



Miniwakan Tiyospaye News

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Brown-Sequard Syndrome

An article by SLC President Dr. Erich Longie

When playing in pool tournaments, pool players frequently come up to me and ask, "What's wrong with your leg?"

I injured my spinal cord in a car accident more than twenty years ago and have since walked with a limp. Over the years I have become quite accustomed to the questions about my "limp" so I prepared two versions (long and short) to respond. I usually give pool players the short version which is, "It's not my leg; it's my back. I broke it twenty some years ago and have been partially paralyzed ever since." That usually satisfies them. But for the more inquisitive ones, I tell them the long version. Here is what I share...

People often lump all types of spinal cord injuries under the term "broken back." There are spinal cord injuries that result when bone(s) that make up your backbone are fracture or, broken due to a traumatic injury. The type of Spinal Cord injury depends on location and how the bones were stressed, fractured, or broken. In my case several of the fingerlike bones that project out from my spinal column were fractured or broken which led to a rare type of spinal cord injury called Brown-Sequard Syndrome.

Back to my long version...One spring Sunday afternoon in March, twenty four years ago, during a two-day drinking binge, Bob, my future brother-in-law and I decided to drag race our cars. My girlfriend's brother jumped in with me. Bob and his friend got into his car. It was cold and the snow that melted the previous day had frozen into ice. My recollection of the race that changed my life forever is a series of flashbacks of excitement and anticipation. Shortly after starting the race Bob began to pull away from me. I glanced down at the speedometer to see how fast I was going and observed the speedometer rapidly climbing toward 60 mph. Shortly thereafter, I can't recall exactly how long, my car hit a patch of ice and slid sideways down the road until it hit dry pavement. We flipped over and over several times (from what I been told). My mind went blank after the first roll. I "came to" lying on my bed at home. Because I was in extreme pain, an ambulance was called and I was transported first to Mercy Hospital in Devils Lake, then to Grand Forks, where I was taken immediately into surgery.

After the operation, I was placed in the Intensive Care Unit and my family was told that I had a 10% chance of walking again. Besides the back injury, I had a broken ankle, two broken ribs, a broken collar bone, and numerous scrapes and bruises. Most of the skin on the left side of my face was scraped off. The doctors were not sure I would make it through the night. Thanks to the Creator, I did make it through the night and began a long and painful recovery that culminated in me walking with a permanent limp and knowing I will live the rest of my life with some serious physical shortcomings.

My desire to be accurate in explaining the medical aspect of my spinal cord injury and because it has been over twenty years since the accident, I had to surf the web to refresh my memory. The medical information in the next section was taken from a website titled neurosurgerytoday.org. Readers of this article are going to have a much more accurate and expanded version of my spinal cord injury than what I usually tell the curious.

A **Spinal Cord Injury (SCI)** that results in total loss of all motor and sensory function below the level of injury is called a complete SCI. Both sides of the body are equally affected. For example, a person with this type of injury will experience total loss of sensation and movement in the areas below the injury. Most people think a complete SCI results in the spinal cord being completely severed. This is not true. Even with a complete SCI, the spinal cord is rarely cut or transected. More commonly, loss of function is caused by a contusion or bruise to the spinal cord or by compromise of blood flow to the injured part of the spinal cord.

There are many different **Types and Levels of Spinal Cord Injuries**. The severity of an injury depends on the part of the spinal cord that is affected. The higher the SCI on the spinal cord, or the closer it is to the brain, the more effect it has on how the body moves and what one can feel. Tetraplegia (a.k.a. quadriplegia) results from injuries higher up on the spinal cord in the cervical (neck) region, with associated loss of muscle strength in all four extremities. Paraplegia results from injuries that are lower on the spinal cord in the thoracic or lumbar areas, resulting in paralysis of the legs and lower part of the body.

An injury that results in a person being able to move one arm or leg more than the other, or having more function on one side of the body than the other is called an Incomplete SCI (my case). With an Incomplete SCI, some function remains below the

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primary level of the injury and falls into one of several patterns.

1. **Anterior cord syndrome** - these injuries result in some types of crude sensation via the intact pathways in the posterior part of the spinal cord, but movement and most sensation are lost.
2. **Central cord syndrome** - Symptoms may include paralysis and/or loss of fine control of movements in the arms and hands, with far less impairment of leg movements.
3. **Penetrating SCI** - symptoms produced by this injury depend upon the pattern of distribution of the specific nerve root involved. Neurological symptoms including numbness, tingling, electric shock-like sensations, and burning in the extremities occurs.
4. **Brown-Sequard syndrome** – This was the diagnosis of my injury.

