

Spinal Cord Injury (SCI) Patient and Family Guidebook



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I am **GINA** your **G**uidebook **I**nformation **N**avigating **A**ssistant

Throughout this recovery guidebook I will provide information and education about spinal cord injury care and treatment. I know that I will not know all of your questions but our incredible healthcare team is available to you and your family to answer all questions in real-time.

We are here for you.

Please keep the guidebook in your hospital room so that your healthcare team may add material specific to you. This guidebook is intended to be an introductory resource and to serve as part of your comprehensive rehabilitation program.

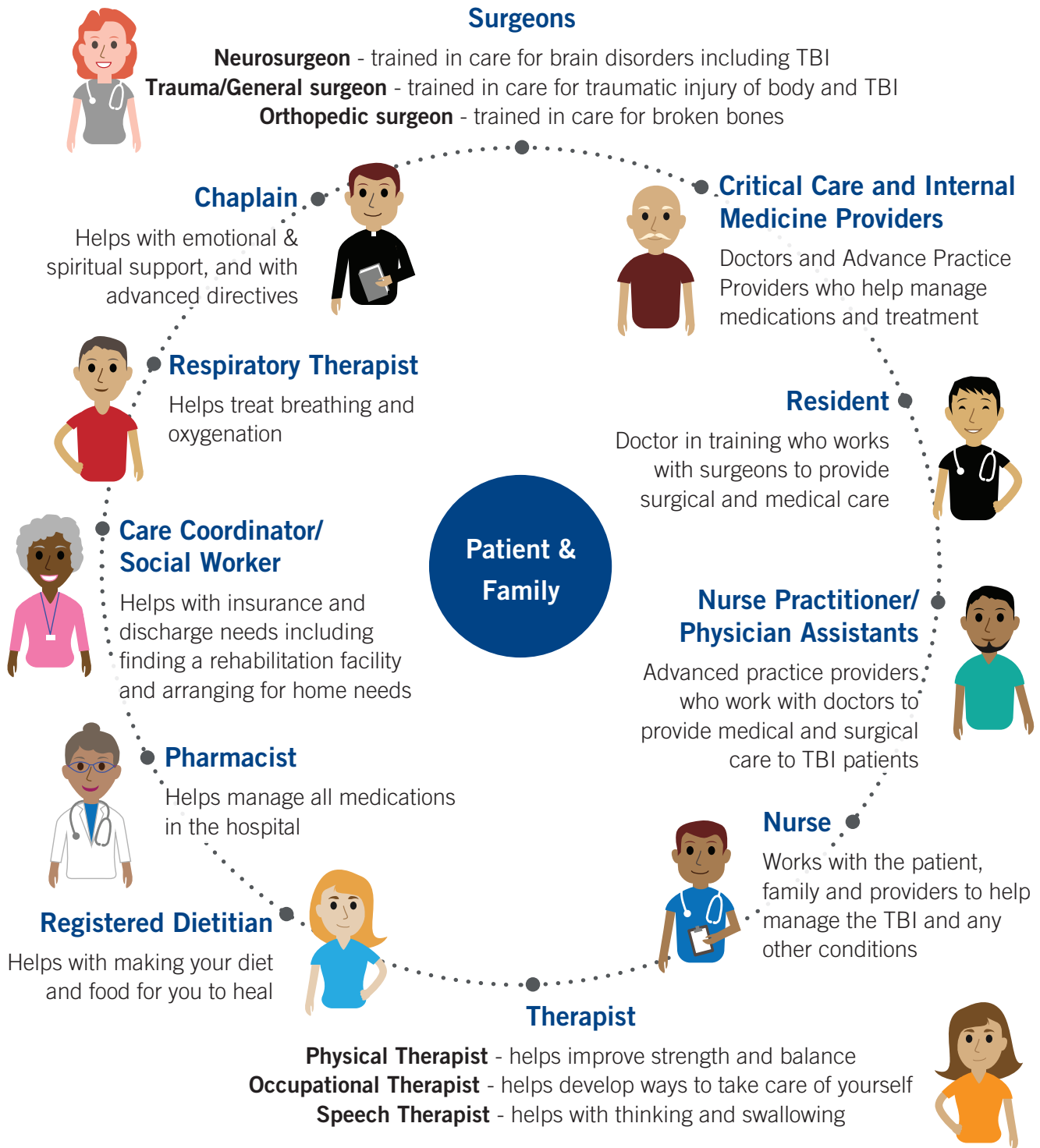
Please let us know if we can assist you in any way.

