

# **Spinal Cord Injury: You *Do* Have *CHOICES***

**Research & Training Center  
On Independent Living  
University of Kansas**

## **Project Co-Directors**

Kenneth J. Golden, Pam Willits, Glen White

## **Editor**

Judith Galas

## **Contributors**

Barbara Bradford	John Chappell
Cielo Dehning, M.D.	Tim Elliot
Ken Gerhart	Mandy Goodnight
Linda Born Heimer, CRRN	Cindy Higgins
Donovan Lee	Frederick M. Maynard, M.D
Kim McGinnis, OTR	Mike Oxford
Lori Richards	Dana Solomon, OTR
Spain Rehabilitation Center	Jim Verbout
Sandra Wicina	Dean Wilson

## **Consultants**

Diane Aaron, Regional Director  
Steve Palermo Chapter of the  
Kent Waldrep National Paralysis Foundation

## **Reviewers**

Cee Abbey	Karen Embry	Jeff Farney
Bob Mikesic	Shelia Roth	Ann Sampson
Chris Sampson	Jill Street	Debbie Waggener
Sandi Wicina		

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I've dreamed of **CHOICES** for so long! My hope is that the information you find will act as a road map through the storm and help you to find the sunshine in your life once again.

My son-in-law, Steve Palermo, was shot and paralyzed on July 7, 1991. He was told he would never walk again. Due to the extent and degree of Steve's injury and due to his vigorous rehabilitation, he is now walking with a short leg brace and cane. In December of 1992, the Steve Palermo Foundation for Spinal Cord Injuries was founded based on the desire of Steve and my daughter Debbie's desire to help others with spinal cord injury. In January 1995, the Foundation merged with the Kent Waldrep National Paralysis Foundation, a foundation with the same vision.

Many families going through the same uncertainties that our family went through have called or written the Foundation asking for support. I soon realized the great need for a publication or directory that would put people in contact with those who could simplify the unknown at a most devastating time in their life. This is what Debbie needed at the time of Steve's injury . . . **CHOICES!**

Someone once said to me, "When a spinal cord injury happens, you feel like standing still, but you know you must move forward." But how? There are many questions to ask. We know that **CHOICES** can't answer all of your questions, but we have attempted to give you information that will help you to make educated decisions. **CHOICES** allows you to have a sense of control over your life . . . providing reassurance that there IS life after spinal cord injury.

"Poetry is a translation of feelings into words, an attempt to understand." When Steve was first injured, many words of wisdom were sent to us. The following poems are but a few that helped me and my family. I hope that they can bring you and your loved ones some comfort as you go through this very trying time.

My thanks to the Research & Training Center on Independent Living at the University of Kansas in Lawrence for their hard work in developing this directory; to the Paralyzed Veterans of America for their financial support in making it possible, and thanks to the many who have offered their knowledge and support in bringing **CHOICES** to completion.

Use **CHOICES** well,

A handwritten signature in black ink, appearing to read "Diane", written in a cursive style. The signature is positioned to the left of a vertical red line.

Diane Aaron

## ***DON'T CALL ME LUCKY***

*By  
Dorothy Mercer*

*I live with my injuries.  
People say to me, "Aren't you lucky!"  
And they don't understand  
Why my face suddenly freezes  
And my voice becomes tense.*

*I can say I'm lucky  
If I so choose on any given day.  
But when others say it,  
I feel as if  
They discount my pain  
And don't recognize my costs,  
Counting me only as alive or dead  
No matter how hard it may be  
To endure living.*

*Some days I am glad:  
Life itself is all that matters,  
And I savor it.*

*But when I hurt too much,  
Or am told I won't fully heal,  
When I cannot work or play as before,  
Or feel I'm a burden on others,  
Then I don't feel lucky at all!  
I feel cheated!*

*Some days I even wish  
I had died rather than live like this.  
So please don't tell me  
That I'm lucky  
To only be injured.*

*Tell me instead  
You are glad I'm still here,  
And let me know why.  
Tell me that you care about  
My grief, pain, anger and adjustments.  
Tell me you willingly rehear  
My disappointments, loss and frustrations.  
And have patience while I relearn to live.*

*Then someday I can tell you  
How lucky I am -- to have someone  
Who understands and accepts my sorrows  
And who also shares my joys!*

## ***LISTEN***

*By  
Anonymous*

*When I ask you to listen to me  
and you start giving advice  
you have not done what I asked.*

*When I ask you to listen to me  
and you begin to tell me why I shouldn't feel that way,  
you are trampling on my feelings.*

*When I ask you to listen to me  
and you feel you have to do something to solve my problem,  
you have failed me, strange as that may seem.*

*Listen! All I asked was that you listen,  
not talk or do - just hear me.  
Advice is cheap: 25 cents will get you both Dear Abby and  
Billy Graham in the same newspaper.  
And I can do that for myself, I'm not helpless.  
Maybe discouraged and faltering, but not helpless.*

*When you do something for me that I can and need to do  
for myself, you contribute to my fear and weakness.*

*But, when you accept as a simple fact that I do feel what I feel,  
no matter how irrational, then I can quit trying to convince  
you and can get about the business of understanding what's  
behind this irrational feeling.  
And when that's clear, the answers are obvious and I don't need advice.  
Irrational feelings make sense when we understand what's behind them.*

*Perhaps that's why prayer works, sometimes, for some people,  
because God is mute, and He doesn't give advice or try to  
fix things. "They" just listen and let you work it out for yourself.*

*So, please listen and just hear me. And, if you want to  
talk, wait a minute for your turn; and I'll listen to you.*

## ***ATTITUDE***

*By  
Charles Swindoll*

*The longer I live,  
The more I realize the impact of attitude on life.  
Attitude to me, is more important than the past,  
Than education,  
Than money,  
Than circumstances, than failures,  
Than success,  
Than what other people think, or say, or do.*

*It is more important than appearance,  
Giftedness, or skill.  
It will make or break an organization,  
A school, a home.*

*The remarkable thing is we have a choice everyday  
Regarding the attitude we will embrace for that day.*

*We cannot change our past...  
We cannot change the fact that people will  
Act in a certain way.  
We cannot change the inevitable.  
The only thing we can do  
Is play on the one string we have,  
And that is our **ATTITUDE**.*

*I am convinced that life is 10% what happens to me  
And 90% how I react to it.*

*And so it is with **YOU**.*

# **ROADBLOCK**

By  
Judy Clouston

*We are not deprived of choice.  
We may have limitations  
of movement,  
sight, sound, speech,*

*Yet choice is all,  
choose laughter over longing  
companionship, as well as solitude;  
rise above pain  
accepting that which we cannot refuse;  
respect the thorn along with the rose  
and forgive the unforgivable.*

*Life would be a dreary sentence  
were it not punctuated with  
question marks,  
exclamation points,  
dashes here and there  
and a liberal sprinkling of commas;  
perhaps we have more pauses than most.*

*Disability is not a stop sign  
but a yield to change our life sign.  
A call to alter the charted journey  
choose to make way in a world  
less user-friendly than a computer;  
choose to battle barriers  
of architecture and attitude*

*Yes, choice is all,  
set sights to the right of the moon;  
summon all the strength within  
and more.*

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# INTRODUCTION

## Spinal Cord Injury: *You Do Have CHOICES*

### Why you should use this manual?

The overall goal of *CHOICES* is to present information that will allow the SCI survivor to be informed about acute care and the rehabilitation process and to have some sense of control over his or her life. This goal may be accomplished by informing the SCI survivors and family members about acute care, the rehabilitation process and its components, different types of rehabilitation settings, and the financial resources involved. Moreover, this goal can be accomplished by providing information to the SCI survivor so that a person with SCI or a family member can communicate his or her concerns to the rehabilitation professional.

