

Spinal Cord Injury

A Guide for Patients





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Introduction

Spinal cord injury (SCI) may happen when you are in an accident, fall, or have a disease that affects your spinal cord. This book was written by health care providers who care for patients and their families as they deal with these injuries or conditions. We hope it teaches you about the injured spine and spinal cord, and answers your questions about what to expect in the days and months to come. Exact answers may not be known because the long-term effects of SCI can be hard to predict. Research is still being done to improve treatment and outcomes of SCI.

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How does the spinal cord work?

The brain and the spinal cord work together. The spinal cord is the link between the brain and the nerves in the rest of the body. It helps the body:

- Move
- Feel hot and cold temperature, vibration, sharp, and dull sensations
- Sense the position of your arms and legs
- Control blood pressure, heart rate, and body temperature
- Control bodily functions, such as breathing, urination (peeing), and bowel movements

When the body moves, messages travel from the brain down the spinal cord. Messages also are carried up the spinal cord to the brain so a person can feel sensations.

There are nerves that branch off the spinal cord. They are called spinal nerves. The nerves are divided into five main sections (from top to bottom): cervical, thoracic, lumbar, sacral, and coccygeal. The spinal cord and nerves are very fragile.



How is the spinal cord protected?

The spinal cord is protected by bones, discs, ligaments, and muscles. The spine is made of 33 bones called vertebrae. The spinal cord passes through a hole in the center (called the spinal canal) of each vertebra. Between the vertebrae there are discs that act as cushions, or shock absorbers for the spine. Ligaments and muscles help keep the vertebrae in the right position.

There are many pathways or "tracts" in the spinal cord. The motor tracts are in the front and middle parts of the cord. These nerve paths tell the body to move your arms and legs. If there is damage to the motor tracts, a person may have weakness or not be able to move below the level of damage.

The sensory tracts are in the front and back parts of the cord. These nerve paths allow sensation. Damage to the front part of the spinal cord can cause loss of the ability to feel pain, as well as hot and cold sensations below the level of damage. Damage to the back part of the spinal cord can cause loss of the ability to feel the sense of position of the arms or legs.



What causes spinal cord injuries (SCIs)?

The causes of SCIs can be put into two groups: traumatic and non-traumatic. The most common cause of traumatic injury in the United States is motor vehicle accidents (MVAs). MVAs cause 44 out of 100 of all SCIs. Other injuries caused by trauma are:

- Ischemia: decreased blood flow to the spinal cord
- Contusion: bruising of the spinal cord
- Fractures: broken bones (vertebrae)
- Dislocation: displaced or misaligned vertebrae

Non-traumatic injuries are caused by diseases that affect the bones, nerves, or spinal cord. Some of these types of injuries are:

- Degeneration of bone (vertebrae)
- Bone spurs
- Infections or tumors in the spine
- Diseases of the spinal cord such as: multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Guillain-Barré syndrome, and transverse myelitis

How common are SCIs?

There are about 12,000 new SCIs in the U.S. each year. The number of people living with spinal cord injury is about 250,000 to 400,000. Of these, 82 out of 100 are male and 18 out of 100 are female.

What types of vertebral injuries can happen?

The two main types of injuries to the spinal bones (vertebrae) are fractures and dislocations. A fracture is a break to any part of the vertebrae. A dislocation is when the vertebrae do not line up correctly or are out of place. These may cause damage to the spinal cord. There are many types of fractures and dislocations that can happen.

Compression fracture: This often results from a hyperflexion (front to back) injury where part of the spinal column is forced forward and downward.



Burst fracture: This is a very serious form of compression fracture. The bone is shattered from the injury. Bone fragments may pierce the spinal cord. It often happens from a downward or upward force along the spine. It often results in serious SCI.



Subluxation: The joints in the back part of the vertebrae are weakened by the abnormal movement of the bones. It is a partial dislocation of the vertebrae. This happens if the muscles and ligaments in the spine are injured. It may also cause injury to the spinal cord.

Dislocation: This may happen when ligaments are torn or badly stretched from an injury. It causes too much movement of the vertebrae. The vertebrae may "lock" over each other on one or both sides. An SCI can happen; it depends on how much extra movement the torn ligaments allow. The vertebrae that are not lined up correctly are returned to a normal position by a "reduction." Traction or surgery is often needed for a reduction. A brace, halo vest, or surgery to fuse the vertebrae is sometimes needed to keep the vertebrae lined up correctly.

Fracture-dislocation: This happens when there is a fracture and a dislocation of the vertebrae. There is often serious ligament and soft tissue injury. It may also cause injury to the spinal cord.



What happens to the spinal cord?

The two main types of SCIs are complete and incomplete. A complete injury causes a total loss of sensation and movement below the level of the injury. An incomplete injury causes partial loss of sensation and movement below the level of the injury because only part of the spinal cord or nerves have been damaged.

Complete SCI

A complete SCI is least likely to get better.