Spinal Cord Injury (SCI) Patient and Family Guidebook

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Meet Your Team



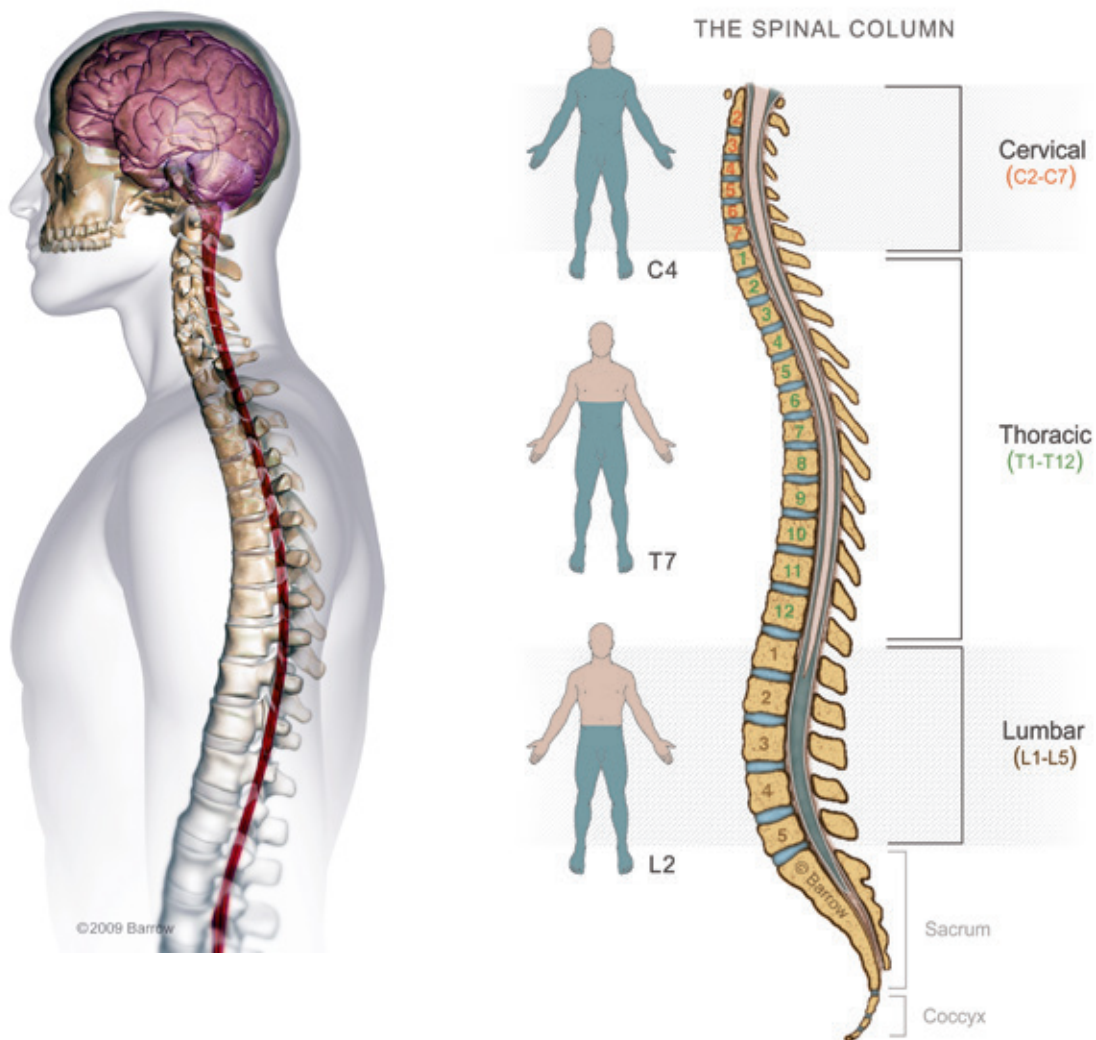
What does the Spinal Cord Do and What Protects the Spinal Cord?

The spinal cord is the main relay station that carries signals of information from the brain to the body and from the body to the brain.

The spinal cord uses nerve roots that go out into specific areas of the body to send signals to control movement, feeling, and functions such as breathing, heart rate, urinating and moving your bowels.

What Protects My Spinal Cord?

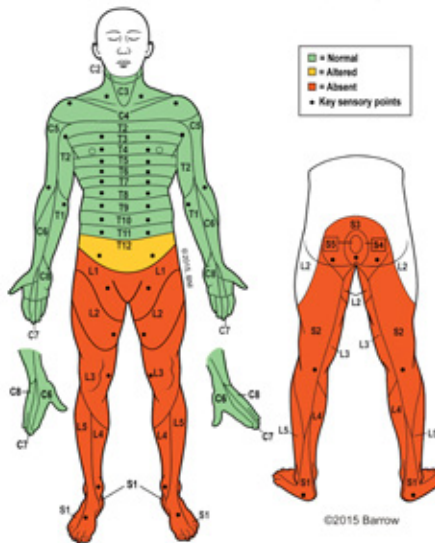
Your spine is composed of 33 bones divided into 5 sections: Cervical, Thoracic, Lumbar, Sacral, and Coccygeal. These bones surround and protect the spinal cord.



What Happens after SCI?



