

LIVING WITH SPINAL CORD INJURIES

Individuals who are involved in impaired driving crashes often incur bruises, broken bones, and thermal burns. But unlike many victims/survivors, those with spinal cord injuries face permanent and lifelong changes, often resulting in paralysis and/or loss of sensation below the site of the injury. Spinal cord injuries can be physically and psychologically devastating. Fortunately, survival and mortality rates have improved substantially as a direct result of medical advancements. With survival comes the need for support and information to cope with the emotional, mental, and spiritual issues related to living with spinal cord injuries.

THE SPINAL CORD

The spinal cord is part of the most complex system of the human body, the central nervous system. Because of its complexity, it may be beneficial to discuss the various parts of the spinal cord and spine, bit by bit, as well as to take a thorough look at spinal cord injury. This may provide you with a better understanding of how a spinal cord injury affects a person's physical well-being.

The spinal cord is the largest nerve in the body. It is composed of a delicate bundle of nerve fibers and connects the control center, the brain, to the rest of the body. Due to its delicacy and importance in maintaining bodily functions, the spinal cord is

protected by a long, tubular structure called the vertebral column, commonly referred to as the spine.

Vertebrae are the small bone structures that together form the spine. Bands of cartilage called intervertebral disks separate and provide cushion between each of the 24 vertebrae. The disks consist of an outer layer called the *annulus fibrosus*, and an inner layer called the *nucleus pulposus*. The outer layer is designed to be very strong and connects to the vertebra by thin plates of cartilage called vertebral end plates. The inner layer is jelly-like and provides for movement and cushion.

The vertebrae and disks are bound together with ligaments (connective tissue). This chain of vertebrae, disks, and ligaments runs from the base of the skull to the lower back. The spine not only protects the spinal cord, but also provides the body structure and support. It allows one to bend and move freely.

In order to explain how the whole spine works, it is named by region of the body. By isolating different segments, we are able to better understand what can go wrong with the various parts of the spine and spinal cord.

The cervical spine refers to the seven vertebrae that protect the eight cervical nerves, located at the neck. Twelve thoracic vertebrae protect 12 thoracic nerves, located at the chest region of the torso. The lumbar vertebrae are five vertebrae that protect

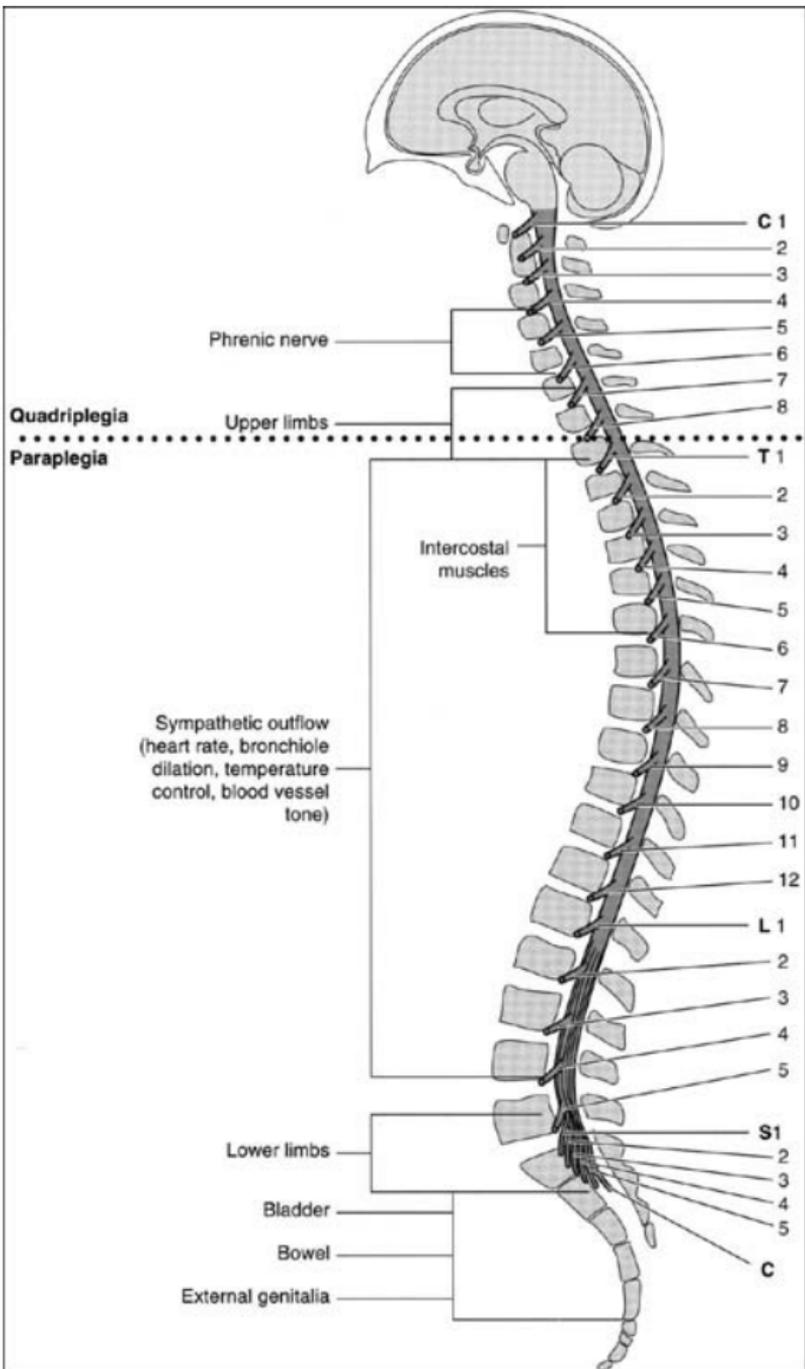
five lumbar nerves, located in the lower back region of the body. Five sacral vertebrae, which are fused together, protect five sacral nerves at the posterior of the pelvis.