There is no function below the level of injury:

- No movement
- No sharp/dull feeling
- No hot/cold feeling
- No vibration sensation
- No feeling of light or deep touch
- No sense of position of the arms or legs



Incomplete SCI

The three main types of incomplete injuries are: anterior cord syndrome, central cord syndrome, and Brown-Séquard syndrome.

Anterior cord syndrome: This happens when the front part of the spinal cord is damaged. It causes loss of movement and loss of sharp/dull and hot/cold feelings below the level of injury. A person still has the sense of position of the arms and legs, vibration, and sense of light/deep.

It is caused by acute disc herniations, tumors, and when the head is forced to the chest (cervical flexion).



Figure 10. Anterior cord syndrome

Central cord syndrome: This happens when the middle part of the spinal cord is damaged. It causes more loss of movement and sensation in the arms than in the legs.

It is caused by a hyperextension injury (when the head is forced backward). It also can be due to degenerative bone changes in the spine and/or narrowing of the spinal canal that surrounds the spinal cord.



Brown-Séquard syndrome: This happens when one-half of the spinal cord is damaged. It causes one side of the body to be stronger than the other side below the level of injury. The side of the body that is weaker is able to feel sensations of hot/cold and sharp/dull better than the other side of the body. The strength and sensations differ based on the degree of damage to the spinal cord.

It can happen from bullet or knife wound injuries, and rarely with acute ruptured discs.



How is an SCI diagnosed and examined?

SCI may be diagnosed and evaluated using one or more of the following tests. Movement of the neck or arms by the health care team members may be needed when getting these tests.

Test used for diagnosis:

- X-rays
- CT or "CAT scan" (computerized axial tomography)
- MRI (magnetic resonance imaging)

Spinal cord exam:

- Movement and strength of arms and legs
- Ability to feel sharp/dull or hot/cold
- Position sense of the arms and legs

How are SCIs treated?

The main goal when treating an SCI is to keep the highest level of function possible. Treatment is also aimed at preventing complications and further injury. Treatments may be non-surgical and/or surgical.

Non-surgical treatments

Steroid infusion: Intravenous (IV) steroid infusions may be given for an SCI that happens suddenly (trauma). The goal is to lower swelling from the injury. When appropriate, the steroid treatment is started soon after injury.

Stabilization with cervical (neck) traction/alignment: These types of traction are often needed to reduce or re-align the spine:

- Halo traction
- Gardner-Wells Tongs traction

Bracing: Based on the level of injury and doctor's recommendation, a brace may be placed. Pictures of the braces are on the next two pages. These braces may be used before and/or after surgery if needed.

Cervical (neck) and high thoracic (upper chest) injuries





Figure 13. Philadelphia collar



Figure 14. Miami J collar



Aspen CTO (cervical thoracic orthosis)

Halo vest

Lower thoracic and lumbar injuries



Figure 17. Thoraco-lumbo-sacral orthosis (TLSO) (Also known as "shells") (Photo used with permission from Donald G. Shurr, CPO, PT)



Surgical treatments

Surgery may be needed when the injury has caused the bones to be unstable or when there is pressure on the spinal cord or spinal nerves. The spine is not stable if, in spite of bracing, the bones can move and cause further injury.

Decompression: This is removing the pressure on the spinal cord. The cause (bone, disc, blood clot, tumor) of the pressure on the spinal cord or spinal nerves is removed.

Internal fixation and instrumentation: Internal fixation means to put metal rods, screws, and/or hooks (instrumentation) on the vertebrae to protect the spinal cord or spinal nerves from further injury. Think of this as a brace on the inside of the body. Often a bone graft is also done. The three figures below show how this looks, with the titanium screws, hooks, and rods.



Bone grafting for fusion: When internal fixation and instrumentation is needed, a bone graft will also mostly likely be needed. The bone graft may be taken from the back of the pelvis or rib. This bone is then placed onto the injured bony area. Often, this bone will bond to the vertebrae and fuse within 3 to 6 months. When the vertebrae have completely fused, this further stabilizes the spine.

What equipment might you see?

This will depend on how stable the vertebrae are and the level of the spinal cord injury. Please talk with the nurse or other health care team member if you have any questions about the equipment or why it is being used.



Based on an original illustration by James Abel

Anti-embolism stockings (TEDs): White, elastic stockings used to prevent pooling of blood in the legs and help prevent blood clots

Arterial line: A catheter put into an artery that is used to measure blood pressure and to get blood for testing

Cervical collar: A foam or rigid plastic collar that provides support to the neck and limits neck motion. It is also shown in figures 13, 14, and 15.

Cervical traction: This is to pull the cervical vertebrae back into position. The goal is to relieve pressure on the spinal cord. A metal ring (Halo crown) or tongs are attached by pins to the skull. Weights are then attached for traction. Traction cannot repair injury already done to the spinal cord, but it helps to avoid further injury.

EKG lead wires: Wires connected to the chest with small patches that measure heart rate and rhythm

Endotracheal tube: A tube through the nose or mouth into the trachea (windpipe) to help with breathing and suctioning

Fracture bed: A bed in a slightly tilted position, head higher than feet. It can have 1 or 2 mattresses. Then traction weights can hang from the head.

