



# SPINAL CORD INJURY PATIENT AND CAREGIVER EDUCATION

THIS BOOKLET IS FROM:

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This booklet provides basic information about spinal cord injury. We hope you find it helpful during your stay in the hospital and beyond. If you have questions about the contents of this handout, please talk with a member of your health care team.

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## My Care Team

Trauma Intensive Care Unit Phone#: 216-844-1475

<b>Team Member</b>	<b>Name</b>
<b>Attending Doctor</b>	
<b>Physical Therapist</b>	
<b>Occupational Therapist</b>	
<b>Speech Therapist</b>	
<b>Social Worker</b>	
<b>Care Coordinator</b>	
<b>Nurses</b>	
<b>Other Staff</b>	

## Your Hospital Care Team

The members of this team are an important source of information and support. They may include:

- **General medical team:** Doctors, nurses, nursing assistants who provide daily care.
- **Intensive care specialists:** Medical team members who specialize in trauma care and recovery. They include surgeons and critical care doctors. They treat people in intensive care, monitor their condition closely and help diagnose and treat medical problems.
- **Critical care nurses:** Nurses who work in the intensive care unit. They perform bedside neurological exams, help doctors perform procedures, communicate with you and your care team and provide education and support.
- **Neurologists:** Doctor who evaluate and treat disorders of the brain. They may perform tests to help determine the extent of the brain injury. They may perform bedside tests to guide diagnosis and monitor brain recovery.
- **Pulmonologists or respiratory therapists:** Specialists that diagnose and treat breathing problems. They determine whether a person needs a breathing tube or machine to help them breathe.
- **Dieticians:** Dietitians monitor a person's nutritional status and manage their dietary needs. They may also help determine if a feeding tube is needed to provide nutrition.
- **Pharmacists:** In a hospital setting, they work closely with doctors to monitor a person's medicines. They may also provide education about the purpose of medicines given and their side effects.
- **Physiatrists** (fiz-ZAHY-uh-trists): Doctors that help diagnose and treat medical conditions that include pain, muscle, joint or nerve problems during the rehabilitation process. They direct and oversee the team of physical therapists, occupational therapists, and speech therapists. People with TBI receive these rehab services while they are in intensive or acute care units.
- **Physical therapists:** Rehab specialists that focus on recovery of strength, conditioning, flexibility, walking, balance, body mechanics, posture, positioning for pressure relief, assistive devices, and mobility.



- **Occupational therapists:** Rehab specialists that focus on activities of daily living such as bathing, feeding, showering, dressing, toileting and grooming. They also work to help patients with thinking (cognition), sensation, visual perception, strength and endurance, equipment training, orthotics, and safety.
- **Speech Language Pathologists:** Sometimes called Speech therapists. These rehab specialists evaluate and treat feeding and swallowing abilities, and speech cognitive-language impairments. If a person needs a communication device if needed. A person may need a communication device if they are intubated with a tracheostomy or on a ventilator.
- **Neuropsychologists:** Psychologists that evaluate and diagnose changes in behavior, thinking, and emotion caused by TBI. They may perform bedside tests to help determine levels of consciousness, plus educate you and your family.
- **Case managers and social workers:** Staff who coordinate the health care plan by handling insurance benefits, financial matters and discharge planning. They are also a valuable resource who can give you emotional support and information about TBI.
- **Other health care team members:** Our chaplain and/or patient representative may be available to provide spiritual and emotional support to people with TBI and their family members.

## What to Expect in the Hospital

### Being cared for by a team

While your loved one is here, they will be seen by many health care workers, but only one team oversees their total plan of care. This team is led by **an attending doctor**.

Once a patient's medical concerns are stable, our physical, occupational and speech therapists evaluate them and create a rehab plan of care. The therapy team works with patients throughout their stay and adjusts their rehab plan of care as needed. This team also talks with the medical team and nurse care coordinator to form a discharge plan. The goal is ensure your loved one has the proper level of care after they leave the hospital.

### Daily rounds

The hospital care team sees patients each day during their **daily rounds**. Rounds are often done in the morning. During rounds, the team looks at things like vital signs, weight, lab results and test results. It is very helpful family take part in rounds. Rounds are a great time to ask questions, take notes, share thoughts or concerns and learn about your care. If you need more time to ask questions, or if a family member cannot attend, please let us know.

## Common Tests and Procedures

- **Neuroimaging studies (CT scans or MRIs):** Helps doctors see the injured parts of the spinal cord.
- **Bone image studies (x-ray):** Helps doctors to see which bones, if any, are broken in the spine.
- **Surgeries:** surgery works to take pressure off of an injured spinal cord (if there is any) and stabilize any instability in the structures around the spinal cord. Decompression surgeries often involve laminectomies or discectomies and stabilizing surgeries could include fusions with rods, screws, or other devices.

## Spinal Cord Injury (SCI)

Note - this section of the handout may be slightly intimidating for some SCI patients and their family members but please know that this is not the intent. Spinal cord injury is a complex, multifaceted condition, thus, our intent is to inform, educate, and ultimately empower our patients and their families regarding the many considerations that are play when an individual sustains a SCI. Also of note, the beginning of this section of the handout contains foundational information that is essential to understand in order to understand concepts discussed later in the handout. It is important that you read the handout in order so that you are not confused about information provided towards the end of the handout.

### What It Is

- When the spinal cord or its nerve roots within the spinal canal are damaged. A SCI can ultimately result in either temporary or permanent loss of movement and/or feeling. The loss of movement or feeling happens in different places in the body depending on the specific circumstances of a given SCI<sup>1</sup>.
  - You can think of the spinal cord as the “electrical cable” that connects the brain to the rest of the body. If an electrical cable is cut or damaged, the flow of electrical current will be impaired, or possibly even absent depending on the severity of the cut in the cable. Similarly, if the spinal cord is cut or damaged, the signals to and from the brain and the rest of the body could be disrupted. This ultimately results in changes in movement and feeling.

### Who Gets Spinal Cord Injuries and How?

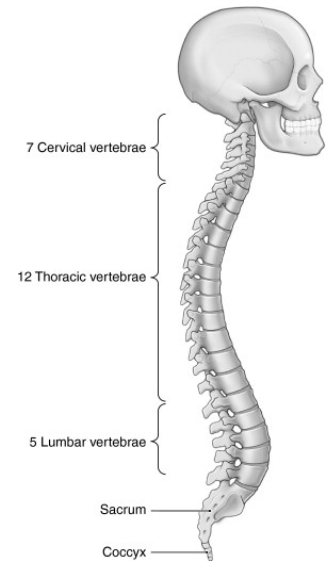
- Approximately 250,000-500,000 people experience a SCI each year worldwide, with about 12,000 of those injuries occurring in the United States<sup>2</sup>.
- Injuries often result from traumatic events such as motor vehicle accidents, falls, gun shot wounds, and sports accidents but can also come from viruses, tumors, or lack of blood flow to the spinal cord<sup>2</sup>.

### Basic Structure and Function of the Spinal Cord

- The spine (the “backbone”) is made up of many bones stacked on top of one another with each bone being called a “vertebra” (plural “vertebrae”)<sup>1</sup>.

