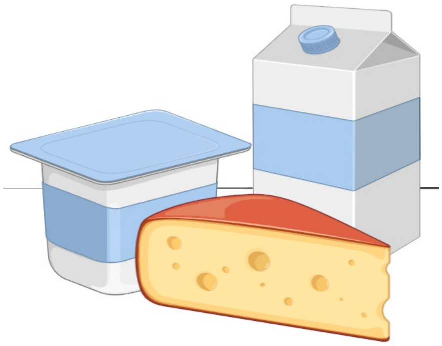
4 or more servings/day
Nutrients: Vitamins A, B's, C, fiber, iron and other minerals
Serving size: ½ to 1 cup cooked
1 piece of fruit

Fresh, canned, frozen, or dried fruits and vegetables contain vitamins, minerals, and fiber, as well as varying amounts of starches and sugars. Vitamins and minerals are substances used in the chemical processes of your body. Fiber is the indigestible part of the plant, which helps keep your bowel healthy and also draws excess fats out of the body. It is best to eat fresh, whole fruit and vegetables whenever possible because they have more nutrients than processed foods. For the best nutrition, eat at least one leafy green vegetable, such as spinach, greens or cabbage each day. Eat an orange vegetable such as carrot, pumpkin, or sweet potato two or three times a week.

Vegetables are so important for your digestion and health that you should find ways to fit them into your meals even if you do not particularly care for them. Pumpkin pie, vegetable soup, carrot and raisin salad, spinach quiche, tacos with tomatoes and peppers, or celery in your tuna salad are just a few examples of how vegetables can be included in your meals. You might try baking them in a crust or sauteed like stir fry!

One or more fruit can be eaten each day. Sometimes too much fruit can cause diarrhea. If you have trouble with loose bowels, try limiting your fruits or fruit juices to one or two servings a day, or try a different kind of fruit. If constipation is a problem, fruit can often help make your bowel move more smoothly.

Dairy



2-4 servings / day

Nutrients: Phosphorus, calcium, riboflavin, protein
Serving size: 8 ounces milk or yogurt
1 ounce (1 slice) cheese

Milk, cheese, yogurt, buttermilk, and kefir (a cultured milk drink) are all high in calcium, protein, and other nutrients. Calcium is good for strong bones and teeth, as well as for many chemical processes in the body. Dairy products combined with vegetable protein foods such as beans or lentils increase the protein value of these foods. Dairy products can be a valuable part of the diet.

However, some people should not eat too many dairy foods. Early after SCI, your bones may lose some of their mass, and the lost calcium may contribute to stones in the kidneys or bladder. Long term, dairy is important to get the calcium you need to maintain your bone health. Check with your doctor about whether you need to limit or increase your intake of dairy products. Whole milk products also contain a lot of fat, which is high in calories and cholesterol. It is best to use non-fat or low-fat dairy products whenever possible, such as skim milk, cottage cheese, and non-fat yogurt. If you are lactose intolerant, consider calcium-fortified, unsweetened soymilk.

Water

Water is one of the most important nutrients. Digestion, urination, skin tone, blood pressure, and all body processes require water in order to work properly. If you get dehydrated (too dry) you can become seriously ill quite quickly. For some people, too much water can also cause problems. Find out how much liquid you should drink and get in the habit of drinking at regular times throughout the day.

Water is also found in milk, juice, tea, coffee, sodas, and other sweet drinks, and in foods such as soup, watermelon, Jell-O, and ice cream. If your fluids are restricted, these should all be counted in your total liquid for the day.

Others: Sugars, Salt, Fats and Oils

Nutrients: Calories & essential fatty acids

The last group includes all the miscellaneous oils, fats, sweets, condiments, and other foods we use mostly for flavor and enjoyment. These foods are often high in calories but low in nutrients.

Sugars

Sugar comes in many forms. Whether white or brown granulated sugar, honey, molasses, syrup, or malt, it is a refined product with little or no food value except calories. It is better if you can limit your intake of foods high in sugar, such as cookies, candy, pastries, cake, pie, ice cream, soft drinks, and other sweets as much as possible, substituting natural sweets such as fruits, which have more nutritional value.

Salt

Salt is a mineral, which serves some particularly important functions in your body. But after SCI, too much salt can cause edema (swelling) and kidney problems. Potato and corn chips, candy, salt-cured lunch meats, fast food meals, pizza, canned soups, cheese, and many other processed, frozen, and canned foods have large amounts of salt and should be eaten only occasionally. If you must purchase canned or frozen foods, look for the kinds that say no or low sodium, or "No Salt Added." Try to avoid the habit of putting extra salt on food; after a short while, the food will taste fine without it.

Fats and Oils

This group includes vegetable oils, lard, butter, margarine, shortening, and foods high in fat such as chocolate and many candies, mayonnaise, salad dressings, sauces, olives, salami, bacon, and other fatty meats.

The average American diet is overly high in fats and oils. Only about one tablespoon a day is needed to provide the essential fatty acids required for good health. Eating too much fat may contribute to being overweight, digestive problems, and heart disease. Fats have also been linked with certain cancers.

It is best to eat fried foods, pastries, candy, and salad dressings only in tiny amounts and as occasional treats. Eat low-fat or non-fat dairy products. Trim the visible fat from meats and limit butter and oils.

When choosing fats, try to include more healthy unsaturated fats, which support heart and brain health. These can be found in foods like avocados, olive oil, nuts, seeds, and fatty fish. Replacing saturated and trans fats with these options can make your diet healthier overall.

General Dietary Recommendations

Research has shown that the healthiest food plan is LOW in fats, salt, and refined sugars, with LIMITED amounts of red meat, and full-fat dairy products, and HIGH in whole grains, fruits, and vegetables.

Eat a variety of foods from the basic food groups as the foundation of your food plan. This ensures that over time you will get all the needed nutrients in good balance. Use “extra” foods such as sweets in lesser amounts only to enhance - but never to replace - nutritious meals.

Adjust the amount of food you eat to maintain your ideal weight. If you want to lose weight, cut back on the “extras” you eat and limit yourself to the recommended number of servings from each food group.

Problems Related to Digestion and Nutrition

Overweight

Just as a car gets its energy from gasoline, your body gets its energy from the food you eat. The more active you are, the more food energy you use. If you take in more food than you can use, the extra is stored as fat, and you gain weight. If you are less active now, you need to take in less food or you may become overweight.

Being overweight after an SCI can pose some special problems. Extra weight will put more pressure on your pressure points. It will make it harder for you to transfer, or for others to assist you. It will further impair your slowed circulation. It will be very difficult for you to lose the weight once you gain it, since your activity is limited by your injury.

You may lose weight right after your injury, because your appetite may be poor, and the muscles that are not being used tend to get smaller. But when you get home, your appetite may improve as you fall into your old eating patterns. If you find your appetite calls for more food than you now need, it is best to start on a reasonable, moderate eating plan that will keep you as close to your ideal weight as possible.

Start by substituting low-calorie foods for some of the high-calorie foods you were eating before. If you are unfamiliar with the calorie content of foods, get a “calorie counter” app or speak to a nutritionist to find out the contents of the foods you eat most often. Limit or eliminate fried foods, rich sauces and gravies, extra desserts and snacks. Stick with your basic food groups and use fruits or vegetables for snacks. Use non-fat dairy products and diet soft drinks or herb tea instead of drinks high in sugar. Weigh yourself once a week or so and if you notice you are gaining weight, do something about it immediately. Do not wait until you are 10 or 15 pounds overweight to cut back. By then, it will be much harder to lose it.

Underweight

Being underweight can also be a problem because your body's muscle provides a natural "cushion" to protect your pressure points. Therefore, if you are underweight, you may be at higher risk for pressure injuries.

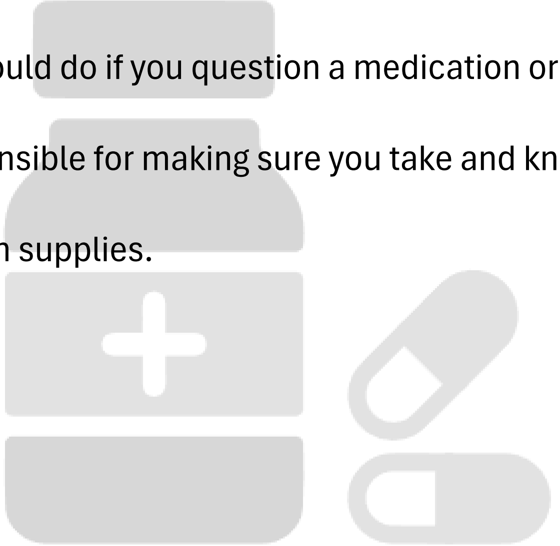
If your appetite is poor, and you are not eating enough nutritious food, you can lose energy, become depressed, and be more prone to disease. Make a point of eating high quality foods such as lean meat, poultry and fish, whole grains, fresh fruits, and vegetables. Avoid junk food such as chips, candy and soda, which will satisfy your appetite without nourishing you. Substitute snacks rich in nutrition and calories such as custard, milk shakes, dried fruits, and nuts. Eat several times a day to increase your total calories. Talk to your doctor about any prolonged loss of appetite. This may be a sign of an underlying physical or emotional problem.

For more information about nutrition, use this QR Code:

CHAPTER 7:
Medications and Supplies

In this chapter you will learn:

- What you should know about your medications.
- What you should do if you question a medication order.
- Who is responsible for making sure you take and know your medications.
- How to obtain supplies.



Medications

After SCI, you may be given medications to prevent complications or to treat infections or other abnormal conditions. Medications can help you stay healthy and comfortable, but they also can cause discomfort and damage if they are misused. You should always check with your doctors, in making any decision about your medication. You have the right to question whether medication is needed or not, and to get another doctor's opinion if you are not sure. But for your own safety, never start, change, or stop taking any medication without a doctor's advice.

In the hospital, the nurses will give you your medication. But while you are here, you need to learn what medications you are taking and become an expert on them, so that when you go home you will know when and how much to take. This is a responsibility you should take seriously because this can make the difference between health and serious illness for you. Use the medication summary page (Appendix 3) to keep track of your medications and why you use them.

Before you leave the hospital, your prescriptions will be sent to the pharmacy of your choosing. You should always consider YOURSELF responsible for taking your medication and for looking out for any side effects, even if someone else helps you take them. This is because it is YOUR body and YOUR health at stake. Be sure to let your doctor at home know what medications you are taking and report any problems or side effects right away.

Rules For Safe Drug Use

1. Never start, stop, or change a medication without talking to a doctor.
2. Take your medications at the right time and correct the dose.
3. Learn the side effects of your medications so you know what to look out for.
4. Know if your medications interact with each other, alcohol, or can impact any other activities you enjoy.
5. Never hesitate to ask your doctor a question about medications.

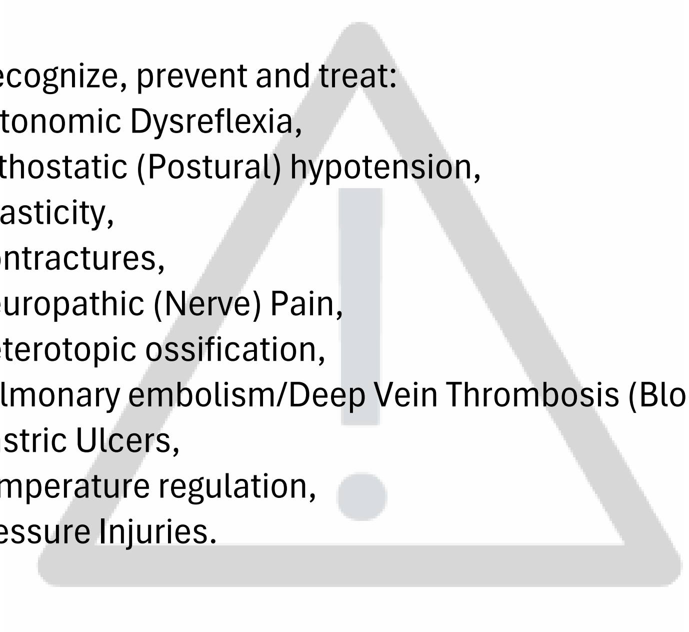
Supplies

If you have changes in bowel and bladder function after your SCI, you may need special equipment to manage your care. You will be sent home with a short supply of bowel and bladder supplies. You will be referred to a supplier in the community before you leave the hospital (note: the hospital is not your supplier). You will be given the name and telephone number of the supply company. If you have not received any supplies on the morning of the third day after you return home, you should call the supplier who received your referral.

CHAPTER 8:
Complications

In this chapter you will learn:

- How to recognize, prevent and treat:
    - Autonomic Dysreflexia,
    - Orthostatic (Postural) hypotension,
    - Spasticity,
    - Contractures,
    - Neuropathic (Nerve) Pain,
    - Heterotopic ossification,
    - Pulmonary embolism/Deep Vein Thrombosis (Blood clots),
    - Gastric Ulcers,
    - Temperature regulation,
    - Pressure Injuries.



Complications

In this situation, a “complication” is any medical problem or disease resulting from having had a spinal cord injury (SCI). The “normal” or “usual” changes seen in your bowel, bladder, circulation, and nervous system after a SCI have already been discussed and are not considered complications.

This chapter discusses how to recognize, prevent and treat some conditions, which may become a problem for you. By learning about these complications now, you will understand more of the reasons behind your care. You will be able to avoid many serious problems by using these simple but important preventive measures.

Autonomic Dysreflexia

Autonomic dysreflexia (AD) is an abnormal reaction of your nervous and circulatory systems to some irritation below the level of your injury. It commonly occurs in some people whose injury is at or above T6. It may be mild or severe, frequent, or rare, but it is considered a medical emergency because it can cause a stroke and even death if not controlled. Therefore, you should be aware of the possibility of dysreflexia and know the signs, causes, and treatments so that you can take immediate measures to eliminate it.

What Happens Inside Your Body During AD

An irritation below the level of injury sends nerve impulses up the spinal cord saying something is wrong. Typically, you would feel this and be able to fix the problem. However, in SCI your ability to detect the problem, and your body's ability to calm down after being irritated are impacted. This sets off a reflex reaction in the blood vessels below the injury. The blood vessels contract, increasing the blood pressure throughout the body. It is defined as an increase in 20 mmHg of the top number of your blood pressure. It is therefore important to know what your typical blood pressure is.

The brain attempts to reverse the rise in pressure by sending messages to the heart to slow down, and to the blood vessels to relax. But these messages can only reach the blood vessels ABOVE the level of your injury. The heartbeat may slow down, but the blood vessels below the injury remain contracted. Your blood pressure may continue to rise to dangerous levels. High blood pressure in the brain can cause a seizure or a stroke if not relieved.

<u>You should memorize the signs and symptoms of AD. You will also have a handout (Appendix 4) with the information in case you ever forget.</u>

Above the level of injury	Below the level of injury
Hypertension (A fast increase in blood pressure, 20-40 mm Hg systolic higher than usual)	Nausea
Bradycardia (slow heart rate) or Tachycardia (fast heart rate)	Chills (without fever)
Pounding headache	Clammy
Apprehension/anxiety/ uneasy feeling	Cool
Changes in vision	Pale
Nasal congestion	
Sweating/Flushed skin/Goosebumps	
Tingling sensation	

What To Do:

Take immediate steps to lower your blood pressure:

1. Sit up—Sit up or raise your head 90 degrees. Stay sitting or upright until blood pressure is normal.
2. Take off—Take off or loosen anything tight or restrictive.
3. Check blood pressure—Monitor your blood pressure every 5 minutes if it is greater than 20 mm Hg over your baseline. Be sure to use an appropriate size cuff.

Remove the cause:

1. Check bladder— Empty your bladder (i.e., catheterize your bladder). If you have an indwelling catheter, check for kinks and blockages.
2. Check the bowel— Disimpact bowel after inserting anesthetic jelly or ointment.
3. Check skin— Examine skin for new wounds, pressure injuries, burns, cuts, insect bites, etc.
4. Find other source— Assess for any other source of harmful/painful stimuli or irritant if symptoms have not resolved.

While checking for causes you should check your blood pressure. If the top number is >150 or the bottom number is >100, you should use your "as needed" blood pressure medication. Your team will review when and how to use this medication. If you cannot find a cause, please go to the nearest emergency room so they can help to treat the problem. Be sure to tell them you have AD. You can give them the wallet card you have to review. This is important because they may think your blood pressure looks fine, but they do not realize that this is a big increase from your baseline.

Please fill out your AD Wallet Card and carry it with you. This is for you to show others in case you have AD and need assistance. You can also carry the pamphlet (Appendix 4) if you would like.

For more information on autonomic dysreflexia use these QR Codes:

Orthostatic (Postural) Hypotension

Your blood pressure is often lower after SCI because your blood vessels cannot constrict to help keep it at a higher level. When you sit up with your legs down, or when you stand up, your blood pressure may drop even lower. This happens because blood tends to collect (pool) in the veins in your legs and feet instead of being pushed back to the heart. Lower blood pressure can decrease the amount of blood to your brain. This makes you feel lightheaded or dizzy when you change positions. This problem usually improves with time.

For mild or occasional dizziness, it may help to raise or lower your head very slowly, giving the blood time to make the shift gradually. Do not change positions quickly. Wear your compression stockings and abdominal binder (if prescribed) as they help blood get back to your heart and help prevent blood from collecting in your legs. Compression garments should be washed often by hand in warm water with mild soap. Roll in a towel to absorb extra moisture. Dry on a flat surface at room temperature. Do not wash or dry stockings by machine. Harsh detergents, bleach, cleaning fluid, scrubbing, wringing, and ironing are harmful to the elastic and will shorten their life. These need to be replaced every few months as the elasticity fades.

