



# Learning About **Spinal Cord Injury**

**SANFORD**<sup>®</sup>  
HEALTH

# Welcome

This book has been written for patients who have had a spinal cord injury (SCI) and their families. What you learn in this book will be useful during your hospital stay and throughout your life. It will be important to bring this resource with you to your follow-up appointments.

You may have many questions about what will happen as a result of the injury. We will help you and your family learn about your injury and be involved in planning your care. If any of you have questions, please ask. It is often helpful to choose one person to be the main contact to speak with the health care team.



# Table of Contents

The Team..... 4

Advice for Families..... 5

About the Spinal Cord ..... 6

About Spinal Cord Injury ..... 7

Goals for Function ..... 9

Breathing Health..... 12

Circulatory System ..... 14

Skin Care..... 16

About Pain ..... 18

Nutrition ..... 19

Bowel Care ..... 20

Bladder Care..... 22

Range of Motion and Limbs ..... 24

Autonomic Dysreflexia ..... 25

Abnormal Bone Growth (Heterotopic Ossification)..... 27

Social and Emotional Needs ..... 28

Depression and Anxiety ..... 29

Sexuality ..... 30

Managing Your Care at Home ..... 32

Your Transition Home..... 34

Your Rights..... 35

Resources..... 36

# The Health Care Team

## The Patient

You are the most important member of the health care team.

## The Family

Your family is a vital part of the health care team. They can:

- Support you and your goals
- Give information about your pre-injury health
- Read and learn more about SCI

## The Caregivers

You will meet many experts who care for people with SCI. The team includes doctors, advanced practice providers (APPs), and nurses.

Other members of the team may include:

- Case Management team (Registered Nurse Case Manager and Social Worker) creates your discharge plan. They will help find answers to financial or insurance questions.
- Spiritual Care helps with spiritual support and links to other spiritual leaders if you request it.
- Respiratory Therapists (RT) help with breathing problems.
- Occupational Therapists (OT) focus on increasing self-care skills, adapting equipment for daily tasks, and helping you return to valued activities.
- Physical Therapists (PT) provide treatments to promote movement, reduce pain, restore function, and prevent further disability.
- Speech Language Pathologists work with speech, language, and swallowing problems. They may also do a cognitive (thinking) evaluation.
- Recreation Therapists focus on your return to everyday life.
- Registered Dietitians help find the best foods and supplements for healing. Some food choices will be based on what you can safely take in.
- Psychologists help you and your family adapt to changes in your life.



# Advice for Families and Loved Ones

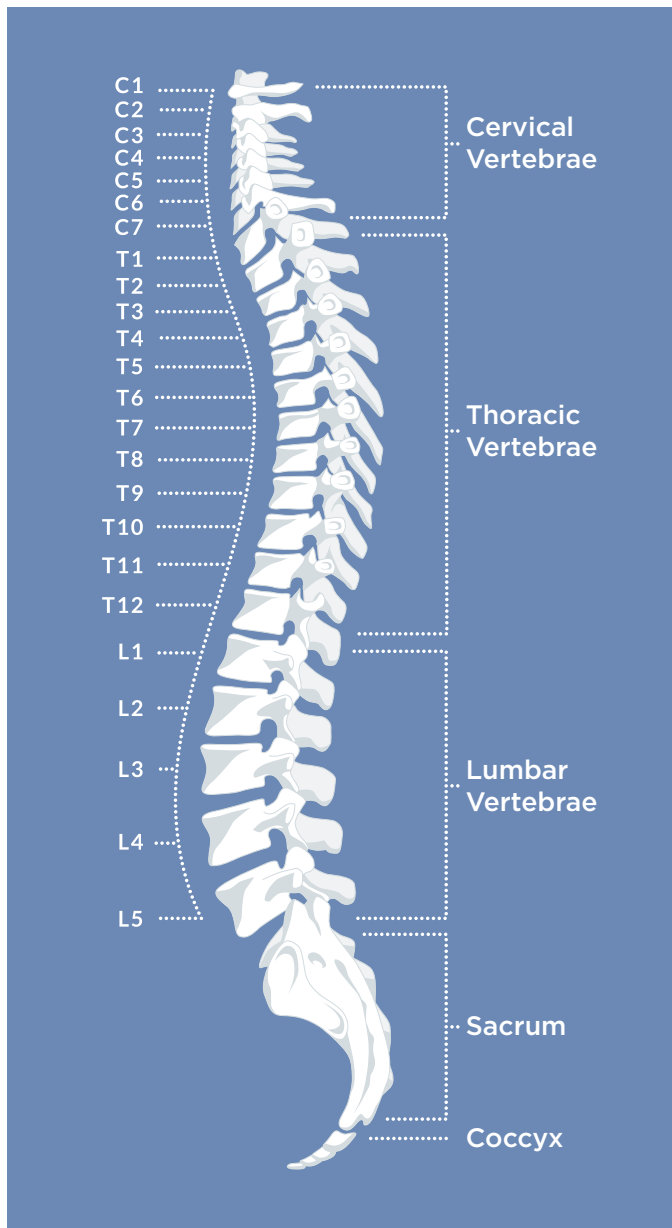
Family and friends will be able to visit, but visits may be limited. Visiting a patient with SCI may be hard. Focus on what the person is able to do.

Family often spends a lot of time and energy caring for and thinking about their loved one. Families of former patients have offered these tips to help loved ones cope with the stress:

- Get a notebook and write down questions as they come to mind. Ask the doctor or nurse. Then write down the answers so they can be shared with others.
- Share what is happening so family and friends can support each other:
  - Set up a group text message or email.
  - The family member chosen as the contact person can leave a message on their voicemail with updates.
  - Keep a journal in a notebook or online such as Caring Bridge. [www.caringbridge.org](http://www.caringbridge.org)
  - Create a private social media group page.
- Seek out support from:
  - Family and friends
  - Church and/or chaplain services
  - SCI support groups
- Allow time away. Take a walk. Invite friends or family members to join you.
- Many people will want to help but are unsure how. Here are some ideas:
  - Ask a family member to be the contact person for others to take calls and give updates.
  - Ask a family member to file and organize medical papers, bills, insurance statements, rehabilitation information, and other paperwork.
  - Let friends and others give food, transport visitors, and help with children as needed.



# About the Spinal Cord



The bones of your spine are called vertebrae. There are 33 vertebrae:

- 7 cervical vertebrae in the neck
- 12 thoracic vertebrae in the upper back
- 5 lumbar vertebrae in the lower back
- 5 sacral vertebrae or sacrum
  - In adults, these bones have fused together to form the sacrum
- 4 coccygeal vertebrae or coccyx
  - In adults, these bones have fused together to form the coccyx

The spinal cord is a bundle of nerves that looks like a rope. It is about as wide as your little finger.

When the vertebrae are stacked on top of each other, the opening in the middle of the bones forms a tunnel. The spinal cord passes through this tunnel from the brain to the lower back. This allows the vertebrae to surround and protect the spinal cord.

Above and below each vertebrae, spinal nerves branch out from the spinal cord. These nerves are named with a letter for the section of the spine and a number for the nerve (see image).

The spinal nerves carry messages between the brain and the rest of the body. These messages:

- Make you aware of feelings such as touch, pain, hot, or cold
- Tell your muscles how to move

# About Spinal Cord Injuries

Many accidents or diseases can damage the spinal cord. These can include:

- Falls
- Vehicle accidents
- Gunshot or stab wounds
- Infections or tumors near the spine
- Arthritis that affects the vertebrae
- Problems with the blood supply to the spinal cord

SCI can happen at any level of the spinal cord. It prevents messages from being sent between the nerves below the level of injury and the brain. This reduces feeling and movement below the level of the injury. It can also affect how your brain controls the organs inside your body. A physical exam will be done to check for spinal cord damage. Testing may include X-ray, CT scan, or other imaging tests.

The SCI is named for the lowest nerve that works the way it did before. Generally, the higher the level of spinal injury, the less function you have. SCI may be complete or incomplete.

## Complete Injury

- No feeling or voluntary movement below the level of injury
- Both sides of the body are equally affected

## Incomplete injury

- Some voluntary movement below the level of injury
- May have more voluntary movement in one limb than the other
- May have more feeling in one limb or part of the body than the other
- There are different types of incomplete SCI:
  - **Brown-Sequard Syndrome:** Loss of feeling on one side of the body and weakness or paralysis on the other side below the level of injury.
  - **Anterior Cord Syndrome:** Loss of movement, pain, and temperature sense below the level of injury on one side. The ability to sense touch and vibration on the other side.
  - **Posterior Cord Syndrome:** Able to move the body below the level of the injury. Loss of ability to feel pressure, vibration, and sense of location of the limb.
  - **Central Cord Syndrome:** More loss of movement in the upper limbs than the lower. Below the level of injury sensations vary.
  - **Cauda Equina Syndrome (CES):** The bundle of nerves below the spinal cord is damaged. CES can include low back pain, pain down the leg, numbness around the anus, and loss of bladder or bowel control. Weakness depends on which nerves are affected.