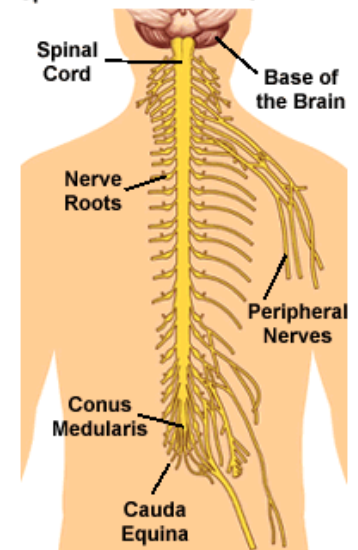


- There are 5 sections of the spine including cervical, thoracic, lumbar, sacral, and coccygeal. The cervical spine is the highest region in the spinal column - this portion of the spine forms the neck. The coccygeal region is the lowest region, sometimes called the “tailbone”<sup>1</sup>.
- Each section of the spine has a specific number of vertebrae – 7 cervical, 12 thoracic, 5 lumbar, 5 sacral, and 3-5 coccygeal<sup>1</sup>. Each vertebra is labeled according to the section of the spinal column that it belongs to and its corresponding number within that section. For example, the 6<sup>th</sup> vertebra in the thoracic region is referred to as “T6” while the 5<sup>th</sup> vertebra in the lumbar region is referred to as “L5”.



- The spinal cord, which is a bundle of nerve tissue that is connected to the brain, is surrounded by the vertebral bones. The cord runs through a canal that is formed by the stacked vertebrae<sup>1</sup>.
- The spinal cord essentially functions as the connection between the brain, the “command center of the body”, and the rest of the body<sup>1</sup>.
- Spinal nerve roots come off of the spinal cord and begin the connection of the spinal cord to the rest of the body. There are 31 pairs of spinal nerves coming off of the spinal cord on both the right and left sides of the cord<sup>1</sup>.
  - Nerve roots are labeled similar to vertebrae. For example, the nerve root that passes through a small hole below the T8 vertebra is labeled as the “T8” nerve root and the nerve root that passes through a small hole below the L4 vertebra is labeled as “L4”.

Spinal Cord and Nerve Structures



- Spinal nerve roots are the beginning of the complex network of nerves that run throughout the body to allow for sensory (feeling), autonomic (reflex actions) and motor (muscle activity) functions<sup>1</sup>.

### Expected Impairments after SCI

- As stated above, the spinal cord is like an “electrical cable”. Normally, the spinal cord helps to transmit information from the brain to the rest of the body as well as bring information from the

body up to the brain. Signals going out from the brain to the rest of the body are called “efferent signals”. Signals going from the periphery back to the brain are called “afferent signals”.<sup>3</sup>

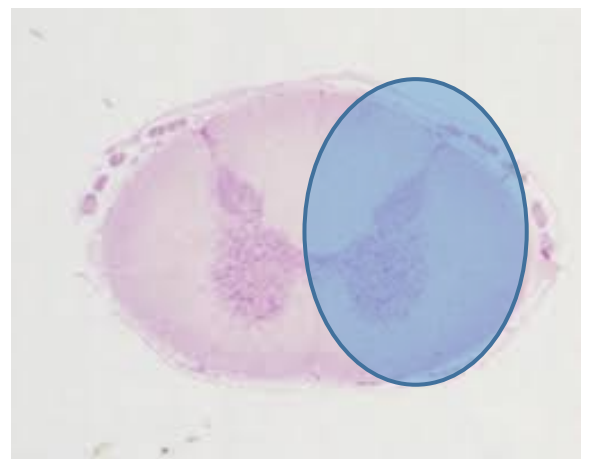
- Therefore, when there is an injury to the spinal cord, the transmission of afferent and efferent signals can be affected.
- Motor, sensory, and autonomic nervous activity can all be impacted when the spinal cord is disrupted.
- **Motor** – motor function essentially refers to the ability to move. Successful transmission of an efferent signal from the brain to the rest of the body would indicate normal motor function<sup>3</sup>.
- **Sensory** – sensory function essentially refers to the ability to feel different sensations such as light touch, pain, temperature, etc. Successful transmission of an afferent signal from the rest of the body up to the brain would indicate normal sensory function<sup>3</sup>.
- **Autonomic** – autonomic nervous function includes functionalities that are not under conscious control. In other words, you cannot control the autonomic nervous system under your own power. Thus, the autonomic nervous system can be thought of as the “automatic” nervous system<sup>3</sup>.

## Different Spinal Cord Syndromes

**Everybody’s spinal cord injury will be a little bit different and have unique deficits based upon how an individual was injured, their size, their unique anatomy, etc. These descriptions attempt to provide broad descriptions of general patterns that are seen when an individual sustains a SCI.**

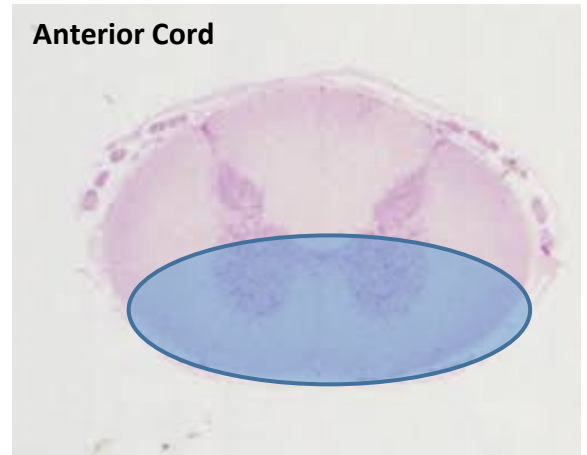
- **Brown-Séquard**<sup>3</sup>
  - This injury involves one half of the cord being injured, leaving the other side of the cord relatively intact and unaffected.
  - Brown-Séquard syndrome typically results from a traumatic mechanism of injury such as a gunshot and involves loss of motor (movement) function and loss of touch and vibration sensation on the same side of the body as the lesion. Pain and temperature sensation are impaired on the side of the body opposite to the lesion.
    - This complex mixture of symptoms is due to how the different nerve tracts run and cross over within the spinal cord.

**Brown-Séquard**



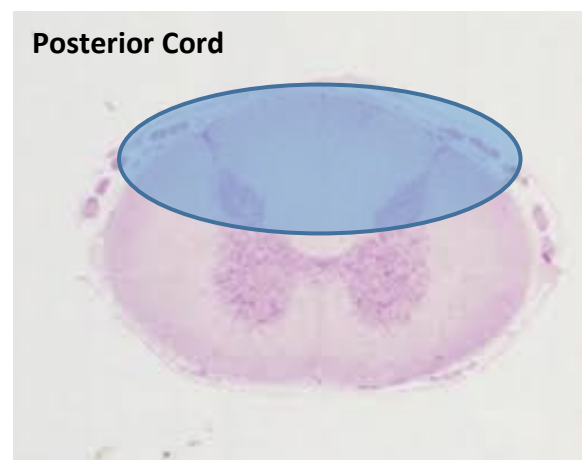
- **Anterior Cord**<sup>3</sup>

- This injury involves a lesion to the anterior (side of the cord closest to the front of the body) 2/3 of the spinal cord.
- Anterior cord syndrome results in complete loss of motor (movement) function below the level of the lesion because both tracts that run through the spinal cord to control voluntary movement are lesioned.
- The sensory tracts that carry information regarding pain and temperature also exist in the anterior (front) portion of the spinal cord, therefore, pain and temperature sensation are lost below the level of the lesion.
- The sensory tracts that carry information regarding vibration and proprioception exist in the posterior (back) portion of the spinal cord, therefore, these tracts are unaffected in anterior cord syndrome.
  - Note – “proprioception” is essentially the body’s ability to recognize its own position in space<sup>3</sup>. For example, you can picture the position of your arms and legs even when your eyes are closed and describe the positioning of your body to somebody. Another example of proprioception is when a golfer initiates his/her downswing – the downswing was initiated because the golfer could feel that the club had reached the “top” of their backswing.