Be sure to drink enough fluids; this will keep your blood volume up and may help prevent hypotension.

If you continue to feel dizzy or lightheaded, despite following all these suggestions, tell your physician or nurse. You may need to be put on medications to increase your blood pressure for a while.

Spasticity

Sometimes, even though your arms and/or legs are paralyzed, the muscles contract in what is called a “spasm.” You do not control these contractions or movements because they are involuntary movements. You can also experience spasticity, a velocity dependent increase in tightness—if you move it faster, your body resists it more. This happens because the spinal cord below the injury is still working up to the point of injury. Because a message cannot pass the injured part of the spinal cord, the message cannot get to the brain. Since the brain does not get the message, it cannot control the force with which the muscles react to a stimulus. So, in a person with a SCI, unintentional and often repetitive movements occur. This is a result of some form of stimulation. Because the person cannot feel as before, they often do not know what is causing the spasm.

These spinal cord reflexes are sometimes confusing to paralyzed people and their families. They are often mistaken for a return of function to the limbs. If you have any questions about spasticity, how they can be controlled, or why they happen, ask your doctor for a full explanation. Spasticity is neither good nor bad, it just is. They help keep your muscles in better shape and improve your blood circulation. Some people use them to perform certain tasks. If spasms are severe, they can be painful and bothersome. There are some medications and other measures that can be taken to reduce them.

An increase in the severity of frequency of spasms may be a warning that there is something wrong. Constipation, urinary infection or stones, burns, and pressure injuries are some of the more common causes of an increase in the severity of muscle spasms. Contact your doctor or clinic nurse if you notice a marked increase in your spasms.

Contractures

A contracture is the result of tightening of the tissues, muscle, or joint capsule around a certain joint. This tightness limits the joint’s movement and decreases the joint’s functional ability. There are a few or no benefits of contractures. Sometimes, a person with SCI may benefit from tightness of the hand joints. A person with limited hand function may improve their grip strength with this tightness; however, contractures do not normally prove to be useful. Contractures can interfere with hygiene, transfers, positioning both in bed and your wheelchair, and daily activities, and therefore may lead to skin problems.

Prevention and Management

Perform daily range of motion exercises to all joints on a routine basis. If a person has severe spasticity, range of motion exercises may have to be performed more often (2-3 times each day), and the spasticity management may need to be re-evaluated. Always assume proper positioning in your bed and wheelchair. Use your casts, splints, or braces as prescribed.

For more information about spasticity, use this QR Code:

Pain

Each person who suffers a SCI will usually experience some type of pain. At the time of the initial injury, the pain comes from damage to bones, muscles, skin, and tissues (sometimes related to the surgery). As the body begins to repair itself, most of this pain goes away. Factors affecting pain include anxiety, stress, mental attitude, overall health, sleep, and cultural/social factors.

There are many types of pain. The way that it presents impacts how it is treated. Our goal is to get your pain to a place that is tolerable enough to do therapy and live your life.

Neuropathic Pain

Neuropathic or nerve pain is a pain that happens when nerves or your central nervous system is damaged. This may be new to you. It often feels like burning, electricity, or painful tingling at or below your level of injury. Some people even feel a band of tightness at the level of injury. All of these are ways this type of pain presents. If this occurs, let your team know so they can discuss treatment options with you.

For more information about pain, use this QR Code:

Pain Management

Healthy Living:

Eat a well-balanced diet. Keep a regular bowel and bladder program, you may notice that if something is wrong with these your pain will worsen. Perform stretching and strengthening activities. Evaluate wheelchair posture on a regular basis. See your doctor for regular checkups. Keep a positive outlook. Talk about feelings to family, friends, or counselors. Keep mentally and physically fit.

Coping Strategies:

Learn to develop coping strategies from a support group, counselor, or psychologist. Learn relaxation techniques. Try distraction techniques such as music, imagination, massage, or group activities.

Medications:

There are different types of medications that can help to reduce different types of pain. There are oral and topical (creams and patches) medications, prescription and over the counter (OTC) options. Regardless, talk to your medical team to help find the best option(s) for you.

Heterotopic Ossification

Heterotopic ossification (HO) is the development of abnormal bone in soft (non-skeletal) tissue below the level of the SCI. HO occurs mostly in the region of the hip, knee, shoulder, and elbow joints. The cause of HO is unknown. It does not occur in all people with SCI. Once the process of HO has begun, there is little that can be done medically to prevent or stop it.

<u>Signs & Symptoms</u>
You may have limited range of motion, redness, warmth, localized swelling, and/or limited ability to do daily activities. This may happen because HO interferes with joint mobility. This physical change may also lead to an increase in spasms or fever. In some cases, symptoms occur rapidly.

<u>Diagnosis</u>
If signs of HO occur, a blood test will be done to check for chemical changes in your body. The affected joint will be x-rayed to reveal abnormal bone tissue. A bone scan may also be done.

<u>Treatment</u>
Range of motion exercises and ice may be used to reduce stiffness and pain. Your physician may order medication. In some cases, surgery may be needed to release the hardened joints.

Deep Vein Thrombosis/Pulmonary Embolism

When you are not moving around, your blood flows more slowly and may pool in the lower part of your body, a condition called venous stasis. This can cause swelling in your legs. You can wear compression stockings and regularly elevate your legs to reduce the swelling and complications from it. In the first 8-12 weeks after your injury the stasis increases your risk for developing deep vein thrombosis (DVT). A DVT is the formation of a clot (thrombus) on the inside of a vein. This problem is most likely to occur immediately after your injury. However, it is possible for clots to form at any time. This condition can impair the circulation in your leg and foot and lead to other more serious problems.

<u>Signs of DVT</u>
1. One leg is red or more swollen than the other.
2. If you have sensation, you may feel pain and tightness in the leg.

<u>Treatment</u>
1. Get in bed and stay there. Do not get up until the doctor says it is safe.
2. Inform your doctor of your symptoms immediately. The doctor may prescribe medications or other specific measures to take.
3. Avoid moving your leg around or putting pressure on it. Do not massage or rub your leg.

Prevention

1. You will typically be on a blood thinner for the first 8-12 weeks after your injury. The exact duration will vary depending on your condition and circumstances.
2. Wear your elastic stockings if ordered and keep them on for the recommended time.
3. Do your weight shifts as recommended and avoid long periods of sitting without breaks. Put your feet up periodically to allow better blood flow in your legs.

In addition to impairing circulation in the leg, a DVT can lead to pulmonary embolism. This is a rare but life-threatening complication in which a blood clot breaks loose and gets into the bloodstream. The clot travels to the lungs and blocks the flow of blood into the lungs. You should be aware of this possibility because prompt treatment may save your life. If you notice the signs below, even if you are unaware of having a clot, call an ambulance or go immediately to the nearest emergency room for treatment.

Signs/Symptoms of a Pulmonary Embolism

1. Chest pain
2. Shortness of breath
3. Rapid pulse
4. Feeling of anxiety/doom
5. Reduced oxygen saturation

For more information about blood clots, use this QR Code:

Gastric Ulcers

Sustaining SCI and staying in the hospital for a long period may cause physical and emotional stress, which can lead to the development of a gastric ulcer. You should be aware of the early warning signs of a gastric ulcer, pain, and indigestion. It is important to prevent stomach irritation and to watch for any signs of bleeding from the digestive tract. You will be on a preventative medication for 4 weeks after your injury. Beyond that time, the risk is low, and they are no longer needed (unless you have another medical condition that requires one).

Temperature Regulation

People with SCI, particularly higher-level injury (above T8) may have difficulty keeping warm when the temperature drops, and their body temperature may go up because of warm temperatures or direct exposure to sun. In addition to increasing body temperature, you may feel dizzy, headachy, faint, or nauseated. To prevent overheating, use fans or air conditioning, stay in a cool place or in the shade, sponge with cool water and drink more fluids, and spray any exposed skin (head, neck, and arms) with cool water from a spray bottle. If you do get overheated, and your temperature does not come down to 100^{oF} with the above tactics, call your doctor.

Pressure Injuries

A pressure injury (often called bed sores) is a damaged area of skin, which results from sitting or lying too long in one position. How long is "too long" depends on many factors. A sore can develop in a matter of hours in some cases. This is why it is so important for you to shift your weight frequently and inspect your skin daily for problems. A pressure injury is much easier to prevent than to cure.

<u>How it happens</u>

Sores can start on the surface, from an abrasion caused by rubbing or any other break in the skin. Or they may start under the surface, if pressure keeps fresh blood from getting to the skin. Before long, the skin starts dying from lack of oxygen and buildup of waste products.

The injury usually appears as a reddened, bruised, warm, or hard area. If you press on the area and it becomes white and then turns red again, we say that it "blanches" which means there is still a good blood supply to the area. If the area is soft and does not blanch, this means the small blood vessels in the area are breaking down and fluid is leaking out. The skin affected is starting to die.

If you continue to put pressure on a sore like this, a blister will soon form under the surface, as fluid builds up between the surface layer of skin and the damaged layer below. When this breaks open, there is an open wound involving one or more layers of skin and underlying tissue. Infection may easily develop if this wound is not treated. Continued pressure causes deeper and deeper layers of skin and flesh to break down, until the wound reaches the bone. At this point, osteomyelitis (infection in the bone) is a danger, and permanent bone damage can result. Even more dangerously, an infection can get into your blood stream and affect your whole body. This can kill you if it is not treated.

For more information about pressure injuries use this QR Code:

Edema

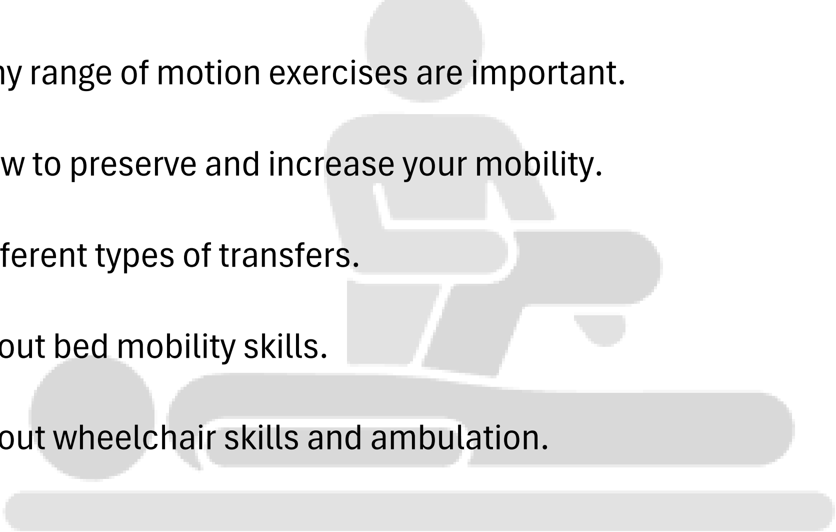
Depending on your level of injury, your legs and perhaps your hands may swell. Swelling occurs when fluid leaves your blood vessels and goes into the spaces between tissue cells. This swelling is called "dependent edema." "Dependent" refers to any area that is below the level of your heart and "edema" refers to swelling. This edema is caused by the loss of the use of the muscles in your legs or hands because muscle action and movement help return blood to your heart.

To prevent your legs from swelling, you can wear your compression stockings routinely and do daily range of motion exercises. If swelling does occur, elevate your legs to or above the level of your heart for 10-15 minutes, 4-5 times a day. Do more range of motion exercises and do them routinely or get someone else to do them for you.

If swelling continues in your legs for more than one week, despite your efforts to treat it, if you notice a sudden increase in swelling, or if swelling is only in <u>one</u> of your legs, notify your physician.

CHAPTER 9:
Physical Therapy

In this chapter you will learn:



- The purposes of Physical Therapy.
- Why range of motion exercises are important.
- How to preserve and increase your mobility.
- Different types of transfers.
- About bed mobility skills.
- About wheelchair skills and ambulation.

Welcome To Physical Therapy

The overall goal of rehabilitation is to help you become as independent as possible. In Physical Therapy, we will help you:

1. Increase your strength, flexibility, and endurance.
2. Learn to use your wheelchair and other equipment.
3. Learn to move around in and get out of bed.
4. Learn to transfer to and from your wheelchair onto various surfaces.
5. Ambulate if it is feasible.
6. Instruct you or your caregivers in safely performing/assisting you with all the above.

As you know, your ability to move has been impaired because of your spinal cord injury (SCI). Just how much you will be able to move depends mostly on the nature of your injury, the level, the severity ("completeness"), and whether your injury was upper motor neuron (robust reflexes) or lower motor neuron (reduced reflexes). Physical Therapy cannot restore lost movement, but it will help you make the most of what you have and teach you compensatory movements. It will also help you keep your body flexible so that if and when movement does return, you will be able to take advantage of it.

Our general approach is to set goals based on your CURRENT level of ability, always keeping open to new developments. This keeps our work with you realistic as well as optimistic. As you progress in therapy, we may set new goals to keep you challenged but not overwhelmed.

Your effort is a key factor in how useful and effective your therapy will be. Try to keep a cheerful outlook and celebrate the little steps along the way. As in other areas of life, you will get satisfaction knowing you have tried your hardest and done your best. Keep your aim set on INDEPENDENCE. Remember, this is a process and an opportunity to improve.

Keep in mind, too, that you and your therapist are human beings. You both have good days and less than good days. Sometimes you feel discouraged, or it may seem like no one appreciates all the work you are doing. BUT WE DO. Talk about any problems you have; let us know what you need. With your full participation, we can work together to overcome the obstacles and achieve our goals.

Range Of Motion

Range of motion (ROM) refers to the movement of joints and the flexibility of the connective tissues surrounding the joints. Normally, each joint has a certain range through which it can be moved. If a joint is not moved every day, the range tends to get shorter. Eventually, a contracture may form, the tendons, ligaments, and capsule surrounding the joint become tight and stiff and bony deposits may form within the joint itself. This can be hard to correct once it occurs.

The best way to avoid contractures is to take every joint through its complete range regularly. This keeps the tissues stretched out and flexible. ROM exercises also help reduce spasms for many people.

You will be taught how to position your limbs to help keep your joints flexible. You will be encouraged to lie prone (on your stomach) to stretch out the joints in your hips and knees, which are flexed all day while you are sitting. Other measures which may be used are the tilt table or standing frame. These devices provide valuable weight-bearing activity, and they are good for your joints.

ROM exercises will be done for you during the early part of your rehabilitation until you can learn self-ranging techniques. They may need to be done for you consistently if your arms are not strong enough or when spasticity or other medical problems limit your ability to do exercises by yourself.

Your therapists will teach you self-ROM exercises or your caregivers how to perform ROM exercises safely. A written ROM program for you will be provided.

Strength And Mobility Activities

Due to your injury and subsequent inactivity during hospitalization, your muscles have lost a lot of their strength. With this loss and weakness, your functioning muscles will have to take on extra work to compensate. Because of these factors, strengthening will be an area of major emphasis.

Strengthening will be achieved through manual resisted exercises and exercise equipment. Additional strengthening will occur when you begin instruction and practice in functional activities. You may need to learn special ways to turn, sit up, lie down, and balance yourself. We will work on new movement patterns and balance techniques to help you become as mobile and independent as possible.

As you strengthen your muscles you will improve your stamina and endurance. Individual activities will also be designed for you to work, specifically in this area. Some of these activities will include wheelchair propulsion for speed and/or distance and multiple repetitions of exercises.

Balance

Balance is a prerequisite for performing all activities safely, smoothly, and independently. Weakness and lack of trunk and leg musculature will interfere. You and your body will need to learn new techniques for control. It will be important to strengthen your remaining muscles. Initially, you will want to use your arms to support yourself in sitting to allow you to experiment with finding your balance point, but you will need to free up your arms for functional activities as soon as possible.

Transfers

There are many ways to transfer. How you transfer from one place to another depends on many factors, including your size, flexibility, strength, motivation and level of injury. You will learn to transfer yourself or to instruct an assistant to help you transfer from your wheelchair to the bed, car, tub, or shower, and back again. You may also work on wheelchair to floor transfers, also called "fall recovery."

As you develop your strength and mobility, you will practice various methods and on different surfaces until you feel comfortable with the transfers that suit your needs. If you need assistance, you will be trained to describe each step so that you can instruct a helper quickly and effectively when necessary.

Sometimes equipment may be needed for a safe transfer. Some people who find it hard to transfer by themselves can do so with the help of a transfer board, which provides a smooth, even surface to bridge the gap between their wheelchair and the object they are transferring to. Some people with very high injuries, or who are too tall or large to manage safely, may require a hydraulic pump lift (e.g. Hoyer or Transaid lifts). Equipment will be provided when it is necessary, but we encourage you to use as little equipment as possible. This keeps your life simpler and reduces your costs, but even more important, it keeps you as strong and independent as you can be.

Bed Mobility

Bed mobility includes being able to roll, scoot, come to sit, and move your legs on and off the bed. Any loss of strength in your trunk and/or lower extremity muscles will require more effort from your upper body. Coordinating the movements of your head, neck, and shoulders to create momentum and shift your body weight will be necessary. Practicing these activities on the mat will involve trial and error and experimentation to find the movements that work best for you. You will be working on various preliminary exercises to improve your strength, ROM, and balance to help you achieve these bed mobility skills.