The spinal cord is much shorter than and runs through the middle of the vertebrae. Two pairs of nerve roots connect with the spinal cord at every level. The spinal nerves branch from these roots, through the vertebral column and between the vertebrae to form the peripheral nerves of the body. Much like the spine, the spinal cord and spinal nerves are named and numbered by region of the body.

The spinal cord sends nerve impulses to and from the brain, communicating with the rest of the body. This communication informs the body to move, to send and receive messages of sensations, as well as to regulate body functions, such as heart rate and body temperature.

ABOUT SPINAL CORD INJURY (SCI)

A Spinal Cord Injury (SCI) is a result of a traumatic insult or disease to the spinal cord, which subsequently causes injury to sensory and motor function. Sensory loss refers to the loss of sensations, such as pain, touch, or temperature. Motor loss refers to muscle weakness and the inability to use the body. Trauma to the spinal cord damages nerve fibers passing through the injured area and may affect all or part of the corresponding muscles and nerves below the injury site. Consequently, the injury



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interferes with communication between the brain and the rest of the body.

A spinal cord injury is usually a result of damage to the vertebral column. The spine can be either fractured or dislocated. A person can have a “broken back,” however, without sustaining a spinal cord injury. Because the spine is longer than the

spinal cord, the level of the injury to the spine may be different from the spinal cord injury it causes.

Since 2000, the leading causes of spinal cord injuries are motor vehicle accidents, falls, acts of violence, and sports activities (NSCISC, 2004). The lasting effects of a SCI depend upon the level of injury and type of injury. Just like individuals, no two spinal cord injuries are alike.

Level of Injury

The level of spinal cord injury determines what parts of the body might be affected by paralysis and loss of function. The level of injury refers to the lowest point on the spinal cord where there is a decrease or absence of motor and/or sensory function. Generally speaking, the higher the spinal cord injury, the more effect the injury has on movement and/or feeling. For example, an injury of the cervical spinal cord may result in full paralysis and make it impossible to breathe without a respirator, while an injury of the lumbar spinal cord may result in paralysis or weakness in the legs and cause some loss of body function in the lower extremities.

Cervical Spinal Cord Injury. An injury of the cervical spinal cord (levels C1-C8) causes quadriplegia (also called tetraplegia), which refers to paralysis or weakness in both arms and legs. All parts of the body located below the neck may be affected. Involuntary functioning, such as breathing, regulating body temperature,

and sweating may be impaired, necessitating a respirator and other mechanical devices.