At first, the spine may only be bruised or swelling may put pressure on the spinal cord. As the bruise heals or the swelling goes down, the nerves may start to work again. Your spinal cord may also be in “spinal shock” and stop working for a time right after the injury. It may take weeks or months for this to improve. The care team will watch for changes in your ability to move or feel. It may not be possible to predict if or how much this will improve.



SCI is classified by how much sensation and function you lose. The classifications are:

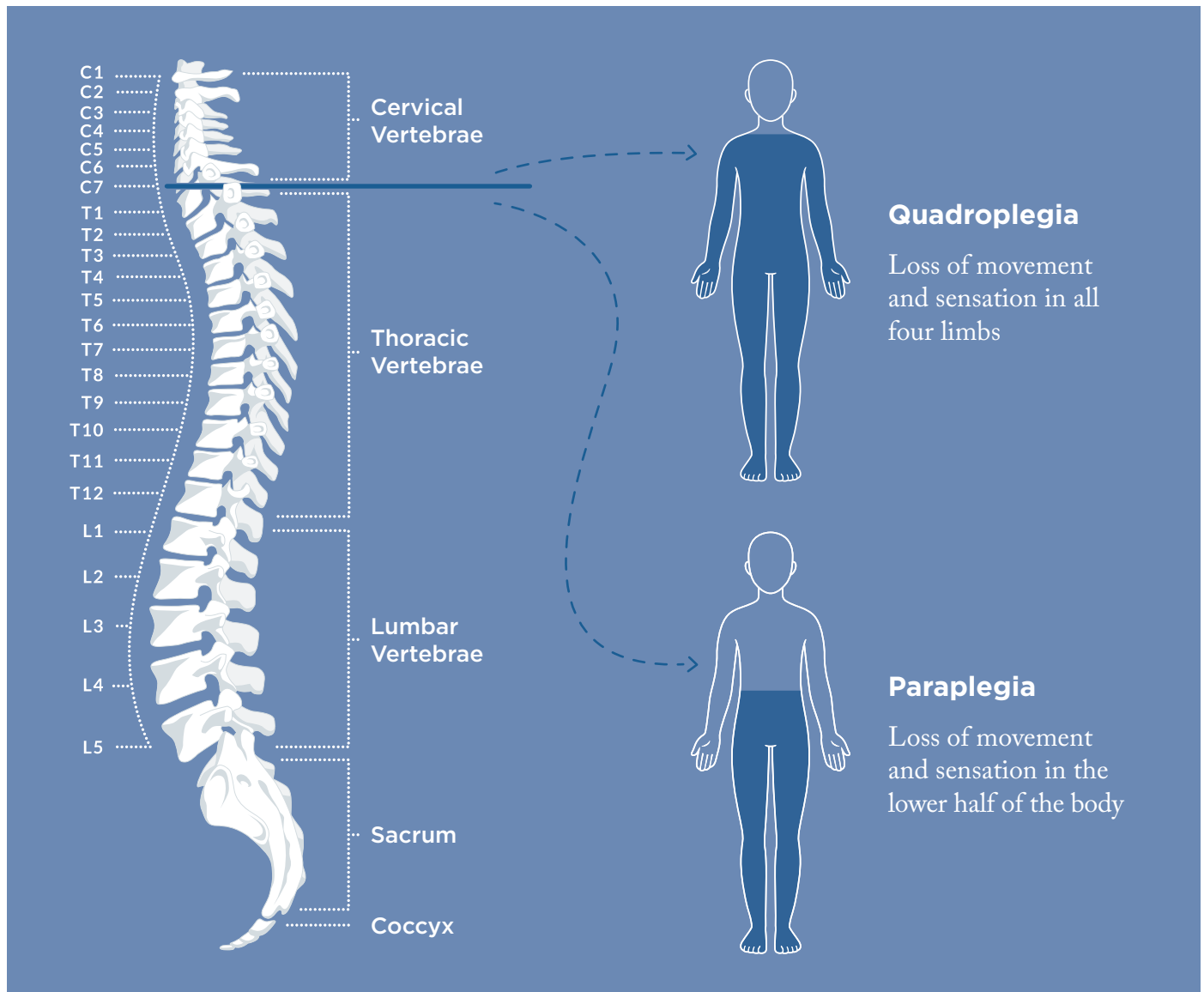
- **Quadriplegia or Tetraplegia:** Loss of movement and feeling in both arms and both legs. It can also affect the chest muscles. Injuries from C1 to T1.
- **Paraplegia:** Loss of movement and feeling in both legs. Injuries from T2 to S5.
- **Triplesia:** Loss of movement and feeling in one arm and both legs.

Many body functions can be affected by SCI. After SCI, you may have:

- Muscle weakness or paralysis
- Loss of feeling in the trunk of the body, arms, or legs
- Muscle spasms, twitching or shaking
- Breathing problems
- Circulation problems
- Digestive problems
- Loss of bowel and bladder function
- Loss of sexual function

Everyone with SCI is different even with the same level of injury. Many people with all levels of SCI have a high quality of life. Your doctor and care team can help you set goals and learn what outcomes to expect with your injury.

## Acute Spinal Cord Injury

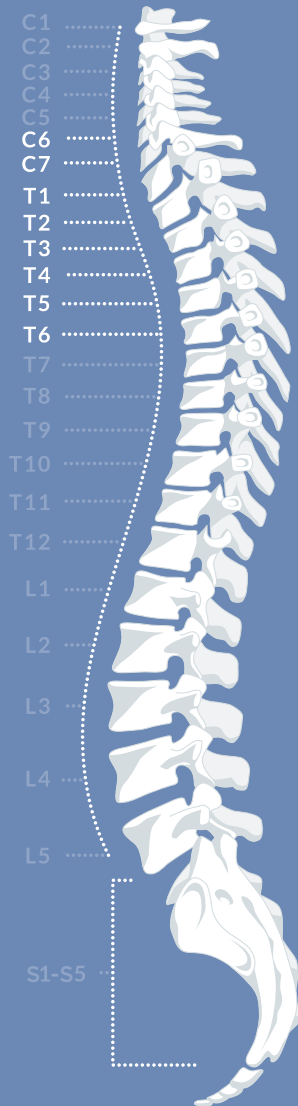


# Goals for Function

The goal for SCI rehabilitation is for you to function at your highest level – physically, emotionally, and socially. It may be helpful to know what is possible with each level of SCI.

This table will give you a clearer view of what you may be able to do based on your level of injury. Other things like your body type and health issues may also affect what you will be able to do after SCI. Your health care team will help set goals with you. Improved technology offers many options to help you return to what you want to do.

	<b>Level of Injury: C1 - C3</b>	
	<b>Ability</b> <ul style="list-style-type: none"> <li>• May be fatal due to breathing problems</li> <li>• Quadriplegia</li> <li>• Some head and neck movement</li> <li>• Talking is often limited or impossible</li> </ul>	<b>Goals</b> <ul style="list-style-type: none"> <li>• Must use a ventilator to breathe</li> <li>• Use devices to help:               <ul style="list-style-type: none"> <li>- Communicate</li> <li>- Use a telephone</li> <li>- Turn lights or appliances on and off</li> </ul> </li> <li>• Use an electronic wheelchair</li> </ul>
	<b>Level of Injury: C4</b>	
	<b>Ability</b> <ul style="list-style-type: none"> <li>• Quadriplegia</li> <li>• Head and neck control</li> <li>• May shrug shoulders</li> <li>• Able to talk normally</li> </ul>	<b>Goals</b> <ul style="list-style-type: none"> <li>• Usually need a ventilator to breathe at first but may be able to breathe on own later</li> <li>• May be able to feed self using special equipment</li> <li>• May be able to adjust bed with an adapted controller</li> </ul>
	<b>Level of Injury: C5</b>	
	<b>Ability</b> <ul style="list-style-type: none"> <li>• Quadriplegia</li> <li>• Head, neck, and shoulder control</li> <li>• Bend elbows</li> <li>• Turn palms up</li> </ul>	<b>Goals</b> <ul style="list-style-type: none"> <li>• Usually can breathe without a ventilator</li> <li>• May be able to feed self, wash face, brush teeth, and comb or brush hair using special equipment</li> <li>• Can cough and lean side-to-side in chair</li> <li>• May be able to use a manual wheelchair on a smooth surface</li> <li>• May be able to drive a motor vehicle using special equipment after special testing</li> </ul>



### Level of Injury: C6

#### Ability

- Quadriplegia
- Bend elbows
- Turn palms up and down
- Straighten wrists

#### Goals

- May be able to dress self
- Do light housekeeping chores
- Turn in bed and relieve pressure
- Get into and out of a wheelchair using a sliding board

### Level of Injury: C7

#### Ability

- Quadriplegia
- Bend and straighten elbows
- Some hand movement

#### Goals

- Do household chores
- Do wheelchair push-ups
- Use manual wheelchair even outside
- Get into and out of a wheelchair more easily
- Help with bowel and bladder programs

### Level of Injury: C8 - T1

#### Ability

- Quadriplegia
- Use of arms
- Hands and fingers may be weak

#### Goals

- Do daily self cares without help or special equipment
- Use manual wheelchair
- Get into and out of a wheelchair without help