Will I need a new bed at home?

There are three issues to consider when deciding whether to keep the bed you have at home or choose another:

1) Size: Is there room to position your wheelchair, or is the bed too large for the room? Positioning the bed against a wall may provide better wheelchair access.

2) Skin tolerance: A medium to firm mattress is recommended for proper orthopedic and postural support. An egg crate or special type of mattress given to you during your hospitalization may be required on top of that if you are prone to skin breakdown or may be desired for greater comfort. Frequently, a sheepskin is all that is needed. A waterbed will NOT prevent all skin problems. Proper positioning, turning and skin checks will still be necessary.

3) Mobility & independence: Soft or mushy bed surfaces (including waterbeds & Tempur-pedic) are more difficult to balance on, scoot across, and move your legs on. Height of the bed may affect our ability to transfer. Often, your own bed can be built up or lowered to the height of your wheelchair with minimal expense or effort. Size of the bed may interfere with rolling. A twin or hospital bed may be too narrow for you to turn from side to side. However, a wide bed may be more difficult for those assisting you with dressing, personal hygiene, or bladder and bowel care.

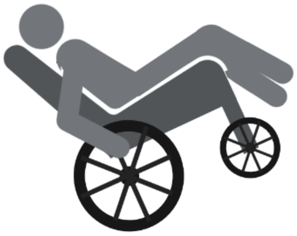
A hospital bed can be considered when you need assistance in positioning, bed mobility, dressing, and personal care. A fully electric bed is recommended because you can assist yourself more effectively if the bed raises and lowers to allow for transfers, or if raising the head of the bed will allow you to come to sitting for transfers or dressing with less help. Hospital beds are not recommended unless necessary.

Wheelchairs

There are many kinds of wheelchairs and many optional features available. When you come to UCDRH you will use one of the hospital wheelchairs until we can decide exactly the best type of wheelchair for you.

If you use a manual chair, the wheelchair skills you will learn in Physical Therapy will include manipulating the brakes, armrests, foot plates and other movable parts, pushing on flat surfaces and then on increasing levels of graded surfaces, turns, and stops. You will also learn to mount and descend curbs, to balance on your rear wheels ("wheelies"), to do weight shifts, and to transfer from the chair to a mat, a car, or the floor and get back again.

If you use a power wheelchair, you will learn how to use your special controls, how to maneuver curbs and other obstacles, how to perform weight shifts, and how to transfer in and out of the chair. If you require assistance in any aspect of wheelchair use or transfers, you will also be trained to instruct your assistants in how to perform these tasks safely.



Every type of wheelchair is different, but some parts are basic to all chairs. These will be described here so that you can become familiar with the parts and how they are maintained.

Upholstery: This is the leathery, vinyl, or cloth covering on the seat, back and armrests of the chair. Upholstery will stretch evenly with daily use but should be replaced if worn or stretched.

- Maintenance: It should be kept clean and dry. First, sponge or dust off the frame. Then use leather or vinyl cleaner to prolong the life of those materials. Water will damage the upholstery. Do not use corrosive detergents.

Brakes: An important safety feature because they keep the wheels from turning when you transfer or park on an incline. They will need to be adjusted at intervals.

- Maintenance: Water will rust the bolts and hinges.

Frame: The metal parts, which support the chair, are called the frame. This also needs to be kept clean and dry. Moving parts will need to be lubricated on a regular schedule. There are two types of frames, folding and rigid.

- Folding Wheelchair
    - Pros: More affordable and portable. Versatile for short term use and transportation if you do not have a wheelchair accessible van.
    - Cons: Heavier. Less energy efficient for self-propulsion. Fewer advanced seating or postural support options.
- Rigid Frame Wheelchair
    - Pros: lightweight and durable and designed for active users. Offers better energy efficiency for self-propulsion. It can be broken down to be put in a car independently.
    - Cons: Chair breaks down but does not fold. Not ideal for users with fluctuating mobility needs.
- Maintenance: When cleaning your chair, first sponge or dust off the frame.

Wheels: There are many components of this part of the chair, and the parts you choose impact the amount of maintenance required as well as durability .

- Tires can be pneumatic (filled with air) or solid.
    - Solid: low maintenance but a little heavier. They only need to be replaced when worn.
    - Pneumatic: lighter and able to handle different terrains. However, you will need to keep them inflated to the proper pressure.
        - It is recommended to have a tire patch kit and know how to change a flat tire.
        - It can be helpful to get to know a local bicycle repair person because they can help in a pinch.
        - Black rubber tires are less expensive, but they leave black marks on the floor, unlike gray rubber tires.
- The bearings are little balls in the wheel mechanism where the frame joins the wheel.
    - They need to be lubricated and replaced when worn.
- The wheels can have spokes (like you think of with a bike) or “mag wheels.”
    - The spokes maintain the wheels in circular alignment and need to be adjusted with a spoke tightening wrench, available at bicycle shops or through your wheelchair vendor.
        - Get someone experienced to show you how to do this before attempting it yourself.
    - You might consider mag wheels as an alternative to spoke wheels. Mag wheels require less maintenance but are heavier.
- The casters are the small front wheels.
- Maintenance: Keep wheel and caster axles free of hair, string, or lint. Frequent cleaning will prolong the life of your chair.

Footrests: Footrests support and protect your feet and should be replaced if broken. A drop of machine oil will keep the joints moving freely.

- Make sure the wheelchair footrests are adjusted to the right height for you.
    - If in doubt, too low is better than too high to reduce risk of skin breakdown.

Battery: An electric wheelchair uses a battery for power, so it needs to be regularly charged. It should be hooked up to the battery charger as soon as you get into bed at night, so you never have to wake up to a dead battery and a useless wheelchair.

- Maintenance: Monitor the battery pack for water level, corrosion at the poles, and ability to hold a charge. You will need to recharge the battery routinely. Check for proper contact at connecting wires.

Wheelchair Cushions

A good wheelchair cushion is essential for providing pressure relief. It helps distribute your body weight evenly over the wheelchair seat. There are many types of cushions available. Your therapist will work with you to decide which is best for you. The decision should be based on factors such as the amount of pressure relief the cushion gives you, how the cushion feels to you, your balance and sitting posture, how you do transfers, your ability to perform independent weight shifts, climate where you live, cost, durability, weight of the cushion, continence, your skin condition, and personal preference.

In general, cushions are made from four materials: Foam, air, gel, water, or a combination of these materials. Life expectancy varies by type of cushion and the use and care it receives.

- Foam cushions: suitable for individuals with low risk of skin breakdown, have some sensation, or a budget friendly option for short term use.
    - Pros: Affordable, lightweight, easy to transport and handle. Foam cushions come in a variety of densities and designs. They require minimal upkeep compared to air cushions.
    - Cons: May not provide adequate pressure redistribution for those at high risk for pressure injury. Foam can compress and lose shape over time, reducing its effectiveness. Foam tends to trap heat which can lead to skin irritation or discomfort.
- Gel cushions: Are best for those needing stability and moderate pressure relief especially those prone to overheating. The evenly distributed pressure minimizes the risk of pressure injury. It provides good stability for individuals who might have difficulty balancing their bodies during a transfer.
    - Pros: durability & easy maintenance.
    - Cons: Heavy, in cold conditions gel may become harder and less comfortable, and needs manual gel redistribution each time before you transfer.
- Air cushions – ideal for users at high risk of pressure injury.
    - Pros: provides the best pressure relief reducing risk of skin breakdown
    - Cons: Air cushions can feel less stable for those with impaired sitting balance, require daily adjustment of air levels to maintain effectiveness, and are susceptible to punctures or leaks. High cost.
- Honeycomb cushions- A great option for those seeking breathability, durability, and moderate pressure relief. Currently it is not reimbursed by insurance.
    - Pros: Breathability, durability, lightweight, excellent shock absorption, and last longer than foam cushions.
    - Cons: Does not distribute weight as well as gel or air cushion. May feel firmer than gel or air and those that need softer support may feel it is uncomfortable. It is more expensive than foam but is less expensive than gel or air cushions.

To ensure good skin condition, you should also do the following:

1. Cushions should be replaced as soon as they begin to wear out.
2. Use only manufacturer recommended covers for the cushion. Follow manufacturer's instructions for laundering the cushion cover.
3. Never use rubber air rings or doughnuts as cushions. They block the flow of blood to the skin inside the ring, acting as a tourniquet.
4. Sit up straight in your chair. Slumping may cause pressure over the end of your tailbone.
5. Perform weight shifts every 30 minutes and hold the position for 1 minute to avoid skin breakdown.
6. Lift your hips when transferring. Do not drag or slide your as this may cause skin damage.

General Wheelchair Maintenance

Since your wheelchair may well be your main (if not your only) method of mobility, it seems obvious that maintenance is critical. Once you have your own chair, study the Owner's Manual carefully and learn how to maintain and repair your chair. Even if you cannot do the repairs yourself, you should be the one to keep track of routine maintenance and you should know how to trouble-shoot the most common problems. That way, you will not be stuck at home if your chair breaks down. Most insurances will replace the wheelchair every five years. Therefore, you need to keep up with maintenance in between. You should be able to get repairs addressed with an order from your doctor to go to the vendor you used.

A major overhaul should be done yearly for light use and every 6-9 months for heavier use. This would include:

- repacking or replacing bearings in all four wheels (unless they are sealed),
- tightening the spokes and "balancing" the rear wheels,
- brake adjustment,
- lubricating frame axis and posts,
- cleaning the frame,
- replacement of worn rubber-ware and upholstery as needed.

It is advisable to keep a wrench, screwdriver, extra spokes, inner tube, brake, bolts, and even upholstery on hand for emergency repairs. Parts can be obtained from a medical or wheelchair supply company. Often, the metalware (bearings, spokes, axles, bolts) as well as tires and inner tubes can be found at a hardware or bicycle shop at a lower price than from a wheelchair dealer.
You or an assistant can do much of the maintenance on a manual wheelchair. A wheelchair repair shop can provide any of the necessary servicing and will often provide a loaner while your chair is in the shop.

On a power chair, the frame, upholstery, footrests, rubber-ware, and brakes are essentially the same as on the manual models.

Anticipate your service needs and make sure the parts needed, financial clearance, medical prescriptions, and paperwork are available to the wheelchair repair shop. Rely on a person specially trained with your particular style of wheelchair, or warranties may not be honored.

For more information on wheelchairs use this QR Code:

Ambulation

One of the first questions on everyone's mind after a SCI is, "Will I be able to walk again?" This is a difficult question to answer, especially if you have an "incomplete" injury. Right after an injury, it is difficult to predict exactly how much function will return to your limbs. People may have varying degrees of return for one or more years after an "incomplete" SCI.

Many people with complete cervical (above C8) and high thoracic (T1 to T8) injuries stand either on a tilt table or in a standing frame as part of their therapy but are not able to walk. With a lower thoracic injury (T8 to T12) you may be able to walk with crutches and long leg braces. An injury in the lumbar area may allow you to walk with crutches and long or short leg braces. However, all this depends on your size, strength, motivation, and the completeness of your injury.

It is important to understand that even if ambulation is possible, it will probably be limited. Time and energy limitations may require that you use your wheelchair most of the time.

Nevertheless, even limited walking can increase your mobility at home, at school, or at work. It will also be good for your bones, your circulation, your skin, your bowels, and your state of mind. Even standing on a tilt table or in a standing frame can help reduce contractures, spasms, and improve circulation and kidney function. This is why we encourage standing and walking activities from the beginning.

Gait Training

Gait training usually begins at parallel bars. If possible, you will then progress to the use of a walker or forearm crutches. There are several different ways of walking; you will be trained according to your abilities and motor control. Your training may include stairs or inclines as well as flat surfaces. Learning how to fall and to regain a standing posture is important too, since sooner or later you are bound to have an opportunity to use these skills!

Equipment

By the time you have completed the rehabilitation program at UCDRH, you may have accumulated various types of equipment or devices to help you be more functional and independent. These may include your wheelchair, sliding board, braces, walker, crutches, or other devices.

It is important that you learn to maintain your equipment in good condition. Keep and study any manuals or instructions included with your equipment. Establish a relationship with the company that provides your equipment before you need parts, repairs or modifications. They are an important link in your support system.

CHAPTER 10:
Occupational Therapy

In this chapter you will learn:

How occupational therapy will help you with your:

- Activities of Daily Living (ADLs)
- Strengthening
- Range of Motion
- Adaptive Equipment
- Durable Medical Equipment
- Architectural Modifications

Introduction To Occupational Therapy

Occupational therapy (OT) is essential in the rehabilitation process for individuals with spinal cord injuries (SCI). It emphasizes the individual to be able to complete activities of daily living (ADLs) such as dressing, grooming and hygiene, self-feeding, phone use and toileting to the best of their ability based on the level of injury. Occupational therapy also includes the individual participating in meaningful activities to enhance their overall quality of life. Our goal is your independence, empowering the person to use their strength and abilities, and improving quality of life in a holistic approach.

Therapy may include the following treatment areas:

Activities of Daily Living Training:
The therapist provides training and equipment as needed to permit you to become more independent. This may include such things as getting from your wheelchair to a bed, toilet, car, and other places. It may also include eating, hygiene, dressing, bathing, cooking, homemaking, communication skills, community reorientation, home equipment assessment, and home accessibility.

Strengthening, Coordination and Range of Motion:
This may include activities or exercises to increase the strength in your arms. You may also be taught how to use substitute muscles for paralyzed muscles. You may be taught to hold and manipulate objects used for daily living skills. The therapist will assist you in maintaining or improving the range of motion in your arms and teach you how to do self-range of motion on your arms, if needed. If appropriate, and as ordered by the physician, hand splints may be fabricated to prevent problems, enhance muscle function, or protect the hand(s).

Adaptive Equipment:
The goal of occupational therapy is to teach the individual how to utilize the strength and abilities the person has while incorporating compensatory techniques to complete their daily tasks. However, depending on several factors such as level of injury, age, and body type, a person may need to use adaptive equipment to be more independent with bathing, dressing, feeding, toileting, and cooking, with greater ease, independence, and safety. You may also be able to find everyday items that are adaptable to you. There are many different types of adaptative equipment.

This section describes assistive devices and techniques that may help you to be more independent. It may also be used to teach others how to assist you. Even though it may be more difficult initially, you will be encouraged to learn to do the tasks with the minimum amount of equipment. There are several reasons for this. It will be less expensive, and you will not have to worry about losing, breaking, or forgetting the equipment. This section does not include all the types of equipment available, nor is it meant to imply you have to do things this way. You are encouraged to talk with therapists and people with similar disabilities. Most importantly, use your knowledge of your own body and your imagination to come up with solutions that are safe and work for you. In recent years, smart homes and 3D printing have expanded what people can achieve on their own.

For images and examples of the equipment described, please use the QR code and check the “Misc Adaptive Equipment” tab on the SCI Clinic Website:

Eating & Drinking

- Universal Cuff: attaches to your hand and then feeding, grooming, and/or hygiene accessories can be held by the device, so you do not have to.

- Food Guard: snaps onto plate to prevent food from sliding off while you are trying to eat. Available in a variety of shapes, sizes, and styles.

- Rimmed Plate: serves the same purpose as a food guard but is built into the plate.

- Non-slip padding (e.g., Dycem) or slightly damp face cloth may be used to keep the plate from sliding on tabletop.

- Recommend water bottles with firm loop and pop top that can fit easily into wheelchair beverage holder.

- Commuter Mugs: Repurposed for our use as they reduce spills and are often insulated.
  - If you have difficulty grasping a cup handle, look for one with a large handle and slide your whole hand into the handle.
  - **NEVER** place a cup with hot liquid between your legs- though insulation can protect you, it is still a risk.

- Long or modulated straws: may be used if you have difficulty picking up a drink. Fleximug is a commonly used brand.

- Adaptive Utensils: for those with reduced hand function there are ways to modify utensils you have, or you can buy modified versions.
  - For Example: Rocking T knife, offset spoon, built up handle.

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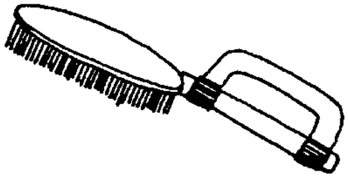
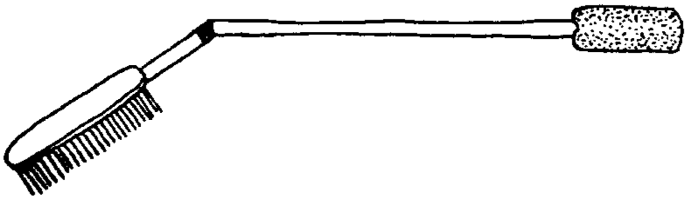
Hygiene

Alterations can be made to the equipment you already have to make it more accessible.

- Straps or padding may be added to the handle of a device to make it easier to grasp.





- Adding suction cups or fastening a device in one place makes it easier to use.
    - Often helpful with scrubbing brushes, nail clippers, or nail files.

Dressing

- Button hook – available in a variety of sizes and shapes. Strap handle can be added if grip is weak.

- Cuff extender – available in fabric stores. Attached to button at cuff so you do not have to unbutton cuff when you dress and undress.
    - An alternative is to sew button on with elastic thread so there is more “give” when the hand goes through the sleeve.

- Dressing stick –useful if you have trouble reaching your feet to put on and remove clothing.

- Long shoehorn – may be used to help put on your shoes if you have trouble reaching your feet.