A person with quadriplegia may not be able to sense touch (or other sensations) may lose bladder and bowel control, and may experience sexual dysfunction.

Thoracic Spinal Cord Injury. An injury of the thoracic spinal cord (levels T1-T12) causes paraplegia, which means paralysis or weakness in the legs. Depending upon where the injury is located on the thoracic spinal cord, an individual with this level of SCI may also experience weakness in their torso, although will generally possess good control of their hands. These injuries may also result in loss of sensation, loss of bladder and bowel control, as well as sexual dysfunction. Due to the rib cage, thoracic spinal cord injuries occur less often, as the rib cage offers protection from such injuries.

Lumbar Spinal Cord Injury. An injury of the lumbar or sacral spinal cord (L1-L5) causes paraplegia, again referring to paralysis or weakness of the legs. Because of the lower location of this injury, upper body functions are usually not affected. However, a person with a lumbar SCI may experience the loss of many of the sensory functions associated with thoracic spinal cord injuries.

Sacral Spinal Cord Injury. An injury of the sacral spinal cord (S1-S4) is rare and generally causes loss of bladder and bowel function as well as sexual dysfunction. Some sacral injuries can result in weakness or paralysis of the hips and legs.

Complete or Incomplete Injury

While the level of injury tells us where the damage is, the type of injury describes the degree of damage to the width of the spinal cord. Spinal cord injuries are therefore categorized as complete or incomplete in conjunction with the level of injury.

A complete injury indicates that there is severe damage to the spinal cord and consequently there is no motor or sensory function below the level of injury. An incomplete or partial injury indicates that there is some evidence of motor and sensory function. The brain is able to send and receive some messages. The incomplete or partial injury manifests itself in a variety of ways. Someone who has an incomplete SCI may have feeling, but little or no movement. Another person may have feeling and movement on one side of their body, but not on the other.

TREATMENTS OF SPINAL CORD INJURIES

Spinal cord injuries are not always easily detectable. First responders to crashes are trained to treat trauma victims/survivors with head and neck injuries as if they have a spinal cord injury. Therefore, the first intervention is to immobilize the spine in order to prevent injury or to deter further damage.

When a victim/survivor reaches any trauma unit or emergency room, the initial concern is to stabilize the body's vital functions. The medical team works to maintain life-sustaining functions, such as respiration and circulation. They can then work to rule out a spinal cord injury by assessing the patient with medical interview, neurological examination, and diagnostic testing. Because SCI is often accompanied by other serious injuries, the medical team must be thorough in their diagnostics.

Immediately or gradually after the injury, bleeding or swelling occurs around the spinal cord. When the swelling goes down, the nerves may be

Initial treatments of spinal cord injuries include medication, surgery, and traction.

able to work. There is no way for the medical team to determine how much or how little will be regained after the

swelling goes down, but it is clear that the time between injury and treatment can influence the level of recovery. With this knowledge, it is common protocol to quickly treat SCI victims/survivors with

high levels of steroids to reduce inflammation and swelling. A precise prognosis will take time as recovery of motor and/or sensory function can continue for months.

Many victims/survivors require surgery in the first several days following the initial injury. Surgery helps to decompress the spinal cord and stabilize the vertebral column. The level of injury indicates the specific interventions or treatments that follow.

Cervical Spinal Cord Injury. In the event of a cervical spinal cord injury, treatment includes measures to decompress the spinal cord and stabilize the spine. Two metal braces are attached to the skull with a pin on each side. Weights are connected to the braces with a pulley system: the weight is gradually increased to decompress and realign the cervical spine. This procedure is called traction. Long-term stability of the spine requires surgery or bracing because of the neck's inherent flexibility.

Thoracic Spinal Cord Injury. As mentioned previously, thoracic spinal cord injuries are not as common because of the protection the rib cage offers. Although surgery may be required for decompression, traction is not usually necessary. Bracing may be required to provide additional stability to that of the rib cage.

Lumbar or Sacral Spine Injury. Lower back injuries tend to involve the *cauda equina*, not the

spinal cord itself. The cauda equina is the group of nerve roots that extend beyond the spinal cord. This type of injury may require surgery and external bracing for stabilization.