“**Brown-Sequard syndrome** is a rare spinal disorder that results from an injury to one side of the spinal cord. It is usually caused by an injury to the spine in the region of the neck or back. In many cases, some type of puncture wound in the neck or in the back that damages the spine may be the cause. Movement and some types of sensation are lost below the level of injury on the injured side. Pain and temperature sensation are lost on the side of the body opposite the injury because these pathways cross to the opposite side shortly after they enter the spinal cord (Retrieved from the Internet, May 3, 2006).”

I was in excruciating pain for several days following the operation which was intended to stabilize my spinal column. For the first couple of weeks, I was flat on my back, unable to move except for my head and right arm. I lived from pain killer pill to pain killer pill. After the pain subsided, I was transferred out of ICU and I took stock of my condition. I was completely paralyzed from the waist down caused by an injury in my lower back. My right arm was extremely weaker due to a spinal cord injury in the upper back. To the chagrin of the doctors, I refused to accept the reality of the possibility of spending the rest of my life in a wheel chair. I absolutely believed that I would walk again. After about three weeks, I was visited by a “new” doctor. This doctor performed the usual examination but he did something different



Dr, Erich Longie

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than the other doctors. He asked me to move my big toes...first my left toe, then my right. Apparently, my right toe moved because he said something to the effect, “Good! “We’ll have you up and walking in no time.” Those were the sweetest words I had ever heard and I never doubted them one bit.

I remember being totally embarrassed every time the nurses bathed me, and doctors examined me (keep in mind that at this stage I was still completely paralyzed below the waist and couldn’t lift my left arm, it was so weak. This reservation boy was not used to having strange people constantly observing him in his “birthday suit.” I also remember being wheeled out of my room and into a classroom where the doctor/instructor more or less used me as a guinea pig. He described my condition to a group of medical students all the while pointing or lifting different parts of my body. I was extremely embarrassed through it all. However, after several weeks I became accustomed to medical staff seeing me in my “birthday suit” and became indifferent to medical personnel when they examined me. Many doctors came by to examine me because I was diagnosed with Brown Sequard Syndrome, an extremely rare injury.

Eventually, I was transferred to Rehab where I stayed for a couple of months. At first, I was extremely depressed and uncooperative with the therapists. In fact, I refused to take part in Occupational Therapy because the therapist tried to teach me “living skills” designed to show me how to live on my own in a wheel chair. I felt that attending these sessions would weaken my resolve to walk again so I absolutely refused to attend. As a result of being uncooperative, a Catholic priest was sent to my room to talk to me and I promptly chased him out. On the other hand, I developed a good rapport with my physical therapist and would spend hours in the exercise room doing the exercises she instructed me to do. Noticing my hard work, she spent more time with me than with any of her other patients. Eventually, due to my hard work and the compassion of the Creator, movement to my right leg slowly began to return. By the time I left Rehab and went home, most of the movement had returned to my right leg although I still could not walk, even with help of crutches.

Before I go any further, let me tell you where all my motivation/determination to walk again originated. It was not from where you may think. At the time of my accident I was a very healthy twenty-nine year old Indian boy. I immensely enjoyed my life which consisted of drinking every weekend, going from bar-to-bar, party-to-party, carousing, and the rest of the "excitement" that came from living that life style. Well, no injury, spinal cord or not, was going to prevent me from living that lifestyle. All the long hours I spent exercising and sweating in the Rehab exercise room was with this in mind. And it worked.

Anyway, back to my story. Shortly after getting discharged from Rehab I went to court for DUI and was sentenced to thirty days in an alcohol treatment center. Incidentally, this was the second time I went to treatment; I was in treatment six weeks while I was in the Marine Corp. Because I was a veteran, I chose the Veteran's hospital in Fargo to undergo treatment. After thirty days of counseling, going to AA meetings, group discussions and eating healthy, I was discharged. It was all a waste of time. After serving my thirty days, my sister came to pick me up and I was drinking a can of beer before we were out of town.

Or was it? Within two years, I was back at the Fargo treatment center once again. The mother of my sons was threatening to leave me if I did not stop drinking. Fortunately for me, I did learn some things from my previous two times in treatment. As a result, this time I went with a different attitude. I really wanted to quit, and I did and haven't taken a drink since.

Being sober, I was able to face in much healthier manner the prospect of never being able to jump, run, lifting heavy objects, etc. Instead, now I choose to consider myself extremely lucky. At least I can walk (somewhat). I have been in rehab with numerous people who also had spinal injuries but were forever confined to a wheelchair. With my ability to perform manual labor gone forever, I had no choice but to return to school. First I attended the tribal college on the reservation, then I transferred to UND where I received a Bachelor's Degree in Elementary Education, returned in a few years to obtain a Master's Degree in Education Administration, and I finally earned a doctorate in Education Leadership.