- If you have difficulty tying your shoes, consider using slip-on type shoes, Velcro, or searching online for adaptive shoes (“Hey Dude” is a common brand)

    - See the “Adaptive Clothing” Tab on the SCI Clinic website.

- Sock aid – may be useful for pulling on socks if you cannot reach your feet.

- Zipper Pull – can add lops to your zippers or get a separate device (dowel with hook) that threads into the zipper for use between several items of clothing.

Bathing

- Wash mitt – often made from terry cloth. It has a Velcro strap at the wrist to hold it in the hand. A loop or D-ring may be added to the strap so a person with limited hand use can tighten the strap. The thumb shape is optional. A pocket with elastic may be added to hold soap.

- The back scrubber may be made from terry cloth and webbing or ribbon for the hand loops.

- A long-handled sponge may be used for bathing when you cannot reach your back or feet. A handle can be added to brush if grasp is limited.

- Grab bars – can be placed by professionals or self-installation.

Tub benches and shower seats are available in many shapes and styles. You will work with the occupational therapist to determine which type is most appropriate for you. You will be able to try different types of bath seats in occupational therapy. Some of these options are custom and some are purchased "off the shelf". Custom items require an assessment with your therapist, Assistive Technology Professional (ATP), and may be covered by your insurance depending on your plan. Custom items typically tend to last longer, however they are more costly, and are not always covered by your insurance. It can take months to get your custom equipment. Non-custom items are readily available for self-purchase, are not covered by insurance, but tend to be more affordable. However, non-custom items may need to be replaced more frequently.

There are multiple versions and brands available to fit your home shower or tub. For custom systems, an ATP vendor will usually measure the space of your tub or shower to determine the proper fitting for ordering. Have a backup plan of alternative bathing options or self-purchase of a temporary non custom bathing seat while awaiting the delivery of your equipment as it may take months to obtain. Consult your occupational therapist to determine what is most appropriate for you and your bathroom environment.

Roll in shower chairs are designed for complete roll in or zero entry showers. Discuss with your occupational therapist to determine which features are most appropriate for your needs and bathroom set up. These options lessen the number of transfers needed for completing toileting and showering needs. This is the ideal setup after a SCI.

Toileting

As above there are custom and non-custom options that the team will discuss with you. Everything selected is based on your level of function.

You and your occupational therapist will determine the type of toilet equipment most suitable to your needs. You will have the opportunity to try this equipment as part of your occupational therapy.

The less equipment you need, the more independent you will be in the community and when traveling.

- Suppository Inserter/Digital Simulator– allow more independence in bowel program if there is reduced finger function or are unable to reach their rectum.

- Inspection Mirror—modulated mirror to check skin for break down and can facilitate self-catheterization.

- Modify a current toilet – A raised toilet seat, grab bars, and/or safety frame may make toileting easier and safer.

- Padded equipment is recommended to prevent skin breakdown.

- Commodes– allow alternate locations for bowel programs when a toilet is not the best option.
    - Removable or flip up arm rests are necessary to allow you to transfer to the surface.
    - Rotating Seat is helpful to allow insertion of a suppository.
    - It can be stationary (often at the bedside) if mobility is limited or if the bathroom is inaccessible.
    - It can be on wheels if it is used for toileting and the shower.

Communication

- Smart Homes— allow for hands free control of the environment around you. Examples include Amazon Alexa & Google home.
    - It can be partnered with smart lightbulbs and other smart technology to allow complete control of your home.

- Smart Phones—similarly allow for hands free control of the device. Your therapist can help you to set up accessibility features.

- Phone/Tablet Mounts—modulated devices can be purchased to mount your device to a bed, wheelchair, or any other surface so that you can easily access and see your device.
    - You can also use rings, hand loops, or neck straps to hold or position your device.

- Universal Cuff or other devices can be used to allow you to hold on to and use a pen or marker.
    - A clipboard may be used to stabilize paper if you cannot hold it with your other arm.

- Writing Aids are devices that attach to pens, pencils, markers, or other utensils that allow you to use them without precise finger function.

Bed Mobility

- Quad Ladder— assists with pulling to sit up in bed when you have impaired core strength but good arm strength.
    - You can use hands or forearms to pull up on the ladder.

Architectural Modifications

Architectural Barriers

Architectural barriers are defined as any architectural feature of a facility, which makes it difficult or impossible for people with disabilities to use. Architectural barriers decrease the opportunities to become socially re-integrated into the community for employment, leisure time activities, and the necessary activities of daily living functions such as entering the home and bathing. The following are some problems and solutions to architectural barriers within the home that affect the physically disabled.

General Considerations:

1. Width of your wheelchair from the widest points—this will help you to determine any adjustments of door frames needed.
    a. Manual wheelchairs are the widest from push rim to push rim.
    b. Power wheelchairs are typically the widest from the outside of the arm rests.
    c. Measure the narrowest part of the doorway. Typically, it is inside the frame.
        i. Include measurements with the door on and if you were to take the door off.
    d. You will need to add ~3 inches on each side to get through the door.
        i. For example, a 16-inch wheelchair needs 6inches (3inches per side) or about 22 inches—your hands are often outside of this width when pushing.
2. Height from the floor to the top of your knees when sitting in the wheelchair—to make sure you can access counters, tables/desks, and thermostats.
3. Width and height of any steps or thresholds to your front door or inside the home to determine what size ramp you may need (details below).
4. Width of the front door or door that you will use to enter your home, all bathroom doors, and bedroom door.

Bathroom Considerations

1. Ensure enough space to allow the equipment you need as well as space for transfers.
2. Wheel-in-shower stalls need at least 4’ x 4’, no lip on entrance and a gentle slope so water can drain off.
3. Faucets located at wheelchair height - 54”.

Bed

1. The bed should be placed so there is enough room on one side for easy transfer into and out of bed.
2. Placing the bed in a corner with one side and the head against the wall will ensure stability while transferring and provide a surface for the patient to lean against while dressing.
3. Measure floor to top of mattress, floor to top of bed frame, and floor to bottom of bed frame.
    a. If the bed is too low to allow independent transfers or for mechanical lift (e.g., Hoyer), blocks can be placed under it to raise the level.
4. Scatter rugs and shag rugs make it difficult for a wheelchair to maneuver. If carpets are needed, they should be short-napped.

Ramps

1. The ramp should be at least 32” wide.
2. A railing is suggested when a pusher is involved, or the patient is ambulating. The railing should be waist high.
3. There should be a level surface at both top and bottom of at least four feet square.
4. There should be an edge along the base to prevent wheeling off if a person is propelling themself.
5. It should have a non-skid surface (i.e., non-skid paint and non-skid surface material).
6. If space is limited, the ramp can be angled in allotted space.

Formula for Ramp Specifications

Maximum slope: For every inch of vertical raise, 6” of ramp length.
Electric wheelchair only, rare that manual chair can navigate.

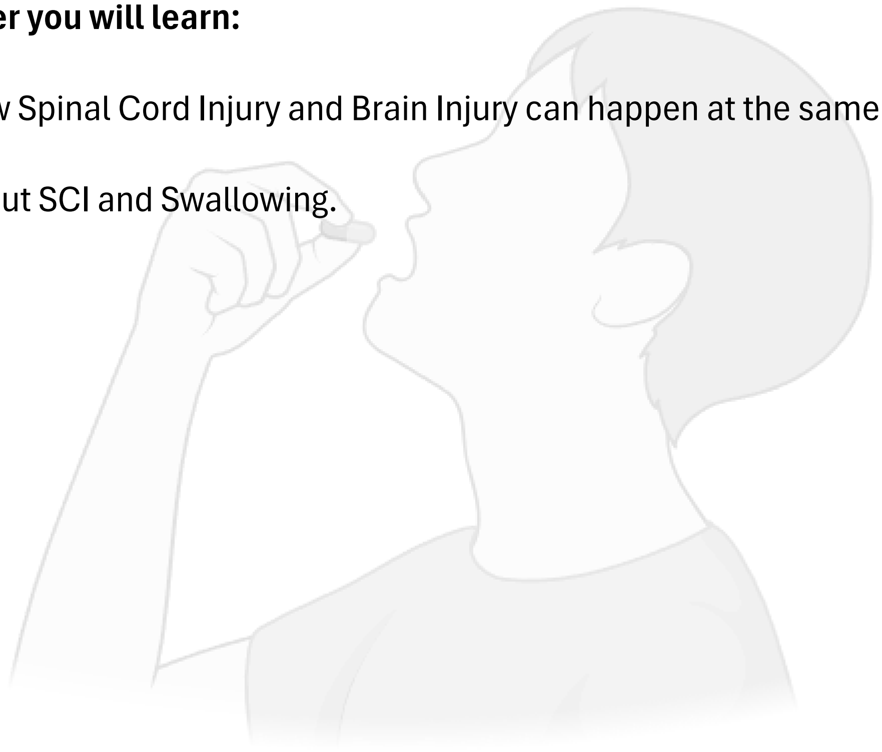
Moderate slope: For every inch of vertical raise, 10” of ramp length.
Strong paraplegic and/or electric wheelchair.

Minimal slope: For every inch of vertical raise, 14” of ramp length.
Paraplegic and/or strong tetraplegic.

CHAPTER 11:
Speech Therapy

In this chapter you will learn:

- How Spinal Cord Injury and Brain Injury can happen at the same time.
- About SCI and Swallowing.



Co-Existing Spinal Cord Injury and Brain Injury

If a person has a spinal cord injury (SCI) from a car accident, fall, or some other accident, they may also have a traumatic brain injury (TBI).

A brain injury can be mild, moderate, or severe. In a mild brain injury, the person may be knocked out for a few minutes but is usually awake on arrival at the hospital. Another name for this mild brain injury is concussion. In a moderate brain injury, the person will be more deeply unconscious and take longer to awaken, but not as long as in a severe brain injury. A severe brain injury usually causes someone to be knocked out immediately, followed by a coma lasting several hours to days.

A person who has had any brain injury will usually be unable to remember the accident or events that occurred for a while after the accident. This memory gap is called post-traumatic amnesia. The memory gap is a sign that the brain was shaken badly enough that it could not operate properly and was not able to record events. During this period, the person may ask what happened to them but cannot remember even after they are told about the accident.

For most people who have both SCI and TBI, the brain injury symptoms will be worse during the first few weeks and months after the injury. If the brain injury is severe enough, they may have lasting symptoms. The major symptoms that occur and suggestions for coping are listed below.

Difficulty Paying Attention:

The person may have a tough time paying attention to one thing if something else is happening to distract them. For example, this can happen if two people are talking at the same time in the room. Another example is trying to talk on the phone while the TV is on. To help them pay attention to what they are doing:

- Limit the extra noise in the room. For example, the person may need only one person to talk at a time or might need the TV turned down during a phone call.
- Help them finish one task before starting another one.

Difficulty Keeping Track of Time and Place:

Sometimes the person may not be able to keep track of time (such as the day of the week, month, and year). They may also have trouble knowing where they are or how to find their way around new or even familiar places. This is called orientation. To help them with orientation:

- Keep a calendar and clock where they may be seen easily. Mark off each day.
- Point out signs and landmarks when going to a new place.

Remembering Recent Experiences:

The person may forget what they are told or neglect to do the things they are supposed to do. Often, they will remember them if they are reminded. For example, they may want to ask their doctor a question but forget to ask it when they see the doctor. Later, something will remind them of the question they forgot to ask. To help them recall information:

- Use an appointment book or similar notebook for writing down appointments, questions for the doctor, and special events. It may also be used as a diary. Go over the entries each day.
- Use a watch with an alarm to remind them to take medication, perform a weight shift, or other such activity.

Word-Finding:

The person may not be able to think of the right word for what they are trying to say. Usually, the word will be a name for something that they know but does not use very often. To help them think of the word:

- Ask them to describe the object or event to you if they can.
- Using what they can tell you, say some words that might include the one that they are trying to remember.

Judgment and Reasoning:

It may be hard for them to make decisions and to understand the possible results of their actions. For example, they may have trouble keeping track of bank accounts and making appropriate decisions about spending money. Help them to:

- Set up a budget for expenses and a notebook for keeping track of those expenses.
- Talk through decisions; talk about what can happen before a decision is made.

Processing Speed:

This is how fast a person can think and understand information. For example, they may need extra time to answer questions or think of solutions to problems. To help them:

- Use short questions and sentences.
- Allow them as much time as they need to answer; repeat the questions if needed.

Mental Fatigue:

The person may get tired quickly after making a mental effort. For example, they may feel worn out after an important meeting or discussion. They may need to take a short rest period or nap.

Personality Change:

The person’s emotions may come out more easily than before. For example, they may get more irritated by little things and not control their anger as well. They may say hurtful things to family members. These symptoms are often caused by injury to special parts of the brain and do not mean that they are truly angry with family members. Remain calm and talk quietly; do not lose your temper or yell at them.

Denial:

The person who has some of the above symptoms may not know that they have the symptoms. They may deny having them even when the symptoms are pointed out to them. They may feel that they are ready to return to work and to drive even though their symptoms would prevent this. They may feel that people who point out their symptoms are just picking on them. Like personality change, this symptom is usually caused by injury to special parts of the brain.

Speech and Language

Speech:

The person's ability to speak clearly may be affected. This may be because of direct damage to the bones and muscles of the face, mouth, and throat. Sometimes, the part of the brain that controls the muscles for speech may be damaged, making the muscles weak and uncoordinated. This does not have anything to do with being on a ventilator or having a tracheotomy. Encourage them to talk slowly.

Language:

Word finding is only one part of language. Some people may have problems with other language skills that affect understanding information and expressing thoughts and needs. Understanding things that are said and written may be hard, and they may have difficulty using the right words in the right order when talking or writing. They may also have difficulty understanding and using *nonverbal* communication skills such as tone of voice, facial expression, gestures, and/or body language.

There are social customs we use when we talk with someone, such as looking at them, staying on topic, and listening without interrupting. Someone with a brain injury may not use these social skills and may seem rude.

Any of the problems described will affect a person's ability to manage daily tasks, as well as the ability to return to work or school. The suggestions listed in this chapter are only a few of those that may help. Members of the rehabilitation team, including the Speech-Language Pathologist, Neuropsychologist, and Occupational Therapist, will provide specific suggestions and make recommendations for any further help that is needed.

Swallowing:

There are many forms of swallowing difficulty (dysphagia) that can be associated with SCI. A SCI may result in difficulty using the facial muscles primarily used for keeping food and liquid in the mouth, controlling, moving, and/or chewing food. Muscles within the throat that are responsible for further swallowing and protection of the airway may also be affected by an injury to the spinal cord or because of surgery.

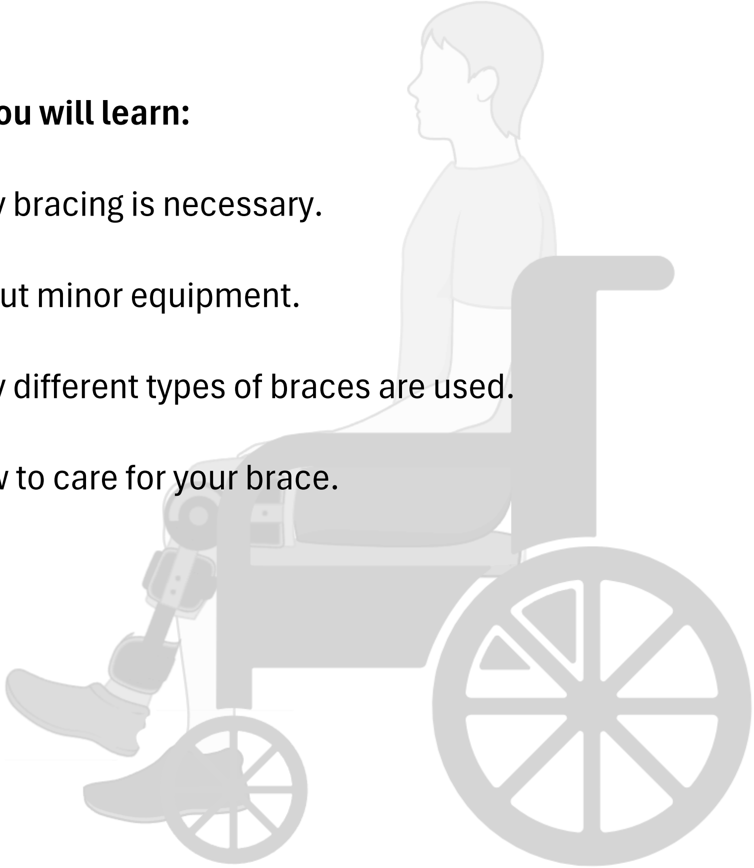
A primary concern regarding dysphagia is the risk of aspiration. Aspiration can be described as penetration of foreign matter into the airway (trachea), leading to the lungs. Typically, this is seen when a patient with dysphagia is eating/drinking, and the food/liquid "goes down the wrong pipe." Repeated aspiration can lead to respiratory complications and infections. Signs and symptoms that may indicate aspiration include coughing with eating or drinking, a wet or gurgled vocal quality after swallowing, any difficulty with swallowing foods or liquids. Often times, patients experience persistent temperature spikes after meals. Recurring upper respiratory infections or pneumonia is a major symptom. Persistently watery eyes or runny nose when swallowing is another red flag.

What patients do to improve swallowing capabilities are to follow some simple guidelines called aspiration precautions:

1. Sit up at least 80 degrees for all eating and drinking.
2. Take small bites of food and small sips of liquid and chew thoroughly.
3. Reduce distractions while eating (e.g., turn off the television, limit conversation, focus attention on eating safely).
4. Complete meals with a tongue sweep or liquid wash to clear any residue.
5. Always remain sitting up for 30 minutes after eating.
6. Always eat and drink slowly and cautiously.