Halo vest: A rigid vest can be used depending on the injury. Most often, people can be out of bed after the halo vest is on. It keeps the neck bones in place while they heal. See figure 16 to see what the vest looks like and Appendix IV for clothing suggestions.

Intravenous catheter (IV) and IV fluids: A catheter placed into a vein for giving fluid and medicine

Monitor: A machine that shows heart rate, breathing rate, blood pressure, and blood oxygen levels

Nasogastric feeding tube: A tube placed through the nose into the stomach used to suction the stomach or to give liquid food directly into the stomach

Sequential compression stockings (SCDs or Kendalls): Plastic leg wraps that help prevent blood clots by inflating and deflating around the legs

Urinary "Foley" catheter: A tube placed into the bladder, used to drain and measure urine

Ventilator: A machine used with an endotracheal tube to help with breathing

How do SCIs affect the body?

Injuries to the spinal cord can affect many functions of the body, such as:

Spinal cord reflexes

Normally, messages are sent from the brain through the spinal cord to parts of the body, which leads to movement. When the spinal cord is damaged, the message from the brain cannot get through. The spinal nerves below the level of injury get signals, but they are not able to go up the spinal tracts to the brain. Reflex movements can happen, but these are not movements that can be controlled. They may happen when the foot is touched or with coughing.

Spinal shock

This is the temporary loss of all spinal cord reflexes below the level of injury. This could last days to weeks. When spinal shock ends, spasticity or stiffness starts below the level that the spinal cord was injured. Spinal shock cannot be prevented and must resolve on its own.

Breathing

The muscles (diaphragm, intercostal, and abdominal) needed for breathing and coughing may become weak after an SCI. Coughing is needed to clear the lungs of secretions and bacteria. If a person has a weak cough or cannot clear secretions from their lungs, they will be at higher risk for an infection, such as pneumonia.

An injury at C4 or higher will affect the diaphragm, the muscle that moves the lungs for breathing. A T1 to T11 injury will affect the intercostal muscles, the muscles between the ribs. A T7 to T12 injury will affect the abdominal muscles. The body needs the diaphragm, the intercostal muscles, and the abdominal muscles to breathe and cough well.



If the SCI is cervical (in the neck), a person may need support breathing with a ventilator, either for a short time or forever. If a ventilator is needed, a breathing tube will be placed in the mouth or nose, and then attached to the ventilator. If the ventilator is needed for a long time or you have a lot of lung secretions, a person may need a tracheostomy (trach).

A trach is a tube placed in the trachea (windpipe). It will make it easier to cough up phlegm and for the nurse to suction the lungs. At first, a person will not be able to talk while the trach is in place. As they get better, a talking trach may be used. A trach may not be permanent.



If you are not on a ventilator, you will be encouraged to cough and deep breathe hourly while awake to help keep the lungs healthy and prevent infection. You may also be asked to use an incentive spirometer, a plastic breathing device. You can see on the device how much air is being taken into the lungs. The nurse or therapist will help you to set goals for using this breathing device. Families are welcomed to be involved in helping you use the incentive spirometer.

Neurogenic shock (low heart rate and low blood pressure)

The brain normally controls blood pressure and heart rate. Signals from the brain send messages through the spinal cord to constrict blood vessels and raise the heart rate to keep the blood pressure and heart rate normal. When these signals cannot get through, a person can have low blood pressure and slow heart rate.

Blood pressure may drop when the head of the bed is raised suddenly because blood vessels below the level of injury are dilated. They cannot constrict fast enough to prevent low blood pressure. This is called orthostatic hypotension. To lessen your risk of this, the head of the bed is gradually raised, and an abdominal binder may be used.

Altered temperature regulation

A person may not be able to sweat or make goose bumps below the level of injury. The body cannot adjust its temperature. A person may feel cold and need blankets, then later, feel hot and need a fan or to be uncovered.

Autonomic hyperreflexia (also known as autonomic dysreflexia or hyperdysreflexia)

People at highest risk for this condition are those with SCIs above T6. This tends to happen after the spinal shock phase. Autonomic hyperreflexia happens because nerve messages that used to go up the spinal cord to the brain are blocked.

Conditions below the level of injury that may lead to autonomic hyperreflexia are:

- Full bladder
- Constipation or a full bowel
- Pain
- Infection
- Skin breakdown
- Ingrown toenail
- Sudden temperature changes in the environment

Symptoms may be:

- High blood pressure
- Low heart rate
- Anxiety
- Severe pounding headache
- Sweating above the level of the injury
- Nasal stuffiness

Each person may have slightly different symptoms.



Autonomic hyperreflexia is a serious condition and needs to be treated right away. Prevention and looking for signs are very important. Stroke, heart attack, or seizures can happen if this is not treated. This is a condition that may happen throughout the rest of your life.