Other Medical Concerns and Complications

The spinal cord is an essential component in our body's functioning. It is imperative that a victim/survivor receives care by those familiar with SCI as

<p>Complications related to SCI:</p> <p><i>Lung and breathing problems;</i></p> <p><i>Bowel and bladder management issues;</i></p> <p><i>Pressure sores;</i></p> <p><i>Deep vein thrombosis and pulmonary embolism;</i></p> <p><i>Increased risk for stroke or seizure;</i></p> <p><i>Weight control issues;</i></p> <p><i>Sexual dysfunction.</i></p>	<p>the injury affects so many life-sustaining functions.</p> <p>Victims/survivors with SCI can experience complications related to the injury, including: lung and breathing problems; bowel and bladder management issues; pressure sores; deep vein thrombosis and pulmonary embolism; increased risk for stroke or seizure; weight control issues; and sexual dysfunction.</p>
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Doctors and other medical personnel are careful also to monitor and treat pain. Pain may be associated with the original injury to the spine, or it can be neurogenic pain. Neurogenic pain is caused by the spinal cord, not by an external stimulus, so it is very difficult to treat. This pain is described as burning or tingling. Some classes of antidepressant medications are found successful at treating neurogenic pain. Relaxation, meditation, and

imagery are techniques often applied to treat pain that does not respond well to medication.

THE HOSPITAL AND REHABILITATION EXPERIENCE

The Spinal Cord Injured Victim/Survivor. Spinal cord injury victims/survivors are often unconscious or are in shock when they reach the emergency room, and may have little knowledge of the gravity of their circumstances. The first several days can seem confusing or hazy. Victims/survivors are quickly treated with surgery, medications, traction, or a combination of the three, and there is little time to think or feel. It is later, after interacting with family, friends, and medical personnel, that victims/survivors are able to develop a sense of their condition and its implications.

Surgery, traction, and initial interventions usually take place in an acute setting, like a hospital or trauma unit. Treatment continues for weeks or months in the form of rehabilitation at a rehabilitation facility or on a rehabilitation unit (sometimes located within an acute hospital). It is in rehab that victims/survivors are introduced to special therapies to assist them in improving strength, mobility, and independence. A rehab team is led by a physiatrist (a physician who specializes in rehab) and usually consists of a physical therapist, occupational therapist, rehab nurse, rehab psychologist, rehab social worker, nutritionist, and recreation therapist.

As a spinal cord injury victim/survivor, you may have spent those first days or weeks in the hospital fearing the unknown and the uncertainty of the future. You may remember being fearful of both physical and emotional pain. You may have wondered what would happen to your family, what pain and suffering they might experience as a result of your injury. Some spinal cord injury victims/survivors rely heavily upon hospital and rehab staff to meet their physical and emotional needs as not to burden their families. Because of the nature of the injuries and the treatments of spinal cord injuries, rehab becomes a comfortable, protective, and insulated environment that may be difficult to leave.

The Family Member and Friend Victim/

Survivor. While the injured victim/survivor may be confused or in a daze for some time after the crash, family and friends are acutely aware of the gravity of the situation. When you learned of your loved one's crash and subsequent injuries, your initial reactions may have included shock, despair, and fear. Because spinal cord injuries are often complicated by other serious injuries, you may have been fearful of how your loved one would suffer, or that they would die from their injuries. You may still be fearful.

You may feel anxious, depressed, guilty, and worried when thinking of your future and the future of your loved one. Anger may follow after learning of the consequences of the spinal cord injury.

Nonetheless, a victim/survivor's adjustment is heavily dependent upon the love and support you offer them.

Children of victims/survivors may feel frightened, anxious, sad, guilty, or angry, just like adult family members and friends. They might be fearful and anxious about their parent's ability to care for them. Fortunately, with rehabilitation and adaptive equipment, a parent with SCI can frequently continue to participate in many, if not most, of daily caregiving tasks. It is important to provide children with love and support as well as ongoing information that is accurate and age appropriate. If this support and care does not seem to ease the worry and fear of the child or children, pursuing professional counseling may be in order.