If you are experiencing any problems regarding your ability to swallow foods or liquids, please inform your physician or speech therapist so that a specific program can be tailored to meet your needs.

CHAPTER 12:
Orthotics



In this chapter you will learn:

- Why bracing is necessary.
- About minor equipment.
- Why different types of braces are used.
- How to care for your brace.

The Purpose of Bracing the Spinal Column

Following an unstable vertebral fracture or dislocation, the unstable segment must be repaired and returned to its initial position to prevent further damage to the spinal cord. Provided appropriate bracing most fracture/dislocations will typically heal within about 12 weeks. If not braced, the unstable segment may continue to move which can markedly slow the healing process or cause more damage. This also places the spinal cord at risk for re-injury.

Types of Braces

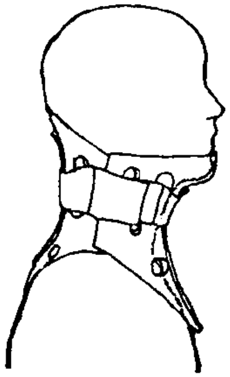
In general, two different types of braces are used. Cervical (neck) braces are used when the injured area is in the neck. Injuries in the middle or upper back will usually require a TLSO (**T**horaco**l**umbo**s**acral **O**rthosis). Each category of brace may have several different types of braces that are used. The next sections will explain a little about the most common types and also explain how to wear and care for them.

Cervical Braces:

The Cervical Collar is worn at the neck and provides mechanical support to reduce the weight of the head on the neck and to prevent motion. In addition, it acts as a reminder that you are not completely healed yet, and that you should not overdo it.

The collar should be worn snugly for maximum effectiveness but should not choke you. The front chin piece should be flush with your chin when cradled by the plastic tabs. The back piece has a Velcro strip, which is pulled to buckle the plastic frame to reduce pressure on the knob at the back of everyone's head. The Aspen, Miami, and Philadelphia collars are the most common types.

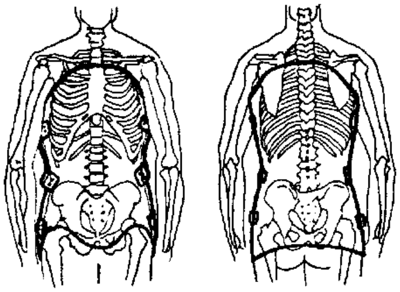
Hygiene can be maintained by washing the gray foam liner, which is held in place by Velcro and can be removed with gentle pulling. The liner should be washed in mild soapy water with gentle squeezing action. *Never pull, wring, or twist the liner, as it may easily tear.* Rinse the liner with fresh water, gently squeeze out any excess water, and air-dry. *Never use a clothes dryer to dry the liner.*



Thoracic Braces:

The TLSO is made to immobilize the spine and allow proper healing following an injury or surgery. It can be custom made or “off the shelf.” It may be used before and/or after surgery and should be always worn unless otherwise prescribed by your doctor.

Special care must be taken to apply the body jacket properly. A clean T-shirt should be worn beneath it with all wrinkles smoothed out prior to application.



To put it on, you should log roll to one side, apply the back piece of the brace, and then log roll onto your back with the back section in place. The trunk of the body should fit into the mold of the brace without gaps. The front section of the brace should be placed with the front edges overlapping the back section. Sliding the front section of the brace up and down can ensure proper placement; the front will catch on to the ribs and center itself. Finally, the Velcro straps should be placed through the loops snugly secured.

Loose fitting clothing such as sweats or pants/skirts with elastic waistbands are most easily worn. Underwear should be put on after the brace is in position and worn over the bottom brace. A bra without metal clasps may be worn without endangering the skin. People with large breasts or soft tissue in upper arms might find support bras or Spandex tops with long arms helpful to reduce chafing.

When the brace is off, you should always lie flat in bed with no rotation or bending of the waist. When lying on your side with the brace on, prop one or two pillows behind the back and another between the knees for comfort. When traveling in a car, use the reclining front seat or lie across the back seat for comfort. Never play contact sports or activities that could cause a fall or put stress on the spine during the period in which you are wearing your brace.

Skin inspection should be performed daily after wearing to fully inspect all areas that the brace covers to look for redness, irritation or broken skin. Although some redness is normal, all marks should fade within 30 minutes. If a red spot persists longer than this, please contact your doctor or orthotist as soon as possible. Bathing should be performed by sponge bath with warm water and mild soap each day. The skin should be dried well with a soft towel, and creams, lotions or powders may be used sparingly. Hair washing should be performed over a sink or bathtub to keep the brace dry.

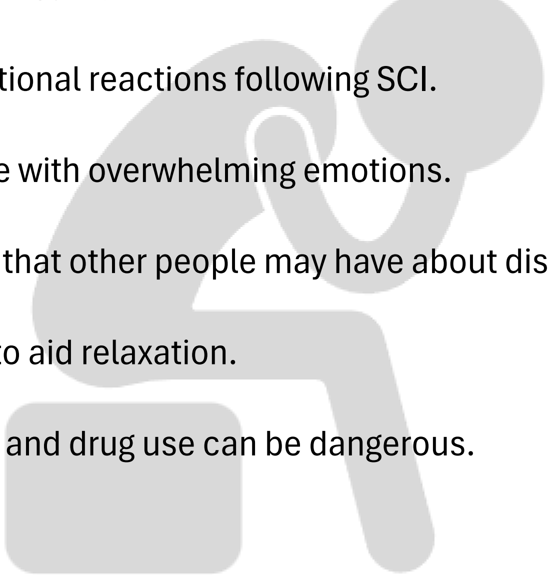
The brace itself should be cleaned daily with rubbing alcohol and allowed to air dry. If any part of the brace cracks or breaks, contact your doctor or orthotist as soon as possible. Never immerse the brace in water.

CHAPTER 13:

Adjustment And Coping

In this chapter you will learn:

- Normal emotional reactions following SCI.
- Ways to cope with overwhelming emotions.
- Impressions that other people may have about disabilities.
- Techniques to aid relaxation.
- How alcohol and drug use can be dangerous.



Emotional Reactions Following Spinal Cord Injury

Having a disability, such as a spinal cord injury (SCI), produces a lot of questions about who you are, who you want to be, how others will react to you, and how to regain a sense of enjoyment and control over your life. Having a disability such as SCI also introduces a variety of intense, unpleasant feelings. You are likely to have already experienced anxiety or panic, anger, *("how could this happen to me?"),* despair, denial *("it doesn't matter what they say, I'll Walk again!"),* guilt, and sadness or depression. This section will discuss these feelings and ways to cope with them.

It is *normal* to have a variety of feelings about your physical limitations and their effect on your life. You can expect to continue to feel hopeful, frustrated, and angry about what has happened to you. You can also expect to feel sad and will need to grieve in whatever way works for you. All these feelings will come and go. They may hit you at times when you feel unprepared to deal with them. That is okay. But you need to practice recognizing that the feelings are normal reactions to your injury and are not the fault of those around you. This will help you identify and talk about your feelings *with* people around you rather than venting these emotions *at* those around you.

Am I The Same Person?

One of the first questions that often arise after SCI is *"am I the same person I was before the injury?"* The answer to this is *"Yes!"* You must now deal with new challenges. You may feel that this injury is the worst thing that ever happened to you, but just because it caused some physical changes does not mean that your life experiences, personality, intelligence, basic competence, or social being has changed. You are still a valuable human being.

Why Me?

Some people ask themselves this question. This is also a *normal* phase of adjusting to your injury. You may feel that you did nothing to deserve this injury, or you may feel the opposite, that you are being punished for some part of your past. You may even find yourself *"bargaining"* with G-d or a Higher Power. Regardless of how you make sense of this injury, you need to understand that bad things do happen to good people. Blaming yourself or someone else may feel good temporarily but does not help you get on with your life. You will eventually need to stop looking back and begin the process of looking forward, of planning how you would like your life to go from here.

Anger

If you find yourself snapping at others, yelling, or refusing to participate in therapy tasks, you are likely experiencing anger. Anger is a *normal and appropriate* reaction to frustrating situations. It is what you *do with your anger* that can be inappropriate and cause problems for you. All the behaviors listed above are non-optimal ways to deal with anger and frustration. Ask yourself the following question to decide whether you are managing your anger well: "Would I like to be treated the same way I'm treating others?" If your answer is no, try to figure out what is making you angry and what would help you feel less angry. *(Be careful here. Your first inclination about what is making you angry may not be correct. Really think about it.)* You may want to get some help from someone you trust to make a positive plan to deal with your anger in better ways.

Sadness

It is very normal to have some sadness after a major loss or crisis of any kind. Sadness takes many forms: Tears, withdrawing from others, not wanting to do anything (including therapies), feeling overwhelmed, etc. Talking with a friend, family member, religious leader, or mental health professional about these feelings can often help you re-establish a hopeful feeling about the present and future.

However, sadness can sometimes turn into depression. If you feel hopeless, are having trouble eating or sleeping or have thoughts of hurting yourself, you may be suffering significant depression. Talk to someone you trust on your rehab team (or contact a doctor if you have been discharged already) about these feelings. You can expect to feel some sadness, but it should not overshadow every day. Treatment for depression is available and will help you.

Anxiety

Many things can make you feel anxious following SCI. Worries about the future, about being desirable to others, concerns about future medical procedures, worries about discharge, and many others occur. Anxiety can take many forms, too: Shortness of breath, nausea, sweaty palms, trouble sleeping, nightmares, and thoughts about the initial accident or injury to your spinal cord. It often helps to talk about these feelings and get reassurance when appropriate. You can also learn to use *"self-talk"* and practice deep breathing to help yourself relax. Help yourself focus on things you do have control over and remind yourself of your ability to be strong and cope with difficult situations you may have faced in the past. If your anxiety is overwhelming and does not respond to your efforts to calm yourself, talk to a doctor (psychologist or physician). You may need some assistance to deal with your anxiety until you begin to feel in control of your life again.

Support

It may help to know that you are not alone. Although each person is an individual and experiences different emotions at different times, almost all SCI patients need time to reach acceptance and to adjust to the changes in their lives. You can talk about these emotions and how they are affecting you in a community-based SCI support group. Also, someone with a disability may visit you during your hospital stay as a peer counselor. You can also choose to stay involved with other SCI individuals after you leave the hospital.

Coping Mechanisms

Frequently, stress is the result of too many demands without the resources to meet these demands. Daily life is stressful and filled with hassles. In rehabilitation, the stresses of daily life are compounded by a busy schedule with multiple individuals involved, physical pain from your healing body, and emotional pain as you accept and adjust to your disability. This section offers you some specific *"dos and don'ts"* for coping with stress during rehabilitation and in the months to follow.

Social Skills and Assertiveness

To avoid feeling isolated and to *"reclaim"* your life, you will want to be out in the community, doing things, as you were before your injury. Initially, it may be hard to find the courage to do this if you are afraid of how others will react to your wheelchair, or if you feel that activities will not be accessible to you. Community re-integration activities while you are in the rehab unit will help you learn about accessible opportunities, but you may have to take the initiative once you are home in letting others know that you are able and available to participate in social activities. Before you do this, it may be helpful to assess your own beliefs about disability and how to manage other people's biases.

Many people have attitudes and impressions that affect how they feel about and act toward disabled people. You may also possess some of these beliefs, even though you now have a disability! Here are some examples:

1. The assumption that you should show pity or sympathy to a disabled person.
2. The assumption that you should avoid disabled people so they will not see that you are uncomfortable or anxious about how to interact with them.
3. The assumption that physical disability is the same as mental or cognitive disability.
4. The assumption that physical disability is the same as being dependent.
5. People may also offer unearned or undesired praise for "overcoming" disability.

You may find that you have strong feelings when faced with these attitudes in other people (and in yourself). It is not too soon to start thinking about how you want to respond to these "biases" and whether you want to help others change their attitudes toward disabled individuals.

The remainder of this section will discuss communication skills that are relevant to all people but may be particularly relevant for you because: a) you are a member of a minority group in our society and may face the biases listed above; b) you may need the assistance of another person (like an attendant) more than you did before your injury; and c) you may be dealing with government agencies and other bureaucracies more than the average person.

There will be times when you need to ask for assistance with something you cannot accomplish on your own, or you may need to let someone know they did something that upset you. You may also find yourself taking extra steps to reassure or demonstrate to other people that you are the same person you have always been, and they need not feel uncomfortable around you.

The best way to let others know what you need (or do not) without being rude is to use an *assertive* style of communication. This allows you to express your feelings or needs honestly without placing blame on others or forcing them to accept your views. It involves listening to their views openly and without becoming defensive. It requires a willingness to find a solution that meets the needs of both parties without giving up on your request or demanding that it be done “your way.”

Often, this is best accomplished by letting the other person know how you feel. For example: “Mom, I do not want to upset you but when you do everything for me, I feel helpless. I need to do things independently so I can feel like a competent adult. I appreciate your efforts though.” In this example, “mom” is not blamed, and the speakers’ needs and feelings are clearly communicated.

It can be difficult to act assertively. You may be afraid that you will upset someone you care about or on whom you depend. Or, you may feel very angry with that person and have difficulty respecting their views. However, if you act passively, not addressing the issue and letting negative feelings build, you only avoid the inevitable confrontation. If you act aggressively, the main issues may not get solved because the other person becomes angry and defensive. Then you are both angry and the initial problem remains unsolved.

Visualization

Visualization is quite effective for both stress management and pain management. The rationale behind this technique is a tense body and mind cannot exist at the same time as a relaxed body and mind, so if you relax you will get rid of bodily tension and mental stress. If you are good at “picturing” or “imagining” things visually, you may find this particularly useful. Even if you have trouble imagining, this can be helpful.

Begin first by getting into a comfortable position, often lying down. Let others know not to disturb you during this time. Close your eyes and try to imagine yourself floating (floating in a warm pool or bath or floating like a cloud in the sky). As you do this, let your body relax and breathe deeply. Concentrate on parts of your body that are comfortable, warm, or relaxed. Next, imagine someplace you would rather be. This may be someplace you have been (like on a vacation) or someplace you saw in a picture or movie, or just someplace you made up. Most importantly, it should be a safe, comfortable, pleasant place. Now, try to make the image as ***VIVID*** as possible. Imagine in detail all the shapes, sites, and colors you would see…look around in your mind at this peaceful vision. Then, imagine all the things you would be hearing. Experiment with making the sounds quieter and louder, as if you could adjust the volume on a television. Go through all your senses---touch, smell, taste…again, making this place as real as possible. Now just enjoy being there. This review of your senses should occur slowly and take 5-15 minutes.

Before you reorient to reality, to your actual setting, notice how your body feels and tell yourself that you will take this sense of relaxation with you through the day. Reassure yourself that you can regain this peaceful sense at any time by simply closing your eyes, taking a deep breath, and imagining a peaceful scene. Then, take a deep breath, open your eyes, and look around your actual setting to get re-oriented. This entire activity will become a better tool for you with practice. If you have trouble using these techniques, request assistance from the rehab psychologist who can help make the exercises work for you. You can also check the internet for guided visualization videos.

Time Management

Often, we cause our own stress by setting inappropriate goals and expectations for ourselves. You can learn to eliminate some of this through some simple steps as well as recognizing the time required to complete new tasks in your routine (i.e., bowel and bladder care).

1. Establish your priorities so that you are aware of what things are important to you and which are not. You can use these priorities to make decisions about how to spend your time.
2. Create realistic scheduling by giving yourself enough time to do high priority jobs. Remember to schedule enough time for inevitable problems and interruptions. You may be able to eliminate the low priority tasks.
3. Learn to make and carry out basic decisions. Learn to say *"no"* to unimportant time demands.

Once you have created a list of your priorities, break this list into groups depending on when they need to be accomplished (i.e., next week, next month, next year, etc.) Begin with the immediate goals and break these down into manageable steps that can be easily accomplished. Then try to take one step toward your goal each day, no matter how small the step is. If you still find your day too hectic, schedule in some quiet time for relaxation exercises mentioned earlier. This may sound counter-productive (i.e., "your day is too busy…we'll add one more thing."). However, people tend to be more efficient and effective when they are relaxed.

Using Positive Emotions

Two mental states can help you deal with difficult, stressful events: Humor and gratitude. It has often been said that laughter is the best medicine. Now, experts are finding that laughter has positive effects on physical and mental health. It can also put you in a positive frame of mind that facilitates finding solutions to tricky situations. And, in rehab, humor helps build good relationships and helps combat isolation and loneliness.

During difficult transitions, like going through inpatient rehabilitation, calling on strength and resilience helps many people. It can also help to choose to focus your attention on good things. These might include family support, small gains made, pets, a good book or TV show, music, favorite foods, etc. Even during change and challenge, cultivating feelings of gratitude can make everything easier. This attitude can help you take on difficult challenges, feel good about yourself, reward yourself for gains and adjust to new physical limitations.