Other reasons why SCI survivors and family members need to read *CHOICES* and be informed about acute care and rehabilitation are:

- ◆ The newly injured person and their family members need reassurance that there is life after SCI and that rehabilitation can help.
- ◆ The newly injured person is often times at the mercy of the insurance providers, hospital administration, and rehabilitation staff. The rehabilitation providers and insurance providers are sometimes the gatekeepers of information and may use this information to make decisions for the person.
- ◆ The shortened treatment of SCI and rehabilitation require people to make decisions quickly. People with traumatic injuries and their families need information immediately after the injury to make decisions about the upcoming rehabilitation and available resources.
- ◆ The newly injured person may be receiving inadequate or incomplete rehabilitation and not know it. This may affect the consumer's future health, independent living skills, and community reintegration.
- ◆ A person, who had rehabilitation in the past, may want to seek additional rehabilitation because of a change in a life area, health, or physiological function.

After reading the information in the chapter(s), it is hoped that the SCI survivor will know what options are available to him or her.

### How to Make *CHOICES* Work for You.

**Spinal Cord Injury: *You Do Have CHOICES*** is a guide consisting of **fourteen chapters** that provide information for the SCI survivor and family members through the rehabilitation process and beyond. Before entering a particular phase in the recovery process, the SCI survivor or family member should look over the chapter that applies to that phase of the process. For example, the



person who is about to start physical therapy, should read the chapter on physical therapy. This is important so that the person is familiar with the process, aware of the person's needs, and can communicate the person's needs to the rehabilitation staff.

In each chapter you will find certain words that are *italicized* and have an asterisk \* next to them. These are words that can be found in the Glossary Section.

## **Acknowledgements**

Special thanks to Diane Aaron of the Steve Palermo Chapter of the Kent Waldrep National Paralysis Foundation who saw the need for a resource like ***CHOICES***. We also extend our appreciation to the Education and Training Foundation of the Paralyzed Veterans of America for funding this project, with special advisement from Trish Armstrong and Andrea Censky-Dietrich.

In addition, we extend our gratitude to all the chapter contributors who shared their knowledge and experience about topics which newly spinal injured patients and their families need to become better informed to make wise ***CHOICES***.

Finally, we wish to thank each of the reviewers who provided quality feedback regarding the accuracy and relevance of these materials to enhance positive rehabilitation outcomes in the lives of people with spinal cord injury.

Ken Golden, Pam Willits, Glen White  
Research and Training Center on Independent Living

***Disclaimer: Please note that the information contained in this publication is for general information only and may not apply to your specific situation. You are responsible for your own specific situation and should not rely only on this publication. It is meant to be used only as a guide. If you have questions, please contact the appropriate rehabilitation professional.***

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# Chapter One

## Understanding Spinal Cord Injury

Medical RRTC on Secondary Conditions of SCI  
Department of Physical Medicine and Rehabilitation  
University of Alabama at Birmingham

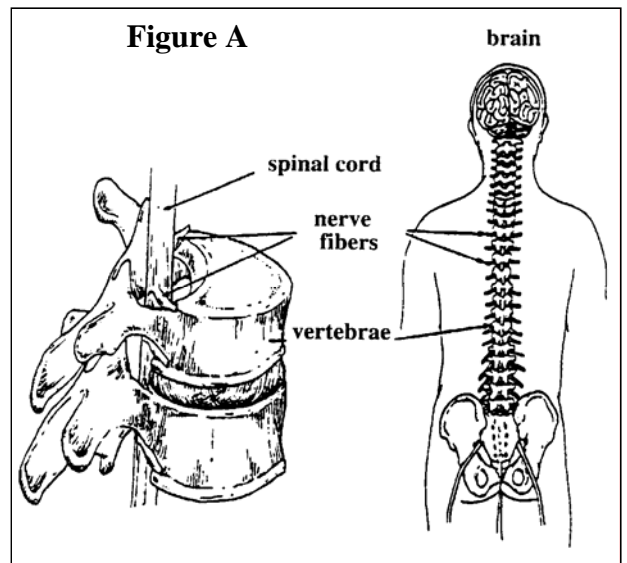
*Any damage to the spinal cord is a very complex injury. Each injury is different and can affect the body in many ways. This is a brief summary of the changes that take place after a spinal cord injury. It tells how the spinal cord works and what can happen to the body following a spinal cord injury.*

### The Normal Spinal Cord

The spinal cord is a part of your nervous system. It is the largest nerve in the body. Nerves are cord-like structures made up of many nerve fibers. The spinal cord has many spinal nerve fibers. Nerve fibers carry messages between the brain and different parts of the body. The messages may be for motion, telling a body part to move. Other nerve fibers bring messages of feeling or sensation back to the brain from the body, such as heat, cold, pleasure, or pain. The body also has an *autonomic nervous system*\*. It controls the involuntary activities of the body; such as, blood pressure, body temperature, and sweating.

These nerve fibers make up the communication systems of the body. The spinal cord can be compared to a telephone cable. It connects the main office (the brain) to many individual offices (parts of the body) by telephone lines (nerve fibers). The spinal cord is the pathway that messages use to travel between the brain and the other parts of the body.

Because the spinal cord is such an important part of our nervous system, it is surrounded and protected by bones called *vertebrae* (ver-te-brae). The vertebrae, or backbones, are stacked on top of each other. This is called the vertebral column (ver-te-bral col-umn) or the spinal column. The vertebral column is the number one support for the body. The spinal cord actually runs through the middle of the vertebrae. [See Figure A]



*The spinal cord goes through the center of the stacked vertebrae. These bones protect the spinal cord. The nerve fibers branch out from the spinal cord to other parts of the body.*

\* All italicized words appearing in this chapter can be found in the Glossary Section

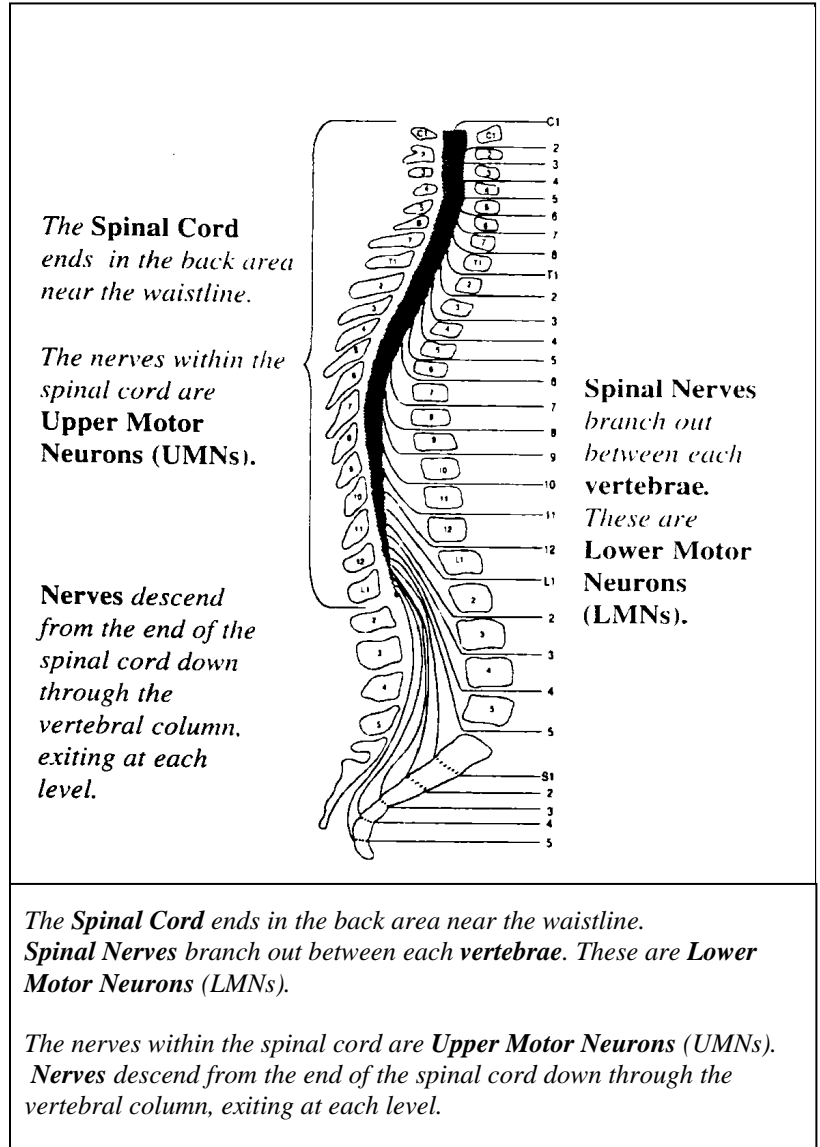
The spinal cord is about 18 inches long. It extends from the base of the brain, down the middle of the back, to about the waist. The bundle of nerve fibers that make up the spinal cord itself are *Upper Motor Neurons* (UMNs). Spinal nerves branch off the spinal cord all the way up and down the neck and back. These nerves, *lower motor neurons* (LMNs), exit between each vertebrae and go out to all parts of the body. The spinal cord ends near the waistline. From this point, the lower spinal nerve fibers continued down through the spinal canal to the sacrum or tailbone. [See *Figure B*]