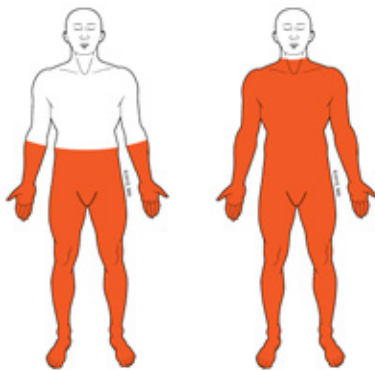
When you have a **Spinal Cord Injury (SCI)**, damage at the level of injury in the spinal cord prevents the information/signals to be sent from the brain to the body and the body to the brain.



There are 2 types of blockage in SCI

1. In **Complete SCI**, no information/signals can go through below the level of the injury. This causes paralysis of movement and no feeling below the level of injury
2. **Incomplete SCI** allows for some messages from the brain to go to the body and the body to the brain. Depending on the part of the spinal cord damaged, you may have some movement and/or feeling at or below the level of injury

Complete
Spinal Cord Injury



Paraplegia

Tetraplegia/
Quadriplegia

Incomplete
Spinal Cord Injury



Paraplegia

Tetraplegia/
Quadriplegia



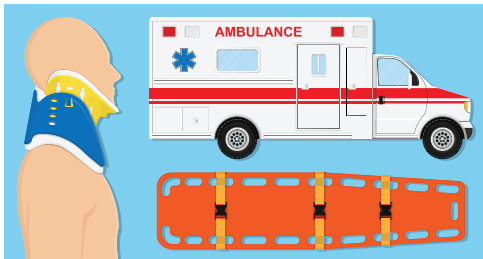
Where is My Injury and What Can Happen to My Body?

	Level of injury	Need help breathing with a ventilator in the hospital	Breath on my own over time	Move and feel my arms	Move and feel my hands	Move and feel my legs	Have control of my bowel and bladder
Neck/Cervical	C1-C4	Yes	Possibly	No	No	No	No
	C5	Possibly	Yes	Partially	No	No	No
	C6	Possibly	Yes	Partially	No	No	No
	C7	Possibly	Yes	Yes	Partially	No	No
	C8	Possibly	Yes	Yes	Yes	No	No
Chest/Thoracic	T 1-6	No	Yes	Yes	Yes	No	No
	T6-12	No	Yes	Yes	Yes	No	No
Waist & Pelvis/Lumbar	L1-5	No	Yes	Yes	Yes	Partially depending on whether injury is complete or incomplete	Partially depending on whether injury is complete or incomplete
Groin/Sacral	S1-S5	No	Yes	Yes	Yes	Partially depending on whether injury is complete or incomplete	Partially depending on whether injury is complete or incomplete

What Treatments and Tests are Used?

You will be placed in a collar and on a board at the accident by the medics or in the emergency department to keep your spine from moving and to prevent more injury.

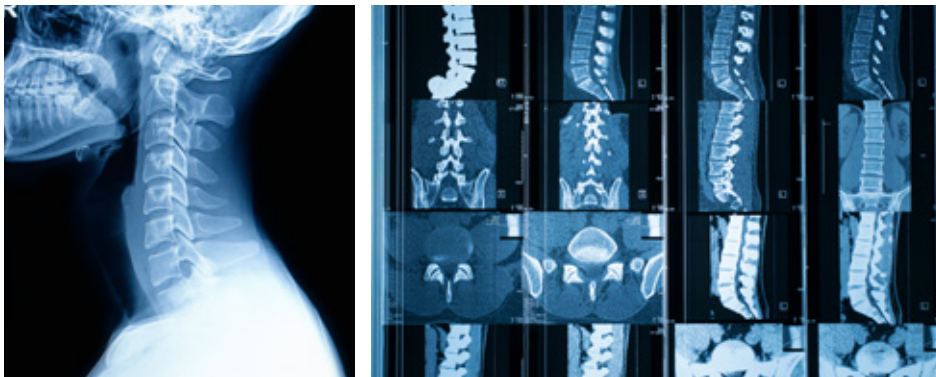
You will be “log rolled” by all members of your healthcare team from the accident scene and in the hospital until your spine is fixed.



At the hospital, you will have tests done to determine the type and location of the injury. The tests may include X-rays, CT and MRI scans of your spine.

Other tests may be done to determine if you have other injuries such as traumatic brain injury or broken bones.

Once the tests are completed, you may need surgery to remove pressure off of your spinal cord from broken bones or other swelling around the spinal cord. The surgeons and medical doctors will talk to you about your injury and what is the best plan to treat the injury. If you need surgery, the doctors will make sure you are safe for surgery.



X-rays, CT and MRI scans

Will I Need a Brace?



With or without surgery, you will usually be placed in a brace. The brace acts like a cast to prevent movement and allow for your bones to heal.