Deep vein thrombosis (DVT)

A DVT is a blood clot that can develop in the legs and arms. It is often caused by a lack of movement. Elastic stockings, sequential compression devices, and/or foot pumps will be placed on your legs or feet to help prevent a DVT. A blood thinning medicine may be used, or a filter may be placed in a blood vessel. Regular exercise of the arms and legs, and turning will be done to help prevent DVTs from forming.

Stomach ileus

Sometimes after an SCI, the stomach and intestine will stop working for a short time. This is called an ileus. Even though the stomach may not be working, it still makes acid. The acid may damage the stomach lining and cause stomach ulcers if it is not removed. A nasogastric (NG) tube may be placed through the nose into the stomach. This tube will be used to help remove stomach acids. Medicines may also be given to help prevent stomach ulcers.

Swallowing

Higher cervical injuries may make it harder to swallow. If this happens, an NG tube may be needed for nutrition and medicines. The tube is placed through the nose into the stomach. Liquid formula will be given either continuously or several times a day. The hospital dietitian helps the health care team choose a formula based on your calorie and fluid needs. If long term tube feeding is needed, a gastric tube (G-tube or PEG tube) may be placed surgically through the wall of the abdomen into the stomach.

Bowel control

Changes in bowel control may happen after an injury. A person may have constipation or diarrhea. A bowel training program including diet, medicines, and digital stimulation may be used. Digital stimulation means to touch inside the rectum to help the bowels move. Developing a bowel training program takes time, but it can be successful.

Bladder control

SCI may also cause the messages between your bladder and brain to be changed. Normally, when the bladder gets full, nerves in the bladder send a message up the spinal cord to the brain signaling the need to urinate (pee). The message to the brain may be lost after an injury. There is also no bladder tone when spinal shock is present.

At first after a SCI, a urinary catheter will be placed to drain the bladder. As the body starts to adjust to the injury, the catheter will be taken out. Nurses will check the bladder volume. If it is full, a catheter will be put in to drain the urine and then the catheter will be taken out. Over time, a bladder training plan will be started.

Bladder tone may or may not come back depending on the level of your SCI. The bladder may be flaccid (weakened) or spastic (hyperactive). A urologist may be asked to evaluate the bladder and medicines or surgery may be recommended.

Skin

Skin is a protective covering for your body. Too much pressure, heat, or wetness can lead to skin breakdown (bedsores or pressure ulcers) due to a lack of blood flow and oxygen. The skin ulcer can then become infected. After a SCI, the body may not be able to warn of dangers to the skin. So, regular repositioning, turning, and thorough cleaning after going to the bathroom will be needed.

Muscles and tendons

Spasticity can happen after a SCI when signals from the brain to the muscles are blocked. This is often not seen until spinal shock resolves. When spasticity happens, there is resistance to stretching the muscles. It can be painful and lead to contractures, a shortening of the muscles and tendons.

If spasticity is a problem, it can be treated. Repositioning and medicine, such as Baclofen, may help. Botox injections may also be used.

Bones and joints

When there is a lack of motion in joints due to long term bed rest, hard calcium deposits (bone spurs) can form. This is called heterotopic ossification. It can cause pain, spasms, and a lower ability to function. It happens when calcium lost from the bones builds up in muscles, tendons, or joints. This most often starts 2 weeks to 4 months after injury. The most common places in the body where this can form are the hips, knees, shoulders, and elbows.



Pain

With SCI, pain may be acute or chronic. Acute pain may be caused by bruising, broken bones, surgery, or positioning. Chronic pain may be caused by overuse of joints and muscles, or changes in muscles, joints, and ligaments. Pain is treated based on the type and cause of the pain. The most important thing to remember is that pain is real and there is a physical cause. Talk with the health care provider about pain.

Brain injuries

Many people who have had severe trauma to their neck and back may also have injuries to their brain. These can range from a mild concussion to more severe injuries. They can cause difficulty with memory, concentration, or communication, and can cause personality changes.

Sexuality

Love and intimacy are basic needs all people share. A person with SCI still has sexual needs. There may be loss of sensation to the genitals for both men and women. Each person's injury affects his or her sexuality in a different way. Often, both men and women will still be able to have sexual intercourse.

Men will have erections, some uncontrolled, that may be brought on by sexual thoughts or as a reflex with catheterization or erotic stimulation. Maintaining an erection may be difficult. This is called erectile dysfunction (ED). There are many medical treatments to help with this. The ability to ejaculate may also change. So, men may have difficulty with fertility (the ability to have children). These functions all depend on the level and extent of injury.

For women, nothing prevents sexual intercourse, but vaginal secretions may be less. Women may still be able to have orgasms. For women of childbearing age, menstrual periods often are disrupted and may not start again for 3 to 6 months. Women can still get pregnant and have children, and they may deliver vaginally.

Though sexual intercourse is important, love and intimacy can be shared in many ways. Touching a loved one's face and hair, kissing, being hugged, sharing ideas and problems, memories, and laughing together are also important.