The spinal column is divided into four sections. The top portion is called the *cervical* (cer-vi-cal) area. It has seven cervical vertebrae. The next section, the *thoracic* (tho-rac-ic), includes the chest area and has twelve thoracic vertebrae. The lower back section is called the *lumbar* (lum-bar) area. There are five lumbar vertebrae. The bottom section has five *sacral* (sac-ral) vertebrae and is called the sacral area. The bones in the sacral section are actually fused together into one bone. [See *Figure C*]

### The Spinal Cord After an Injury

A spinal cord injury can occur from either an injury or from a disease to the vertebral column or the spinal cord. In most spinal cord injuries, the backbone pinches the spinal cord. The spinal cord may become bruised or swollen. The injury may actually tear the spinal cord and/or its nerve fibers. An infection or a disease can have similar effects.

After a spinal cord injury, all the nerves above the level of injury keep working like they always have. Below the level of injury, the spinal cord nerves cannot send messages between the brain and parts of the body like they did before the injury.

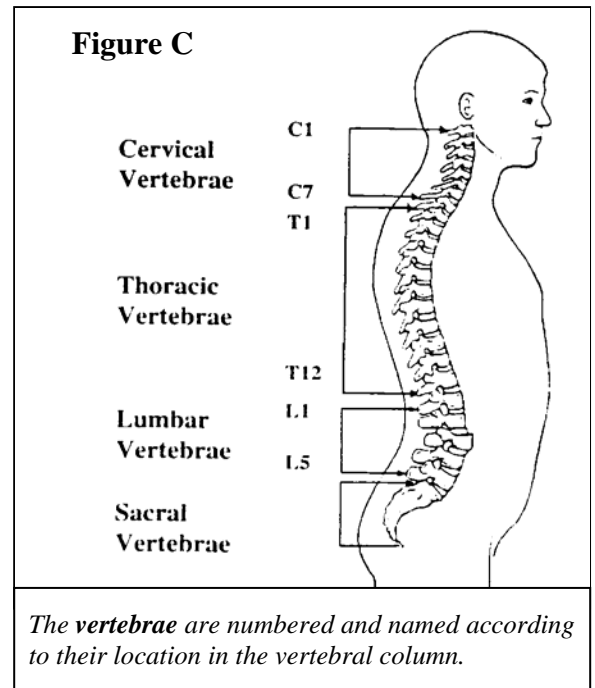


The doctor examines the individual to understand what type of damage has been done to the spinal cord. An X-ray shows where the damage occurred to the vertebrae. The doctor does a "pin prick" test to see what feeling the person has all over his body (*sensory level*). The doctor also asks, "What parts of the body can you move?" (*motor level*). The exams that the doctor does are important because they tell the doctor what nerves and muscles are working.

Each spinal cord injury is different. A person's injury is described by its **type** and **level**.

### Complete or Incomplete Injury

The **type** of spinal cord injury is classified by the doctor as complete or incomplete. The complete injury is like cutting off all the telephone service to a building. No messages can reach the offices. An incomplete injury is like stopping telephone service to some offices in a building. Some messages can get through to some offices, while others cannot. The amount and type of message that can pass between the brain and the parts of the body will depend on how many nerves are not damaged.



Some people with an incomplete injury may have a lot of feeling, but little movement. Others may have some movement and very little feeling. Incomplete spinal injuries will differ from one person to another because different nerve fibers are damaged in each person's spinal cord.

### Level of Injury

The level of injury is determined after the doctor does the different tests. The level is the lowest point on the spinal cord below which there is a decrease or absence of feeling (*sensory level*) and movement (*motor level*).

The higher the spinal cord injury is on the vertebral column, or the closer it is to the brain, the more loss of function (feeling and movement) there is. Fewer parts and systems of the body work normally with a higher level of injury.

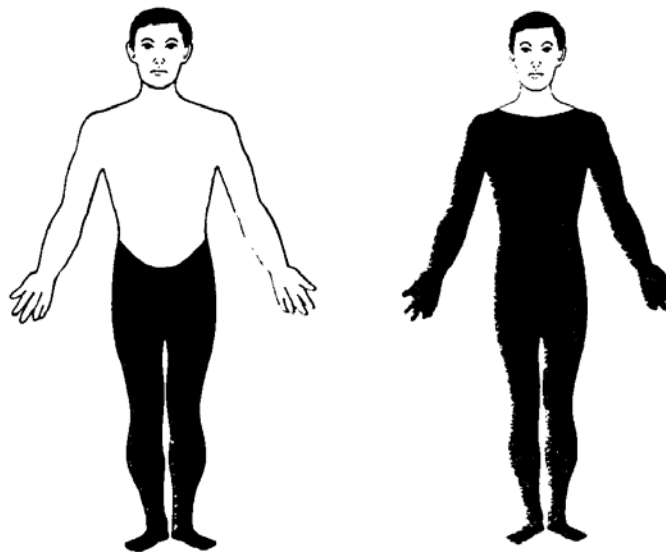
For example, an injury at the T-8 levels means the individual has a decrease or loss of feeling and movement below the 8th thoracic spinal cord segment. A person with C-5 level of injury has a decrease or loss of feeling and movement below the 5th cervical spinal cord segment. Someone with a T-8 level of injury would have more feeling and movement than someone with a C-5 level of injury. Remember that the amount of feeling and movement also depends on if the injury is complete or incomplete.

A person is said to have *paraplegia* (par-a-plegi-a) when he has lost feeling and is not able to move

the lower parts of his body. The injury is in the thoracic, lumbar, or sacral area. [See Figure D]

A person with *tetraplegia* (te-tra-ple-gi-a) [formerly called *quadriplegia*] has lost movement and feeling in both the upper and lower parts of his body. This injury is in the cervical area. [See Figure D]

**Figure D**



*The shaded area shows those parts of the body that do not work in the same way after a spinal cord injury.*

[left] *The dark shading shows the areas of the body affected by a T-11 level injury to the lower spinal cord. This person has **paraplegia**.*

[right] *The dark shading shows the areas of the body affected by a C-3 level injury to the neck. This person has **tetraplegia**.*

### **Changes After the Initial Injury**

Sometimes the spinal cord is only bruised or swollen after the initial injury. As the swelling goes down, the nerves may begin to work again. The longer there is no improvement, the less likely it is that there will be improvement. If a little recovery in function does occur, there is considerably more hope. This is no guarantee that more function will return.

Some individuals have involuntary movements, such as twitching or shaking. These movements are called spasms. Spasms are not a sign of recovery. A spasm occurs when a wrong message from the nerve causes the muscle to move. The individual often cannot control this movement.