### Level of Injury: C8 - T1

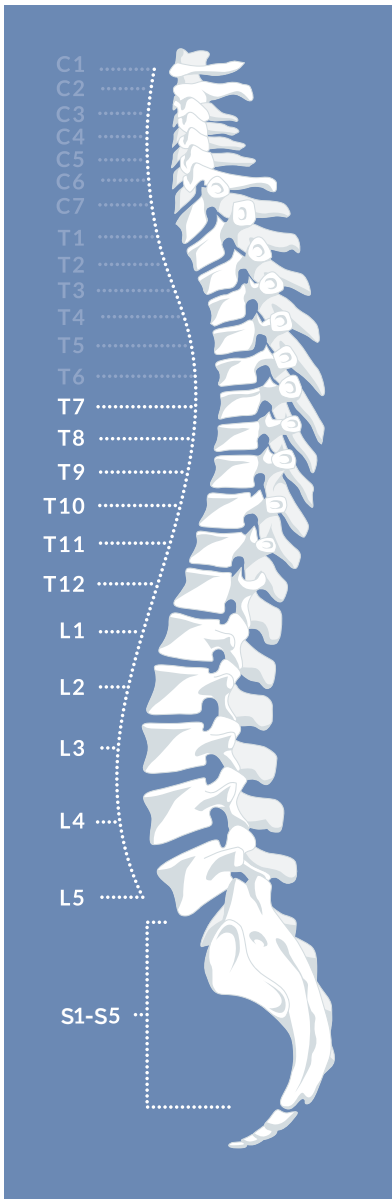
#### Ability

- Paraplegia
- Normal use of head, neck, shoulders, arms, hands, and fingers
- More use of rib and chest muscles
- More control of body trunk

#### Goals

- Do all self-care activities without help





**Level of Injury: T7 - T12**

**Ability**

- Paraplegia
- More abdominal muscle control

**Goals**

- Good sitting balance
- May be able to do adaptive sports
- Better able to cough

**Level of Injury: L1 - L5**

**Ability**

- Paraplegia
- Some movement of hips and knees

**Goals**

- May walk with special braces and devices

**Level of Injury: S1 - S5**

**Ability**

- Paraplegia
- Some control of bladder and bowel
- Some sexual function

**Goals**

- May be able to walk with fewer devices

# Breathing Health

Your body is made up of billions of tiny cells. All of these cells need oxygen. The respiratory (breathing) system supplies oxygen to the body cells and removes carbon dioxide.

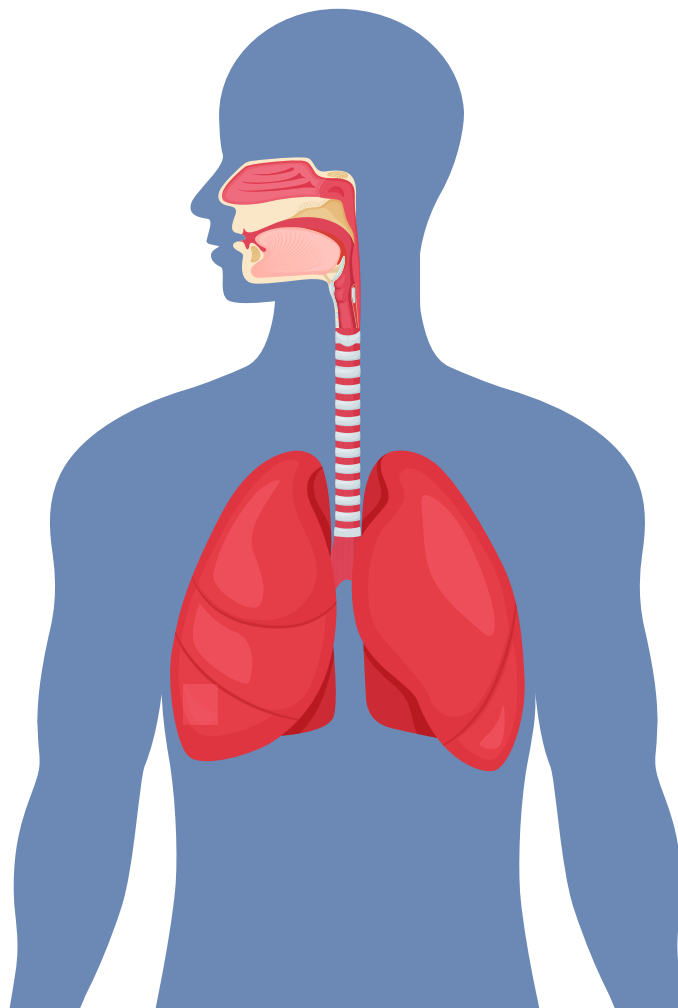
Your respiratory system has two parts, the lungs and the air passages. The air passages divide and get smaller as they go further into the lungs. At the end of the air passages are tiny clusters of air sacs. The walls of these air sacs are very thin so oxygen and carbon dioxide pass through easily.

When you breathe in, air rich in oxygen flows through the air passages into your lungs. Oxygen and carbon dioxide are exchanged in the tiny blood vessels surrounding the air sacs. When you breathe out, your lungs deflate and carbon dioxide leaves the body.

It does not take any muscles to breathe air out of the lungs. But it takes 4 muscle groups to breathe air in.

- **Diaphragm:** A large, dome-shaped muscle that stretches across the body just below the lungs. When you breathe in, the diaphragm pulls down causing your lungs to expand and fill with air. When you breathe out, the diaphragm relaxes up.
- **Intercostal muscles:** Found between the ribs and help to expand the ribs as you breathe in
- **Neck muscles:** Help the upper chest to expand as you breathe in
- **Abdominal muscles:** Help you breathe deeply and cough

Normally, you breathe in and out without thinking about it. After SCI, you may not be able to breathe on your own. The higher the level of SCI, the more likely you are to have problems with breathing. Injuries of the lower spinal cord in the lumbar or sacral regions do not usually affect breathing.



## Ventilators

Many people who have SCI have trouble breathing on their own right after the injury. A machine called a ventilator may be needed to help you breathe. A ventilator can push air and extra oxygen into the lungs.

If a ventilator is needed for more than a few weeks, a small opening (called a trach or tracheotomy) may be made at the base of your throat so a breathing tube can be placed. This allows air to move in and out of your lungs without having a tube through the vocal cords in your throat.

If you have a high level SCI, you may need a ventilator to help you breathe even when you go home. Ventilators used at home are usually small and portable. Your care team will teach you and your loved ones how to use the ventilator safely.

## Respiratory Problems

Lung problems after SCI can be very serious. Pneumonia or lung infection is common. This is because the muscles used to cough are usually weak and it can be difficult to get mucus out of your lungs. You will be taught how to help yourself cough and move mucus out of your lungs.

Things that can help to move mucus out of your lungs:

- Cough often, have someone who is trained help you cough
- Drink more fluids to keep the mucus thin
- Change your position often
- Do breathing exercises often
- Wear an abdominal binder
- Take a warm bath or shower to keep the air you breathe moist
- Stay away from smoke, dust, and dangerous chemicals in the air
- If you smoke, stop!

Let your health care team know right away if you have any symptoms of pneumonia which can include:

- Fever and chills
- Shortness of breath
- Coughing up green or yellow mucus
- Sweating with pale, clammy skin

If you have any of these symptoms, you may be taught ways to help move the mucus out of your lungs more quickly.



# Circulatory System

Your circulatory system is made up of your heart and blood vessels. The heart pumps blood through the vessels and pressure keeps it moving. Blood carries oxygen and nutrients to every cell in your body. It also carries carbon dioxide away from the cells. SCI affects how well your body moves blood through the circulatory system.

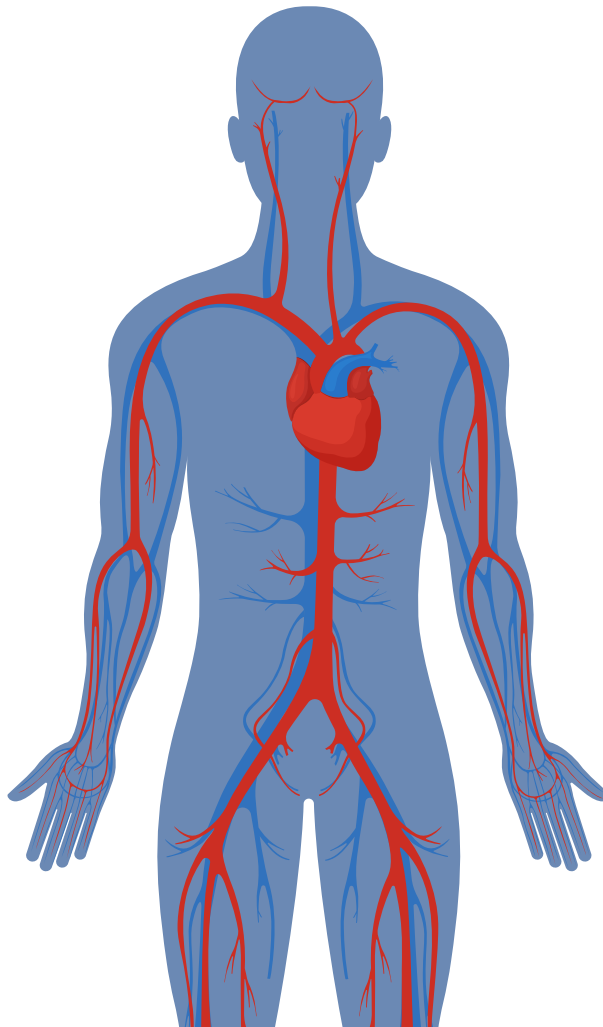
## Circulatory Problems

The two most common problems with the circulatory system after SCI are:

- **Orthostatic hypotension:** A drop in blood pressure when you change position, such as going from lying down to sitting up. If your blood pressure is low, less blood is pumped to your brain. This can make you feel dizzy or lightheaded and you may faint. While you are in the hospital, your care team will watch you carefully and take steps to reduce large drops in blood pressure. Compression stockings and/or ace wraps to the legs and an abdominal binder may help your symptoms.
- **Deep vein thrombosis (DVT):** A blood clot in your leg. Tension in your muscles and the walls of your blood vessels help your blood to circulate. After SCI, you have less tension in your muscles and blood vessels. This makes it more likely a blood clot will form. You may be given medication to keep your blood flowing more easily. Compression stockings may help prevent blood clots.

Other problems include:

- **Pulmonary emboli (PE):** A blood clot in the lungs
- **Problems controlling your body temperature**
- **Slower heart rate**
- **Edema:** swelling of your legs, feet, and/or hands



## You Can Do Some Things to Help:

- Wear compression stockings, ace wraps, or abdominal binder if advised to do so
- Elevate your legs, feet, or hands if they tend to swell
- Do your range-of-motion exercises
- Change your position often but take your time
- Make sure braces, splints, urinary devices, clothing, and shoes are not too tight
- Maintain a healthy weight
- Drink more fluids
- If you smoke, stop!

Let your health care team know right away if you feel:

- Swelling for more than a week or a sudden increase in swelling
- Tightness, warmth, or more swelling in one leg than the other – the area may be red
- Sudden shortness of breath or tightness in your chest
- Pain in your side, chest, or back that is worse when you breathe in
- Dizzy, weak, or faint

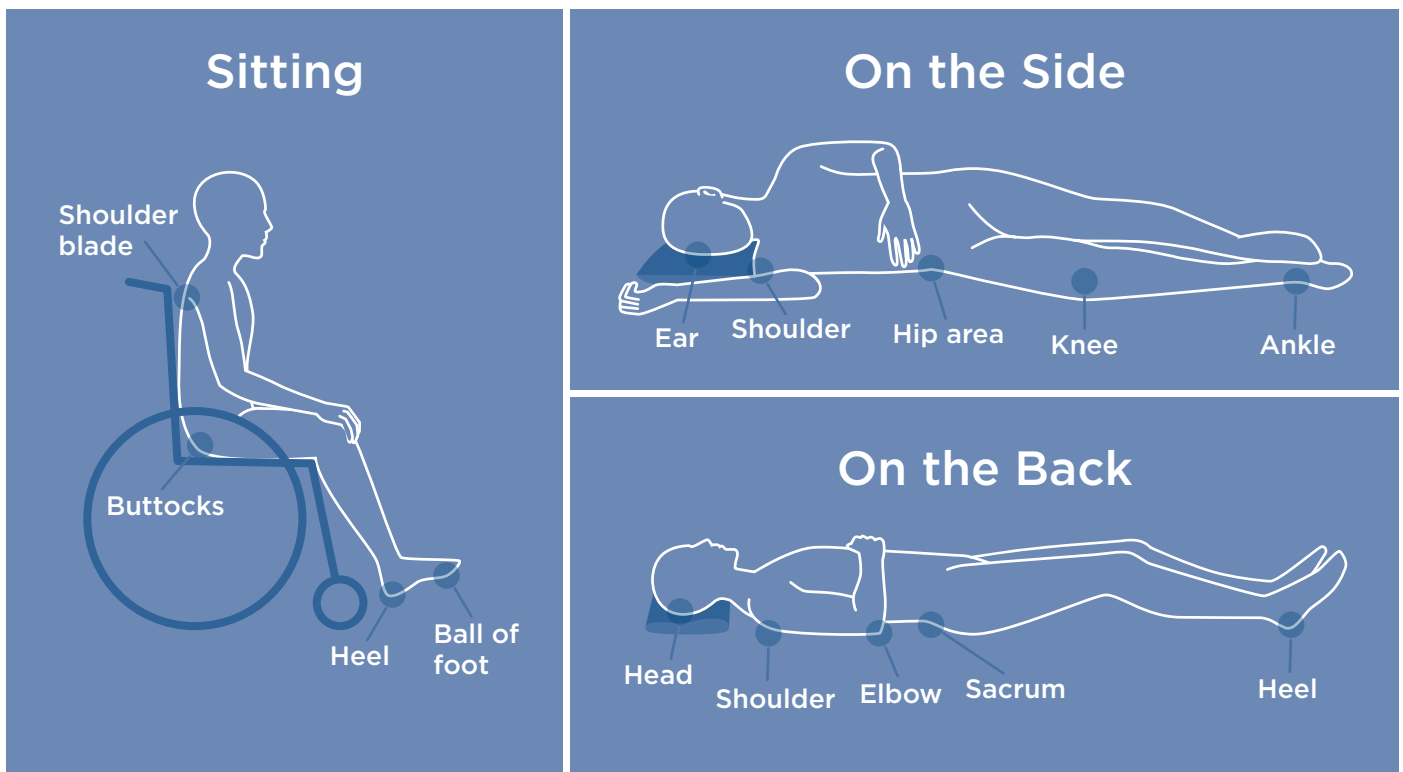


# Skin Care

Healthy skin prevents infection. Pressure injuries can harm your skin and the tissue underneath by reducing blood flow to those areas. Having SCI affects your ability to feel and move. It also causes changes that make skin more fragile. Changes to the way you move can cause injury. Damage can occur from:

- Continued pressure in the same place (especially over bony areas)
- Sliding to the bed or chair
- Braces or other things that cause pressure to the skin

These are common areas to watch for pressure.



The best way to avoid problems with your skin is to prevent pressure injury. It is important to:

- Change how you are sitting or lying often.
  - Use a schedule for turning in bed. Lift rather than slide across the sheets.
  - Change your position in the wheelchair every 15 to 20 minutes. You may be taught ways to shift your weight such as wheelchair push-ups.
  - Use a timer or phone to set reminders to move.
- Keep your skin clean and dry.
- Check your skin at least 2 times each day, in the morning and at night. Pay special attention to bony areas. Use a mirror for hard to see spots. You may choose to have pictures taken to watch areas of concern.
- Make sure to check areas that are in contact with a chair, bed, or device such as a neck collar or brace.
- Make sure clothing and shoes fit well and are not too tight.
- Know if you need to limit or stop caffeine. Beverages such as coffee, tea, and soft drinks can cause you to become dehydrated and may trigger bladder spasms.



- Eat a healthy diet and stay active.
- Drink plenty of non-alcohol liquids.
- Keep a healthy weight.
- Do not smoke.

Special beds and pressure relief aids can also be used. It is important to watch for red spots on the skin or any areas that show signs of damage or drainage and to avoid more pressure. If a sore gets worse, it can result in infection, fever, and the need for long hospital stays. Bad pressure sores can cause a general body infection called sepsis, which can lead to organ failure and death.

- Let your care team know right away if you see any of these signs of pressure injury:
- Skin redness that does not go away in 15 minutes
- Other skin color changes
- A spot that is soft, warm, or cool
- Swelling
- Scrapes, cuts, or blisters
- A spot that hurts or itches (if it has sensation)

Skin problems can lead to another problem called autonomic dysreflexia. This problem can be life threatening. You will find more about autonomic dysreflexia in another section of this book.



# About Pain

Pain tells the nervous system about a possible injury. Pain after an injury or surgery can usually be treated and gets better over time. Pain that lasts a long time or keeps coming back is called chronic pain. After SCI, you may or may not have pain.

## **Bone, Muscle, and Soft Tissue Pain**

This pain happens when bones, muscles, or soft tissues are injured due to overuse, overstretching, or falls. After SCI, muscles that still function may be used more or differently than before. This may cause aching, gnawing, or throbbing pain. Activity may make it worse and it often improves with rest.

## **Organ Pain**

This pain happens when internal organs, such as your stomach, bladder, or intestines, are overstretched or lose their blood flow. It may be described as pressure, deep aching, or cramping.

## **Nerve and Spinal Cord Pain**

This is often called neuropathic pain. It comes from irritation, stretching, or pressure on the nerve. This pain may be described as burning, aching, prickling, tingling, or itching. It may feel like you are getting short electric shocks.

# Managing Your Pain

Although your pain may not go away completely, the goal is to reduce your pain so you are able to take part in therapy and things you want to do. It is important to share as much as possible about your pain with your health care team. Keep a pain diary and write down:

- When did you have pain?
- Where was your pain?
- What did it feel like? Describe the pain.
- What were you doing when the pain started?
- What helped the pain get better?
- How long did the pain last?