Types of braces can include the following examples:



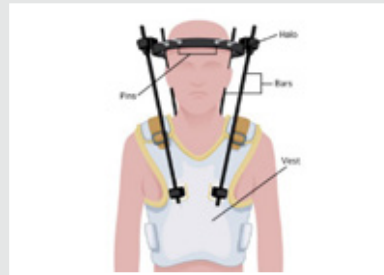
Cervical (Neck) Brace



Thoracolumbarsacral orthotics (TLSO) or hard shell clam braces or soft aspen braces



Aspen Lumbosacral Orthotic (LSO)



Halo Brace

Braces are typically used for 2-3 months. They will be discontinued by your neurosurgeon when your bones are healed.

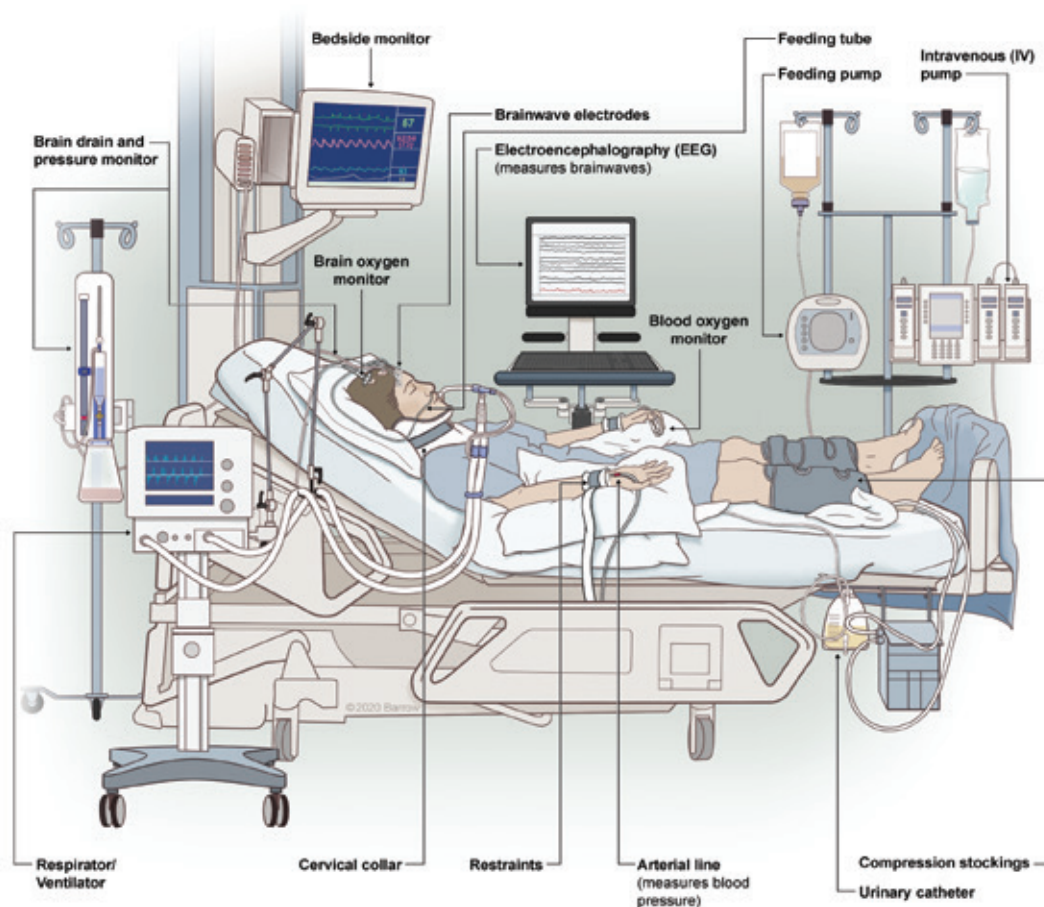
Where Do I Get Care in the Hospital?



Following admission to the hospital you may be admitted to the intensive care unit.

You may have many tubes and devices that help with your care and monitor your stability.

Your doctors, nurses, and respiratory therapists will show you what lines and machines you are using and may need in the future.



Where do I go after the ICU?

Once your surgeons and doctors have stabilized your spine with a brace or surgery, and your vital signs such as your blood pressure, heart rate, oxygen, and temperature are stable you will be transferred to regular floor bed, rehabilitation facility, or home depending on your recovery needs.

How Does SCI Affect the Rest of the Body?

Lungs & Breathing



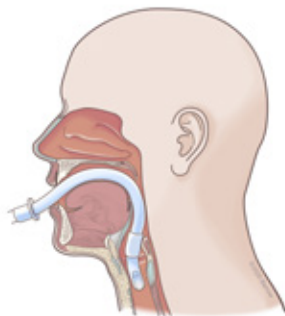
Oxygen is measured in the blood by a probe placed on the person's finger. This is called a pulse oximeter.