In addition to movement and feeling, a spinal cord injury affects other body function. The lungs, bowel, and bladder may not work the same as before the injury. There may also be changes in sexual function. During *rehabilitation*, the medical team teaches the individual with spinal cord injury new ways to manage his/her bodily functions.

**See Resources:**

- *Spinal Cord Injury & Disability Information*
- *Spinal Cord Injury Foundations/Organizations*
- *Magazine/Books/Pamphlets*

## Chapter Two

### After Spinal Cord Injury: What to Expect from Acute Medical Care

Frederick M. Maynard, M.D  
Marquette, MI

Most spinal cord injuries result from an accident, such as a fall or car crash. These injuries are called *traumatic injuries*\*. There are two major types of traumatic spinal cord injury (SCI). *Penetrating injuries* result from gunshot wounds or stabbings. *Non-penetrating*, or closed, spinal cord injuries result from injuries to the bones of the spine, or *vertebrae*. The spinal cord provides the major communication link between the brain and the muscles, the skin, and other organs of the body. The loss of feeling and loss of movement are the major signs of injury to the spinal cord.

When people refer to the extent of someone's spinal cord injury, they are describing the amount of the body that has lost its connection to the brain. For example, *cervical* injuries involve injuries to the neck, and these injuries impair the body as high as the arms. Sometimes these injuries may also affect internal organs, including the muscles that enable someone to breathe. Cervical injuries are often referred to as *quadriplegia* or *tetraplegia*.

*Thoracic* injuries are those that affect the back below the neck and that involve the trunk area where there are ribs. *Lumbar* injuries occur in the lower back. Back injuries in both these areas involve the legs as well as the lower bowels, the bladder, and sexual organs. These injuries are commonly referred to as *paraplegia*.

When people refer to the severity of someone's injuries, they are describing the extent or degree of loss of feeling and movement in the areas of the body involved by the SCI. They can describe the severity as a *complete lesion* or as an *incomplete lesion*.

Complete spinal cord injuries are the most severe and describe the loss of all feeling and all movements in those parts of the body affected by the SCI.

Incomplete spinal cord injuries can cause some marked changes in bodily functions, but they don't result in a complete loss of all feeling. Incomplete injuries also result in a little or a lot of muscle weakness, but not a complete loss of all muscle function in those parts of the body affected by the SCI.

#### Phases of Initial Care

After a spinal cord injury, people usually are first seen by *paramedics* or emergency services personnel. They provide life-saving first-aid and immobilize the spine. People with suspected or obvious signs of SCI are usually evacuated to *trauma centers* on backboards, often traveling by

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

helicopter as well as by ambulance. This emergency care and quick evacuation are the first of several medical steps on the injured person's road to *rehabilitation*.

- ***Stabilization and Evaluation***

The injured person is then taken to an emergency room. In this first hospital, the medical staff first wants to maintain essential body functions. These trauma professionals make sure that the patient is breathing, that the heart is pumping, and that they have stopped any bleeding. Emergency room physicians or trauma surgeons will then carefully examine patients for bodily injuries. Many patients with SCI have other injuries, also known as *associated injuries*. These can include limb fractures, broken ribs with bleeding into the chest, head injuries, or abdominal bleeding. Examinations for the extent and severity of SCI will include tests for feeling the sharpness of a pin prick and for feeling being touched lightly on the skin over the entire body. Patients will also be asked to move various muscles of the arms and legs.

Following a complete evaluation and any urgent treatments to stabilize the body, the patient is X-rayed to determine the type and exact location of all injuries. In addition to regular X-rays of the spinal bones, *CT Scans* may be performed to obtain more detailed three-dimensional pictures of the vertebrae, of abdominal organs, and perhaps the head. *MRI Scans* are also commonly done to show different detail about the injury to the spinal cord and brain. *Angiograms* also may be done. These give pictures of major arteries in the body and are taken by injecting dye into the blood vessels. All these studies may be needed to evaluate internal bleeding or injuries involving blood vessels.

- ***Acute Medical/Surgical Care***

Most patients with acute SCI are admitted to Intensive Care Units (ICUs). These units have many nurses for each patient and monitoring equipment to constantly assess key body functions, such as breathing and heart beat.

Most patients with SCI will have *intravenous catheter* lines to bring fluids and medications into the body. For example, within 24 hours of injury, patients will receive high doses of intravenous steroids. This medication helps the body to heal spinal cord damage and promotes recovery. Patients often will have rubber catheters to drain urine from the bladder, and they may have tubes leading from their nose or mouth into their stomach so they can be nourished.

The acute medical team's first major goal is to make sure the patient survives. Its second major goal is to decide if surgery on the spine will be helpful. ICU patients have access to specialist surgeons, such as those who operate on the spine.

- ***Spine Surgery***

Using X-rays and other imaging studies, *neurosurgeons* and *orthopedic surgeons* may decide to operate on the spine. They have two possible aims for operating shortly after SCI. One is to remove any damaged bone, clotted blood, or other body tissue that may be squeezing against the

spinal cord. Removing this pressure may not assure recovery of the spinal cord, but it may help the



body heal nerve damage more quickly.

Their second aim may be to stabilize the spinal column. A major fracture or dislocation of spinal vertebrae with tearing of surrounding ligaments may make the spinal column unstable. The injured spine may not be able to support the body in an upright position.

In time, most injuries to the spinal column will heal after a prolonged bed rest and preventing movement of the injured bones. However, operating to stabilize the spinal column may allow a patient to get out of bed and move around sooner and lead to a quicker return home.

- ***Post Surgical Care***

Even after surgery to stabilize the spine, most people with SCI will need braces, neck collars, or other devices that prevent movement of the spinal column when a patient sits upright. Some types of spinal fractures may heal by only using immobilizing devices. *Halo vest fixation* may be used for patients with neck fractures either after surgery or in place of surgery. The "halo" refers to a metal ring that is attached to the skull by pins placed against the skull. Vertical metal bars then attach the metal ring to a vest worn tightly around the chest. This special brace prevents all neck movements and stabilizes the cervical spine while the patient is sitting up.

## **Continuing Medical Management**

- ***Breathing***

Many people with SCI have difficulty breathing in the early phases after injury. This difficulty may result from paralysis to breathing muscles, from chest injuries, or from prolonged *anesthesia* during surgery. In the early stages, patients with SCI are at great risk for pneumonia or partial collapse of the lungs. *Respiratory treatments* are often given to encourage deeper breathing. Special efforts are made to promote coughing to get rid of any fluids in the lungs. If stomach muscles are paralyzed, the patient may need assistance with coughing.

Patients who are unable to breathe deeply enough may have an *endotracheal tube* placed through the mouth or nose and extends from the back of the throat into the windpipe. This tube may be connected to a *ventilator*. People who need prolonged help from a ventilator are often given a *tracheostomy* operation. This operation puts a breathing tube directly into the windpipe. The advantage of a tracheostomy tube is that is more comfortable than the endotracheal tube in the back of the mouth or nose and throat. A person can use a variety of techniques to talk and better communicate with the mouth and tongue after the endotracheal tube is replaced by a tracheostomy.

- ***Bladder Management***

A plastic or rubber catheter, known as a *Foley catheter*, is usually placed into the bladder through the *urethra* initially after SCI. It remains in place until the patient's general medical condition has

stabilized. Sometimes a tube is placed directly into the bladder through the lower abdomen. This tube is called a *suprapubic tube*. Both types of catheters let urine drain into a collecting bag. After a

person's condition has stabilized, he or she may begin *intermittent catheterization*, where urine is removed from the bladder through a straight catheter every three to six hours. Any of these urinary drainage techniques may be continued during rehabilitation or after hospital discharge. A patient may learn many other means of draining urine from the paralyzed bladder and many ways to recover normal urination. When newly-injured and throughout life, people with SCI are at great risk of developing infections and other problems with the bladder and kidneys.