" ... my sister came to pick me up and I was drinking a can of beer before we were out of town."

“There were times when I wished my life would end, too.”

After a few years, I didn't notice my disability except when I tried to do some physical task but couldn't. I believe by accepting my disability my family did too. I remember once when I told my son he should be hanging the curtains instead of an "old cripple" like me, he said, "But Dad, I don't look at you as a cripple." Throughout the years many, many people would tell me something very similar to what my boy said.

I always did like to run as kid and I also did a lot of running when I was in the Marine Corp. When I came home I continued to run although not as often. For several years after my accident I had (and continue to have although not as often) this one reoccurring dream; the dream always starts with me having to walk someplace in a hurry. First, I start walking, then I start walking faster, as I walk faster I find myself being able to "run" a little. I become excited and try harder to run and sure enough I find myself eventually running full out. It's a good dream. It is similar to what happened to Forrest in the movie "Forrest Gump" when he is being chased by kids on bicycles. Although crippled with leg braces, he starts running and eventually out runs his tormentors"

I eventually became Academic Dean and then President of our tribal college where I served for ten years. Shortly after leaving the college my second oldest son, Joel, was killed in a car accident. I struggled. There were times when I wished my life would end, too. He was only seventeen years old! Fortunately, with the help of numerous friends and relatives I was able to endure the horrible pain that comes from losing a son and I began to enjoy life again.

In closing, I have to conclude I am one of the luckiest men alive. I was born into a wonderful family, had a wonderful mother to whom I credit all my success, I managed to overcome alcoholism, I escaped from being totally paralyzed in a horrendous car accident, and I have obtained a measure of peace over the death of my son. My two other sons and daughter are now completely grown up, doing well, and have presented me with beautiful grandchildren. I have a full-time job as an Even Start Coordinator which I enjoy. I and Ann Maria (DeMars) started our own company, Spirit Lake Consulting, Inc. which is doing well. In September I will resign from my job as Even Start Coordinator and work for myself full time...something I have always looked forward to doing.

Spirit Lake Consulting presents ...

We are proud to present our latest project, Latino/Disability Access. We had our first presentation at the Educating Bilingual Students conference at the University of Riverside on May 17th and found that there is indeed a great need for this product in the community. The site is a pilot site provided as a public service by Spirit Lake Consulting, Inc., created in response to the lack of information that exists on Latinos with disabilities. We have found that many Latino parents run into problems when it comes to researching their children's disabilities. Libraries and even the most in depth websites do not address the fact that people can be both Latino and disabled.

The Latino/Disability Access site is not unlike our own Disability Access pages, containing information on everything from the definition of a disability to resources for parents. To date, we cover disabilities such as learning disabilities, emotional disorders, communication disorders, and attention deficit disorders. However, this website differs from our initial Disability Access site with its section of information in Spanish. Finding bilingual pages on the Internet can be quite a struggle, so we try and make that search easier. Also added to our site is a section on cultural knowledge for teachers serving Latino students with disabilities.

SLC has a great deal of experience in working with teachers serving English language learners, so this topic is not unfamiliar to us. We have developed this website to be worked on a great deal in 2007 and plan to have many revisions based on the community's reaction to the site. This way, we are able to address the community's real life issues. As with our other projects, Latino/Disability Access is made onto a CD-ROM that can be used without Internet for families who do not have access. It is then distributed at conferences/workshops. Our main goal is to eliminate health care disparities for Latino communities who do not have proper access to these resources.

If you would like to contact us and receive more information on this project, please visit http://www.spiritlakeconsulting.com/Latino_Disability/index.html. You can be placed on our mailing list and receive updates on the progress of Latino/Disability Access.

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Family Life & Disability Training

Funded by a grant from NIDRR

For tribal members with disabilities, vocational rehabilitation clients or any other family members/caregivers of individuals with disabilities

This workshop covers:

Family Life & Disability:

Information & solutions to common problems by people with disabilities and their families

Information on coping with diagnosis, behavior problems, becoming independent, substance abuse and sexuality



All Attendees will receive:

A Free CD-ROM, Door Prizes, Free Lunch, College Credit, and **A \$50 STIPEND!**

On the Spirit Lake Reservation

When: June 16th & 17th

Where: Crow Hill Recreation Building

Time: 9:00 a.m. to 4:00p.m.

Contact: Derrick Dauphinais at 351-2667 or Erich Longie at 351-2175

On the Turtle Mountain Reservation

When: June 6th and June 13th

Where: Turtle Mountain Community College

Time: 11:00 a.m. to 5:00 p.m.

Contact: Willie Davis (701) 278-2920