- If oxygen is low, more oxygen will be given through tubes in your nose, a mask over your mouth or if necessary through a breathing tube that is connected to a ventilator (respirator)



Potential Problems with Lungs after Spinal Cord Injury

- Spinal cord injuries at the cervical/neck and thoracic/upper chest can make the muscles used to breathe weak or paralyzed.
- You may need help breathing to get oxygen to your body and have a breathing tube inserted through your mouth into your lungs. The tube will be connected to a breathing machine (ventilator) to give you oxygen and help you breathe.
- Because the muscles are weak or paralyzed, you are unable to cough to clear your lungs or swallow safely. This can cause infection (Pneumonia). The goal is to PREVENT pneumonia. If pneumonia develops, antibiotics are given to help treat pneumonia.
- Some people need more time to be able to breathe on their own. They may have the breathing tube removed from their mouth and placed in their neck. This is called a tracheostomy.



Breathing Tube



Tracheostomy

How do I keep my lungs healthy after SCI?

- Your lungs will be suctioned through your breathing tube or tracheostomy and the respiratory therapists will give you medications to help your lungs work better.
- The respiratory therapist will also help you cough by using machines to help your diaphragm work.
- If you are breathing on your own, you will use an incentive spirometer to keep your lungs healthy and exercise your lung muscles throughout the day. Your respiratory therapist and nurse will show you how to take deep breaths to use the incentive spirometer



How do I talk and eat with a breathing tube?

- You cannot talk or eat with the breathing tube in place in your mouth. Once it is removed, the speech therapist will evaluate your speech and swallow.
- If you have a tracheostomy, once the ventilator is removed, the speech therapist will place a speaking and swallowing valve over the tube to evaluate your swallow and help you speak.

Heart & Blood Pressure

- Heart monitor pads are placed on their chest to measure heart rate.
- Blood pressure monitors are connected to blood pressure cuffs on the arm.
- If more frequent blood pressure monitoring is needed a wire with a sensor is placed in the artery of the wrist and connected to a blood pressure monitor.
- Intravenous (IV) fluids, blood products (with patient/ family approval), and medications may be used to raise or lower blood pressure.



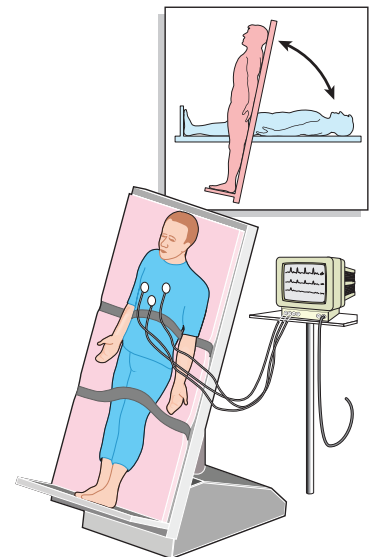
Orthostatic Hypotension

When you have a SCI, your blood pressure is affected and it may be lower than normal.

When you get out of bed, you can have a drop in your blood pressure. This drop in blood pressure can make you may feel dizzy, light headed, and even “faint”. This is called orthostatic hypotension. Your nurses and therapists monitor your heart rate and blood pressure to keep you safe.

What is the treatment for orthostatic hypotension?

- Long leg stockings called TED hose are placed to squeeze the blood out of the veins of the leg to the heart.
- Abdominal binders are placed to push the blood in the belly to the heart
- Medications are also used to help raise your blood pressure
- It is important for you to try to sit up and get out of bed to train your heart and blood vessels



Orthostatic Hypotension

Postural hypotension is a low BP that happens when transitioning to an upright position from sitting or lying down.

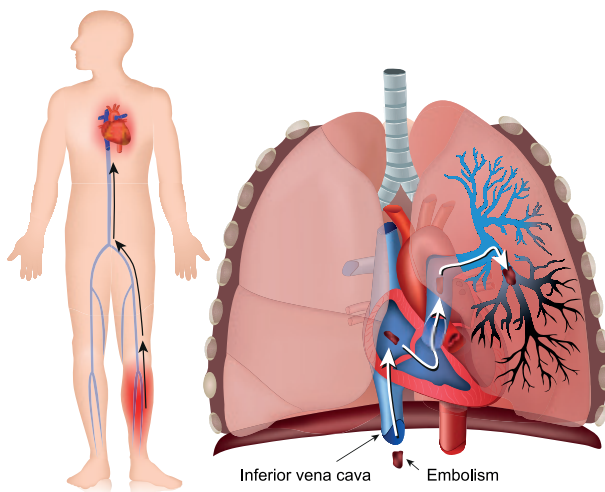
Blood Clots (Deep Vein Thrombosis)

You have a higher risk of blood clots (deep vein thrombosis/DVT) after SCI because the muscles are paralyzed or weak and blood pools in your legs and arms.