- ***Gastro-intestinal Management***

Patients generally cannot begin to swallow and take food until there are no problems with the throat or with breathing. They also must wait for the return of automatic contractions of the intestines. This is usually indicated by bowel sounds that can be heard with a stethoscope over the abdomen. Most people with SCI will need special stimulation techniques to evacuate stool from the lower bowel. Special techniques for bowel evacuation or *bowel program* must begin within the first week after injury, and great effort must be made to prevent constipation or incontinent (involuntary) bowel movements throughout later care and recovery.

- ***Skin Care***

Patients who have a loss of feeling in the skin of their lower body are at risk for skin breakdowns. These breakdowns are also known as *bedsores*, *decubitus ulcers*, or *pressure sores*. Prolonged pressure to the skin that lies over bone and gets squeezed between the bone and the bed is what causes bedsores. Friction from sliding over bed sheets can also irritate the skin, as can wetness from stool and urine.

A patient who cannot easily move or wiggle while in bed is at risk for bedsores over the lower spine, the *sacral* bone, the buttocks, the feet, and the sides of the hips. Nurses must turn and reposition patients often, at least every two hours, to prevent pressure sores.

- ***Pain Management***

Patients with acute SCI normally do not have severe pain after their injured spine is immobilized. Severe pain may result from other injuries, from surgical procedures, from nerve damage, or from fear and isolation. Medication is given to reduce pain, but efforts should be made to reduce medications that interfere with clear thinking and judgment. Patients with new SCI must be able to think clearly, for they must learn a great deal about SCI and its consequences. They must understand the medical care system and their options for care and recovery, so that they can take an active role in decisions about their current and future care.

- ***Joint Management***

Soon after injury, patients should begin daily exercises that move the joints through their usual *range of motion*. These exercises can help prevent joint and muscle tightness that can later restrict movements and interfere with rehabilitation.

- ***Circulation***

Patients with new spinal paralysis are at high risk for blood clots in the legs. This risk comes from reduced circulation in the veins because the muscles are not pumping blood back toward the heart. Patients who are not bleeding or having surgery are commonly started on some type of blood thinning medication soon after injury. These thinners can help keep clots from forming. They may also have plastic air bags wrapped around the legs that blow up and squeeze the leg muscles in order to pump blood out of the legs.

## **Preparing for Rehabilitation**

Almost all patients with acute SCI will need rehabilitation to achieve their best recovery and optimal level of independent function. Most often patients are transferred to a rehabilitation setting when they begin getting out of bed. Unless they've had a tracheostomy, they should no longer need help to breathe. They should be able to eat or have a stable means of getting nutrition. Their heart and circulation should be stable enough to allow them to sit up and move around. Their spine should be stable—with or without external bracing—and their skin should be healthy enough so that sitting up does not worsen any bedsores. Some patients are ready for a rehabilitation setting within a few days of their injury. For others, it may take weeks before they are stable enough to safely begin rehabilitation.

- ***Choosing a Rehabilitation Setting***

Most often a Rehabilitation Hospital or Rehabilitation Unit in a hospital cares for people with new SCI. These settings are sometimes called "acute rehabilitation" hospitals to set them apart from settings in skilled nursing facilities. Many complications can develop in people with new SCI, so it is *often wise for them to be cared for at a SCI Center* (see Resources for a list of SCI centers). These centers have a full range of services, including early surgery, comprehensive rehabilitation, and follow-up care. The Council on Accreditation of Rehabilitation Facilities (CARF) has a strict accreditation process to ensure rehab centers meet high quality standards. Check to see if your rehab facility is "CARF Accredited." (See Resources: Rehabilitation)

When selecting a facility, look at the number of people with new traumatic SCI that it sees in a year. Those that see thirty or more spinal cord injured people a year generally are skilled in caring for people with traumatic SCI. The staff should also work closely with experienced surgical and medical specialists who are interested in SCI-related conditions.

People in less populated areas may be concerned about having rehabilitation in a facility that is far from family and community supports. Generally, the advantages to being in a specialized SCI center out-weigh receiving frequent emotional support from family and friends in the home community. The more severe the extent and severity of SCI, the more this general principle applies.

Patients with injuries or complications may need a prolonged period of immobilization. They may be cared for in a sub-acute setting that is related to a SCI center program. This may be an appropriate intermediate step before comprehensive inpatient medical rehabilitation in an "acute rehabilitation" setting. Prolonged rehabilitation therapy services—*physical therapy, occupational therapy, recreational therapy, vocational therapy*—may also be given in a sub-acute setting after the high risk of medical complications is over and major medical problems have all been stabilized.

### **Communicating With Your Healthcare Team**

People with new SCI and their families or friends may find it hard to obtain information about their SCI and about proposed treatments. It is important to know whom to ask for what types of information. The following points will assist you in obtaining the information you want.

- ***Who Is In Charge?***

All patients who are hospitalized have one identified *attending physician*. The attending physician is the doctor with overall responsibility for a patient's hospital care. Tell the nurses or other healthcare professionals that you want to speak to your attending physician and to know his or her name. Generally after an acute SCI, the attending physician is a trauma surgeon, a neurosurgeon, or an orthopedic surgeon. While patients are in an Intensive Care Unit they may also have a physician who is an internal medicine specialist. Often several physicians will work as a team. If surgery is performed, the surgeon usually becomes the attending physician.

Patients and families always have the right to speak directly to the surgeon doing any proposed surgery. Patients are always entitled to a second opinion for any *elective* surgical procedure. Ask a surgeon if a proposed surgery is elective. If it is, there is always time for a second opinion. If a procedure is not elective, it should be clear what makes it urgent or emergent. Almost all procedures for spinal stability are elective. When considering different surgeons or surgical opinions, you may ask about a physician's board certification. Does he or she have advanced training in spine surgery? Membership in specialty society? Experience with similar injuries? A volume of SCI cases seen annually? SCI organizations and their special Hot Lines can offer more information.

- ***Asking About Prognosis***

You should ask your attending physician about your chances of recovering from spinal paralysis. You may also ask the most knowledgeable and experienced specialists working on the healthcare team. Do not expect clear answers during the first few days after injury. Doctors are understandably concerned about not frightening people or destroying their hopes for recovery. Recovery from SCI is never 100 percent predictable. By a few weeks after the SCI, physicians can be more accurate about the chances for recovery. Detailed questions about recovery and the likelihood of regaining

independent functioning, such as walking, are often best asked after the physicians have completed their initial evaluations.

- ***Was My Spinal Cord Severed?***

This is a common question after SCI, but it is not a very helpful question. Most patients with permanent paralysis do not have a severed or completely cut, *transected*, spinal cord. Most SCI's occur along with spinal fractures, so spinal cord tissues are most often crushed; it is uncommon for the cord to be partially cut or pulled apart. You will get more precise news about your likely recovery a few weeks after your injury. Exams during your recovery will help your physician better assess the extent and severity of any loss of feeling and movement.

- ***Learning About Options***

Most of the medical problems (often called “secondary conditions”) people with SCI face can be managed or prevented. Ask the nurses for written resources such as books, pamphlets, manuals, or videotapes. These will help you to learn about SCI and the common secondary conditions, such as pressure sores, urinary tract infections, chronic pain, etc., associated with it. The materials will also provide specific strategies to manage and prevent secondary complications.

- ***Getting Help for Communication Problems***

If you have trouble getting information, talk to the social workers assigned to work with Intensive Care Units teams. Or mention the problem to the nursing staff, particularly nursing supervisors or clinical specialists. These people can also help you make a list of questions for busy physicians, and tell you which physicians are in the best position to answer specific questions. Nurses and social workers may also arrange times for families and various members of the physician team to meet.

- ***Planning for Next Phase of Care***

The day will come when you will be discharged from an acute hospital setting and transferred to a rehabilitation setting. A nurse, case manager, or a social worker working with the acute care trauma team will arrange the transfer. This person can help you get specific information about options for rehabilitation settings and can answer questions about costs and insurance. People on the acute care physician's team may also discuss the pros and cons of various rehabilitation facility options and put you in touch with various community agencies or national SCI advocacy groups.