Depending on the type and cause of your pain, treatment may include:

- Medication
- Cold or hot packs
- Massage
- Nerve stimulators
- Splints, pads, or positioning aids
- Surgery

To manage chronic pain, focus on things that can help you live better, such as:

- Managing stress
- Keeping a steady level of activity every day so you don't overdo it on the good days
- Using mindfulness, meditation, or music to reduce muscle tension and stress
- Counseling to help you find new ways to cope and treat pain

Your health care team will work with you to help prevent and treat pain. Understanding what makes your pain worse as well as having goals and plans to manage your pain will help you to be in charge of your own life and comfort.



# Nutrition

Your food needs will be different after your injury. At first, you may have problems getting enough nutrition. Later, due to less activity, you may be concerned about weight gain. Eating well helps the body recover and fight disease.

There are 2 main concerns about what you eat after SCI. The first is getting the right nutrition to heal, stay healthy, and prevent problems. The second is managing your weight. Working with a registered dietitian nutritionist, you will learn more about what you need to eat. Supplements may be advised.

In general, you will need enough protein to support healing and strength. This will also prevent tissue or muscle breakdown. You may need more protein if you have a pressure sore.

## **Sources of Protein Include:**

- Eggs
- Lean meat, poultry, fish, shrimp
- Nuts and grains (including oatmeal)
- Milk, cottage cheese, yogurt
- Broccoli and brussel sprouts

## **Other Eating Guidelines Include:**

- Eat mostly vegetables, fruits, and whole grains. These foods provide fiber and help prevent bowel problems.
- Add canned or dried beans to recipes. Rinse canned beans. Read the label to choose low sodium options.
- Use nuts such as peanuts, almonds, cashews, pistachios, and walnuts for snacks. Choose natural peanut butter to avoid unhealthy fats.
- Eat fish 2 times a week or more. Grilling and baking are healthy ways to prepare fish.
- Try olive oil, peanut oil, or canola oil as a healthy replacement for butter or margarine.
- Eat fewer foods with high-fat and sugar to decrease your risk of heart disease and diabetes.
- Replace some red meat with fish and poultry. Limit red meat to 2 times per week. Avoid sausage, bacon, deli-meat, and other high-fat, highly processed meats.
- Switch to low-fat dairy such as skim or one percent milk, low-fat yogurt, and low-fat cheese. Limit high-fat dairy such as ice cream.
- Drink plenty of fluids to prevent dehydration and keep your bladder and kidneys flushed. This helps prevent infection.
- Season your meals with herbs and spices rather than salt. Limiting your salt intake can prevent swelling and high blood pressure.
- Consider having a glass of wine or purple 100% grape juice, or having a small portion of grapes at one meal each day to provide some heart healthy nutrients. Alcohol has no food value and affects how the body uses the food it takes in so talk with your doctor about the value of adding wine to your diet.

# Bowel Care

Nerves from your lower spinal cord allow you to control your bowel. After SCI, you may not feel when you need to have a bowel movement (BM) or be able to control it. The care team will help you plan a bowel program.

## How SCI Effects the Bowel

The effect on your bowel and how it empties depends on the level of your injury.

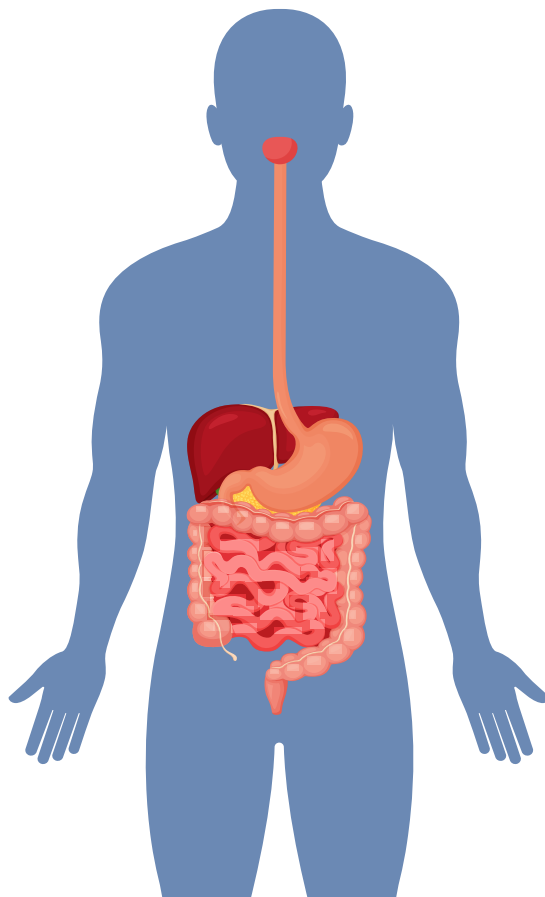
- **Upper level SCI (T12 or higher)** may cause your bowel to release stool when the bowel is full which can cause accidents. This is called a spastic or reflex bowel. You may not be able to feel when this happens.
- **Lower level SCI (below T12)** may cause the bowel to have trouble emptying even though the muscle around your anus is relaxed. Stool needs to be removed from the rectum with a gloved finger. This is called digital stimulation. Removing the stool will help prevent the bowel from being too full or leaking stool.

The goals are to:

- |   |  |
|---|--|
| <input type="checkbox"/> Have a BM every 1 to 2 days                                    | <input type="checkbox"/> Complete each BM within a reasonable time (no longer than 60 minutes) |
| <input type="checkbox"/> Empty your bowel at your planned time                          | <input type="checkbox"/> Feel secure to take part in activities                                |
| <input type="checkbox"/> Avoid leaking stool or an unplanned BM                         | <input type="checkbox"/> Be healthy  |
| <input type="checkbox"/> Keep your stool soft and formed (with results of about 2 cups) |  |

Your bowel program will be tailored to meet your needs. It will include:

- |  |   |
|--|---|
| • Eating a well-balanced, high fiber diet                  | • Regular exercise, including range of motion |
| • Drinking plenty of fluid (unless you are told otherwise) | • Having privacy                              |



A bowel program may work best after a meal. Being upright helps move the stool down. Some people may need one or more of the following:

- Stool softeners to add fluid to the stool so it is easier to pass.
- Stimulant laxatives to increase bowel activity causing the stool to move through the bowel more quickly.
- Manual removal to take the stool out of the rectum with a gloved, lubricated finger. This can be done as you bear down. Do not bear down if you have a heart condition.
- Digital stimulation, which is a circular motion with the index finger, causes the anal sphincter to relax.
- Suppositories that cause nerve endings in the rectum to contract or draw water into the stool to cause a BM.
- Mini-enemas that soften, lubricate, and draw water into the stool causing it to pass.

Many foods, medications, and illnesses can affect how and when you have a BM. Contact your care team if you have:

- Fever of 100.4 or more
- No BM for 3 to 4 days past your bowel program schedule
- Hard stool that is difficult to pass
- Diarrhea that lasts more than 24 hours
- Rectal bleeding that is more than usual for you – You may have a slight amount of red blood due to hemorrhoids or after a BM
- Black, tarry-looking stool and you are not on iron supplements
- Swollen, hard, or painful stomach
- Nausea or vomiting



# Bladder Care

Nerves from your lower spinal cord allow you to control your bladder. After SCI, your bladder may not work the same way as before. Your care team will help you plan a bladder program to help manage these changes.

## How SCI Effects the Bladder

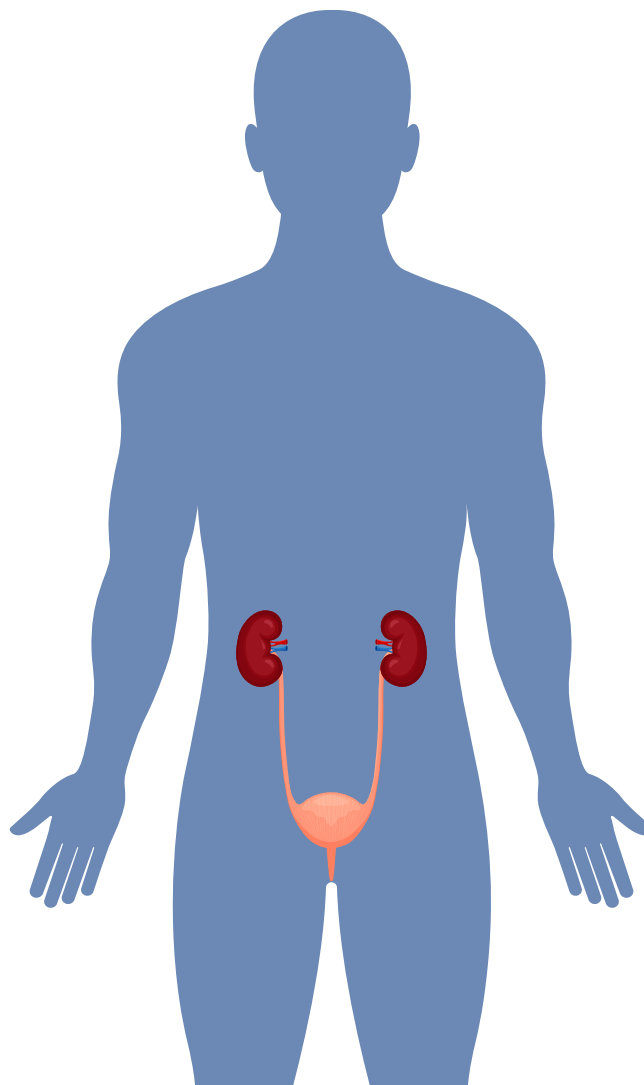
The effect on your bladder and how it empties depends on the level of your injury.