Poor Coping: Alcohol And Drug Use

Substance use, both before and after an SCI, are associated with poor health outcomes, less reported life satisfaction, and increased risk of mental health issues. It is easy to imagine reasons why an individual might self-medicate (use alcohol or non-prescription drugs) following a SCI: To "deal" with physical pain or spasms; to "deal" with emotional pain; to "get up the nerve" to be assertive with attendants or to go out in the community again; or, simply to continue a pattern of use or abuse from prior to the injury. People may *incorrectly* believe that alcohol or drugs help to *"deal"* with problems. Actually, use of alcohol or prescription drugs impairs the ability to deal with feelings and situations, and limits opportunities to learn other, more effective coping strategies. Furthermore, alcohol is part of a class of *depressive* substances that may make it *harder to deal with difficult emotions and physical pain.*

Not only do drugs and alcohol interfere with emotional adjustment, but they interfere with physical health & neurologic recovery. Alcohol and drug use can lead to the following serious complications:

- Interactions with other prescription medications.
- Bladder infection or distention (enlargement).
- Reduced neurologic recovery (not get back as much strength or sensation).
- Decreased respiratory function (ability to breathe).
- Malnutrition, which leads to increased fatigue and weakness and poor healing of other complications such as pressure sores.
- Forgetting to perform self-care activities such as pressure relief.

Drinking may be an important part of "socializing" for you as an adult. Only you can decide whether it poses a problem for you now that you have a SCI. But if you feel defensive as you read this, you may need to consider how important alcohol or drug use openly and honestly is in your life. The following questions can be useful in helping you objectively assess your own drug or alcohol use.

- Have you ever attempted to cut down on alcohol or drug use?
- Have you ever felt annoyed with criticisms about your drinking or drug use?
- Have you ever felt guilty about your drinking or drug use?
- Have you ever used alcohol or other drugs as an "eye-opener" (i.e., to get going in the morning)?

Answering yes to two or more of these questions *strongly* indicates that you may have a problem with drug or alcohol use. Help and treatment are available to you. Talk to your team if you feel comfortable. Some members of your team have received additional training to help individuals in situations like this. If you feel you would like more information about how alcohol or drug use might be impacting your life, ask your team for more information. You can also call the Substance Abuse and Mental Health Services Administration (SAMHSA) at 1-800-622-4357.

For more information on mood after SCI use these QR codes:

Depression & SCI
(Consumer Guidelines)

Depression & SCI
(Model System)

Adjusting after SCI
(Model System)

PTSD & SCI
(Model System)

CHAPTER 14:
Sexuality

In this chapter you will learn:

- The ways people become aroused.
- How arousal can change after SCI.
- Ways to compensate for changes in arousal and sexual function.
- How fertility and childbirth are changed by SCI.
- Recommendations for self-care prior to sexual intimacy.
- How to re-think sexuality in ways to achieve the utmost pleasure.

Sexuality After Spinal Cord Injury

Since your spinal cord injury (SCI), you may have been wondering about how you will function sexually. You may have been embarrassed to ask this question. But sex is a natural part of your life and is as important to discuss as any other topic in this manual. You can ask your nurse, psychologist, physician, or therapists any questions you have about your sexual functioning following SCI. If you are not ready to talk about sexual issues that is also ok. Information about sex and changes following SCI will be available to you in this manual so you can read it when you are ready.

General Information About the Mechanisms of Arousal

It is important to understand the physiology involved in sexual excitement so that you will understand how your body may be different, and how it may be excited by different stimuli following SCI. There are two general types of stimuli that can lead to arousal or excitement: Mental stimuli and direct physical stimulation of the genital area.

Mental stimuli could be thoughts, images, hearing or saying something “sexy,” watching sexy movies, or reading sexy books or magazines. These stimuli, which originate in the brain, are turned into messages that are sent from the brain down the spinal cord to the genitals. The body responds with some typical signs of excitement. In people of all genders, the nipples become erect or “hard,” the skin of the upper body can flush, muscles tense, and the pulse, breathing, and blood pressure increase. In individuals with a penis, the penis becomes erect as it fills with blood. In those with a vagina, the vaginal area thickens and lubricates as the blood vessels in these areas fill. If you have a SCI, these mental messages may not be able to pass through the injured portion of the spinal cord to the genitals. You may no longer get an erection (for a man) or become lubricated (for a woman) by mental stimuli. Later sections will discuss psychogenic arousal (arousal due to mental stimuli) in more detail and explain what levels of injury are most likely to be impacted.

Direct touching of the genitals or genital area can cause arousal as well. In those with a penis, direct handling of it can lead to erections (which are referred to as reflexogenic erections) due to a reflex mechanism in the body, like the mechanisms causing spasms in the legs. In individuals with a vagina, direct clitoral stimulation can similarly cause lubrication and vaginal engorgement. You may have experienced this already in certain situations (e.g., during catheterization).

Following a SCI, it will be necessary for you to experiment to find out what types of stimuli are exciting to you. This can be done individually or with a partner. And remember, your *brain* is the most important body part necessary for the enjoyment of a sexual relationship. This means you are most likely to have a pleasant experience if you can relax and remove stressors from your mind. Activities such as "body mapping" can help you identify what feels good. Body mapping involves using aids such as feathers, massage oil, vibrators, or anything you deem appropriate to understand which body areas have high arousal potential. Remember that some areas, often just above and below your SCI level, may feel uncomfortable to touch, while other areas may respond more than before your injury to pleasurable touch.

In the following sections, changes that are typical for people after SCI are discussed. Obviously, not all spinal cord injured individuals are the same. Function, sensation, and movement vary due to the level of injury and whether the injury is complete or incomplete. You will need to know your level of injury and whether you have a complete or incomplete injury to make full use of the following sections. If you are unsure, check with your physician.

Sexual Information for People with a Vagina

SCI in those with a vagina is likely to affect lubrication and sensation below the level of injury. This affects both arousal and ability to achieve orgasm.

<u>Lubrication:</u>
As discussed earlier, lubrication is a function of excitement and can be achieved through mental stimuli or direct physical stimulation. If the injury to your spinal cord is complete *above T12,* direct physical stimulation to your genital area will be the most successful route to lubrication. If your SCI is complete below T12, you may achieve lubrication from mental stimuli (i.e., sexy thoughts or feelings). If your SCI is incomplete*,* lubrication is more likely to occur, and you will have to experiment to see how it is best achieved. Remember, lubrication can be affected in any woman by her mood, interest, hormonal variation, age, or vaginal/bladder infections. With loss of sensation below your injury, you will probably not be able to sense moisture associated with arousal. Therefore, you will have to check, or have your partner check, to see that you are lubricated enough to allow intercourse. If you have difficulty getting lubricated enough, use a water-based lubricant.

<u>Menstruation and Fertility:</u>
The shock to the body after a SCI can alter your menstrual cycle temporarily. Some people with a uterus may skip their periods for 3-6 months after the initial injury. But *<u>you have the same chance of getting pregnant as you ever did, even when you are skipping your period</u>*. Use appropriate contraceptives to avoid unwanted pregnancies and speak with your physician about good birth control options for individuals with SCI—some birth control devices are not good choices for you now that you have a SCI.

During your period, you can still use sanitary napkins or tampons like you did before. However, you need to check pads or napkins frequently to avoid pressure sores. Pads and tampons should be changed at least every four hours, and you will need to use a mirror to clean yourself and check for skin irritation. Because you may have lost sensation to this area, you will not feel pain or discomfort if something is wrong, *so you need to check often.* Depending on your level of injury menstruation or some of the sanitary products can trigger autonomic dysreflexia, if this is happening, talk to your doctor about how to best manage it.

Pregnancy and Childbirth:

SCI does not affect your ability to get pregnant and deliver a healthy baby. However, there are many things you must take into consideration before and throughout your pregnancy so that problems can be prevented, or at least planned for ahead of time. First, you must find a physician who knows about the problems associated with pregnancy and SCI. Your rehab doctor may be able to refer you to an appropriate physician.

The following list of potential problems should be discussed ahead of time with your physician and anyone involved in your care (i.e. friends, family, partner, caregivers, etc.) since they are likely to be involved in providing any extra assistance needed. Remember, these are only *potential* problems, and planning can help to avoid some of these.

- You may experience labor that begins before the 36th week (pre-term labor).
- You may experience more bladder infections during pregnancy.
- You may have more incontinence from the baby pressing on your bladder. This may happen more as the pregnancy continues.
- You may have more trouble with transfers and pressure relief toward the end of your pregnancy because you are transferring additional weight.
- You are at higher risk for pressure sores because of the additional weight, increased incontinence, and more limited mobility.
- You may experience swelling of your legs and feet with increased risks of blood clots in your legs.
- If you are a candidate for experiencing autonomic dysreflexia, (T6 level and above), you may experience it now as the baby begins to press on pelvic bones. T**his is very important and needs to be discussed with your doctor.**
- You may experience increased spasms and increased back pain.
- You may need to stop some of your medications because they could hurt the baby's development. Be sure to take a list of all the medications you use regularly, as well as occasionally, to your first doctor's appointment so the two of you can discuss how to proceed.
- You will need to learn how to tell when labor has started if you have no sensation at that level.
- Vaginal deliveries are possible but may be complicated by your ability to use your abdominal muscles to push.
- Breast-feeding is also possible but may be complicated by decreased milk production or positioning of the baby if your upper extremity function is limited by your SCI.

Sexual Information for People with a Penis

SCI in those with a penis is likely to affect erection and sensation below the level of injury, which affects both arousal and ability to achieve orgasm.

Erection:

As discussed earlier, erection is a function of excitement and can be achieved through mental stimuli or direct physical stimulation. Following a SCI, many people with a penis report that erections are not as strong as before and/or erections may not last as long as they did before the injury. If the injury to your spinal cord is complete above T12, direct physical stimulation to your genital area is likely to be the most successful route to erection. This may happen when you are touched during sexual relations, but may also happen when you are cathing, putting on your pants, or bathing. If your SCI is complete below T12, you may achieve erection from mental stimuli (i.e., sexy thoughts or feelings), but not when someone touches your penis. You may have to practice mental arousal using all your senses to maintain erection. If your SCI is incomplete, erection may be possible by either route discussed above. You will have to experiment to see how it is best achieved.

Attaining and Keeping an Erection:

Many strategies and techniques have been used to assist individuals with a penis with SCI attain functional erections or maintain erections for a longer duration. Some will be briefly reviewed here but it is always a good idea to discuss these issues with a physician or a rehab psychologist who can address these issues.

If you are able to get erections through direct stimulation of your penis, you can try to directly have intercourse or try the “stuffing” technique. This method involves inserting a soft or semi-erect penis at the start of intercourse and then using stimulation from your partner’s thrusting to produce or maintain an erection.

Other assistive techniques include the use of vacuum devices, medications, or penile implants. Each of these options has advantages and disadvantages that should be discussed with your doctor. Vacuum devices allow blood to be “pumped” into the penis to cause an erection. The penis is placed into a tube with a rubber ring at the base of the penis. The vacuum then draws blood into the penis and the ring blocks the circulation of the blood. The ring can be used by itself to assist with maintaining an erection. Erectile medications like Viagra, Levitra, or Cialis work by increasing blood flow to the penis. Shots of medication directly into the penis tissue can cause erection or assist with maintaining an erection too. These are initially given in a doctor’s office, but some people with a penis learn to administer them at home. Lastly, plastic, silicone or metal material can be surgically implanted into your penis to assist with erections. Implants are of two varieties: Permanently erect or with an attached pump to allow erections as desired.

Fertility and Ejaculation:

Two things will affect your fertility, or your ability to have children. Your doctor can help you with both. First, are you ejaculating sperm and, if so, are your sperm healthy enough to cause conception?

Regardless, it is important to know *<u>that you can still get someone pregnant and are susceptible to sexual transmitted diseases</u>*. Therefore, when/if you decide to engage in sex, please use protection unless you are trying to have a child.

Ejaculation occurs when milky, white fluid comes out of the end of the penis. This often occurs in conjunction with orgasm, but they are, in fact, separate events. If you have a complete injury to your spinal cord, you may not achieve unassisted ejaculation. If you have an incomplete injury, you will need to experiment to see whether you are ejaculating as you did before your injury. If you are unable to ejaculate, different techniques can be used. These include the use of a vibrator on your penis, a physician performing electro ejaculation (electrical stimulation leading to ejaculation), or surgical retrieval of the sperm. Therefore, if you are having trouble, please ask your doctor for help. It is also important to recognize that autonomic dysreflexia is a risk with any of these procedures.

Even if you can ejaculate, your sperm may go the wrong way (retrograde ejaculation) or may not be healthy enough to lead to conception. Some things are out of your control but, there are things you can do if you are interested in keeping healthy sperm: avoid urinary tract infections. A doctor can test your sperm to determine their health. This is not something you need to think about too much now, because even if there are some limitations with your sperm, techniques for fertilization have improved enough to help most people still get pregnant if they desire.

General Sexual Information

<u>Arousal and Orgasm:</u>

If your injury is incomplete, you may have partial sensation at your genitals. This means that you might be able to feel arousal from touch to the vaginal area/penis and for those with a vagina, you might be able to sense moisture with lubrication. If you cannot feel arousal by touch to the genital area, other areas of your body will continue to give you pleasure, perhaps heightened pleasure, when touched. It is up to you to shift your focus to other areas and experiment to see what is pleasurable. Areas to focus on might include: The upper body and nipples, the shoulders, face, nape of your neck, or your ears. If your injury is incomplete, you might experiment with suggestions that other people with SCI have found to increase arousal, such as gently pulling your pubic hairs, stroking your genitalia, or using a vibrator. It may also help to enlist all your senses in reaching arousal; rather than relying on touch alone, use sight, sound, smell, or taste in creative, pleasurable ways. You might imagine past pleasurable experiences, sexual or non-sexual. Many people can achieve orgasm through fantasy alone. Remember that the mind, creativity, and a willingness to try new things are all factors in attaining a healthy and enjoyable sex life for *all individuals*, not just those with SCI. Some spinal cord injured people have reported that they experience orgasms that are as intense as before their injury because they have learned to enjoy erotic stimulation from many more parts of their bodies. Others say they no longer have orgasms but still enjoy being sexually intimate with another person.

Recommendations for Self-Care Prior to Sexual Activity:
Planning ahead will allow you to be ready and comfortable during sex. This may not seem as fun as being "spontaneous," but it will help you avoid potentially embarrassing situations.

Sexual activity can trigger bowel and bladder reflexes, causing accidents. You may want to have sex shortly after completing your bowel program (when you know your bowel is empty). You should also cath or empty drainage bags prior to attempting any sexual activity.

Educating your sexual partner is also part of preparing to have sex. If you are in a relationship, your partner may already know of any needs you have with undressing, transferring, equipment, and positioning. However, if this is the beginning of a new relationship, addressing these issues with your new partner prior to beginning sexual activity allows you both to ask questions and come to mutual solutions.

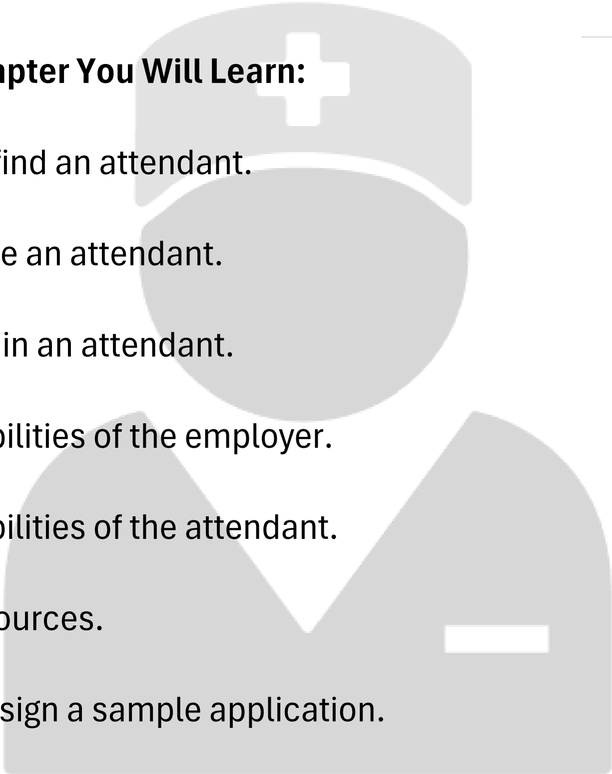
Educating yourself is also part of preparing to have sex. Some activities that occur during sex can be interpreted by the body as unpleasant and can lead to autonomic dysreflexia, which is a risk for those with complete injuries at or above T6. This can include too much blood in the penis (especially if using assistive devices such as rubber rings), use of a vibrator, inadequate lubrication, or being stimulated too roughly. If you need to, speak to your doctor about ways to manage symptoms of dysreflexia during sex. Do not ignore signs of dysreflexia. You will also learn through experience and suggestions from others with similar injuries, about positioning, spasms during sex, and dealing with complications as they arise. It may take time, but sex and intimacy are important and valuable parts of your life. Give yourself the time to make this experimentation a priority.

For more information about sexual function after SCI these QR Codes:

Sexuality & SCI
(Consumer Guidelines)

Sexuality & SCI
(Model System)

CHAPTER 15:
Attendant Care



In This Chapter You Will Learn:

-Where to find an attendant.

-How to hire an attendant.

-How to train an attendant.

-Responsibilities of the employer.

-Responsibilities of the attendant.

-Funding sources.

-How to design a sample application.

Introduction

Often, one of the first things a disabled person must do after the hospital stay is to find an attendant. The information contained in this section will be a guide to where to find an attendant, how to interview an attendant, payment sources, and how to have a good relationship with your attendant.

This information has been gathered from publications, interviews with attendants, employers of attendants, and many health care workers who are directly involved with this issue.