## **Medical Care After Discharge**

After discharge, it is very important to have a physician who is familiar with your condition and who is readily accessible. These physicians are generally called a *primary care physician* (PCP) or the physician who will be called first with a new or urgent medical problem. It is best to have a PCP who is knowledgeable about SCI and its common medical problems. Often this is not possible in rural areas. If a person had a general doctor with whom he or she should had good rapport before the SCI, it is good to continue with this same physician. He or she should be willing to learn about spinal cord injuries and to work with a SCI physician specialist by phone or mail. Most SCI Centers

have a follow-up program. This program includes regular re-evaluations of patient's medical condition and *functional* activities, including re-evaluations of their equipment.

It is generally wise for all people with chronic SCI to have a continuing relationship with a SCI specialty center or facility. They would generally turn to this facility for more serious or unusual problems associated with SCI. If a SCI Center is far away, more than one to two hours from a person's home, the patient must have a closer general physician. They can see this person first for urgent or more routine medical concerns. If serious questions develop, people are generally wise to ask for phone consultation or a transfer to the SCI Center. For some patients, it may be wise to continue their regular medical care and follow-up through the SCI Center and to limit their use of local healthcare to minor, urgent issues only.

Some people didn't have a doctor before their injury; others are moving to a new area. These people need help to find doctors who know something about SCI and its complications and who are willing to take SCI patients. A rehabilitation nurse or therapist may suggest some doctors. Groups that serve people with disabilities also may have information on local doctors. These groups can include a *center for independent living* (see Chapter 11), paralyzed veterans, the Easter Seals office, or county medical societies. State and national organizations that advocate for people with SCI may also be helpful.

**See Resources:**

- *Rehabilitation*
- *Advocacy*
- *Support/Self-Help*

## Chapter Three

### What Factors Affect Your Rehabilitation?

Cielo Dehning, M.D.  
Linda Bornheimer, CRRN

Kim McGinnis, OTR  
Dana Solomon, OTR

#### What is Rehabilitation?

Rehabilitation, or rehab, is defined as the process to develop people to their fullest potential. This potential can be physical, psychological, social, vocational, or educational, and can include areas of personal interests and hobbies. For a person with a spinal cord injury (SCI), this development must match the person's physical abilities and be suitable in their environment. So the person with SCI and those concerned about care must set realistic goals.

A rehab program should address a number of issues. It should look at prevention—how to keep healthy—and how to detect health problems as they arise. When such problems occur, the rehabilitation plan will help the person seek referrals for inpatient or outpatient care or even an extended-care facility.

Rehabilitation programs educate people about their injury and work to restore as much function as possible. Through practice and experience, people learn new skills and learn how to prevent complications, such as infections. Rehabilitation seeks to make the injured person as independent as possible, and it increases the person's quality of life.

Rehabilitation medicine takes a comprehensive approach to medical care and looks at the whole person. It also uses the combined expertise of an interdisciplinary team. This team is defined as a group of health care professionals from different backgrounds or disciplines, who share common values and objectives. A typical team includes several people. The rehabilitation physician, or *physiatrist*<sup>\*</sup>, who has received special training in the area of physical medicine and rehabilitation; a case manager; physical, occupational, speech and recreational therapists; a nurse, a *nutritionist*, a staff *psychologist*, and perhaps a social worker or case manager. Other professionals are included as the need arises. This team approach provides diagnosis, goal setting, problem solving and treatment. Clients and their families also are an important part of a successful team approach and process.

#### The Rehabilitation Team and Its Functions

In certain settings, such as an *acute* inpatient rehabilitation unit, this interdisciplinary team may be assigned to work with SCI clients. The team members may have specialty training and experience in spinal cord care and often they work on a dedicated spinal cord unit.

- *Physical Care*

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

The primary physician, or physiatrist, evaluates the client, prescribes treatment, obtains the necessary consultations and monitors the patients needs. His or her goals are to maximize the client's abilities and to avoid further complications.

The primary physician talks with all concerned about the injured person's care. During hospital rounds, he or she talks with the referring physician, the treatment team, and the client and family. The primary physician also coordinates follow-up rehab visits and connects with the client's local doctor. He or she prescribes outpatient or home-based therapies and any needed medical equipment.

- ***Nursing Care***

Nurses teach clients and family members about the effects of a *spinal cord injury* and care for clients during their recovery.

Rehabilitation nurses work closely with all other treatment professionals and provide moment-to-moment care for the SCI client. They monitor any changes in the client's medical and neurological condition. They work on bowel, bladder, and skin care issues; they give medications and other medical treatments, and they supervise eating for those clients who may have swallowing problems. They assist with hygiene, dressing, and routine *activities of daily living*, and provide in-room activities that enhance what the client learned in formal therapy.

- ***Case Management (CM)***

The case manager keeps the client, family, and funding sources, such as insurance companies, aware of the client's rehab program, expected length of stay, and discharge plans. The case manager coordinates team and family conferences. At these conferences, families learn about the extent of the injury, plans for treatment, and long-range planning issues. The case manager wants the client to be satisfied with the program and wants to help ensure quality of care.

The manager also works with the client, family, and insurance company. He or she wants to make sure the client gets needed services and equipment. She or he reviews the coverage plan with the client and family and may suggest other funding options if the insurance plan doesn't cover all that's needed.

*Discharge planning* starts upon admission to the rehabilitation facility. Client and family are regularly consulted about the discharge plans. They will also learn about the next step after discharge, such as outpatient or home-health therapy, and community resources.

- ***Physical Therapy (PT)***

*Physical therapy* (PT) seeks to improve overall mobility. This improvement can range from simple activities, such as rolling in bed and transferring, to maneuvering power and manual wheelchairs in a variety of settings. The *physical therapist* addresses balance, coordination, endurance, strength, joint mobility, and safe and healthy movement.

PTs, often with *occupational therapists*, make home visits and suggest ways to modify the home to



improve independence and safety. Physical therapists also work with the physician to teach clients how to use assistive devices that can help with mobility.

Before a client begins a therapy program, a PT does an evaluation. The PT evaluates how much or little sensation the client has. The PT will look at the client's movements and try to answer some questions. How much control does the client have over large muscle movement, such as in the arms or shoulders? How much fine muscle movement does the client have, such as in the fingers and wrists? How strong is the client's grasping strength? How much *range of motion* does the client have in the joints of the upper arms or hands and fingers? What is the client's overall muscle *tone* and strength?

Once the PT has this information, the therapist can help the family and client set realistic goals and to answer some important questions. Will the client be able to return home? Return to a job or school? What skills or tasks will the client have to learn to achieve those goals?

Physical therapists also educate the client, family, and friends. Their goal is to help the client get back into the community to "live life" (see Chapter 5).

- ***Occupational Therapy (OT)***

The occupational therapist focuses on helping people care for themselves. By using technology and specially designed equipment, OT's can help people learn a number of important self-care skills. These skills include bathing, dressing, eating, grooming, and toileting. They can also help a person learn how to do daily tasks such as cooking, shopping, housecleaning and laundry, and paying bills and managing a checkbook. They will also help a client do things he or she enjoys, such as reading or other hobbies (see Chapter 6).

*Assistive technology* can help a person return to work, school or to engage in leisure activities or daily life tasks. The technology varies from low technology to high technology and is geared to meet the individual's needs. Various forms of low-tech aids can include adaptive writing aids, feeding aids, and adaptive dressing or bathing aids. High-tech aids can include voice-activated speaker phones or computers (see Resources section).

- ***Speech and Cognitive Therapy***

A *speech therapist* assesses a client's communication skills. How well does the person listen, speak, read, and write? The therapist also looks at cognition skills—thinking, memory, and problem solving. An assessment identifies a client's strengths and weaknesses and includes a treatment program that uses a person's strengths and that decreases the impact of weaknesses.