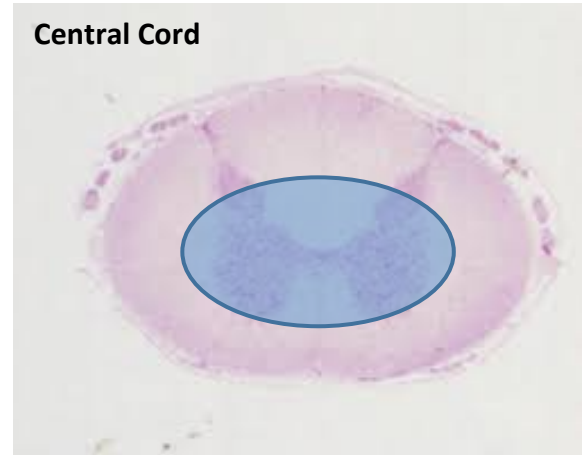
- **Posterior Cord**<sup>3</sup>

- This injury involves the posterior (back) portion of the spinal cord being damaged. This is a rare type of SCI.
- Pain and temperature sensation as well as motor (movement) function all remain intact but vibration and proprioception sensation capacities are lost.
- Vibration and proprioception are specifically lost due to the location of the nerve tracts that carry this information to the brain. These tracts exist in the posterior (back portion) of the spinal cord.



- **Central Cord<sup>3</sup>**

- This type of injury affects the central gray matter of the spinal cord. In the picture to the right, the purple area is called gray matter. The other part of the cord is made up of white matter.
- Typically, the arms are more affected than the legs with this type of injury.
- Loss of hand function may be severe and potentially permanent, but the legs are often able to maintain or re-establish much of their function.



- **Conus Medullaris<sup>3</sup>**

- This type of injury affects the conus medullaris, which is at the L1 vertebral level
- The conus medullaris is the portion of the cord where the cord tapers and ends. The nerves that run through this region and are affected in this type of injury control the legs, genitals, bladder, and bowel.
- Symptoms include deep aching pain in the low back with numbness in the groin, thigh, leg, and foot. Other symptoms that may manifest include urinary retention, bowel dysfunction, and sexual dysfunction.

- **Cauda Equina<sup>3</sup>**

- The name “cauda equina” is derived from Latin and means “horse tail”. This is because, at the end of the spinal cord, the cord forms many branches that look like a horse’s tail.
- Cauda equina injuries happen below the level of L2.

## What is the ASIA Impairment Scale?

- The American Spinal Cord Injury (ASIA) Impairment Scale is the international gold standard for evaluating and classifying spinal cord injuries<sup>4</sup>. Thus, it may be important to have some knowledge of this evaluation tool so that you can better understand your injury.
- This scale helps to identify key muscle groups and sensory points for evaluation, which works to help classify an individual’s level of lesion (see below for description of “level of lesion”). Additionally, this scale provides detailed descriptions of each sensory and motor grade, which allows a practitioner to classify an individual’s injury as “complete” or “incomplete” (see below for description of “complete versus incomplete injuries”)<sup>4</sup>.
  - **Level of Lesion**
    - The word “lesion” is a fancy word that refers to an area in an organ or bodily tissue that has been damaged in some way<sup>5</sup>.

- By definition, the level of lesion is the lowest spinal level at which an individual has normal neurological function. Normal neurological function would be indicated by normal movement and feeling<sup>2</sup>.
- To determine the lowest spinal level where an individual has normal neurological function, a health care provider will implement both strength and sensation tests<sup>2</sup>.
- **Complete Versus Incomplete Injuries**<sup>4</sup>
  - A “complete” injury indicates that all motor and sensory functions are absent below the level of the lesion, including sacral root function. Sacral nerve roots control pelvic muscles including the external anal sphincter. These are essentially the muscles that help you “go to the bathroom”.
  - An “incomplete” injury indicates that there is some degree of motor or sensory functionality retained below the level of the lesion.
- The ASIA impairment scale includes three different examinations including sensory, motor, and anorectal examinations. Sensory refers to what an individual can feel. Motor refers to movement abilities. Anorectal refers to the muscles that help you “use the bathroom”. After the entire examination is complete, the practitioner can accurately assign an injury grade and injury level<sup>4</sup>
- The sensory exam looks at 28 specific areas of skin called “dermatomes”. Dermatomes are essentially specific zones of skin, with each zone being associated with a specific nerve. Both light touch and pin prick sensation are tested. Generally, light touch is assessed using a piece of cotton and pin prick is assessed using a clean safety pin. Don’t worry, the intent with pin prick testing is not to draw blood – the safety pin is applied very lightly so as not to cause harm to the individual. A grade of “0” indicates absent sensation in a given dermatomal area. A grade of “1” indicates impaired or altered sensation, and a grade of “2” indicates normal sensation in a given area<sup>4</sup>.
- The motor examination looks at five specific muscle groups in the arms and five specific muscle groups in the legs. Motor strength is graded on a 0-5 scale with 0 indicating no evidence of muscle activation and 5 indicating normal strength.

- The anorectal examination is an important part of the examination as a whole because this portion of the exam helps to determine if an injury is complete or incomplete. During this part of the exam, the practitioner uses his/her finger to evaluate the motor function of external anal sphincter. This is essentially the muscle that controls a person’s ability to pass a bowel movement or not. The practitioner also assesses for the presence or absence of deep anal pressure sensation.
- At the end of the examination, the practitioner will be able to assign an AIS grade to the patient. Possible grades are A, B, C, D, and E. If a patient has a complete injury, they will be assigned as a grade A. All other grades are different degrees of incomplete injuries. See complete descriptions of each grade in Figure 3.

Grade	Description
A	Complete. No sensory or motor function preserved in sacral segments S4-S5
B	Incomplete. Sensory but not motor function preserved below the neurologic level and extending through sacral segments S4-S5
C	Incomplete. Motor function preserved below the neurologic level; majority of key muscle have a grade < 3
D	Incomplete. Motor function preserved below the neurologic level; majority of key muscles have a grade > 3
E	Normal motor and sensory function

## Considerations with SCI

**Note** – every SCI case is unique and will present with different impairments and secondary complications. Therefore, the considerations listed in this section do not apply to every single SCI case. This section is meant to provide a comprehensive list of potential complications and considerations for your SCI case.