Your nurses, physical, and occupational therapists will do the following to help with blood flow and prevent blood clots:

- Sit you up in bed
- Get you out of bed to a chair (they may slide you from the bed to the chair)
- Move your arms and legs
- Use specialty compression stocking on your legs called SCDs (sequential compression device)
- Give blood thinning medications as a shot into your belly

A blood clot that travels to the lungs is called a pulmonary embolus or PE. This can cause extreme shortness of breath, low blood pressure, and can be life threatening. If you feel short of breath, let your healthcare team or caregiver know immediately.



Pulmonary Embolism



SCD (sequential compression device)

Skin, Sensation, and Muscles



After spinal cord injury, you may be weak or paralyzed preventing you from moving and you may not be able to feel pain or pressure below the level of the SCI.

When you remain in one position too long, pressure from the weight of your body against the surface of the bed or chair decreases blood flow to the skin. This can cause “bed sores” known as pressure ulcers.

The most common places pressure ulcers are:

- Lower back
- Heels
- Buttocks



Stage I

Intact skin with non-blanchable redness of a localized area usually over a bony area

Darkly pigmented skin may not have visible blanching; its color may differ from the surrounding area.



Stage II

Partial thickness loss of dermis presenting as a shallow open ulcer with a red-pink wound bed without slough.

May also present as an intact or open-ruptured serum-filled blister.



Stage III

Full thickness tissue loss.

Subcutaneous fat may be visible, but bone, tendon or muscles are not exposed.

Slough may be present but does not obscure the depth of tissue loss.

May include undermining and tunneling.



Stage IV

Full thickness tissue loss with exposed tendon or muscle.

Slough or eschar may be present on some parts of the wound bed.

Often includes undermining tunneling.



Pressure Ulcer Prevention

1. Your nurses will turn you consistently in bed every 1-2 hours
2. Change position every 15-20 min when up to the chair for 30-60 seconds each time
3. Special Mattresses may be used to lower the risk of getting pressure ulcers
4. Float heels with pillows or specialty boots
5. A special cushion for the chair to relieve pressure



Muscles: Moving Arms and Legs

Depending on the level of the SCI, your arms and legs may not move and may be floppy.

Over time, the floppiness will go away and you may have some tightness in your arms or legs (spasticity). The spasticity can cause your arms and legs to jump or move on their own.

Daily stretching by your therapists and caregiver is important. Arms and legs will need to be stretched through their full range of motion daily by you or another person.

Your physical and occupational therapists will teach you and your caregiver how to stretch your muscles. Sometimes splints are created to prevent the muscles from contracting.

Getting Out of Bed with Therapy

- The therapists will work to help you get stronger and develop a training plan specifically for you
- The physical therapist, occupational therapist and nursing staff will get you out of bed as soon as your vital signs are stable and your spine has been fixed by surgery or by bracing.
- Pain medicines and supportive therapy will be used to help you be comfortable to get up out of bed and work with your therapists to recover
- Braces are used to get up as directed by your neurosurgeon
- Alarms are placed on beds and chairs to help prevent falls.



Eating & Drinking



You will need more protein and calories to help your body heal following SCI. Our registered dietitian will create a personal meal plan for you.

If you have a breathing tube, you will not be able to swallow food or liquids. A feeding tube may be placed through the nose into the stomach to give food and medications.

If you need more time to recover, the feeding tube in the nose can be removed and another tube can be placed directly in the stomach/intestine.

As you improve and the breathing tube is removed, we need to make sure your swallow is safe.

The speech language pathologist (SLP) will work with you to see if you can safely swallow and what consistency of food is right for you.

If you have a tracheostomy, once the ventilator is removed, the speech therapist will place a speaking and swallowing valve over the tube to evaluate your swallow and help you speak.

After the evaluation, the SLP will let your healthcare team know if you can eat and take medications. If you can eat, your diet will be ordered at that time and adjusted to help you heal.



*Temporary
Feeding Tube*



*Standard
Feeding Tube*



*Low-Profile
Feeding Tube*

Going to the Bathroom

Urinating

The bladder is a muscle and is controlled by signals traveling up and down the spinal cord to the brain just like your arms and legs.