During the acute phase of injury, your health care provider may not know the degree of sexual function you will have. As you get further along in your rehabilitation, it will be more likely to predict. Talk with your health care team about any changes you might notice. Many rehabilitation centers have sexual counseling programs for patients and families, which help them understand and cope with these changes.

Who will help after SCI?

Members of the health care team will work together with you, your family, and friends during the hospital stay. Care will be centered on your specific needs. Family and friends are important members of the team.



- Patient: The most important member of the team. Care will be planned based on how you and your body respond to treatment.
- Family and friends: Family and friends offer emotional support. They may also give the health care team important facts about your history and can help watch for changes.
- **Doctors:** Neurosurgery and orthopedic doctors are specialists that help decide the type of SCI, as well as the medical and surgical treatment. They may do surgery on the spine. They will work with other doctors in intensive care or to treat injuries to other parts of the body if needed. A rehabilitation doctor (physiatrist) may also talk about what to expect during the hospital stay and go over any questions you may have about what happens if you are transferred to a rehabilitation unit.
- Nurses: Nurses will check vital signs (temperature, blood pressure, heart and breathing rate) and watch for changes in movement and sensation. They will help with daily care, such as eating and bathing. Nurses also coordinate care among the members of the health care team.

- **Social workers:** Social workers provide emotional support and help patients and families adjust to being in the hospital. They coordinate discharge planning, referral to community resources, and questions related to insurance or disability.
- Physical therapist (PI): Physical therapists evaluate and treat weaknesses in strength, balance, rolling, sitting, standing, and if possible, walking. Treatment may be exercises and teaching people how to use equipment, such as braces or wheelchairs.
- Occupational therapist (OT): Occupational therapists evaluate the ability to dress, bathe, and do home-making activities. They provide treatment and/or equipment needed for care after leaving the hospital. They also help with work and leisure activities.

Speech therapist: Speech therapists test and treat speech, language, and swallowing problems.

Dietitians: Dietitians assess nutrition needs. They work with the patient and other team members to help meet nutrition goals.

Other staff that may work with patients and families are:

- Psychiatric nurses
- Clergy
- Patient representatives
- Music therapists
- Activity therapists
- Child life therapists
- Vocational rehabilitation specialists

How can you help prevent medical complications?

It is very important to learn about the changes that have taken place in the body and how to prevent complications. You must learn to speak up and ask questions. It is important to actively participate in care.

Communication

Communicating is important to all of us. Often people with SCIs feel a lack of control. The more a person is able to communicate their needs, feelings, concerns, or thoughts, the more control they will have.

Communicating after an SCI may be different if a person has a breathing tube or trach. It is very important to find a way to communicate as soon as possible. Other ways to communicate that can be used if a person cannot speak are:

- **Communication board:** This is a picture/word board. A person can blink, raise an eyebrow, or respond in another agreed upon way to indicate which letter has been chosen. The board also has pictures of basic needs with the word above the picture.
- **Computerized communication:** This is a computer with responses that are chosen by moving the mouth, eyes, arms, jaw, or shoulder.

Keep the lungs clear

Take deep breaths and cough often. Use the incentive spirometer each hour while awake. Also, a person may be taught how to do a "quad cough." This is done by using an upward force by the heel of the hand to push in and up on the diaphragm while a person is trying to cough.

DVT prevention

Wear the anti-embolism stockings and sequential compressive devices or foot pumps. Also, family can help with range of motion exercises for the arms and legs, and with turning as directed by the health care team.

Nutrition

Nutrition plays helps with healing and keeping the skin healthy. When under stress or during illness, the body needs more calories. A hospital dietitian will help to figure the calories needed for the best healing and skin protection.

Skin care

Changes in sensation create a need to make sure there is regular repositioning and turning, and good cleaning after bowel or bladder incontinence. Extra attention to the skin is very important to prevent problems. Use of heating pads and cold packs must be closely checked. Frequent skin checks can also help prevent problems. Specialty mattresses, wheelchair pads (Roho cushions), and other skin care items may be used.

Signs of skin breakdown (bedsores or pressure ulcers) are:

- Red areas that do not go away
- Blisters
- White skin after the pressure source is moved
- Skin spots that turn black or brown
- Tear, cut, or "rug burn" look to the top layer of skin

To help prevent skin problems, a person is fitted for a wheelchair. This most often happens at rehabilitation. Even in a personalized wheelchair, a person should shift their weight often.

Bowel and bladder control

Follow the recommendations of the health care team on diet, fluid intake, and on bowel and bladder programs. Bladder training will start to help with bladder control. This may involve catheterizations every 4 to 6 hours. This depends on the amount of urine in the bladder. The goal is to keep the bladder from being too full. Based on the level of injury, a person may learn to do catheterizations.

Muscle maintenance

A program to keep the joints and muscles moving is called "range of motion." Physical and occupational therapists work with people to keep their current strength and range of motion. Gentle stretching of the muscles helps to do this. In spite of therapy, a person may have less range of motion. If this happens, changes in therapy, medicines, or surgery may be needed.