- **Autonomic Dysreflexia (AD)**

- The “autonomic nervous system” can really be thought of as the “automatic nervous system” because it happens automatically and is not under voluntary control<sup>6</sup>
- AD is a potentially life threatening condition that can come on secondary to pain or discomfort below the level of lesion (even if the pain or discomfort cannot be felt by the individual)<sup>7</sup>.
  - Pain or discomfort can be caused by a variety of stimuli, including but not limited to: a full bladder (that cannot be emptied due to a kinked/blocked catheter), irritated bowel (constipation, gas, or irritated hemorrhoids), irritated skin (cut, ingrown nail, pressure ulcer, exposure to extreme heat or cold), broken bone, sexual activity, and menstruation in female patients<sup>7</sup>
- The reason that AD can happen after SCI is because SCI changes the way that autonomic reflexes occur in the body<sup>7</sup>. Autonomic reflexes are a function of the nervous system and,

- with the spinal cord being a very important part of the nervous system, an injured spinal cord leads to changes in the nervous system. These changes include changes in the autonomic nervous system.
- The majority of first AD cases happen 3-6 months after SCI. Only 5.6% of individuals with injuries at T6 or above have AD within the first month of SCI<sup>8</sup>
  - Patients with lesion levels at or above the T6 level are prone to AD<sup>8</sup>.
    - Not all individuals with injuries at or above T6 will have AD. Studies have demonstrated 48%-91% of individuals with injuries at or above T6 will experience autonomic dysreflexia<sup>8</sup>.
  - AD can be life threatening because, when AD comes on, blood pressure can elevate to dangerously high levels<sup>7</sup>
    - Blood pressure values will continue to be elevated as long as the cause of the pain or discomfort below the level of the lesion is still present<sup>7</sup>.
  - Symptoms of AD may include extreme headache, piloerection (hairs standing up), stuffy nose, blurred vision, anxiety, sweating, and flushed skin above the lesion level<sup>8</sup>.
  - If you are having an episode of AD, then the following strategies are important to implement<sup>7</sup>:
    - Take your blood pressure and check for elevation (you will need to know your normal, baseline blood pressure in order to determine this)
    - Sit up, do not lay down
    - Check for stimuli that may be causing the problem – loosen tight fitting clothing, check your catheter, check to see if your bowel is full, check for cuts or sores that you may not have been aware of.
    - If you are unable to identify the cause of your AD or if your blood pressure continues to rise, then call 911
  - Steps to prevent AD include<sup>7</sup>:
    - Maintaining a consistent, hygienic bladder program as well as a consistent bowel program
    - Daily skin checks and pressure relief strategies
    - Avoid any injuries to your skin such as cuts, sunburns, and bruises
    - Wear comfortable clothing and utilize safe transfer techniques (see below for section on transfers).
- **Orthostatic Hypotension (OH)**
    - Orthostatic hypotension is when blood pressure decreases as a result of transitioning from a supine (laying on your back) posture to a more upright position. This could be sitting up or standing up<sup>9</sup>.
    - Symptoms experienced during a bout of OH may include fatigue, weakness, light headedness, dizziness, blurred vision, and neck pain<sup>10</sup>. OH may result in fainting as well<sup>9</sup>.



- Greater than half of all SCI patients with experience a bout of OH within the first month following SCI<sup>10</sup>
- It is important for SCI patients to be aware of OH and its symptoms so that they can alert their health care providers of when they are experiencing symptoms and work to prevent potential injuries that could result from suddenly fainting as well as other potential adverse events.
- **Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)**
  - A DVT is a blood clot that forms in the deep veins of the body and commonly affects deep veins of the legs and pelvis<sup>11</sup>. A PE is another type of blood clot that can result from a DVT that “breaks loose” and travels from the leg or pelvis upward and into a pulmonary artery, near the lungs<sup>12</sup>
  - DVT and PE are common in SCI patients due to many factors that are at work when a patient has a SCI<sup>13</sup>.
  - Both pharmacological (medications) and mechanical approaches (compression stockings and leg pumps) are used to prevent the formation of DVT and resultant PE<sup>13</sup>.
- **Spasticity and Flaccidity**<sup>14</sup>
  - The word “spasticity” comes from the Greek “spasticus”, which is roughly translated as “to pull or tug”.
  - Spasticity is essentially intermittent or sustained muscle activation that happens involuntarily after a specific type of injury to the nervous system. SCI is one type of nervous system injury that results in spasticity.
  - Spasticity can be problematic because it can cause pain, deformity to one’s body, and muscle spasms. Decreased physical function and ability to participate in certain activities can result from untreated spasticity.
  - Flaccidity often precedes spasticity immediately following a spinal cord injury. Flaccidity is essentially a lacking of muscle tone/activation, which results in a limp, floppy appearance of the affected muscles.
- **Pressure Sores**
  - A pressure sore is an area of skin and, potentially, underlying tissue, that is damaged due to decreased blood flow to that skin and underlying tissue. Like any tissue in the body, if skin does not receive blood flow, it will die and a wound can result<sup>15</sup>.
  - SCI patients are more susceptible to pressure sores as compared to the general population due paralysis and sensory loss that often results from the SCI. these impairments result in an inability to properly change positions and offload bodily tissue throughout the day as well as recognize when an area is injured due to prolonged pressure<sup>15</sup>.



- In addition to paralysis and sensory loss, there are other risk factors for developing and pressure sore as a SCI patient. These risk factors may include: decreased muscle mass, being underweight or overweight, poor nutrition, skin that is exposed to moisture (from urine, stool, sweat, water) for long periods, aging, spasticity, and depression<sup>15</sup>.
- Areas where bones can easily be felt through the skin, called “bony prominences”, are at the highest risk for pressure sores. Common bony prominences that can be affected include the back of the head, the elbows, shoulder blades, sacrum/tailbone, and heels<sup>15</sup>.
- Pressure sore prevention should be taken very seriously as there are many potential consequences/complications that can result from a pressure sore<sup>15</sup>. SCI patients can avoid pressure sores implementing the following strategies<sup>16</sup>:
  - Do regular pressure reliefs. This is when you shift your weight in order to relieve an area of pressure and work to redistribute pressure. When seated in a wheelchair, pressure reliefs should happen every 15-30 minutes and last at least 30 seconds (and ideally 90 seconds).
    - If you are unable to independently perform pressure reliefs, then make sure your caregiver can effectively facilitate this process.
    - Therapists can instruct patients regarding pressure relief strategies given a specific set of impairments in a specific patient.
  - Regular skin checks should occur – checking the skin twice daily, at a minimum, is a good strategy.
    - Remember that bony prominences are most susceptible to pressure sores.
    - Use a mirror to independently check your skin in hard-to-see areas.
  - Keep skin clean and dry with regular bathing using mild soaps, drying skin completely after bathing, and immediately washing and completely drying skin following leakage of stool or urine.
  - Get a seating evaluation at least every two years to ensure that the setup and cushioning system in your wheelchair is the best it can be for you.
  - Avoid sheering the skin when transferring in and out of bed, your wheelchair, etc.
  - Lifestyle choices can have a large impact on pressure sores – staying hydrated, giving your body proper nutrition, and quitting smoking can all help to prevent the formation of pressure sores. Consult your provider regarding appropriate hydration and nutrition if you have questions.
- **Heterotopic Ossification**<sup>17</sup>
  - “Heterotopic ossification” literally translates to “bone formation in an abnormal place”.
  - Usually these abnormal bony formations occur between the muscle and the joint capsule and can occur due to trauma, dislocations, neurological damage (including SCI), and other mechanisms.

- **Osteoporosis and SCI**
  - Osteoporosis is condition that involves decreased sturdiness in the bones, which can ultimately predispose individuals to fractures.<sup>18</sup>
  - The changes that occur in the nervous system after a SCI have a direct effect on bone integrity as bone relies on normal input from the nervous system for normal bone integrity to be maintained<sup>19</sup>
  - Since SCI often affects a patient’s ability to achieve an upright, standing position, this decreases opportunities for gravity to act on the body and for the bones of the body to experience loading. This can ultimately lead to bone loss<sup>19</sup>.
  - Both pharmacological and non-pharmacological strategies are used to maintain bony integrity after SCI<sup>20</sup>.
    - “Pharmacological” strategies refer to medications that can be given to help.
    - “Non-pharmacological” strategies are strategies that do not include the use of medications. One example is therapeutic exercise implemented by a physical therapist.
  