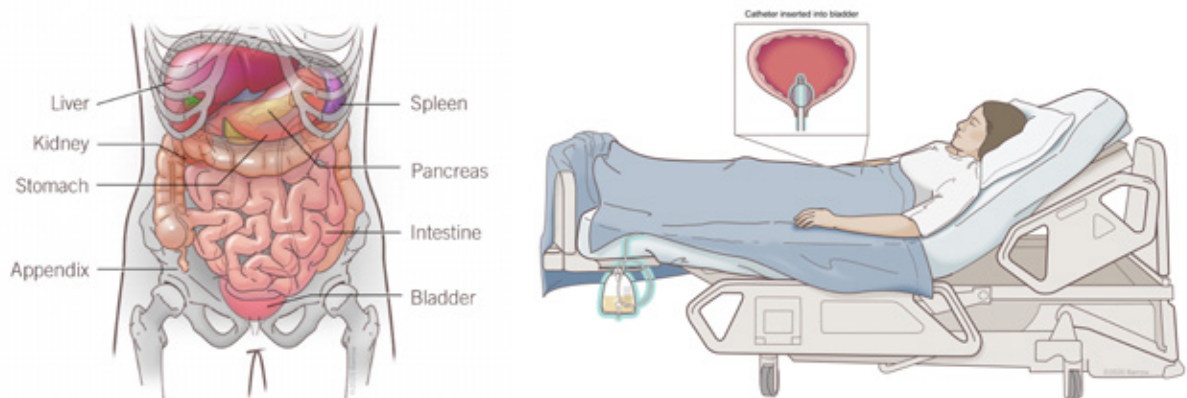
SCI can cause the bladder to be weak or paralyzed. The bladder cannot tell the brain it is full because the messages are blocked and the brain cannot tell the bladder to contract and release urine.

A tube (Foley catheter) is inserted in the bladder to drain urine and prevent damage to your bladder. Once you are stable, this tube will be removed to decrease your risk of a urinary tract infection (UTI).

After removal of the Foley catheter, your bladder muscle still may not work.

The nurse will check the amount of urine you have in your bladder by using an ultrasound machine called a bladder scanner every 4-6 hours.

If you are still retaining urine, the nurses will insert a temporary tube to drain the urine from your bladder. This is called intermittent catheterization. You and/or your caregiver will be taught how to catheterize.



What can you do to help?

1. Drink fluids during the day to reduce chance of infection
2. Make sure to catheterize every 4-6 hour to keep urine volumes below 400 ml
3. Maintain sterile technique to lower the risk of infection
4. Learn and identify the signs and symptoms of UTI, and tell your healthcare provider immediately if you have one:
 - a. Fever
 - b. Urine that smells
 - c. Change in blood pressure
 - d. Feeling sick

Having a Bowel Movement

The bowels are also muscles and are controlled by the brain and spinal cord.

The loss of sensation and weak muscles can cause you to lose control of your bowels and not feel when you do have a bowel movement.

Or you may be constipated and you are unable to have a bowel movement on your own.

Your doctors will order a specific bowel care to help your bowels work again to prevent incontinence, diarrhea, & constipation. This includes using:

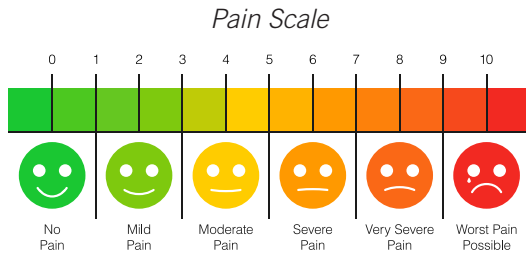
- Oral stool softeners and laxatives AND
- Rectal laxatives
- Consult the registered dietitian to help with your diet to keep your bowels regular

What can you do to help?

1. Drink plenty of fluids
2. Take fiber and have fruits and vegetables daily
3. Increase activity to keep your bowels moving
4. Have a consistent bowel care routine

Pain

You may have more than one type of pain. Your team will develop a pain management program specific to you and your type(s) pain.



Pain Management Goals

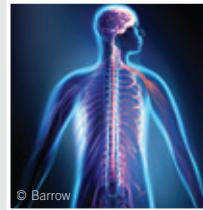
1. Decrease pain so that you can get out of bed comfortably and work with therapist
2. Change medications if you develop bad side effects
3. Use the least amount of medication to get the best results to lessen your pain



Aching and throbbing pain is due to injury and surgery.

Treated with:

- Pain medications
- Muscle relaxants
- Pain patches
- Ice
- Heat
- Massage



Electric shock, cold, burning, tingling, stabbing, prickling or itching is due to injury to the spinal cord and nerves at the level of your injury or below. You may have pain when you are touched.

Treated with:

Pregabalin (Lyrica)
Gabapentin

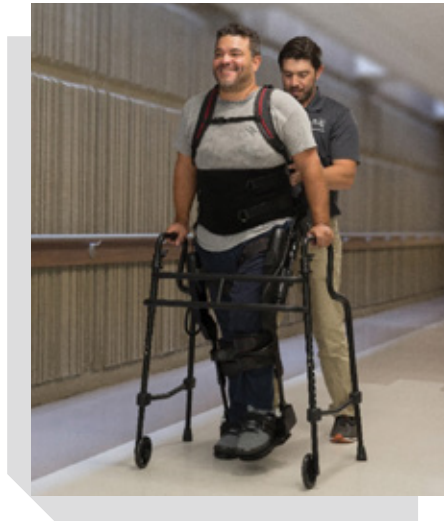
From the Hospital, What Happens Next?



As you become stable and leave the ICU, you may transfer to a regular hospital floor or a telemetry (heart monitored) floor for a few more days of monitoring.