Heterotopic ossification

This means bone spurs have developed around joints. It is important to get early treatment when signs start to prevent or limit complications. Tell the health care team if you have any of these changes:

- Sudden loss of joint motion or less range of motion
- Warmth
- Redness
- Pain with movement or touch
- Swelling

Spasticity

This is uncontrolled muscle spasms in the arms and legs. Spasms can be caused by:

- Pain
- Rapid movements
- Tight clothing
- Touching

Exercises and medicine can help to control spasms. Hand/finger splints and ankle splints may also be used to keep muscles and tendons in the hands, lower arms, feet, and lower legs from shortening.

Autonomic hyperreflexia

If the injury is at T6 or above, a person is at risk for autonomic hyperreflexia. If the injury is incomplete or lower than T6 it can still happen, but with milder symptoms. The main cause of autonomic hyperreflexia is most often a full bladder. The second and third most common causes are constipation (a full bowel) and skin irritation or skin breakdown. It can also be caused by:

- Straps on splints that are too tight
- Wearing shoes that are too small
- Wearing tight clothes or belts, such as wearing jeans when you have been used to wearing sweatpants
- Not taking supplies for bladder or bowel care when away from home
- Small items that may be in your shoes, such as paper that comes in the toes of new shoes, or in your seat cushion, such as small toys
- Sitting on a wallet
- Seat cushion out of position
- Caffeine or alcohol that can cause a higher urine volume
- Drinking too much alcohol or taking sedatives that make you too drowsy to care for yourself
- Being in an accident or emergency and not being able to tell anyone about your risk for autonomic hyperreflexia. A person should wear a medical ID warning of risk for autonomic hyperreflexia.

Ask questions about autonomic hyperreflexia and tell your health care team about any signs right away. This may be a serious medical emergency.

Choose the right rehabilitation facility

It is important to choose a rehabilitation facility that will best meet a person's needs. A social worker will help with this. Family members play a vital role in gathering information about facilities (see Appendix III).

How will you react after SCI?

When you experience an SCI, it is normal to have many emotional reactions. Family and friends may also have these same emotional reactions. These emotions may occur at different times. Some emotions a person may experience are:

Panic and fear

One of the first reactions after an SCI is panic and fear. Fears are intense because you, as well as your family, may be worried that you may not survive. Until you become medically stable, physical and emotional feelings of panic may continue. Some of your physical symptoms may be:

- Fast breathing
- Not able to sleep
- Decreased appetite
- Upset stomach
- Crying uncontrollably

Shock and denial

You may feel that what is happening is not real. You may notice things going on around you, but have trouble remembering information. You may also have a hard time understanding the seriousness of the injury.

Anger

You may feel angry that you are in this situation. This may be justified. You may be angry with family members, friends, or others involved in the accident. On the other hand, your family may be angry that you put yourself in a situation where you could be hurt. You may be upset with the health care team for not doing or saying what you think is right. This is a normal reaction, and it is okay to have these feelings.

Guilt

Guilt is a very normal feeling during this time. You may feel you could have done something to prevent the accident, even when this is far from true. Your family may also think about past events and personal experiences that they wish could have been different or better. Family or friends may feel upset or angry with you; then they may also feel guilty about having those feelings. This too is normal. We encourage you to talk about your feelings.

Isolation

During this time you may feel distant from others. You may have a hard time relating to others. You may think that others will not understand. You may also think others are scared or do not approve of your feelings. As a result, you isolate yourself. However, during a crisis, such as an SCI, it is helpful to accept comfort, support, and assistance from others.

Hope

As you start to stabilize, anxiety about survival will be combined with hope of recovery. Medical complications and slow recovery may cause more anxiety. However, hope may be brought about by the smallest changes.

When you experience any of these emotions, know they are normal reactions to a very stressful situation. You may find it helpful to talk about your feelings with friends, family, clergy, or the health care team (See the Communication section). It may also be useful to write about your feelings and experiences in a journal.

Family and friends: How do you cope?

Family and friends cope with stressful situations in different ways. What works for one person may not be helpful to another. We hope some of these ideas will help you get through this difficult time.

- **Express your feelings.** Talk about your positive and negative feelings with family, friends, clergy, and members of the health care team.
- **Be kind to yourself.** Take time for a walk or have a meal with a friend. Also, try to leave the hospital for a meal or a restful night's sleep. By taking care of your own needs, you will be more ready to respond to the patient's needs.
- When someone offers to help, accept the offer. Try to be specific about how this person can help.
- Write important information in a journal or notebook. Also try to keep records and information together in a file for easy reference.
- **Rotate family visitation.** If you need or want to leave the hospital, you may want to have someone stay with the patient so you can feel reassured they are not alone.

What is inpatient rehabilitation?

Rehabilitation will be ongoing. After your initial hospital treatment, you will need inpatient rehabilitation. You and your family will need to choose a rehabilitation center (See Appendix III).

Inpatient rehabilitation may last a few weeks to many months. You will learn how to care for yourself or to teach others how to do your care. After inpatient rehabilitation, you may go home with family support and return for outpatient physical therapy, occupational therapy, or speech therapy. You will go to rehabilitation until you are taught what to do for yourself, how to do it, and are confident enough to manage your care.