- **Pain**<sup>21</sup>
  - Chronic pain is a common problem for patients who have sustained a SCI
  - Pain can be from nociceptive or neuropathic sources:
    - Nociceptive pain refers to pain that is coming from any structure in the body excluding nerves. For example, a patient who does not have function in their legs but does have function in their arms will rely on their arms for many functional tasks. This situation can lead to overuse of the joints in the arms, which can ultimately lead to pain and injury.
    - Neuropathic pain refers to pain coming from a damaged or dysfunctional nervous system. For example, when the nervous system is damaged, it can become hypersensitive and pain signals can be amplified - this is called “hyperalgesia”. Another example of neuropathic pain is when normal sensations (like a washcloth touching the skin) become painful – this is called “allodynia”.
    - There are medications that can be taken to manage neuropathic pain
    - A combination of medication and physical therapy interventions is typically used to relieve nociceptive pain.
  
- **Psychosocial Implications**
  - The term “psychosocial” describes the psychological and social implications of a given situation<sup>22</sup>. In this situation, we are discussing the implications of SCI for an individual’s psychological and social outlook post-injury.
  - SCI is a unique diagnosis in that it can change the course of one’s life very, very quickly. Patients affected by SCI are often going about their normal daily lives one day, and not

- able to move their legs and doing something as simple as stand up and walk the next day. This is, understandably, a very frustrating reality to face. Being aware of the mental and emotional load that SCI can place on patients can facilitate tackling these inherent psychosocial challenges moving forward<sup>23</sup>.
- In addition, SCI patients often require caregiver support from family and friends, which can place a great deal of demand on caregivers. Thus, support for both the patient and caregiver are often warranted in the area of psychosocial health<sup>23</sup>.
  - In general, the prevalence of anxiety and depression is higher in the SCI population versus the general population<sup>24</sup>. Thus, patients (and their caregivers) should seek support. Recent literature has suggested that cognitive behavioral therapy (CBT) is effective in the management of depression following a SCI<sup>25</sup>.
    - CBT aims to help individuals identify and ultimately move away from unhelpful irrational thoughts, emotions, and behaviors<sup>25</sup>. To learn more about CBT and reap the benefits of this type of therapy, ask your healthcare provider about a referral to a specialist who can implement CBT techniques.
- **Adaptive Equipment for SCI Patients<sup>26</sup>:**
    - For many SCI patients, wheelchair selection is a critical step in the process of learning to live with SCI.
    - Your healthcare team will be able to help you select the best wheelchair based on you and your needs and goals.
    - It is worth noting that you should always pick the best wheelchair for you and your needs and then think about insurance coverage and finances. Your wheelchair will be your primary means of mobility, so picking the best chair for you is very important.
      - There may be financial programs/resources available to assist you in financing your wheelchair – ask your healthcare about resources that may be available to you.
    - Wheelchairs can either be manual wheelchairs or power wheelchairs – your healthcare team can point you in the right direction as far as which type of wheelchair will best suit you and your needs.
      - Manual wheelchairs:
        - If you have the ability to propel a manual wheelchair with your arms, then a manual wheelchair is a great option. These wheelchairs are lighter, easier to transport, and provide a form of exercise when compared to their power wheelchair counterparts.
        - Therapists are experts in training SCI patients on the proper technique for propelling wheelchairs. Proper technique for manual propulsion is important because it allows for more efficiency and reduced fatigue as well as a reduced risk of injury.

- Power wheelchairs:
  - Power wheelchairs are great for SCI patients who cannot propel manual wheelchairs or for those who wish to reduce the strain on the arms so that they can perform other essential tasks during the day (transferring bed to chair, using arms for reaching for objects such as pots and pans, etc.)
  - In general, there are three types of power wheelchairs: rear-wheel, mid-wheel, and front wheel. Each type of power chair has its pros and cons.
- Power-assisted wheelchairs:
  - This type of wheelchair has characteristics of both a manual and power wheelchair.
  - These wheelchairs are essentially manual wheelchairs with a motor attachment. The purpose of the motor is to help the patient propel the wheelchair more quickly and easily and it allows the patient to negotiate difficult obstacles such as steep ramps.
  - Power-assisted wheelchairs can take some of the strain off of the arms, which can help to prevent injury.
- You should strive to develop basic skills to assess and maintain your personal wheelchair. Wheelchair breakdowns are not only frustrating, but can result in extra costs and even injury. Routine assessments and maintenance of your wheelchair can help to prevent wheelchair breakdowns.
- **Bladder and Bowel Management with SCI**
  - **Bladder**<sup>27</sup>
    - SCI can affect your ability to control urination – some patients have difficulty holding urine in while others have difficulty getting urine out, depending on the specific injury to the spinal cord.
    - Inappropriate bladder management can have undesirable consequences but there are many strategies available to keep your bladder and kidneys healthy.
    - Different bladder management options each have their pros and cons – your doctor can help in selecting the best bladder management strategy for you and your needs.
    - In order to understand the concept of bladder management, it is important to first understand how humans produce urine:
      - The kidneys act as filters to remove waste from your bloodstream and this waste is ultimately passed as urine.
      - Small tubes called “ureters” connect the kidneys to the bladder. Eventually, urine will pass from the bladder through the urethra and exit the body.

- When urine is passed uncontrollably, this is called “urinary incontinence”.  
When urine cannot be passed, this is called “urinary retention”.
- The reason that SCI impacts bladder function is because the bladder is under the control of the nervous system. When the spinal cord is injured, the messages to and from the brain and bladder are disrupted.
- Bladder management is a term that describes several strategies that promote effective management of bladder dysfunction associated with SCI. these strategies also work to decrease secondary complications that would likely occur if efforts were not made to manage the bladder.
- Bladder management cannot to cure the bladder dysfunction associated with SCI, but it does work to promote a higher quality of life and improved health as a SCI patient.
- Here are two of the main bladder management strategies available to SCI patients:
  - Intermittent catheterization
    - This strategy involves inserting a catheter into the bladder intermittently throughout the day (the catheter does not remain inserted).
    - This is usually done about 4-6 times per day with a goal of each catheterization being 500mL (comparable amount of fluid to the amount of water in a plastic water bottle) or less.
    - This strategy is a poor option for those with small urinary bladders or those who drink a lot of fluids (and require more frequent trips to the bathroom), if you are unable to catheterize yourself and do not have help available, your bladder is overactive (which can lead to incontinence), or if you have pain with insertion or removal of a catheter.
    - This strategy does avoid the patient having to wear a leg bag all the time.
    - Of note - you will need to partially undress each time you catharize and you may need to take a medication to decrease bladder overactivity if using this strategy.
  - Indwelling catheter
    - This strategy ensures constant protection against the problems associated with urinary retention as well as urinary incontinence.
    - The catheter and urine collection bag remain in place at all times with this strategy.
    - These catheters are changed approximately once every month.