The place you go after your discharge from the hospital can vary depending on your level of recovery and your insurance: Examples include the following:

- **Long-Term Acute Care Hospital**
When a person has stabilized but needs longer hospital care.
- **Acute Rehab Facility**
A person stays here and participates in therapies for hours per day. Typically for a shorter duration rehab needs.
- **Skilled Nursing Facility**
A person stays there and participates in therapies for 2 hours per day. Typically, for a longer duration rehab needs.
- **Home with Family and/or Home Health**
Outpatient therapy and follow-up office appointments.



Care Coordinators are part of your team and will help with making your discharge plans and arrangements.

The care coordinators are experts and work/talk with your insurance to find the appropriate facility, home health agency, outpatient therapy that is covered under your insurance plan.

Frequently Asked Questions

How long will I be in the hospital?

The length of your stay in the hospital depends up on the severity of your injuries and whether surgical intervention was required. You will stay in the Intensive Care Unit (ICU) until your blood pressure, respiratory function, and other medical issues are stable. This may take a few days to a couple of weeks. After the ICU you may be discharged to the recommended level of care.

What is the difference between acute rehabilitation and skilled nursing care?

In an acute rehabilitation program, you receive round the clock nursing care and intensive therapy with the goal of regaining as much independent function as possible and to return home. Your care will be managed by a doctor that specialized in rehabilitation after spinal cord injury (a physiatrist). You will participate in 3 hours of therapy daily. Typically stay in the rehabilitation setting for several weeks.

Skilled nursing facilities also provide round the clock nursing care. You will receive a 1.5 hours of therapy daily. Your medical team can answer specific questions about your anticipated length of stay. Don't hesitate to ask!

Why can't I talk?

Some injuries initially require specialized respiratory management, which may include a breathing tube or tracheostomy. You cannot pass air over the vocal cords to talk. During this time the staff will make every effort help you communicate through other methods. Speech language pathology will work with you to help you speak.

Will I walk again?

The answer to this quest ion depends on the extent of your injury. The medical team can best explain the specifics of your injury and your potential for neurological recovery.

Why are parts of my body swollen?

Depending on the level of your injury, you may find that you have swelling in your hands, legs, and feet. The swelling occurs because the weak or paralyzed muscles in your affected arms and legs cannot help blood return to your heart. This can cause fluid from the blood vessels to seep into the surrounding t issues causing swelling. The staff assists with decreasing the swelling by elevating the swollen body parts, making sure you are wearing TED hose, doing exercises with the affected body part and with medications, if needed.



Will my sex life be affected?

During the first 6-8 weeks after an SCI, swelling of the spinal cord interferes with all function below the level of injury, including sexual function. Once the swelling is gone, sexual function can be fully evaluated and management options provided, if needed. How you experience sex may be different from the way it was before because of weak or paralyzed muscles and loss of feeling in body parts. It is important to stress that people living with SCI are capable of having fulfilling sex lives, marriages and children. Your healthcare team will be able to give you more specific information.

Will I be able to have children?

For women who have sustained an SCI, it may take several weeks to months before the menstrual cycle returns. Spinal cord injury does not affect your ability to get pregnant. However, there may be specific management options needed during the months of pregnancy and during labor and delivery depending upon the level of SCI. Many women with all levels of SCI have delivered healthy babies. If you do not wish to have children, you need to speak to your health care provider about birth control options. Please note that pregnancy can occur before the return of the first menstrual cycle following SCI.

For men, having children is possible. However, whether fathering children will be in the traditional manner or whether it will require some medical assistance depends upon level of injury, severity of injury and other factors. You will need to talk to your health care provider for information more specific to your case.



Who Can I Call for Help, After Leaving the Hospital?



Here are a list of community resources to help you.

Call the number listed, or scan the QR code with your smartphone to be directly linked to the website.



Arizona Spinal Cord Injury Association

5025 E. Washington St., #110, Phoenix, AZ 85034
(602) 507-4209
azspinal.org



Brain Injury Association of America (BIAA)

5025 E. Washington St., #200
Phoenix, AZ 85034
(602) 256-2245
ability360.org



American Spinal Injury Association

asia-spinalinjury.org



Barrow Connection

(602) 406-6280
www.thebarrow.org/Connection

Bridging the gap between hospital and community.



Barrow Spinal Cord Injury Wellness Program

(602) 406-5195
barrowneuro.org/centers-programs/neurorehabilitation/treatments/spine-rehabilitation/



The Christopher & Dana Reeve Foundation

christopherreeve.org



Miami Project
miamiproject.miami.edu



National Spinal Cord Injury Association
spinalcord.org



Paralyzed Veterans of America
pva.org



My Tests, My Team, and My Progress

Tests Completed:

Affected Areas:

Plans:

My Tests, My Team, and My Progress

My Team Members:

Medications:

Activities:

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Dignity Health
St. Joseph's Hospital and
Medical Center