GOING HOME

The length of stay in trauma and rehab units has decreased over the years, yet SCI victims/survivors may be reluctant to go home. Many people feel anxious about leaving the safe and insulated environment provided by the hospital/rehab unit and

Many spinal cord victims/survivors report that counseling just before and just after discharge is helpful with the transition from hospital to home.

its staff. For the injured victim/survivor of a drunk driving crash, going home also means facing the difficulties associated with the crash.

While in the hospital/rehab unit, the medical team cared for the many needs associated with your

spinal cord injury. Upon returning home, both you and your family must assume responsibility for your care. The reality of the SCI and what it entails may not hit until this time. Victims/survivors are confronted with physical impairments, altered appearances, altered self-images, and psychological reactions, all of which can be scary. Many people derive self-esteem and self-image from their physical appearance and their ability to care for themselves.

If you are a spinal cord injured victim/survivor, it is likely that you are unable to operate in the same capacity you once did. At first, it may be difficult for you to fulfill your roles as wife, mother, husband, or father due to physical impairments. Adjusting to physical changes takes time, so be patient with the process and with yourself. It is likely that you will be dependent upon others or devices to complete tasks. But, while you may be physically dependent in many ways, how you choose to adapt to these changes is entirely up to you.

Physical impairments and their subsequent adaptations can contribute to emotional reactions including sadness, anxiety, and anger. Collectively, these reactions are often referred to as grief.

GRIEF

Grief is not an event but a process of experiencing the emotional, mental, physical, social, and spiritual

Common Grief Reactions: effects of a loss. During the initial weeks, months, and perhaps even the first year following discharge from the hospital/rehab unit, a victim/survivor may be very emotional. As a victim/survivor with SCI, you may feel tearful, overly sensitive, and anxious upon returning home. These initial reactions to your injury and to the crash itself are normal. Because of someone's reckless behavior, you must contend with an injury that cost you both function and appearance. Your grief may be compounded by the death of a loved one who was involved in the crash with you.

Family and friends are also profoundly affected by the crash and your injury. They too are victims/survivors and grieve not only for your losses, but also for the losses they suffer as a result. As a loved one, you may feel the fear, sadness, and anger associated with grief. You may also be grieving the death of another family member or friend who was involved in the crash.

Grief is a personal experience. A loss to one person may not be considered a loss to another. Adjustment to losses imposed by the crash hinges upon many factors, including: the coping style of the individual; the quality of the victim/survivor's support system; the nature of the trauma; the damage the trauma caused; and the presence of additional stressors. There is no time limit as to how long or short you will grieve. Your grief is your own and it is your right.

Social Changes. As a victim/survivor with SCI, you may feel stressed about seeing family and friends for the first time since your injury. Spinal cord injuries may change how others see you. You may be using emotional and mental energy to deal with situations the rest of us take for granted. You may feel ashamed, fearful of being devalued, which results in diminished self-esteem.

It may be useful for you to discover new ways to present yourself, to prepare for the staring, comments, and questions of others. It may be easier to have a family member or friend go with you the first couple of times you decide to venture out. Accept that it will be difficult at first, but in time will become easier. You cannot control the reactions of others, but you can control how you choose to cope with these new social situations.

Depression. An impaired driving crash can cause multiple physical, psychological, and social losses. A victim/survivor may also suffer secondary losses that

stem from those primary losses. While grief reactions such as sadness, anger, and fear are normal, a more serious psychological complication can develop over

Signs and Symptoms of Depression:

- *Frequent crying spells*
- *Persistent feelings of helplessness or hopelessness*
- *Inappropriate feelings of guilt*
- *Feelings of worthlessness*
- *Sleep and/or appetite disturbance that affects overall health*
- *Social withdrawal*
- *Suicidal thoughts*
- *Alcohol or substance abuse*

time. As a result, relationships with family and friends may be in jeopardy.

If grief becomes intense and interferes with functioning, depression and anxiety may be present. Depression that is left untreated can lead to thoughts of suicide or death and if so, it is time to ask for help immediately. It is documented that individuals with SCI are at risk for depression and many self-medicate with alcohol.

Clinical depression and anxiety can be debilitating but are treatable.