An upper level SCI (T12 or higher) may cause your bladder to release urine when it is full which may result in accidents (due to a reflex or spasm). You may not be able to feel when this happens. Some urine may remain in your bladder or back-up into your kidneys. This can cause infection or kidney damage.

A lower level SCI (below T12) may cause your bladder not to contract (flaccid) when it is full which may result in accidents. You may not know when your bladder is full. Urine can leak out when you cough or sneeze. If your bladder is often too full, it may cause infection or damage to your bladder.

The goals are to:

- Manage your bladder in a way that fits your needs
- Empty on a regular schedule and not have accidents
- Avoid having too much urine in your bladder
- Keep the skin clean and dry
- Prevent the risk of infection or other problems





Your bladder program will be tailored to meet your needs. It may include:

- **Indwelling catheter (Foley):** At first you will have a tube in your bladder that allows urine to drain into a bag. This is called a catheter. It will usually be removed when you are stable.
- **Intermittent catheterization:** If you are not able to pass urine on your own or only pass a small amount of urine at a time, you or your caregiver will be taught how to place a catheter into your bladder. The catheter will be placed into your bladder and removed several times each day. This will decrease your chance of getting an infection. This will keep your bladder healthy because it fills and empties more like it normally would. You may also be on a fluid limit.
- **Stimulated voiding:** If you still have some control of your bladder, you may be taught how to trigger your urine to empty by:
  - **Crede (kred ā):** Pressing down on the bladder
  - **Tapping:** Tapping with the fingertips or the side of the hand, lightly and repeatedly over the bladder
  - **Valsalva:** Bearing or pushing down as if you were having a bowel movement
- **Medications:** Medications are part of your bladder program. There are many types of medication used depending upon your injury.
- **Surgical options:** such as a suprapubic catheter, may be discussed if needed.

## Preventing Urinary Problems

Urinary tract infections (UTIs) and kidney problems can occur after SCI. Take these steps to stay healthy, avoid problems, and protect your urinary tract:

- Wash your hands before and after your bladder program.
- Empty your bladder on a regular schedule as you or your caregiver are taught.
- Drink plenty of water unless you are advised otherwise by your care team. Water helps flush your system. This helps prevent UTIs or bladder and kidney stones.
- Decrease the amount of caffeine that you eat and drink. Caffeine causes you to make more urine and pass urine more often. This can lead to urgency and accidents. Caffeine may be found in coffee, tea, soda, energy drinks, and chocolate.
- Know when to contact your care team.

Contact your care team if you have:

- Fever of 100.4 or more
- Chills
- Burning when passing your urine
- Aching in your belly or lower back
- More spasms in your belly, legs, or bladder
- Nausea or vomiting
- Extreme tiredness

Cloudy urine or urine that smells bad does not always mean you have a UTI. Cloudy urine is an important sign if you also have a fever, chills, or other symptoms.

If you have cloudy urine:

- Drink more water
- Limit your caffeine intake
- Empty your bladder more often



# Range of Motion and Limbs

Range of motion is how far a joint will move in any direction. Limbs with normal strength and movement stay strong and flexible with everyday movement. After SCI, the range of motion of some of your joints may be less. You may learn other ways to keep your joints flexible. A caregiver or therapist may need to help bend and straighten some of your joints to keep them flexible.

Moving your joints through their range of motion can:

- Improve your posture, balance, and ability to transfer
- Make it easier to change position
- Prevent pressure sores and permanent shortening of muscles
- Help you be as independent as possible

After SCI, it is very important to stretch your muscles to stay flexible. Muscle tightness can limit the daily activities you are able to do such as dressing, eating, or moving to and from your wheelchair. A physical and occupational therapist will teach you and your caregivers the best way to do your range of motion exercises.

## Preventing Injury

To protect your upper limbs from injury:

- Wear gloves to protect your hands when using them to push your wheelchair
- Support your arms, do not let them dangle, and do not let anyone pull on them
- Avoid bearing a lot of weight with your arms or lifting heavy loads
- Avoid repeatedly doing the same movements
- Avoid tasks that need to have your hand higher than your shoulder
- Avoid leaning your elbows on a desk, table, or wheelchair armrests

To protect all of your limbs:

- Be sure all equipment is set up properly
- Exercise as you were taught
- Stay in your ideal weight range
- Avoid overstretching your joints



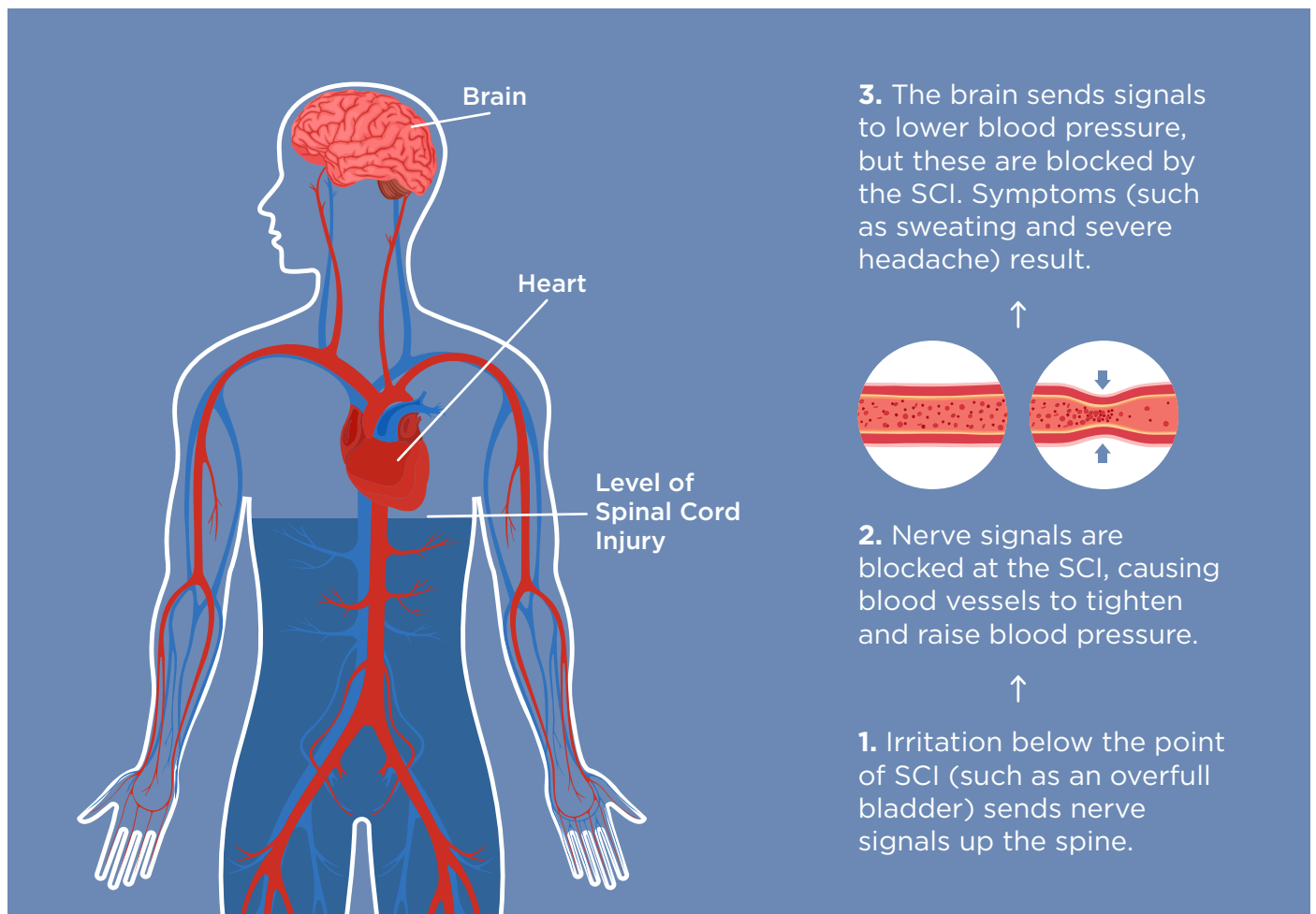
# Autonomic Dysreflexia

Autonomic dysreflexia occurs when your blood pressure rises in response to something that would have caused pain or discomfort before your injury. You no longer feel the pain but your body reacts anyway. Your blood pressure can rise to a dangerous level, causing stroke or death.