May I go back to University of Iowa Hospitals and Clinics after inpatient rehabilitation?

Yes. More than likely, your doctors will want to have follow-up visits after you leave the hospital to make sure your spine is healing. Your nurses and doctors will make sure those appointments have been scheduled. When you are done with inpatient rehabilitation, UI Hospitals and Clinics has rehabilitation doctors, physical therapists, and occupational therapists specially trained in SCI medicine to help provide care and create an outpatient rehabilitation program. There are also research studies on SCI rehabilitation and recovery.

Conclusion

We hope you find this booklet helpful in your care and recovery. Knowledge is power. The more information you learn about SCI, care, and complications, the more confident and successful you will be in managing your care.

Please talk with our staff if you have any other questions or needs.

Appendix I

Self-care after rehabilitation by level of injury

You may have questions about what you will be able to do for yourself in the future. The chart below is a guideline for what most people with a given level of injury will be able to do. Keep in mind that your situation may vary.

- **Dependent** means needing someone to help you.
- Independent means you can do it on your own.

Spinal cord level	Feeding	Dressing	Bladder and bowels	Mobility
C1–3	Dependent	Dependent	Dependent	Electronically controlled electric wheelchair. Can use sip and puff or head control.
C4	Dependent	Dependent	Dependent	Same as above and can also use chin switch
C5	Self feeding with setup and use of equipment	Help with upper body dressing; dependent with lower body dressing	Dependent	Power wheelchair, joystick hand control, high back, seat belt, cushion, removable desk arms
C6	Independent with the use of adaptive equipment	Independent with upper body dressing; need help with lower body dressing	Dependent	Power wheelchair, joystick hand control, high back, seat belt, cushion, removable desk arms, modified van lift, hand controls
C7	Independent with the use of adaptive equipment	Potential for independence with the use of equipment	Bladder: Independent to some assistance Bowel: Some to total assistance	Manual wheelchair, removable desk arms, brake modified hand rims, modified van with transfer board, hand controls
C8 and below, including thoracic, lumbar, and sacra	Independent	Independent	Bladder: Independent with intermittent cath. Bowel: Independent with digital stimulation	Manual wheelchair, independent in car, unloading wheelchair, hand controls

Some types of adaptive equipment that can help a person be independent with self-care are:

- Bath bench
- Button hook
- Doorknob extension
- Dressing stick
- Elastic shoe laces/Velcro
- Environmental control units (computer that helps to turn on and off equipment, such as nurse call light, TV, radio, and fan)
- Leg lifter
- Long handle shoe horn
- Long handle sponge
- Raised toilet seat
- Reacher

Appendix II

Functional ability by level of injury

Level: C1 to C3

Functional goals:

- Breathing requires a ventilator or nerve stimulator to the diaphragm.
- Dependent for bed mobility and transfers
- Independent in wheelchair after helped into it
- Can do pressure relief in power reclining wheelchair with head, chin, or mouth controls
- Communication devices and environmental controls are often needed.
- Dependent for feeding, dressing, and bowel and bladder care

Attendant care:

• Requires 24-hour care

Level: C4

Functional goals:

- Dependent for bed mobility and transfers
- Independent in wheelchair and pressure relief in power reclining wheelchair
- Communication devices and environmental controls are often needed.
- Dependent for feeding, dressing, and bowel and bladder care

Attendant care:

• Requires 8–12 hours of care

Level: C5

Functional goals:

- Moderate to maximum help needed for bed mobility
- Maximum help needed for sliding board transfers, except for rare cases of independence. Able to do side-to-side pressure relief in wheelchair.
- Independent in electric wheelchair with hand drive
- Independent in manual wheelchair with quad pegs for indoor mobility
- Independent in self-feeding with setup and use of adaptive equipment
- Needs help with upper body dressing
- Dependent for bowel and bladder care

Attendant care:

• Needs 6 to 8 hours, often in the morning and evening

Level: C6

Functional goals:

- Independent bed mobility and level transfers; may need minimal help for uneven transfers.
- Independent side-to-side pressure relief.
- Independent with lightweight manual wheelchair on level ground, gentle slopes, and 2-inch curbs
- Can take off armrests and footplates independently
- Drives adapted van independently
- Independent in self-feeding with use of adaptive equipment
- Independent with upper body dressing
- Needs help with lower body dressing
- Dependent for bowel and bladder care

Attendant care:

• May need 2 to 6 hours per day

Level: C7

Functional goals:

- Independent in uneven transfers over greater distances
- Independent with wheelchair push-up
- May be able to transfer floor to wheelchair
- Independent in manual wheelchair on slightly uneven ground, low curbs, and standard ramps
- Independent with all self-cares with some help needed for bowel care
- May stand in parallel bars with braces

Attendant care:

• Changes based on bowel and bladder cares; may need 2 to 6 hours per day

Level: C8

Functional goals:

- Mostly the same as C7, but with greater ease and better hand use
- Independent bladder function with intermittent catheterization
- Independent bowel function with digital stimulation
- Independent car transfers and may be able to get wheelchair loaded

Attendant care:

• This changes, but 2 to 6 hours per day or maybe none at all

Level: T1 to T4

Functional goals:

- Independent in all transfers and pressure relief
- Independent with manual wheelchair on curbs, ramps, wheelies, and uneven ground
- Able to load wheelchair into car and drive with hand controls
- Able to walk short distances with leg braces locked straight and crutches or walker

Attendant care:

• Independent

Level: T5 to T12

Functional goals:

- Walking with leg braces and walker possible
- Walking a long distance may be hard, and wheelchair use is still needed due to the high energy needed.