Post Traumatic Stress Disorder. Today, you may be in your car and suddenly have thoughts of the crash or perceive sensations (images, smells) that “bring you back” to the crash. You may wake-up in the middle of the night in a panic due to a nightmare. Moments such as these may come without warning, and over time can cause you to avoid situations that you connect with the crash or these recurrences. You may feel on edge, anxious, always ready to react. Recollections can feel so painful and scary that they disrupt your normal activities and relationships.

Some people experience recurrent and ongoing recollections of a trauma, which can obviously lead to distress. Things you see, things you hear, things you smell, things you taste, and things you feel can trigger these intrusive thoughts. Sometimes the intrusive thoughts seem so real that you feel that you are reliving the traumatic event. Because you are always anticipating the next intrusion, you may be hypervigilant and easily aroused. On the other hand, you may have found ways to avoid feeling anything at all.

Trauma victims/survivors who consistently experience all of these symptoms for at least one month or longer may be suffering from Post Traumatic Stress Disorder (PTSD). PTSD is an anxiety disorder that is diagnosed by mental health professionals. If you believe you may be suffering from PTSD it is important to seek professional help, as PTSD is treatable with a combination of therapies.

Understanding the Trauma. The world is forever changed when someone experiences a trauma. Safety, security, predictability, and sense of control are all distorted. In order to regain a more accurate perspective of the world around you, it is helpful to work toward an understanding of the crash. This search for meaning involves acknowledging your trauma and asking questions. At times there are no answers but it is nonetheless important to get answers to those you can. Asking specific questions about the crash and obtaining a copy of the crash report are ways to begin.

HOW TO COPE

The methods of coping you choose to employ after your crash can be either productive or self-defeating. Dealing with physical changes and emotional pain may make you feel like you are on a roller coaster ride with many highs and lows. Coping is an attempt to adapt new circumstances into existing life: you may try a variety of means to achieve this; some that work and others that do not. Despite the hurdles, most people adapt well to their injuries.

Tips for the Spinal Cord Injury Trauma Victim/Survivor

- Take things one day at a time. Set simple goals and develop a daily routine. Learn to accept responsibility for your own physical, emotional, mental, and spiritual healing. Allow others to help you as you learn.
- Follow the instructions of your doctors and therapists to insure proper rehabilitation. Attend regularly scheduled medical appointments for continued therapies and follow-up.
- Keep the lines of communication open between friends and family. Tell them how you are feeling and what you are thinking. Remember that they are hurting, too.
- You may experience feelings of sadness, anger, anxiety, and/or fear. Acknowledge these feelings by sharing them with family and friends, a counselor, a support group, or by writing them down in a journal if you can.
- Employ the use of resources specific to spinal cord injury, such as an electric-powered lift, portable shower chair, and other technological and occupational devices.

- Experiment with activities of daily living: challenge yourself to see if you can discover new ways to accomplish old tasks.
- Pursue the professional help of a psychiatrist, psychologist, counselor, social worker or other mental health provider if your feelings of sadness, anxiety and/or anger persist.

Tips for the Family Member and Friend

Victim/Survivor

- Take things one day at a time. Set simple goals and develop a daily routine. Acknowledge to yourself that the SCI victim/survivor is responsible for his/her own physical, emotional, mental, and spiritual healing, but he/she needs your support in order to do this. Pushing the SCI victim/survivor before he or she is ready may produce undesired results. Each victim/survivor's healing and adaptation is highly individual.
- During acute hospitalization and rehab, take shifts in caring for the SCI victim/survivor in order to provide much needed respite to one another. Keep a written schedule.
- Help the SCI victim/survivor follow the instructions of medical personnel. This may include offering encouragement or agreeing to transport the SCI victim/survivor to scheduled appointments. Make certain that the SCI victim/survivor is involved in making decisions about his/her treatment.
- Keep the lines of communication open between friends and family *and* the SCI victim/survivor. Tell them how you are feeling and what you are thinking in a sensitive manner.
- You may experience feelings of sadness, anger, anxiety, guilt and/or fear. Acknowledge these feelings by sharing them with family and friends, a counselor, a support group, or by writing them down in a journal if you desire.