Autonomic dysreflexia can happen to anyone with SCI of T6 and above. It usually does not happen in the first 1 to 2 months after the injury, but often occurs within the first year.

Different people have different symptoms. You may have one or more of these symptoms as well as high blood pressure:

- Severe, pounding headache
- Heart rate less than 60 beats per minute
- Blurry vision or seeing spots
- Flushed skin, goosebumps, and sweating above the level of injury
- Cold, pale skin below the level of injury
- Stuffy nose
- Sick to your stomach (nausea)
- Feeling anxious



Causes of autonomic dysreflexia can include:

- **A full bladder:** the most common cause
- **Bowel problems:** such as severe constipation, bowel filled with gas, or hemorrhoids
- **Skin problems:** such as pressure or sores
- **Pain for other reasons:** such as infections, injuries, burns, pregnancy, labor, menstruation, or sexual arousal

It is important to start treatment right away. If you have symptoms of autonomic dysreflexia you or your caregiver should follow these steps:

1. Sit up
2. Lower your legs if possible
3. Loosen or remove tight clothing
4. Check your blood pressure every 5 minutes
5. Find and remove the cause of the problem:
  - a. Check your bladder. If you have a catheter, look for kinked or blocked tubing or an overfilled collection bag. If you do not have a catheter, insert a catheter. Raise the end of your catheter so the urine drains slowly. Draining your bladder too fast can cause bladder spasms.
  - b. Check your bowel. Remove any stool and gas. Consider using lidocaine to the anus to prevent irritating the area.
  - c. Check your skin. Remove your clothes and look for sores, ingrown toenails, bruises, cuts, areas of pressure, or other injuries.
6. If the top number of your blood pressure remains higher than 150 and you have medication on hand to treat autonomic dysreflexia, take the medication.
7. If you do not find the cause or cannot stop the symptoms, go to your nearest emergency room or call 911.

You can help prevent autonomic dysreflexia by doing these things:

- Empty your bladder or catheter bag on a schedule.
- If you have a catheter, keep it clean and check the tubing for blockage.
- Keep to a bowel schedule.
- Change your position often to relieve pressure.
- Watch for problems with your skin (refer to section on skin care). Choose clothing and shoes that fit well and are not tight. Always wear socks with your shoes.
- Get regular foot care.
- Check water temperature to prevent burning yourself.
- Avoid getting too much sun or overheating. Use sunscreen.
- Be careful to prevent injuries and falls.
- Learn as much as you can about autonomic dysreflexia.

Healthcare providers may not be familiar with autonomic dysreflexia. Carry a card that explains what it is, possible causes, and how to treat it. The cards are free to download or can be ordered. Ask your health care team about where to find resources.



# Abnormal Bone Growth

## Heterotopic Ossification (HO)

Bone growth in soft, non-bone tissue, is called heterotopic ossification (HO). This happens mainly in the hip and knee joints. It may occur within days or months after SCI. HO only occurs below the level of injury. No one knows why this happens.

In a small number of people, HO may limit joint movement. You may first notice problems with daily activities, such as bending at the hips. If this happens, a bone mass could prevent full movement of the joint.

Signs and symptoms may include:

- Less range of motion
- Swelling in the area of the HO
- Swelling of the whole leg
- Increased temperature
- More muscle tightness (spasticity)
- Increased autonomic dysreflexia (refer to section on autonomic dysreflexia)

If you have HO, check your skin often. HO can increase the amount of pressure on the tissue under bony areas. Because of this, talk to your healthcare team to see if any special measures are needed to protect your skin.

Your care team will work with you to make a treatment plan that works for you. Treatment may include gentle range of motion and physical therapy. Medications may be given to slow down or stop the extra bone growth.



# Social and Emotional Needs

Having SCI is a life-changing event for you and your loved ones. You will feel many different kinds of emotions. These can change from day-to-day. Your emotions may be different when you were first injured, during your stay in rehab, or after you return to your community. It is normal for you and your family to have different thoughts and feelings about your injury. Talking about your feelings and finding healthy ways of managing these changes are important. Remember, even though your body has changed, you are the same person you were before your injury.

When life changes suddenly, feelings of anger, worry, and sadness are common. Some people find this time confusing, in part due to decisions that you and your family must make. People often focus on the severity of the injury and what you are not able to do. You are likely going to experience grief related to the losses from your injury, just as you would with other losses in your life. Many people feel anger followed by sadness or worry later. Some people go back and forth between the anger, worry, and sadness. It is okay to feel these emotions. As time passes, the goal is to focus more on your life and what you can do and less on your injury.

If you have found healthy ways to manage stress in the past, those ways may be helpful now. If you have had trouble coping with challenges in your life, you will want to be open about this with your healthcare team. Personality, social support, spiritual beliefs, and other stressors in your life will impact your ability to cope with SCI.

Positive ways of coping can include:

- Journaling
- Relaxation breathing
- Meditation exercises
- Using music

Negative ways of coping can include:

- Using alcohol and/or drugs
- Not sharing your emotions with others
- Lashing out
- Avoiding other people

There may be changes in where you live, who lives with you, and what you do each day. You may not be able to do the same type of work you were doing before you were injured. Through this time, you will not be alone. Many people find joy and strength in ways they had not thought possible before their injury.

Having a spinal cord injury is a disability. People who do not have a disability may not know what to say to a disabled person. They may want to do things for you even when you do not need or want their help, or they may act like you are not there. Speaking openly about your feelings with those around you is the best way for you and others to avoid misunderstandings and hurt feelings. You can help others understand that you are a person, who happens to have a disability.

What you can do to cope with the changes:

- Stay aware of your thoughts and feelings.
- Keep others in your life.
- Talk about your feelings. This may include getting help from support groups and professionals.
- Be active and stay physically healthy.
- Learn to manage stress.
- Use mindfulness.
- Practice relaxation techniques. CDs or apps such as “Calm”, “Breathe”, or “Unwind” can help to guide you.



# Depression and Anxiety

SCI can be challenging. Depression or anxiety can occur with SCI. Some people have both of these diagnoses.

It is common to feel down or sad at times. This is caused by grief about the changes in your life. Some people become so depressed they need medical care. Signs of depression include:

- Feeling sad, hopeless, and worthless most of the time
- No energy or interest in things you usually enjoy
- Withdrawing from other people
- Feeling tired all of the time
- Changes in sleep – trouble sleeping or sleeping more than usual
- Changes in appetite – not wanting to eat or wanting to eat even when not hungry
- Trouble thinking, problem solving, and remembering things
- Being more irritable or grumpy
- Not taking care of yourself such as not showering or not wearing clean clothes

Most people worry or have some stress in their lives at times. When the worry or anxious feelings interfere with your daily activities or how you feel physically, you may need help. Signs of anxiety include:

- Worrying a lot
- Being agitated, restless, or irritable
- Feeling tired all the time
- Trouble falling or staying asleep
- Trouble thinking or problem solving
- Tension in muscles
- Extreme fear
- Panic attacks
- Avoiding social situations

Treatment for depression or anxiety depends on how severe your condition is. Many treatment options are available. Often a blend of medication and talking about your feelings works best. One-on-one counseling sessions with a licensed therapist or therapist-led group therapy are chances to talk about your feelings. Your health care team will help find the best treatment options for you.

If your feelings do not improve, you feel like giving up, or you think about suicide; talk with a member of your care team or call 911. You can get help.

You can also contact the National Suicide Prevention Lifeline by:

- Calling (800) 273-TALK (8255)
- Tweeting to @800273TALK
- Going to [www.facebook.com/800273talk](http://www.facebook.com/800273talk)

# Sexuality

Sexuality and intimacy can be hard to talk about. Talk with your care team about any questions or concerns you have including:

- Sexually transmitted diseases
- Sexual positions
- Orgasms
- Safety
- Fertility, pregnancy, and having a family

If you have difficulty bringing up the subject, writing a list of questions and giving it to your provider is another way to share your questions. There may be adaptive equipment or medications that can help you. Depending on your concerns, talking to a counselor, psychologist, specialized doctor, or a sexual therapist may be helpful.

Sexuality is a deeply personal, natural part of life. It is far more than the physical act of sex. Sexuality includes:

- Intimacy and emotions
- Your attitudes and values about sex
- Who you are attracted to sexually and romantically
- Your sexual orientation

Losing sensation in your genitals can greatly affect your sexuality. But, you can still have satisfying, intimate relationships. You can feel sexual sensations above the level of your injury in areas that can be sexually exciting such as your ears, neck, face, and mouth.

Sexual arousal or other stimulation of the genital area can cause autonomic dysreflexia, a topic covered earlier in this guide. If you have symptoms of AD during sex, stop. If the symptoms do not go away, call 911.

After SCI, women often have changes in lubrication, orgasm, and menstruation:

- A water-based lubricant can be used if you have less vaginal lubrication.
- Most women can reach orgasm but it may take longer and feel different.
- Menstruation may stop for several months after SCI. Let your care team know if you do not menstruate for more than 6 months.