Where To Find an Attendant

Advice from people who have attendants is that it is much better not to have a friend, spouse, or significant other doing the work, which an attendant should do.

It is best to have a hired attendant do most of the personal care because:
1. You can be more exacting if you pay for the service.
2. Your mate will feel less tied down, a feeling which invariably leads to anger and resentment.
3. Having a friend or relative work as your attendant limits your feelings of independence. It is preferable to establish an employer role so that you will have more control over the situation.
4. It is hard to switch back and forth from the role of an attendant to friend or relative.
5. Often, there can be a feeling of dependency on your attendant. It is better to keep these feelings separate from other relationships in your life.

<u>Sources:</u>
This list of places to look for attendants has been compiled from information received from discussions with community people, attendants, and previous patients. Each county will have its own community resources, so find out what is available to you in your own county.

- Newspaper ads
- Centers for independent living
- Public assistance agencies
- Social service agencies
- Senior citizen groups
- Religious groups: Catholic charities/churches or Jewish vocational services
- Bulletin board notices at schools, colleges, churches, and hospitals
- Employment agencies
- Friends
- College and junior college career placement centers
- Convalescent homes
- Word of mouth: Talk with other people in the sci community (e.g., at support groups)
- Care.com

Hiring An Attendant

Prior to the interview, have the prospective attendant complete a written application so that you have a record of information. An example application is provided below. Be sure the prospective attendant has a valid California driver's license or California identification card. Both cards may be obtained at the Department of Motor Vehicles. It is important that the prospective attendant has a telephone. This is necessary for emergencies and to be sure that your attendant will be responsible for calling if unable to come to work. Always Check All References!

The Interview:
At least three important things should occur in the interview:
1. Discuss the job responsibilities and clearly describe the attendant duties.
2. Find out what the applicant is really like and if they can manage the job.
3. Open channels for honest communication.

It is preferable that you conduct the interview along with a parent, friend, or significant. Ultimately, you are the person who must relate to the attendant. In terms of explaining what the job will be, first think back over your routine in the hospital, step by step, and ask yourself how you would explain all the things you need to have done. Be specific. It is extremely important to be completely open and honest if you want to find an attendant who will stay with you. In this way, there will be no surprises later and your attendant is more likely to remain on the job. Discuss hours, rate of pay, time off, etc. After explaining what the job responsibilities will be, find out what the applicant is like. Communicate your feelings regarding usage of drugs, alcohol, and cigarettes. Now is the time to have the rules understood.

In preparing questions for the interview, a helpful hint is to make a list of all factors that you think qualifies someone for the job.

For Example:
- "I need someone who will not be late."
- "I want someone who is a careful driver."

Some characteristics which people think are important for an attendant are:
- Compatibility
- Reliability
- Promptness
- Having transportation which works
- Honesty
- Listening well to instructions
- Willingness to learn.

It is helpful to keep the following points in mind during the interview:
1. Is the applicant paying attention and is interested in what you are saying?
2. Is the applicant listening - would he/she listen to directions?

Remember, this interview is not like other interviews because you must ask specific personal questions.

For Example:

- "Have you done any work with bowel/bladder care?"
- "Would it bother you to have to work with ...?"
- "I cannot go to the bathroom on my own. Do you think you could work with me?"
- Ask questions concerning the applicant's health (does he/she have back problems, etc.).

Training a New Attendant

Staff at UCDRH is available to help with attendant training prior to discharge. Therefore, it is important to have someone identified as your attendant as soon as possible. If you cannot find an attendant prior to discharge, you can also recommend they observe sessions during home health therapy and/or outpatient therapy.

Verbal training will be easier if you are consistent; give the rationale for a method, step-by-step procedure, or time schedule. You will show respect for your attendant and make learning easier by explaining why something is important.

When you find someone that you feel will be a good attendant, a two-week trial period is suggested. In this time period, both you and the attendant should be able to determine if you are compatible and if things will work out.

Responsibilities of the employer:

1. Make sure the attendant's responsibilities are fully explained and a complete description of duties to be performed is given to the attendant in writing (e.g., personal care, cooking, housekeeping, laundry, etc.).
2. Be ready to work when your attendant is scheduled to arrive.
3. Function as independently as possible.
4. Finances should be made clear. Discuss the amount of pay (rate per hour), how you will pay (cash, check, Venmo, etc.), if social security is deducted, and frequency of pay.
5. It is safer to pay with methods that will have a record that the attendant has been paid (limit cash).
6. It is important to keep a record of the attendant's work hours. Often, people have a binder that the attendant can use to document their time of arrival, breaks, and time of departure.
7. Agree in advance on holidays, vacation, sick days, and breaks during the workday.
8. An attendant should be given two weeks' notice before having their services terminated.
9. Give feedback to your attendant as constructively as possible. Always be thoughtful and courteous. Learn to give praise as well as criticism.
10. Keep Communication Open.

Responsibilities Of the Attendant (Example):

1. It is often hard to find a replacement, so give your employer at least two weeks' notice before terminating services.
2. Do not take a job you feel uneasy about after speaking with the employer.
3. Resolve any questions regarding the job before beginning to work.
4. Arrive at work at the scheduled time.
5. Your employer is depending on you, so call as soon as possible if you cannot work or will be late for work.

Funding

Medi-Cal eligible patients/person pay for attendants with money available in California through In Home Support Services Program (IHSS). This service is a state program, which is managed through the County Welfare Departments. The funding source for this program is TITLE XX of the Social Security Act. Each state uses this funding differently, so the following information applies to California only.

In Sacramento County, contact:
Department of Health and Human Services- www.saccounty.net
In Home Supportive Services
4875 Broadway
Sacramento, CA 95820
(916) 874-9471

If you are from another county, contact your local Department of Social Services.

Some of the services covered by IHSS are:

1. General housekeeping.
2. Meal preparation and serving.
3. Routine personal care.
4. Bowel and bladder care.
5. Assistance with exercise.
6. Care of and assistance with prosthetic devices.

The first step in obtaining IHSS funds is to have a needs assessment done by one of their social workers to determine: Eligibility and how many hours of attendant care you are to be allotted. If you think you may be eligible for IHSS, contact their Social Services to determine Medi-Cal & IHSS eligibility. Your hospital social worker/case manager can assist you in making this contact before your scheduled discharge. Every six months or change in condition, the maximum number of hours allotted, and the person's needs are reviewed by a county IHSS social worker. The number of hours allotted may decrease as you achieve greater levels of independence. If you feel that you are not allowed enough hours for your case, there is an appeal process through the State.

Sources Of Funding Other Than IHSS:
If you are covered by private insurance or have long-term insurance, contact the company to find out the policy coverage. A County social worker will tell you about any coverage available through Medi-Cal or Medicare.

For more information about personal care attendants use this QR Code:

Helpful Hints on How to Keep Your Attendant

1. Keep communication pathways open. If you sense or notice any problems or misunderstandings, try and confront these and discuss them quickly. To avoid blow-ups, try not to keep bad feelings inside.
2. Try to be organized. Use your time efficiently and anticipate what you will need for your daily activities.
   a. Are you running out of food?
   b. What day will you go shopping and when?
   c. Is your laundry done so that you have clean clothes?
   d. Could you do your bowel program in the evening so that things will go quicker in the morning?
3. It is upsetting when someone is being taken for granted. Always try to show your appreciation by thanking your attendant.
4. Try to put yourself in your attendant's place. Think about how you would want someone to talk to you.
5. Do not be demanding. It is important to be kind and courteous even when you are asking someone to do something for you.
6. Remember that someone else might not do the job as well as you could – Be patient.
7. Establish your position as an employer early so that things will be done your way, since you know best what your needs are.
8. If your attendant is leaving your service, be sure that you get back any house keys.
9. It is difficult to keep attendants at such a low pay rate. If you can add any money to the minimum wage, you will have a better chance of keeping your attendant.
10. Something to be aware of is that often the first attendant will not keep the job very long. The average time that an attendant will last is only a couple of months, so try not to demand too much at first.
11. It is often easier to have a couple of attendants so that there is evening and weekend relief. Often, two people will share attendants.

A way to establish feelings of greater independence, even though you depend on someone else to do some of your activities of daily living is by communicating assertively.

-Be <u>open</u> - Do not send messages through others.
-Be <u>direct</u> - Send messages as clearly as possible.
-Be <u>honest</u> - With others and yourself.
-Take <u>responsibility</u> for the message- Use “I” statements (e.g., I like it when…)

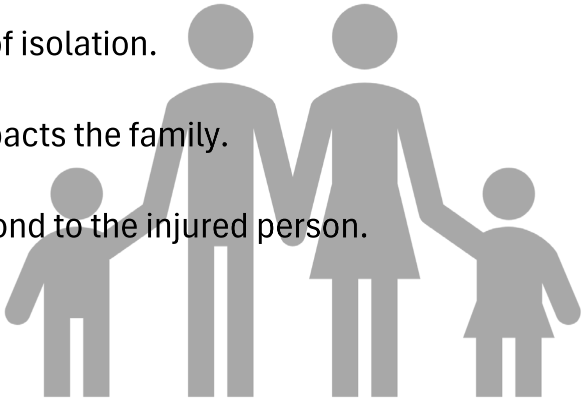
This is different from the aggressive person. The aggressive person often claims that someone else is at fault. It is fine to be assertive, as long as you can also be kind and not too demanding.

For an example attendant application, use this QR Code:

CHAPTER 16:
Family Adjustment

In this chapter you will learn:

- Common emotions experienced by the family.
- The impact of isolation.
- How SCI impacts the family.
- How to respond to the injured person.



Emotions Commonly Experienced by the Family

The following section will have some quotes from previous patients and family members to provide context for what may be experienced.

"At first, we couldn't believe it. There was a lot of shock and fear - afraid for her, for us, our life together, and her life period. I was with her all the time when she was first in the hospital. Just being there with her and becoming more familiar with her situation over time helped," - husband of a tetraplegic.

You have been through an emotional ordeal - wondering if your family member will live, who will help with the care, how much care will be needed, wondering how you will pay for the medical expenses and what your lives will be like since the injury occurred. The feelings brought out by a traumatic event, such as SCI, are thought to be similar in some ways to those experienced when a family member dies. As you begin to deal with what has happened, you will be experiencing many different feelings.

A common first reaction to such a crisis is relief; yes, the family member is still alive, but shocked at the degree of the injury. You may feel numb, confused, frightened, and anxious. Not only is there uncertainty about what the injured family member is going through, but also about what the future will bring. Such feelings and concerns are perfectly normal. One way to work through them is to ask a lot of questions about the staff who will be working with your loved ones. By trying to understand as much as you can about the injury, your confusion and anxiety can be lessened.

"Our situation was kind of different - we didn't know immediately that he had a spinal cord injury. We didn't know the paralysis was permanent at first. At first, it was like nothing - I just blew it off - didn't think much of it. At the time, I was in paramedic school, and I think that knowing what was going on a little bit better helped a lot. It didn't really hit until he came back from the hospital. Once we knew the facts, we had to figure out what to do next," - brother of a paraplegic.

Many people, both patient and family, often try to deny the seriousness of SCI in the beginning. Instead, they may tell themselves, "It's temporary," or "not really that bad." Denial is a normal way of trying to cope with problems that are too big to face all at once. It can be helpful at first in that it prevents you from experiencing overwhelming feelings of despair. However, denial can become a problem if you get caught up in avoiding reality for too long; for example, telling yourself the problem is temporary, and therefore, "I don't need to learn about their care." You need to move beyond this to be able to help with the rehabilitation of your injured family members; they need you to do so. Only by facing the reality of the injury can you be open to learning new information and skills to help your loved one and to better understand the disability and your role in the injured person's life.

During this period of adjustment, you may have feelings of grief. These emotions may include a feeling of sadness for the loss you and your loved one have experienced. Not only may the loved one now be restricted in some abilities, but the whole family may feel like it has lost some of its independence as well. Grief can often be triggered by thoughts of what was or could have been. Such recurring feelings of sadness, however, are normal and are to be expected. Don't be angry at yourself for failing to "get over" the disability, but instead, allow yourself to experience the loss and the pain. You are going through a major change with your loved one, and this is not something that can be worked through in one day. It is not easy to deal with all these emotions at one time. If you can share them with someone who will listen and care, a friend, minister, staff member, or your injured loved one, you can begin to put your life back together again.

As the permanence and "unfairness" of your family member's injury are realized, anger and frustration often occur. Families sometimes experience anger about the cause of the injury and why it happened to their loved one. Anger may be directed toward the doctors because they cannot "fix it" or sometimes toward the hospital staff and sometimes toward G-d. At times, anger is also directed toward the injured person. It is important to explore these feelings before they become too great and get expressed too violently or "taken out" on the wrong person. Writing about your anger, pouring your feelings into a voice note, or having someone outside of the situation (minister, counselor, psychologist, etc.) who will listen and understand are all ways of dealing with your anger.

Not only does the family experience anger, but it is frequently seen in the injured person as well. Family members are often confused and hurt when greeted with the angry and even at times hostile outbursts of their injured loved one. It might be helpful at times for you to remember that frequently these are not personal attacks directed at you. Your loved one is also experiencing frustration and anger about their injury, and they need to express these emotions. Unfortunately, those they love must often receive the brunt of this anger. Again, sharing your feelings of hurt with others and talking with your injured family member about how these outbursts impact you may help you to open lines of communication and cope with their outbursts more effectively.

You may also feel guilty. Even when family members had no direct role in causing the injury, they may still have guilt feelings. Phrases like: "I wish it had been me, they had so much life ahead of them, and why do I deserve to be walking around," describe how many persons feel after a loved one is injured. In some cases, guilt over secretly wishing the injured family member had died has been reported. You may secretly wish that you were not responsible for the injured person's care and resent them or her because of limitation put on your independence.

The injury may mean a big change for you, and such feelings are to be expected. The guilt you may feel over having these thoughts and feelings is also normal and understandable. It is important to explore how your thoughts may be related to the feelings of guilt you are experiencing. Feelings of guilt which are not understood or expressed can lead to over-protectiveness toward your family member with SCI misdirected anger, or in extreme cases, physical symptoms due to the suppression of strong feelings. Guilt over something you may have done said or thought needs to be talked about with others.

“Depression was there. As time went on, the depression seemed harder and harder to come out of. There was never really any denial - no room for it. I took care of her day and night, so that helped limit the time within which to get depressed. A lot of times, I found that there was no time for me - the balance is no longer there. At times I found myself resenting this, but I’ve been able to talk about it with my wife from the very beginning - that helps to keep things out front. Communication is very important, so you don’t hold everything in and then explode. We were able to accept it and move on from the very beginning.” - husband of a tetraplegic.

Depression can be thought of as feeling “blue” or experiencing a sense of hopelessness. Depression is often a phase that helps one face the realities of stress or change. If you notice problems with sleeping, weight change, frequent crying or feeling fearful, loss of interest in previously pleasurable activities or pastimes, decreased energy, or difficulty in being able to concentrate or think clearly - these can all be reflections of depression. However, if you have symptoms like these you should always see your family doctor to be sure they are not coming from some other cause.

One way to get control of these feelings is by trying to identify the thoughts that are causing you so much distress. You may need to step back; look at the whole situation from a distance and try to separate the facts from what you think is true and from your fears. It is important to replace thoughts, which are without a logical basis (and that keep you feeling down and blue) with more realistic alternatives. Most depression runs its course; however, if it persists and begins to interfere with your ability to do what needs to be done, you may need to seek help for yourself.

“At first, we really didn’t know the full extent. My main concern was the use of his hands and arms, as I was eight months pregnant at the time and had two other children. It was a hard, uphill battle from the start. His mother didn’t want to talk about it (the injury), but I did. I thought, ‘He’s to this point now, why not look at the worst of it and move on from there.’ The first thing is to accept it for what it is. It takes months and months and months to see light at the end of the tunnel. Day to day dealing with it was the way we coped - time is the healer of anything - death, sickness, even this,” - wife of a tetraplegic.

You may wonder if you and your loved one can ever “accept” the SCI. If “acceptance” means being happy about it or not bothered by it - perhaps not. There never has been and never will be any “justice” in SCI. But you will eventually come to realize that the injury has indeed occurred, it is long-term, and while there is always hope for a cure, it needs to be dealt with now. At this point, you will be able to take positive action and begin to reorganize your life, so the injury no longer takes all your energy and time.

“I know how bad it was when he first came home. Structured routine day to day was the only way I could survive with time for myself. It’s so important to get your life organized. As quickly as you can, get life in order so things go smoother,” - wife of a tetraplegic.

“The knowledge of the facts - realizing the true extent of his injury and accepting it - helps you to move forward. You need to just pick up the pieces and drive on. He always told us that it did not bother them, why should it bother us. He stressed that he was still the same person - he just got around differently,” - brother of a paraplegic.

In general, as you cope with all these emotions and with the crisis of the disability itself, be aware of the amount of stress you may be under. Trying to perform too many roles at once can threaten your own physical and emotional well-being and your ability to cope. You need to focus only on the things that are of real importance and that must get done. Put others on hold. Be sure to eat and rest (even if it is not uninterrupted, deep sleep) and take breaks from the stress of the rehabilitation environment when you can. Physical activity/recreation are very good for tension release. Also, relaxation strategies (which our Psychology Department can help you with) and being able to talk about your worries and stress to someone who is a good listener can help.

Isolation

“Getting out into the public with the chair, etc., was one of the toughest things for me to deal with. I think it bothered me more than them. It wasn’t that I was embarrassed to be with them, but I felt for them when people would stare or say things. I think time and getting out more helped to smooth things over,” - wife of a paraplegic.