- This strategy is desirable in that it eliminates the need to insert and remove a catheter several times per day, it allows the patient to drink more fluids worry-free, and it does not require undressing to make catheterization possible.
    - This strategy is undesirable in that a urinary bag will always be attached to you, women may find it difficult to keep the area around the catheter clean, issues may exist with a patient's sexuality if this type of catheter is used, and these types of catheters may predispose patients to more bladder infections.
  - Your doctor can help you determine which bladder management strategy is right for you and your lifestyle. Your doctor can also help determine if your current strategy is working well or not and when to consider new strategies.
- **Bowel**<sup>28</sup>
  - Similar to the bladder complications that can result from SCI, SCI can also affect your ability to control your bowels.
  - Some patients have difficulty controlling when they have a bowel movement, causing stool to be passed at an undesirable time. Others may have difficulty moving their bowels, making it hard to pass stool at all.
  - A good bowel program can help to manage dysfunctional bowel patterns that are often seen with SCI.
  - In order to understand the concept of bowel management, it is important to first gain a basic understanding of the human digestive tract:
    - Your stomach and small intestine absorb the nutrients needed to nourish you and keep your body in proper working order.
    - Everything that is not absorbed is passed as waste. Waste forms into "stool" in the colon and is eventually passed from the anus. When a stool is passed, this is called a "bowel movement".
    - SCI can create problems with passing stool out of the body:
      - When stool is not able to be passed, this is called "constipation".
      - When it is difficult to control when a stool is passed, this is called "stool incontinence".
  - SCI affects an individual's bowel control because the spinal cord helps to send signals to the muscles that control when and how bowel movements are passed.
    - The muscles that control when and how bowel movements are passed include the rectum, sphincters, and pelvic floor muscles.
  - In general, injuries above the T11/T12 level lead to tight muscles, ultimately leading to constipation. Injuries at or below the T11/T12 level may produce loose muscles, ultimately leading to stool incontinence.

- Completeness of your cord injury also impacts bowel function:
  - In general, those individuals with incomplete injuries tend to have more muscle strength and sensation (for the muscles that control their bowels). Therefore, these individuals may have less problems with their bowels.
- A bowel program is an overall strategy designed by a doctor or nurse that helps to establish normal bowel habits. This plan will be designed specifically for you and your needs.
  - The main goals of a bowel program include: supporting the patient in having daily or every-other-day bowel movements, preventing unplanned bowel movements, emptying your bowel around the same time each day, and allowing the patient to move their bowels in a timely manner.
  - There are four parts to a bowel program – timing, diet, medications, and techniques.
    - Timing – the bowel program should be done every day or every other day
    - Diet – getting enough fiber and drinking enough fluids. Focusing on a diet with plenty of fruits and vegetables as well as drinking plenty of water are recommended.
    - Medications – there are many medications that can help patients to pass stool (if constipated). Some medications that patients may already be taking can cause constipation. Ask your doctor if you have concerns related to your current medication regimen worsening any constipation that you may have.
    - Techniques (primarily for those who are constipated):
      - Digital rectal stimulation – This technique involves moving your fingertip in a circular motion around the rectum/anus. When performed for 20 seconds every 5-10 minutes, this technique can help to stimulate a reflex that aids in emptying the bowels.
      - Digital removal of stool – this technique involves inserting your finger into your rectum and actively removing stool from the rectum using your finger.
      - Enema – this technique can be performed with several devices. All of them work to flush water into the rectum, which in turn aids in having a bowel movement.
  - Since everybody’s injury is different, there are some individuals who may not benefit from a bowel program. There are surgical options for patients



who cannot perform a bowel program or who are not benefitting from bowel programs.

- Maintaining bowel function is very important because bowel dysfunction can result in many different complications. Always check in with your doctor or nurse if you have concerns or comments about your current bowel program or bowel programs in general.

- **Pregnancy After SCI:**

- Know that women with all levels of SCI have been able resume normal reproductive function and have children after their injury – you should also be able to have a child if you choose<sup>29,30</sup>.
- With that said, SCI often creates a short period of amenorrhea immediately after the injury. Amenorrhea refers to a time in which a woman lacks a menstrual cycle. Normal menstrual cycles typically resume after about 6 months<sup>30</sup>.
- It is important to understand that SCI can make parenting responsibilities more burdensome, but the positives of becoming a parent typically outweigh the drawbacks<sup>29</sup>.
- In order to have a healthy pregnancy, some steps should be taken<sup>29</sup>:
  - Get a complete GYN exam – pre-conception counseling, pap smear testing, immunization check, family history, and genetic testing are all things that may be included in this exam.
  - Talk to a rehabilitation doctor who knows about women’s health and its relationship with SCI – a rehabilitation doctor, also known as a physiatrist, can help explain the implications of SCI in the pregnancy, labor, and delivery processes.
  - Check your medications – some medications that you may be on could harm your baby if/when you get pregnant, so it is important to see your doctor regarding your current medications to discuss the implications of those medications and pregnancy.
  - Get a urology check up – carrying a child in the womb can put extra stress and pressure on the urinary system (bladder, kidneys, etc.), so it is important to see your doctor about the state of your urinary system before getting pregnant.
  - Tell your doctor if you are pregnant or think that you might be pregnant. Some tests that may be conducted in your pre-pregnancy assessment (like an X-ray) could harm your baby.
- You can take comfort in knowing that your injury does not affect the development of your baby. However, being pregnant with a SCI is no different than being pregnant without SCI – the typical discomforts associated with pregnancy are the same, SCI aside<sup>29</sup>.



- While pregnant, it is not uncommon to experience headaches, fatigue, nausea and vomiting, the need to urinate often, indigestion, shortness of breath, and other symptoms.
- SCI does present unique potential challenges throughout the pregnancy process:
  - The first trimester includes weeks 1-13<sup>29</sup>.
    - Headache and nausea are common in the first trimester, but a pounding headache and nausea could also be an indication of autonomic dysreflexia
      - See page 13 for description of “autonomic dysreflexia” is unfamiliar with this term.
    - Your doctor may prescribe antibiotics preventatively during pregnancy to decrease the risk of urinary tract infection (UTI). UTIs can induce early labor in pregnancy, therefore, it is important to keep UTIs from occurring.
    - Hormone and iron supplements are sometimes prescribed by your doctor during pregnancy. In individuals with SCI, these supplements can influence your bowel program, so it is important to discuss the implications of these supplements for your specific SCI case.
  - The second trimester includes weeks 14-26<sup>29</sup>.
    - Since the baby will be growing rapidly during this time, this may be a time when daily activities begin to see changes. For example, transfers from your bed to your wheelchair may become more difficult<sup>29</sup>.
      - You may need to adapt or change the ways that you go about your daily activities. You may also need physical assistance from another person for tasks that you used to be able to do on your own before pregnancy.
    - Carrying a baby puts more pressure on the bladder, which may force you to change the way that you carry out your bladder program<sup>29</sup>.
    - Skin care is a topic of greater concern during this stage of pregnancy due to the significant amount of weight gain that can occur. It is important to know that seating adaptations may need to be performed by your seating specialist if you have a wheelchair<sup>29,30</sup>
      - Weight gain can put you at higher risk for pressure sores.
      - More frequent skin checks and pressure relief periods should be implemented.
    - If you experienced muscle spasms prior to your pregnancy, then you may experience worsening of your spasms during pregnancy. In addition, if you did not experience muscle spasms before pregnancy, then you may begin to experience muscle spasms after becoming pregnant<sup>29</sup>.