After SCI, men often have changes in erection, ejaculation, and orgasm:

- Erections can result from sexual thoughts, touching the penis, or from a full bowel or bladder. Depending on your level of injury, erections may not occur when you want them to. Paralyzed men with erectile dysfunction should seek the advice of a urologist before starting any medication or assistive devices.
- Some men are not able to ejaculate after SCI. Some may ejaculate backward into the bladder (retrograde ejaculation).
- The ability to have an orgasm depends on the level of injury. If you do not have feeling below your navel, orgasm may not occur.

## Fertility and Pregnancy

Being paralyzed may not rule out becoming a parent.

- Men who have SCI may have more fertility problems than women.
- Women with SCI should find an obstetrician they are comfortable with before becoming pregnant. Your pregnancy and childbirth will need to be closely monitored to prevent and manage your special medical needs.

## Getting Ready for Sexual Intercourse

Talking honestly with your partner about your feelings and concerns about sex is important. Touching and exploring your body can help you find what feels good and brings you pleasure. Doing this together with your partner can bring the two of you closer together.

There are things you can plan to improve physical intimacy:

- Do good skin care before and after sex.
  - Have waterproof sheets, towels, and wipes available.
  - Avoid excess rubbing or pressure.
- Do not have sex within 2 hours of when your bowel program is due.
- Pressure during sex can cause urine to leak.
  - Decrease fluids several hours before sex.
  - Empty your bladder just before sex.
- Avoid alcohol.
- If you have an indwelling catheter:
  - Males – place a condom over the folded catheter covering your penis.
  - Females – tape the catheter tubing to your inner thigh.



# Managing Your Care at Home

It is important to have someone you trust help look out for your needs. Usually, this person is a friend or family member called an advocate.

## Getting the Care You Need

Family members are often the main caregivers following SCI. Even so, some people may need to hire personal care attendants (PCAs) for part or all of their care. Choose paid PCAs carefully. The people you hire will need clear direction to carry out what you need.

Funds to pay for PCAs may be available from your state Medicaid program, worker's compensation, private insurance, the Veteran's Administration, or other sources. A social worker or case manager may be able to help you find other resources. You may hire an agency to provide your care. If you do not use an agency, you are the employer and will be responsible for following all employment laws. It is important to keep clear records for each PCA you employ.

## Hiring PCAs

Hiring a PCA starts with creating a list of tasks and a timeline for getting things done. In addition to hours, days on and off, and salary, be clear about all that you expect. Include household rules such as if guests and smoking are allowed. This is especially important if the PCA will live with you.

Advertising for PCAs can be done online or in public areas near colleges or churches. Ask for a written resume by mail or email. Use word of mouth through friends and family to reach trusted people.

A family member or friend should be with you when you interview possible PCAs. Discuss the person's training and comfort doing personal cares. Check references and ask questions. Invite the person to ask you questions as well.

## Directing Care

Directing someone else to do cares is a skill that may need to be learned. You must stay in control, work together to solve problems, and have a healthy professional relationship. It is important that you and your caregivers:

- Have respect for the PCA. Do not be demanding. Use "please" and "thank you."
- If problems occur, discuss those concerns and clear the air. It may be best to allow time to pass first, unless your safety is at risk.
- Talk about changes to your normal routine in advance.
- Be clear that you expect your personal matters kept private. This means:
  - Not sharing or posting information about each other
  - Respecting personal space and property

You should have a back-up plan in case your caregiver or PCA is ill or has an emergency. Talking openly and setting clear expectations are the keys to successful caregiving.

## Care for Caregivers and PCAs

There are things that caregivers can do to take better care of themselves mentally and physically. Some of these include:

- Online support groups that can give advice and allow caregivers to discuss their feelings and concerns
- Gentle exercise such as yoga or tai chi
- Mediation or guided imagery
- Taking a break from caregiving by using respite care or adult day care services

## Abuse and Neglect

Being dependent on others can lead to abuse, neglect, or exploitation (taking control to another's advantage). Signs of possible abuse, neglect, or exploitation include:

- Injuries such as bruises, welts, burns, cuts, scars, broken bones, or an injury that does not match what is being reported
- Needs not being met such as heat, food, fluids, or medical care
- Fear or isolation
- Caregiver acts controlling
- Money is missing or misused

To report abuse, neglect, or exploitation, contact your local law enforcement agency as well as the Department of Human Services in your state.

### Iowa

<https://dhs.iowa.gov/DependentAdultProtectiveServices/Families>

### Minnesota

<https://mn.gov/dhs/people-we-serve/adults/services/adult-protection/>

### North Dakota

<https://www.nd.gov/dhs/info/pubs/docs/aging/fact-sheet-vulnerable-adults-protective-services.pdf>

### South Dakota

<https://dhs.sd.gov/LTSS/docs/Abuse%20Neglect%20Exploitation.pdf>

## Helpful resources

### National Council on Independent Living (NCIL)

[www.ncil.org](http://www.ncil.org)

### Family Caregiver Alliance (FCA)

[www.caregiver.org](http://www.caregiver.org)



# Your Transition Home

You will be asked to take part in planning and decision-making as you prepare to leave. Home may or may not be where you were living before you were injured. Your care team will offer advice and support for making a safe and successful plan for discharge.

Things to think about and plan for will include:

- The type and amount of help you will need from:
  - Family
  - Hired staff
  - Care facility
- Financial needs and other available resources
- Medical and adaptive equipment
- Changes to your home for access and safety
- Medication and care supplies
- Transportation needs for appointments and day to day activities such as grocery shopping
- Emotional support for you and your family
- Therapy needs
- Driving evaluation
- How to stay active and be healthy to prevent problems
- Ways to find meaning, purpose, and joy in life

Adjusting may be hard for you and your loved ones. It is important to:

- Know your own cares and needs
- Find a healthy daily routine
- Set goals that can be reached
- Keep talking! This may include getting help from support groups and professionals

Making the change from the hospital can be scary, but this is part of the process of regaining control of your life and becoming as independent as possible. It is important to allow others to help you while being the leader in your care.

People often return to work after SCI. Some can return to their former job, but others find success learning a new skill. The use of computers, voice-recognition software, blue-tooth, and other devices provide more options for work and leisure. Your care team can provide sources for vocational rehabilitation (job recovery) when you are ready.

# Your Rights

As a person with SCI, you are protected by a law that began in 1990, called the Americans with Disabilities Act (ADA). The ADA protects every qualified person with a physical or mental impairment that “substantially limits one or more major life activities....”

The ADA contains separate sections called titles. The main points of these are:

## **Title I:**

Does not allow job discrimination (not hiring because of your disability).

- The law requires employers to make “reasonable accommodation” unless it causes an “undue hardship” to the employer.
- Employers may not ask about your disability. You can be asked if you are able to do the functions required of the job.

## **Title II:**

Does not allow discrimination in public places, including public transportation.

## **Title III:**

Does not allow discrimination by private businesses that serve the public. Examples of businesses like this include:

- Banks, restaurants, grocery stores, hotels, shopping centers, sports arenas, movie theaters
- Daycare centers, schools, colleges
- Offices, museums, health clubs

If you have concerns about your rights, there are many resources available for you now and in the future. Your care team can help you learn more.

# Resources

There are many resources available to help you when you need it. Ask your care team if you have more questions.

## **American Spinal Injury Association**

Research, information, and other resources  
[www.asia-spinalinjury.org](http://www.asia-spinalinjury.org)

## **Caregiver Support**

Help for caregivers  
[www.caregiver.va.gov](http://www.caregiver.va.gov)

## **Christopher and Dana Reeve Foundation**

Research, information, online community, and other resources  
[www.christopherreeve.org](http://www.christopherreeve.org)

## **Foundation for Spinal Cord Injury Prevention, Care and Cure**

Increase public awareness, education, and funding research  
[www.fscip.org](http://www.fscip.org)

## **Miami Project**

Research  
[www.miamiproject.miami.edu](http://www.miamiproject.miami.edu)

## **Mission: ABLE**

Help with receiving benefits, accessing care, getting job training, and taking part in sports  
[www.mission-able.com](http://www.mission-able.com)

## **National Veterans Wheelchair Games**

Information about organized sporting events  
<http://wheelchairgames.org>

## **Paralyzed Veterans of America (PVA)**

Research, education, and national chapters that provide social support  
[www.pva.org](http://www.pva.org)

## **Project Enable**

Connects people to create new ways to complete common tasks  
[www.projectenable.com](http://www.projectenable.com)

## **Spinal Cord Injury Information Network**

Information about SCI topics  
[www.spinalcord.uab.edu](http://www.spinalcord.uab.edu)

## **Spinal Cord Injury Information Pages**

Information about living with SCI, created and maintained by a C5-6 quadriplegic  
[www.sci-info-pages.com](http://www.sci-info-pages.com)

## **United Spinal Association**

Advocacy, peer support, and information about living with SCI  
[www.spinalcord.org](http://www.spinalcord.org)

## **U.S. Department of Veterans Affairs Spinal Cord Injury & Disorders**

Information and care services for SCI patients  
[www.sci.va.gov](http://www.sci.va.gov)

## **Visiting Nurse Associations of America**

Help with finding home healthcare providers  
[www.vnaa.org](http://www.vnaa.org)