- Know how and when to take care of yourself.
- Pursue the professional help of a psychiatrist, psychologist, counselor, social worker or other mental health provider if your feelings of sadness, anxiety and/or anger persist.

HOPE AND HEALING

The Spinal Cord Injury. During the initial days, weeks, and perhaps even year following a spinal cord injury, it is difficult to speculate what level of recovery a SCI victim/survivor will achieve. Doctors generally regard any impairment that lasts between twelve to twenty-four months as permanent. There is no cure for spinal cord injury, yet advancements, such as our understanding of swift treatment and use of steroids, have improved outcomes for SCI victims/survivors.

We used to think that regeneration of the spinal cord was impossible. We now know that the spinal cord has the power to heal itself to some limited degree. Researchers are working to understand how medications and surgical procedures might encourage regeneration. This research is relatively new and a cure is unlikely for some time to come. However, individuals with SCI are certain to benefit from the ongoing efforts to find new ways of improving function and enhancing rehabilitation.

Your Changed Self. In grief we learn to identify our losses and define our changed selves. The healing that follows can be a long, involved journey. As you acknowledge your spinal cord injury and give

yourself permission to experience the thoughts and feelings that coincide, you begin to assign new meaning to your life. The roles, behaviors, relationships, needs, goals, and expectations you once held will inevitably change. With each new role you assume, each changed relationship you nurture, and each new behavior you adopt, you are reinforcing your changed self.

The love and support of family and friends are crucial in this healing process. As a loved one, it is important to listen to the thoughts and feelings a victim/survivor expresses about the drunk driving crash and about the SCI injury. They may need to tell their story over and over again as they work toward reorganizing the world around them. Regaining physical independence is equally as important and your encouragement will aid in their healing.

Life after a drunk driving crash is redirected, whether or not you were involved in the crash. Spinal cord injuries have the power to change functioning, appearances, and identities. As victims/survivors, you have the power to choose how to incorporate those changes into the rest of your lives.

FOR PARENTS OF CHILDREN WITH SPINAL CORD INJURIES

The love a parent has for a child is special. Parents want to care for their child, to solace them, and to help them find happiness. Parents feel their child's joy and find it almost intolerable to see a child in pain yet be unable to help. In no other relationship is the protective urge as intense or compelling as in the parent/child relationship.

When a child sustains any traumatic injury, it is not uncommon for parents to feel extremely guilty for what has happened. Feelings of guilt, sadness, anger, and rage are all to be expected. However, when guilt and other feelings are prolonged, parents may inadvertently contribute to the ongoing dependence of their child. It is normal for a child who has experienced such a traumatic event to regress or act out inappropriately. When parents set firm limits for inappropriate behavior while offering love and support, the child has an opportunity to move through their treatments and subsequent healing with a hopeful outcome.

Feelings of guilt, sadness, fear, and anger are also to be expected from the child victim/survivor. Some kids show signs of difficulty coping while others seem to take their injuries in stride. Children rely on their parents to model coping behavior that will carry them through their treatments and subsequent healing. The key seems to be unconditional acceptance of family and friends in the wake of something that is life-changing.

Children of different ages have different concerns. Younger children will take their cues from their parents. Older children and teens, however, are heavily influenced by input from their peers. Teens, in particular, struggle with self-esteem and body image. Creating an environment of normalcy is important so that your child will not feel so different from their peers. Helping kids with SCI to identify things that are special about them will rebuild and strengthen their self-concepts.

Going back to school can be a source of fear and anxiety for your child. It may be useful to reintroduce your child to their peers by asking a few close friends for a visit before your child returns to school. Additionally, talking with teachers and counselors is recommended as completing an educational plan is necessary to insure that your child receives all of the necessary accommodations he/she requires.

Treatment, rehabilitation, and healing are arduous, not only for the child with spinal cord injuries, but also for family and friends. As a parent, it is important to tend to your physical and emotional needs as you endure the process. Your child needs you. Although you could not prevent the impaired driving crash that injured your child, you can be present and supportive as they grow to define who they are.

REFERENCES

United States. Dept. of Education, National Institute on Disability and Rehabilitation Research, National spinal Cord Injury Statistical center. *Facts and figures at a glance – August 2004*. H133A011201. August 2004.

NOTES

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