- The third trimester is the final phase of pregnancy and includes weeks 27-40<sup>29</sup>.
  - Breathing may become more difficult as the baby continues to grow and push on your diaphragm (the muscle primarily responsible for breathing). You may need to speak with your doctor or respiratory therapist if you are having difficulty with breathing<sup>29</sup>.
  - Pressure from the growing baby can slow the flow of blood out of the legs, which can result in leg swelling<sup>29,30</sup>.
    - Medications, such as low molecular weight heparins, to prevent clot formation are a consideration – talk to your doctor if you notice increased swelling in your legs.
    - Physical therapists can provide strategies such as range of motion exercises to help reduce swelling.
    - Leg elevation and compression socks may be useful tools.
- Full term pregnancy is 39-40 weeks, but you should start watching for signs of labor at about 28 weeks. At this point in the process, your doctor may want to check your cervix for increased dilation (opening) on a weekly basis<sup>29</sup>. In addition, your doctor should discuss labor and delivery plans with you very early on in the pregnancy process<sup>30</sup>.
  - It is important to know that women with paraplegia can check for labor by feeling the uterus<sup>29</sup>.
    - “Paraplegia” is essentially paralysis from the waist down.
  - Women with tetraplegia (injury affecting all four limbs) can talk to their doctor about a contraction monitor so that they do not go into labor without realizing it<sup>29</sup>.
  - Women with a T10 level of injury or above may not feel the pain associated with labor. Conversely, women with injuries below T10 level may feel the uterus contracting<sup>29</sup>.
  - Even though autonomic dysreflexia (AD) is more commonly observed in individuals with injuries at T6 or above, AD can be seen in women with any level of SCI<sup>29</sup>.
    - Continuous epidural anesthesia can work to combat this issue.
- Women with SCI do not necessarily have to deliver by C-section – most women deliver vaginally no matter what their level of injury is<sup>29</sup>.
- Of note, breast feeding may not be as straightforward for women with SCI relative to women without SCI<sup>29</sup>.
  - Breastfeeding may cause more bladder spasticity.
  - If you cannot feel your nipples, then you may produce less milk than normal. This is because the feeling of the infant’s mouth contacting your nipple triggers breastmilk production.
- Other considerations pertaining to reproductive health in women with SCI:

- Women with SCI may experience increased menstrual and premenstrual symptoms and some potential additional symptoms including autonomic dysreflexia, and bladder and muscle spasm<sup>30</sup>.
      - See page 13 for description of “autonomic dysreflexia” is unfamiliar with this term.
    - Menopausal symptoms do not seem to be different in women with SCI versus women without SCI<sup>30</sup>.
    - Because individuals with SCI are often at greater risk for blood clots, hormonal birth control (“the pill”) should be avoided in the first year after SCI in women who continue to smoke or have a history of circulatory problems<sup>30</sup>.
    - Postpartum depression is more common in women with SCI<sup>30</sup>.
    - Women with SCI tend to have more pre-term deliveries<sup>30</sup>.
- **Transfer Techniques with SCI:**
  - Note – depending on your specific impairments, the information in this section may or may not pertain to you.
  - Also of note – you will likely learn many modified transfer techniques that work best for you and your specific impairments once you are out of the hospital and participating in a more intensive rehab program for your SCI. Thus, this section is meant to serve as a primer for transfers after SCI.
    - Physical therapists are experts in transfer training for patients with SCI and they will work with you to develop the best transfer strategies for you given your body, your needs, and your abilities.
  - If you are not familiar with the term “transfer”, it simply refers to a change in body position. This could include transfer from lying on your back to sitting up in bed or a transfer from sitting on the edge of your bed to sitting in your wheelchair. With SCI, transfer techniques often need to be modified in order to accommodate the specific impairments and functional limitations of the patient.
  - Implementing safe transfer techniques is important to reduce the risk of injury<sup>31</sup>
  - One of the most common transfers that a patient with SCI will need to master is transfer from bed to wheelchair or wheelchair to bed. Here are some tips to increase the safety and effectiveness of your bed↔wheelchair transfer:<sup>31</sup>
    - Only transfer as much as is necessary to reduce the risk of overuse injuries.
    - Transferring downhill is always easier than transferring uphill
      - “Transferring downhill” implies that the surface being transferred away from is higher than the surface being transferred towards. For example, if you are sitting on your bed and you want to get to your wheelchair, then

this transfer would be easier if the bed surface is higher than the wheelchair seat surface.

- You will want the two surfaces to be as close as possible to make the transfer safer and easier.
  - You will want to lock the wheels on your wheelchair when transferring to and from the chair for maximum safety and effectiveness of your transfer.
  - If transferring into your wheelchair, you will want to remove the armrest on the side of the chair that you are transferring across. This will make the transfer safer and easier to execute.
  - You will need to understand the “head-hips relationship” in order to be successful with this transfer.
    - The head-hips relationship essentially refers to relationship between the upper body and the lower body when the upper body is moved. For example, if you are sitting on the side of your bed and you rock your upper body to the right, this will lift your left hip off of the bed surface. This action of rocking to the right and clearing the left hip off the bed surface allows the patient to more easily scoot their bottom to the left while using both arms to push from the bed surface.
    - Your physical therapist will likely be going over this concept in detail at some point in your rehabilitation process.
  - You will need to be sure to try to clear your bottom off of surfaces as much as possible when transferring. Excessive rubbing or bumping can damage the skin and cause wounds or sores.
  - If you are overweight, modified transfer techniques may be very difficult for you and may also place you at a higher risk for injury. Therefore, maintenance of ideal body weight is very important. Ask your health care providers about ideal weight maintenance strategies with SCI.
- **Exercise and Fitness after SCI**
    - Whether or not you were enthusiastic about exercise and physical activity before your injury, you should know that regular physical activity is very important for your health<sup>32</sup>.
    - In fact, some research has said that “exercise is so beneficial for health that it should be considered a drug”<sup>32</sup>.
      - As with any drug, though, dosing exercise appropriately is key<sup>32</sup>.
      - Dosing exercise appropriately becomes even more important when you have a SCI so that injury and adverse events can be prevented. Physical therapists are experts in prescribing exercise programs and giving recommendations for recreational activities that you will be able to perform safely and effectively.

- After sustaining a SCI, activities that you participated in before your injury may have to be modified<sup>33</sup>.
- Adaptive sports, like any other form of physical activity, can work to promote lifelong wellness and give you a sense of identity and belonging within a community of people who share a passion for the same activity or activities<sup>33</sup>.
- There are many different types of adaptive sports and recreational activities<sup>33</sup>:
  - Outdoor recreation (adaptive fishing, kayaking, snow skiing, etc.).
  - Performing arts (adaptive dance groups, for example).
  - Individual sports (wheelchair races or hand cycling, for example).
  - Team sports (wheelchair basketball, wheelchair tennis, sled hockey, and quad rugby [yes, rugby!]).
- If you were not physically active before your injury but would like to participate in some form of adaptive activities, then you should speak with your doctor and physical therapist about finding an activity that fits your abilities, goals, and lifestyle.
- **Driving After SCI<sup>34</sup>**
  - Driving after a SCI may not be possible for every individual with a SCI, but it is certainly possible for some.
  - Vehicles can be modified in a way that accommodates your specific needs and allows for safe, functional driving.
  - Over time, your functional abilities may improve, which can allow for safe, functional driving.
  - Some important signs to look for that may indicate that you are ready to drive again include:
    - You do not need narcotics to control pain while you are driving.
    - You have good enough vision for driving or your vision can be correct to the degree that it allows for driving.
    - You can control the muscle spasms and tightening caused by your injury.
  - Your doctor can make a referral to a driving rehabilitation specialist who will complete a full driving assessment with you. This assessment will include everything from your strength and range of motion to your actual driving abilities and what kind of adaptive equipment you may need in your car.
  - Assistive technology is available to help you transfer in and out of your vehicle as well as manage your assistive device once you are in your driver's seat.
  - Assistive technology also helps individuals modify their gas, brake, and steering controls. Many individuals may end up having to control their gas and break systems with their hands rather than their feet after SCI.