Some persons with SCI need special training to swallow and they need breathe support. The speech therapist will work with the client and other team members on a plan for continuous treatment and monitoring. Patients on *ventilators* are taught breath support to assist in ventilator *weaning*.

Sometimes a SCI means the nerve and throat muscles have been damaged or no longer work properly. Using modified barium video swallow tests, the speech therapist and the radiologist can assess a person's ability to swallow safely. They can also teach a client safe-swallowing skills.

- ***Psychology Services and Psychological Adjustment***

A big part of any rehab program is helping people address the psychological and emotional changes and adjustment that injury brings. Social workers, rehab counselors, or psychologists can provide counseling to the client, family, and significant others. These professionals help with understanding the impact of a catastrophic injury. They also address the importance of the following treatment plans, emotional problems, and behavioral adjustments. This counseling may be with the individual, family, or group setting.

- ***Pulmonary Therapy***

The respiratory therapist addresses the client's pulmonary needs. They care for clients on ventilators and help wean clients from the ventilator. They provide treatment and information on proper airway care, cough and secretion clearance, and infection precautions. They also teach safety in pulmonary management to the client and family. Those who require long-term ventilator care get a home-teaching program.

- ***Nutritionist***

A nutritionist evaluates a person's special dietary needs or restrictions. The dietitian looks at calories, protein and fluid intake, and helps determine the proper consistencies of food and fluid needs. He or she works with other team members to develop strategies that help the person eat well and safely.

## **Types of Rehabilitation Settings and Levels of Care**

Rehabilitation may take place in a variety of settings and at different levels of care. Someone new to rehabilitation may find these many options confusing. However, your physician, social worker, or case manager will help you understand your choices so you can make an informed and proper decision about your care.

Listed below are broad descriptions of levels of care and settings in which rehabilitation can take place. Look at them as a continuum of available care that you may, or may not, need during your entire length of treatment. The descriptions are brief and only meant to be a starting point as you consider your options.

- ***Acute Inpatient Rehabilitation***

Acute inpatient rehabilitation can be provided in a rehabilitation unit within a general hospital or in a free-standing rehabilitation hospital.

Traditionally, rehabilitation care has been provided in the acute rehabilitation setting and this remains the predominant choice. It offers the most intensive and comprehensive level of rehabilitation care and services. This type of facility is appropriate for any rehabilitation diagnosis, and it can manage multiple levels of complex medical and rehabilitation needs. It is the best for those catastrophically injured and disabled, and should provide staff experienced in spinal cord care. Oftentimes a special spinal cord unit is available.

Clients in this type of setting must be able to tolerate and need three hours or more of therapy a day. They must need a wide range of therapy services, have a reasonable expectation of *functional* improvement, and have an anticipated discharge to home or an assisted living setting.

Overall, an acute setting provides the most comprehensive and specialized approach to spinal cord injury rehabilitation care. The goal is to maximize physical function and independence to the highest level possible.

Sub-acute care is an interim stage of care that is less than a full rehabilitation program, but has a higher level of skilled interventions than a skilled nursing home unit. Some nursing homes offer this level of care to more medically and functionally involved persons who are not appropriate for acute hospital care.

- ***Skilled***

A skilled level of care is an additional level available for those clients who cannot qualify for, do not need, or are not yet ready to tolerate the intensity of services provided in an acute rehabilitation facility. A skilled setting is used as a step-down level for therapy services and where functional progress is expected, but perhaps at a slower level.

The skilled facility differs from an acute rehabilitation level in several ways:

- ◆ Providing a less intensive level of services for less cost.
- ◆ Providing rehabilitation services, but generally less than three hours a day.
- ◆ Providing wound care, dressing changes, and initial oxygen therapy and suctioning.
- ◆ It provides opportunity for family education.
- ◆ Providing ongoing medical management.
- ◆ Evaluating and managing an overall plan of care.
- ◆ The client must have had a three-day, acute stay in a general hospital.

The client must have had a three-day acute care hospital stay to qualify for a skilled admission. A discharge to home or assisted living is not required.

- ***Long-Term Acute Hospital***

A recent addition to a rehabilitation setting is the long-term acute level. This is a specialty hospital

for the person with medically complex needs that require a high level of medical care, physician monitoring, and support services. This setting is often used as a continuation of a general hospital stay. Rehabilitation needs, if any, are often low. This level can be used as a step toward an acute rehabilitation setting, if the client progresses to the point where he or she can participate in therapy.

Clients who are catastrophically-injured, but who are medically stable, or clients who are on ventilators, may be best served in an acute rehabilitation hospital setting. This is especially true if rehabilitation, not medical treatment, is the primary need. The overall length of stay must be at least 25 days.

- ***Day Treatment or Day Program***

Day treatment is an outpatient program that extends the services in an acute rehabilitation hospital. Day treatment differs from an acute inpatient rehabilitation setting only in that 24-hour nursing coverage is not required, and clients go home in the evenings and on weekends.

Day treatment offers several advantages. It provides three or more hours of therapy. The client receives meals, rest times, medical supervision, and a specialized program for SCI. Day treatment is also cost effective.

At this level, re-integration into the community can be maximized, and overnight stays can be provided in special circumstances.

Day Treatment may be preferred for catastrophically-injured clients who need staff expertise in SCI care, a specialized program approach, and intensive community re-entry.

- ***Transitional Care***

Outpatient transitional care is for clients who are not quite ready to go home after their general hospital, acute rehabilitation, or skilled level of care stay. Overnight stays are possible. Therapy most often is less intensive and focuses on general therapy needs.

- ***Outpatient***

Outpatient services may be offered in a general hospital, acute rehabilitation hospital, long-term acute hospital, or clinic setting. Therapy is offered for several days, up to five days a week, for several hours a day as part of the facility's continuum of care.

- ***Home Health***

Rehabilitation services may be provided in the home for clients who cannot leave to receive services except for a physician visit. Home health visits require a physician order and may include nursing, therapy, social service, and personal and home care services. These services may be provided by independent home health agencies or as part of a community-based, general hospital or acute rehabilitation facility.

## How Do You Qualify for Rehabilitation?

Many factors affect how a client qualifies for a particular level of rehabilitation care, as well as the type of settings where care is given. Your physician, social worker, or case manager will help you understand the guidelines used by your insurance company and by various facilities, so that you can make the most informed and appropriate choice for your situation.

All the factors listed below will influence the type of setting and rehabilitation level of care you need:

- ***Insurance Coverage***

You can be covered by a private insurance company or by *Medicare* or *Medicaid*. Each of these plans set limits on the amount of money they will pay for medical care and rehabilitation. What level of care you can receive and for how long is set by the agency that will cover your costs. Your social worker can help you understand what your program covers.

- ***Physical Ability***

The coverage agency—whether run by a private insurance company or by the government—will look at your physical progress. The agency will assess how well you can participate in your care and how much and what level of therapy your body can tolerate. The agency also wants to know what kind of progress you are making. Answers to these questions will help the agency that pays the bills decide for which setting it will pay and for how long. So, your ability to make progress during rehabilitation will greatly affect the type of services you will receive.

- ***Facility Requirements***

Many facilities set their own guidelines for whom they will serve.

- ***Level of Care***

Where you can receive care and for how long also will depend on the level and type of care you need. One setting may be better able than another to meet your level of need.

- ***Length of Stay***

This is a term that means how long you will, or have stayed in a hospital environment (in terms of number of days). The National Center on Model SCI Statistics keeps records on patient's length of stay. These are very important to the primary care payor, who will reimburse the hospital for medical expenses.

- ***Your Resources***

This can mean a variety of things. Most obvious is finances, which includes money on hand, as well as medical and health insurance. In addition, resources can include things that you cannot place a price on, including emotional and personal support from family members, the clergy, and friends.

- ***Your Final Destination***

Where you plan to live after you have finished your rehabilitation also affects decisions about where you will receive care. For example, people returning to their own homes may receive a different level of therapy in a different setting than people who will be permanently moved to a nursing home.