Particularly during the early stages after injury, you may feel abandoned by those outside the immediate family unit or find they avoid you. This may be due in part to their shock and uncertainty about how they should react and what they should say to you. Rather than doing or saying the wrong thing, others who were once close to you may pull away. With time to adjust, some may choose to stay away, while others will return. What is important is for you as a family to realize this may occur and not to permanently isolate yourselves from the outside world. You may need to take the lead in re-establishing contacts.

While people who stay isolated may be fairly successful at shielding themselves from hurt, they are also often unable to obtain help and support when they need it. These are some ways that you may be able to handle the cruel or insensitive remarks of others without resorting to isolating yourself:

1. Family role playing - it can be helpful for you to devise and act out responses which can be comfortably used by family members in real situations.
2. Confrontation - learn to stand up to others and let them know how it makes you feel when they do or say certain things. This will enable more honest interchange.
3. A simple explanation may ease the situation.
4. Ignore the situation.
5. Drop the “rejecters.” It will be healthier for you to seek out those who you accept and who accept you, rather than staying with those who are not trying to understand your situation or support your attempts to cope.

How SCI Impacts the Family

In reading this section, remember that family is what you make it. These are not always “blood” relatives, but the family you have chosen to create.

Often, families in crises tend to cope by over-emphasizing attitudes and responsibilities that existed before their family member was injured. Old patterns of behavior, however, may not work given the new family situation introduced by the SCI. The role of each family member may have to change to accommodate the person who is injured. Not only will others have to take on responsibilities previously held by the injured person, but there may also be new duties relating to the injured person’s care (These will vary depending on the extent of your family member’s disability). The entire family should be involved in discussions about the family’s different needs and problems. Tasks should be redistributed so that each family member can assume a fair share of the tasks previously performed by the injured family member, until the injured person can resume some of those responsibilities again. Communication will need to take place on a more effective level. Everyone in the family will need to be responsible for communicating their needs and feelings (positive and negative) to those around them. This is necessary to better understand how the family unit is coping with the disability and to reduce any tensions before they become too great.

“I would say our relationship has really changed for the better. Being together all the time - seven days a week - and we’re still very close. Both parties need to be willing to work through it together. Talking over why you feel down; what makes you angry is really important,” - wife of a tetraplegic.

“Faith was an underlying support for us, but it was mostly a matter of physical and mental adjustment. We had the children and were also determined not to let this steal our lives together and the plans we had made. We were determined to live as normally as we could. I treat her the same as before. Love is probably the most important factor in helping you adjust (to the spinal cord injury). It was never a question that I’d leave her. It happened, and now let’s go on,” - husband of a tetraplegic.

Specifically, when a married person is injured, responsibilities for finances, parenting, and day-to-day upkeep of the home may change. The additional duties created by the disability and the fact that the healthy partner is likely to be responsible for many of the physical duties related to the care of the family can produce severe stress within the family unit. Honest communication and shared decision-making, when possible, can reduce much of the burden of one individual’s responsibility for the entire family’s well-being.

When children are injured, their care will place additional responsibilities on the parents and siblings. If the child becomes the sole focus of the parents, resentment will probably appear in other family members. This situation is more likely to occur if the child is pampered or over-protected. The family needs to know that SCI is not a sickness. While the injured child may still have to depend on the family for some things, they should be encouraged to and, in fact, may need to be forced to do as much as possible on their own. This should lead to an increase in control over his or hover their own life, a decrease in dependence on others, and, therefore, increased confidence and self-esteem.

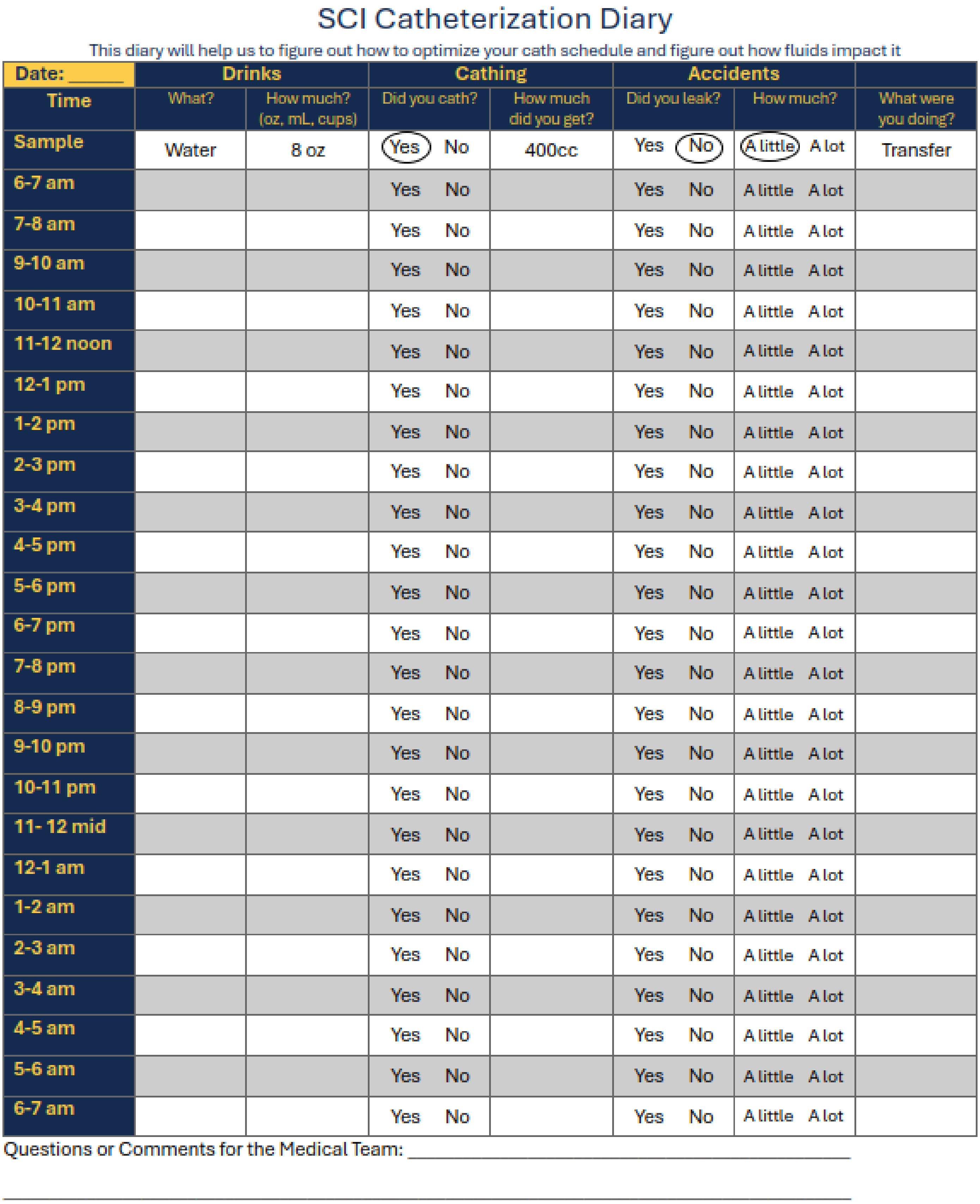
"When he first came home - it was hard to get them to do for themself. Often, it was easier for someone else to do for them. Now, he's much better about taking care of themself - more self-sufficient. I guess that came about when we began communicating to them that we were tired. We told them he could do it just as good as we could," - wife of a paraplegic.

"Now I would say we're about as normal as the people I used to envy. Seeing them cutting grass or playing ball with the kids are the only real exceptions. He is a lot less dependent on me now but it took time. It doesn't happen overnight. It's important to teach yourself not to always be there to pick something up for them. They have to learn to do it all over again," - wife of tetraplegic.

How To Respond to the Injured Person

The person who is injured often experiences and expresses strong feelings, and most often the family will receive the impact of these feelings. It is not unusual, for example, for the injured person to be pleasant, cooperative, and upbeat with staff, but negative, critical, demanding, and passive with family members. You may feel and hear their sadness and anger. You may feel rejected by them and isolated; like they are trying to "shut you out." Family members often receive the most negative emotional reactions, perhaps because you are "safe" and expected to be understanding and forgiving. Family members are often not sure how to respond in such situations. There are no absolute rules. Different situations and people require different responses; however, here are a few guidelines.

1. Try to be a good listener. It is important for the injured person to have someone who knows them, cares about them, and listens to their thoughts and feelings. The best way to be a good listener is to pay attention to be quiet.
2. Do not try to talk the injured person out of negative feelings. Responses like "It could have been worse," or "You don't really feel that way" are probably not helpful. A better response is to acknowledge the feeling and accept it as legitimate. For example, "You must be feeling very down today." A statement like this accepts the feeling as "OK," and shows you have some idea what the person is feeling, but it also implies these feelings may change.
3. Express your feelings, too. Many times, family members feel they must keep up a "brave front." This is not always a good idea. Be honest about your feelings and express them, too. By doing so, you are showing your loved one that you have been hurt, too. Two-way sharing of feelings is the best way of maintaining emotional closeness.
4. Express your support and reassurance. Tell the person that you still value them as a person and will stick with them. Many injured people fear but don't always express concern about being abandoned. You need to tell them and show them that you can be trusted to be there when they need you. It is important for example, if you say you will be there at a certain time to visit or to do something that you follow through. If you do not, the injured person may "read" all sorts of things into your failure to do what you said you would do.
5. Hold on to hope. Express your determination to live today as best as you can and hope for a better tomorrow. Everyone needs hope that things will get better, particularly the injured person. The best message you can give is to reassure them you will work with them as things are now, but you will continue to hope for better things.



SCI Catheterization Diary

This diary will help us to figure out how to optimize your cath schedule and figure out how fluids impact it

Date: ______	Drinks		Cathing		Accidents		
Time	What?	How much? (oz, mL, cups)	Did you cath?	How much did you get?	Did you leak?	How much?	What were you doing?
Sample	Water	8 oz	[✓ Yes] No	400cc	Yes [✓ No]	[✓ A little] A lot	Transfer
6-7 am			Yes No		Yes No	A little A lot	
7-8 am			Yes No		Yes No	A little A lot	
9-10 am			Yes No		Yes No	A little A lot	
10-11 am			Yes No		Yes No	A little A lot	
11-12 noon			Yes No		Yes No	A little A lot	
12-1 pm			Yes No		Yes No	A little A lot	
1-2 pm			Yes No		Yes No	A little A lot	
2-3 pm			Yes No		Yes No	A little A lot	
3-4 pm			Yes No		Yes No	A little A lot	
4-5 pm			Yes No		Yes No	A little A lot	
5-6 pm			Yes No		Yes No	A little A lot	
6-7 pm			Yes No		Yes No	A little A lot	
7-8 pm			Yes No		Yes No	A little A lot	
8-9 pm			Yes No		Yes No	A little A lot	
9-10 pm			Yes No		Yes No	A little A lot	
10-11 pm			Yes No		Yes No	A little A lot	
11- 12 mid			Yes No		Yes No	A little A lot	
12-1 am			Yes No		Yes No	A little A lot	
1-2 am			Yes No		Yes No	A little A lot	
2-3 am			Yes No		Yes No	A little A lot	
3-4 am			Yes No		Yes No	A little A lot	
4-5 am			Yes No		Yes No	A little A lot	
5-6 am			Yes No		Yes No	A little A lot	
6-7 am			Yes No		Yes No	A little A lot	

Questions or Comments for the Medical Team: ____

____

SCI Bowel Diary

This diary will help us to figure out how to optimize your bowel program

<table>
<tr><th>Date</th><th>Medication</th><th>Results</th><th>Comments/Complications</th></tr>
<tr><td></td><td>
<table>
<tr><th>Med</th><th>Dose</th><th>Time Taken</th></tr>
<tr><td>Miralax</td><td></td><td>AM/PM</td></tr>
<tr><td>Senna/Dulcolax</td><td></td><td>AM/PM</td></tr>
<tr><td>Colace</td><td></td><td>AM/PM</td></tr>
<tr><td>Bisacodyl/Magic</td><td></td><td>AM/PM</td></tr>
<tr><td>Enema (   )</td><td></td><td>AM/PM</td></tr>
<tr><td></td><td></td><td>AM/PM</td></tr>
</table>
# of Digital Stimulations <i>(circle one)</i>: 1 – 2 – 3
Position: Bed – Commode – Other _____
</td><td>Time until results: ______
Consistency: _____
Amount ______</td><td><i>(If Accidents, describe #, time, and consistency)</i></td></tr>
<tr><td></td><td>
<table>
<tr><th>Med</th><th>Dose</th><th>Time Taken</th></tr>
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# of Digital Stimulations <i>(circle one)</i>: 1 – 2 – 3
Position: Bed – Commode – Other _____
</td><td>Time until results: ______
Consistency: _____
Amount ______</td><td><i>(If Accidents, describe #, time, and consistency)</i></td></tr>
</table>

Medication List

This is a tool to make sure you know all your medications including when and why you take them.

Medication Name (Generic Name)	How much? (Dose)	How often do I take it? (Frequency)	When do I take it?				Why do I take it?	Comments
			Breakfast	Lunch	Dinner	Before Bed		
		☐As needed (PRN)						
		☐As needed (PRN)						
		☐As needed (PRN)						
		☐As needed (PRN)						
		☐As needed (PRN)						
		☐As needed (PRN)						
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		☐As needed (PRN)						
		☐As needed (PRN)						
		☐As needed (PRN)						

For the Physician

Treatment recommendations:

- Sit patient upright (90 degrees).
- Monitor BP every 2-3 min.
- Quick exam to include abdomen for distended bladder/bowel and any other organ system below the level of injury that can be the source of dysreflexia.
- If an indwelling urinary catheter is not in place, catheterize the individual. If indwelling catheter is in place, check system for kinks, folds, constrictions, or obstructions.
- If systolic BP >150, give an antihypertensive with rapid onset and short duration while causes of AD are being investigated.
    - Nitro Paste—1", apply every 30 min, topically above level of injury, wipe off when BP stable, reapply as needed. Hold if patient has taken PDE5 inhibitors (i.e. Viagra, Cialis, etc.) within 24 hours.
    - Nifedipine IR (if unable to use)—10mg per dose, sublingual form or chewed, may repeat every 20-30 min PRN.
    - Hydralazine: (If unable to use the above)—10mg and repeat PRN.
- Monitor symptoms and BP for at least 2 hrs after the resolution of an AD episode.
- AD can lead to seizures, stroke, or death!

QR Code to the Clinical Practice Guidelines

Created by UC Davis Department of Physical Medicine & Rehabilitation

Design and information based of the Christopher & Dana Reeve Foundation Paralysis Resource Center Autonomic Dysreflexia Wallet Card

Autonomic Dysreflexia (AD)

What is it?

Autonomic Dysreflexia (AD) is a sudden increase in blood pressure, 20-40 mm Hg systolic higher than usual, resulting from harmful, painful, or injurious stimuli applied below neurologic levels in persons with a spinal cord injury (SCI). Someone normotensive may have AD if their baseline SBP is in the 90s.

This condition, which is caused by massive unopposed sympathetic discharge, occurs primarily in those with an injury above the thoracic T6 level. If left untreated, it can lead to a stroke, seizures, or even death. Autonomic Dysreflexia is a medical emergency.

Common Causes:

- Distended bladder (#1 Cause)
- Constipated bowel
- Pressure Injury/Skin damage
- Fractured bones
- Urinary tract infections
- Ingrown toenails
- Uncontrolled Spasticity
- Any condition or procedures that may cause pain or discomfort but is located below neurologic injury level

Common Signs & Symptoms

Above Level of Injury:

- Increased Blood Pressure (A fast increase in blood pressure, 20-40 mm Hg systolic higher than usual)
- Bradycardia (slow heart rate) or Tachycardia (fast heart rate)
- Pounding headache
- Apprehension/anxiety/ uneasy feeling
- Changes in vision
- Nasal congestion
- Sweating
- Flushed skin
- Goosebumps
- Tingling sensation

Below Level of Injury:

- Nausea
- Chills without fever
- Clammy
- Cool
- Pale

My Information

Name:

____

Medical Information:

Baseline Blood Pressure:

____

Level of Injury:

____

Completeness of Injury:

____

SCI Doctor:

Shane Stone, MD (UC Davis Health)

Clinic Number:

916-734-7041

My Common Causes of AD:

____

____

____

What to Do

1. Sit up—Sit up or raise your head 90 degrees. IMPORTANT: Stay sitting or upright until blood pressure is normal.
2. Take off—Take off or loosen anything tight or restrictive.
3. Check blood pressure—Monitor your blood pressure every 5 minutes if greater than 20 mm Hg over your baseline. Be sure to use an appropriate size cuff.
4. Check bladder—Empty your bladder (i.e., catheterize your bladder). If you have an indwelling catheter, check for kinks and blockages.
5. Check bowel—Disimpact bowel after inserting anesthetic jelly or ointment.
6. Check skin—Examine skin for new wounds, pressure ulcers, burns, cuts, insect bites, etc.
7. Find other source—Assess for any other possible source of harmful/painful stimuli or irritant if symptoms have not resolved.
8. Find help—If not able to promptly resolve symptoms on your own, call your healthcare provider for further assistance or go to your nearest emergency room.

IMPORTANT: Tell staff you may have dysreflexia, need your blood pressure checked, need to remain sitting up, and need causes of the problem sought