- Know that there are many programs that can help to pay for the often expensive assistive technology/adapted vehicles required for many individuals with SCI to regain their driving abilities. Some programs include:
  - Your state's vocational rehabilitation program.
  - The Crime Victim's Compensation Program may help you if your SCI happened as a result of a crime.
  - Your state may have a trust fund that can help you.
  - HelpHOPELive helps to organize fundraising efforts to help cover costs for people who have experienced traumatic injuries.
  - The Department of Veteran's Affairs (VA) will offer grants to veterans who experienced an injury or disease as a result of their time spent serving in the military.
- The changes that can occur month to month with SCI can cause confusion and frustration about the right time to start thinking about driving again. Talk to your doctor about driving and seek out a driving assessment before making any purchases. Adapted vehicles and the technology in them is often very expensive, so it is better to be patient when considering buying new equipment to suite your driving needs.
- **Employment After SCI**
  - Obtaining or keeping a job after sustaining a SCI may present some challenges<sup>35</sup>.
  - Working is as important, if not more important for individuals with SCI compared to individuals without SCI. Working allows for a source of income, health insurance coverage and other benefits, interaction with others, and works to provide a sense of meaning in life<sup>35</sup>.
    - Those who find employment after their injury may be in a better financial situation, have stronger social connections, and have a stronger sense of purpose, well-being, meaning, and worth<sup>36</sup>.
    - Your contribution to the world through your work can support your overall happiness and wellbeing, therefore, it is important that you pursue a form of work that you can thrive in and enjoy, whether or not that may include the job that you had prior to your SCI<sup>36</sup>.
  - There is no reason to believe that you cannot go on to have a successful career after SCI, but it is important to be aware of the potential barriers that you may encounter<sup>35</sup>.
    - There are federal and state laws as well as vocational rehabilitation services that aim to help all people with disabilities overcome potential employment barriers.
      - The ADA (Americans with Disabilities Act) is a piece of legislation that was passed in 1990 and amended in 2008. This Act essentially prohibits employers from discriminating against individuals who have disabilities

and are qualified and able to perform the basic functions of a given job, with or without accommodation.

- The ADA protects people who have disabilities that affect major life activities – most individuals with SCI are protected under the ADA.
- An employer must make a “reasonable accommodation” to your disability.
  - Whether or not an accommodation is considered “reasonable” or not depends upon that accommodation producing undue hardship for the business.
  - Whether or not something is an “undue hardship” depends on many factors.
- Employers are able to ask about your abilities during a job interview, but they are not allowed to ask about the existence of or degree of a suspected disability.
- If you feel that an employer has discriminated against you, then you can call the U.S. Equal Employment Opportunity Commission (EEOC). The ADA is a federal law, but many states also have powerful disability rights laws.
- The Individuals with Disabilities Education Act (IDEA) is a law focused on helping young people who have not finished their K-12 education.
- The IDEA helps young people by giving them access to services necessary to help meet their educational and vocational goals. The IDEA also helps young people as they transition into adult life.
- Students eligible under the IDEA may stay in school until 22 years of age, if necessary, to achieve their goals.
- Vocational rehabilitation (VR) programs essentially help people who have disabilities in obtaining employment.
- VR programs help people with disabilities by helping individuals to identify career interests and skills, get education and training that is relevant to their career interests and skills, find and apply for job opportunities, and get accommodations at their place of employment.
- VR programs are paid for by some private health insurance companies, by state vocational rehabilitation programs (state funded), state worker’s compensation programs for individuals injured on their jobsite, and by the Veteran’s Administration for individuals with service related disabilities.
- VR programs can be utilized if you do not have a job and are looking for one and if you currently have a job and are not satisfied with.
- The first step in VR is for your counselor to perform a comprehensive assessment of you to determine opportunities that would be suitable for



- you given your abilities, disabilities, educational background, personality, etc.
- Many VR counselors are able to set up “trial” work, which involves you going into a specific job and determining if it is the right fit for you during a trial period.
  - Your VR counselor will likely help you to write goals to serve as an intermediate step between beginning VR and finding a job. These goals will ultimately help keep you focused on the tasks that need to be completed in order to get you where you need to be in order to obtain employment.
  - If necessary, your VR counselor can educate potential employers and advocate for you regarding necessary accommodations in a given job and how those accommodations could be arranged.
  - Work accommodations can include everything from modifying an individual’s work schedule to modifying the work environment or work tasks.
    - For example, if a patient must perform a lengthy morning care routine, then their schedule could be adjusted to a later start and end to the workday.
    - VR counselors can help to determine what kinds of accommodations would be beneficial for your specific case.
  - There are, of course, individuals who will not be able to work after SCI. There are many reasons why this situation may play out.
    - In these cases, the individual is able to apply for disability benefits from the Social Security Administration (SSA)
    - Individuals who are newly injured with SCI should apply for SSA benefits right away if it seems like they may not return to work for at least one year.
  - If paid job opportunities are not available to you, consider volunteer work.
    - Volunteering may not offer pay, but it helps to provide a sense of accomplishment and enjoyment, which are both very important after an individual sustains a SCI.
    - Volunteer opportunities can also give you the confidence and professional contacts that could lead to a paying job in the future.
  - **Aging with SCI<sup>37</sup>**
    - Aging is a process that happens to every single human being – nobody can avoid it. Discussing the process of aging as it pertains to SCI is especially important because SCI can speed up the aging process.
    - Aging can make individuals more susceptible to chronic health problems.



- Health problems that last 6 months or more and require ongoing medical care are “chronic”.
- When a chronic health condition has a relationship to a person’s SCI, this condition now becomes a “secondary health condition”
  - Secondary health conditions in SCI can result from complications of SCI and the treatments implemented with SCI patients
    - For example, a patient with a SCI may rely on his/her arms to push a wheelchair. The arms are not necessarily designed to be the primary means of mobility for human beings. Therefore, if a patient has to use his/her arms to power their wheelchair all day, every day, then this can predispose their shoulders to overuse injury.
- Research tell us that patients with SCI tend to show more signs of aging in their musculoskeletal (muscles and bones), endocrine (glands), and cardiovascular (heart and blood vessels) systems relative to patients without SCI.
- Patients with SCI are also more vulnerable to chronic pain conditions, bone loss, pressure injuries, and kidney/bladder stones.
- With all of that said, aging is a complicated process that depends on many different variables. Everything from your level of SCI to your diet and physical activity levels can affect the aging process.
  - Note that some variables are outside of your control (your level of injury), but some are very much within your control (how much physical activity you decide to participate in with the abilities that you do have, the foods that you eat).
- Some strategies that can be implemented to promote successful aging with SCI include:
  - Being aware that SCI may impact your overall health and making your health a priority.
  - Visiting your doctor regularly.
  - Adapting how you do your daily activities, if necessary.
  - Using adaptive equipment, such as a wheelchair, to your advantage.
  - Maintain your independence in all things that are possible to maintain independence with.
  - Find housing that accommodates your mobility impairments
    - For example, if a SCI relies on a wheelchair for their mobility, then having a cook top and sink that are able to be pulled up to with a wheelchair would be an important modification.
  - Take part in those activities that you enjoy and are able to participate in as a person with SCI.
  - Keep a positive outlook on life:

- Connecting with those you love/care about is an important part of keeping a positive outlook.
- Engage in regular physical activity.
- Try to push yourself towards new activities and challenges – never stop learning.
- Focus on those activities you CAN do.

## Additional Resources

<https://msktc.org/sci>

<https://www.ninds.nih.gov/Disorders/All-Disorders/Spinal-Cord-Injury-Information-Page>

<https://www.christopherreeve.org>