Attendant care:

• Independent

Level: L1 to L2

Functional Goals:

- Independent transfers from bottom of tub.
- Walking with leg braces and crutches possible, but wheelchair use still needed due to high energy needed.

Attendant Care:

• Independent

Level: L3 to L5

Functional goals:

- Walking with leg braces and straight canes
- May use wheelchair for sports or long distances

Attendant care:

• Independent

Level: S1 to S3

Functional goals:

• Walking without leg braces possible, but may be needed due to muscle imbalances

Attendant care:

• Independent

Appendix III Inpatient rehabilitation

Most people with a new SCI will need inpatient rehabilitation to gain independence and learn new ways to do things. After talking with your doctors, your social worker will talk with you and your family about your choices for centers.

It is best if you can help make the final decision on which rehabilitation center is right for you. Family can tour rehabilitation centers to ask the questions below, and to get a feel for the center and whether or not it may be a good fit for you. If your family is not able to tour the center(s), they may want to ask a friend or other family to visit and share what they see.

The social worker helping with discharge planning also has videotapes about many centers. Talk with the social worker if you would like to have video equipment set up in your room so you can see the centers.

When choosing a rehabilitation center think about:

The rehabilitation center's experience with SCIs

- □ How many people with SCIs have they treated in the last year?
- □ What is the average number of people at the center at any one time?
- □ What is the average number of people with an SCI at any one time?
- □ What is the average length of stay?
- □ What kind of treatment outcomes can the center provide for people with an SCI?

Staffing

- □ How many years of experience do key staff have?
- □ What is the patient-to-nurse ratio?
- □ What is the patient-to-therapist ratio?
- □ Are the following team members full-time staff or consultants?
 - Physical therapist
 - Occupational therapist
 - Physiatrist (a doctor who specializes in rehabilitation and physical medicine who will be overseeing the entire rehabilitation hospitalization). Are they board-certified in SCI medicine?

Therapy

- □ How often do physical and occupational therapists see people (1 or 2 times a day, on weekends)?
- □ Who does evaluations and makes recommendations if a person needs a specialized wheelchair or equipment?

□ What does the vocational (return to work) program consist of at their center?

Emergencies

- □ Is there a doctor on site 24 hours a day in case of an emergency, such as breathing problems, infections, or falls?
- □ Are patients referred to a nearby hospital for medical emergencies?

Environment:

- □ Is there enough physical space for therapy?
- □ Is the center clean?
- □ Is there a positive atmosphere?
- □ Are staff attentive and positive toward the people they are working with?
- □ Is there a daily schedule posted noting the time and place each person should be throughout the day?
- □ After touring all the centers, what is your overall feeling? Sometimes instincts are as valuable as concrete facts.

Family involvement

- □ How far is the center from your home?
- □ If it is a long distance, it may limit visits from friends and family. How will that affect the progress of your loved one?
- □ How often are family meetings scheduled?
 - Routinely scheduled at specific intervals?
 - When progress is made?
 - When no progress is made?
 - Emergency changes?
- □ What is the policy on home visits?
- □ Are there any educational or support groups for family members at the center?

Discharge planning

- □ At what point is a person ready to leave the center?
- □ How does the center help to plan for discharge?
- □ Is there post-discharge follow-up?
- □ Will the center help you get equipment, such as wheelchairs, to go home with?
- □ Do they do home evaluations to give accessibility recommendations?

Financial

- Does your insurance company have "in-network" providers that are covered better?
- \Box After you are at a chosen center, who is responsible for communicating with the

financial/insurance provider? How often?

- □ How long will insurance last (both in months and dollar amounts)?
- □ What other costs may there be?

Appendix IV Halo vest clothing adaptation patterns



AppendixV

Resources

- American Association of People with Disabilities: aapd.com
- Christopher and Dana Reeve Paralysis Resource Center: paralysis.org
- Christopher and Dana Reeve Paralysis Resource Center: Paralysis Resource Guide, Short Hills, NJ, 2006. Toll free 1-800-539-7309
- National Council on Independent Living: ncil.org
- National Family Caregivers Association: nfcacares.org
- National Spinal Cord Injury Association: spinalcord.org
- Paralyzed Veterans of America: pva.org
- The Miami Project to Cure Paralysis: themiamiproject.org

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