## **Life Care Planning**

A plan for your future care is called a life care plan. Attorneys and insurance companies often ask for a client's life care plan. Most often a patient or the family does not have a life care plan.

This plan estimates future expenses for the person's care. It is based on the patient's past history, including pre-injury medical problems, and on the reasoned estimate of professionals trained in making such assessments. These professionals may include physicians, nurses, therapists, or other health-care professionals.

A life care plan anticipates, in today's dollars, a person's future medical needs and expenses of the patient, including day-to-day care and any equipment needs, as well as their replacement costs. Medical needs and expenses include not only doctor visits, but also any anticipated hospitalizations, surgery, medications, nursing care, and expenses for therapy related to the injury.

## **Tips on Choosing a Rehabilitation Facility**

- ***Level of Care***

Look at several facilities and gather information on each. What level of care is being offered—acute rehabilitation, sub-acute, or skilled? Is the facility approved to offer SCI care?

- ***Coverage Issues***

Does the facility have a contract with your insurance company or can it contract a case-by-case basis with your company? If you have Medicare, does the facility have a Medicare contract? If you have Medicaid (state aid), does the facility accept it? Are there any limits on length of stay? Will the facility review your policy and coverage with you?

- ***Program***

How many spinal cord clients does the facility see in a year? Is the staff experienced in treating all levels of spinal cord care? Is there a specialized, consistent, inter-disciplinary SCI team? A

specialized SCI unit? What is the general age group of the clients you would associate with? What are the average number of hours of therapy a day and what types are provided? What is the average length of stay for your level of injury? Is there a day or outpatient component?

Ask for a brief explanation of program goals, structure, and content. If a client becomes medically unstable, are they treated on site or off? Are there laboratory, pharmacy, and radiology services in house? Are there nurses and respiratory therapists present 24 hours a day? Does the facility take people on ventilators? Is there a physician on-site and for how many hours a day? How often does the physician make rounds? Are there sub-specialists available on staff if needed? Can you tour the facility and meet with the team prior to admission? Can a parent stay with a child in the room or family members with adults? What is the availability of on or off-campus housing? What affect will geographical distance have on the client and family? Are activities planned for after hours and on weekends?

- ***Program Structure/Services***

Who are the team members and what are their roles? Is there a medical director? Are there team and family conferences? How often? What is the nurse-to-patient ratio on the floor for each shift? Is the family and client considered part of the team? Is the family encouraged to visit and participate in planning? Is the majority of therapies individualized or in a group setting? Does the program have the following components:

- ◆ Education classes and manuals.
- ◆ Can families attend the program? What topics are included?
- ◆ Peer support group.
- ◆ Counseling. By whom?
- ◆ Community re-entry.
- ◆ Support group.
- ◆ Pain management.
- ◆ Assistive technology.
- ◆ Neuromuscular improvement program.
- ◆ Driving program.
- ◆ Urodynamic fertility and testing.
- ◆ Ventilator care and weaning.
- ◆ *Orthotics and prosthetics.*
- ◆ Seating system prescription.
- ◆ Sexuality counseling.
- ◆ Personal care assistant procurement and training.
- ◆ *Vocational rehabilitation.*
- ◆ *Recreational therapy.*
- ◆ Home visits with day or weekend pass available.
- ◆ Community re-entry program.

- ***Discharge Planning***

Are personalized self-care educational manuals given at discharge? Is there a formal discharge plan? Does it include the following?

- ◆ Contact the local physician and therapists who will continue rehabilitation for follow-up.
- ◆ Contact with local independent living center.
- ◆ Arrangements for evaluation of home for modification.
- ◆ Referral to local specialists, if needed.
- ◆ Referrals to other needed community resources.
- ◆ Regularly scheduled follow-up visits with rehab facility.
- ◆ Urologic evaluation.
- ◆ Seating system review.
- ◆ Laboratory and radiology testing.
- ◆ Thorough vocational rehab assessment and referral to vocational rehabilitation program.

## **Finances**

When reviewing your financial situation, look at your income and medical coverage. To assure your continued medical and rehabilitation care, and to provide yourself and your family with income assistance, you must clearly know what your income and coverage will be. SCI can damage your finances if you are not adequately prepared. Review these financial issues with your social worker or case manager. Follow their recommendations in a timely manner. Hard realities are tough to deal with, but they are necessary.

- ***Income Sources***

When you receive a disabling injury, you must look at two sources of income. Where will you find the income to meet your daily living expenses, and what agency or company will pay your medical expenses and your costs for ongoing care?

In Chapter 9, you will find good information about the income you might receive through Social Security, Medicare, and Medicaid. In that chapter, you will also learn how these programs can cover your medical and rehabilitation costs. In addition to these three common forms of support, you may be covered under some form of disability insurance. Short- and long-term disability comes from a private insurance company or through Workman's Compensation.

Most often people purchase short-term disability through their employers. Short-term disability supplements the income of those who are unable to work for a short period of time. It covers the

period between when the person has stopped working and when a long-term disability policy starts. Illness or injury is covered under short-term policies.

Employers often provide long-term disability coverage. These policies assure you income if through illness or injury you cannot work for a long period of time. If you have such a policy, find out if its coverage is or is not tied to Medicare coverage.



Your health insurance also may continue after your injury if the insurance premiums are paid. Check with your insurance company to find out about your medical coverage. You want to know about your *deductibles* and *co-pay*, the money you must contribute to your medical costs. When you speak with your insurance representative, be sure to give correct and complete information about your diagnosis, your medical and rehabilitation needs, and your life care plan. Find out what your insurance company will provide. Take notes during this conversation and be sure and write down the name and phone number of the person you spoke with.

If you were injured on the job, you will receive some income through the Workman's Compensation program. This program also provides medical coverage until you return to work or until you know your disability status.

Here are some things to remember:

- ◆ Make sure any organization that will provide services has checked your insurance benefits and knows your coverage. This will keep you from incurring large bills.
- ◆ Learn what other financial assistance is available through contacts with your social worker.
- ◆ Check your local community to see what organizations can help you (government offices/CILs).
- ◆ Contact your local *center for independent living* (see Chapter 11).
- ◆ Check your local vocational rehabilitation program. Vocational rehab provides many services to get a person back to work and school. Your city or state will have contact numbers (see your local phone directory).
- ◆ Your employer may also be of assistance. Some larger corporations set money aside for employees who incur hardship.
- ◆ If you are a veteran, you may have services available—contact your closest veterans hospital or Paralyzed Veterans Association (800) 424-8200.

**See Resources:**

- *Rehabilitation*
- *Benefits/Financial*

## **Chapter Four**

### **The Social Worker in the Rehabilitation Setting**

**Donovan Lee, LSCSW**  
**Kansas Rehabilitation Hospital, Topeka, KS**

This chapter will explore the role of a social worker in a rehabilitation setting. One of the highest traditional social work values is to maximize client self-determination. This information will help the consumer ask informed and focused questions about spinal cord injury (SCI) from admission to discharge and beyond.

Consumers can be their own greatest resource. Consumers have the following rights: to be treated with dignity and respect; to be given accurate and useful information about resources; to have their confidentiality protected; and to be encouraged to express their concerns and hopes. At the same time, consumers must take responsibility. They must participate in their rehabilitation to the fullest extent possible. They must read and ask questions about SCI and talk with their social worker and other members of the rehabilitation team to set treatment and discharge goals.

#### **Role of the Social Worker**

The social worker plays an important role in helping the consumer with a SCI and the family make a positive recovery and adjustment to life during and after rehabilitation. This information will help the consumer understand what questions to ask and what help is available during and after rehabilitation.

The social worker is part of the health care team. He or she makes certain the consumer receives adequate information about the rehabilitation process and about what resources and services are needed.

When consumers are admitted for rehabilitation, they and their families usually are just beginning to confront the possibility of a long-term disability. So the rehabilitation process needs to be goal directed, purposeful, and focused on ways to cope. The social worker will meet with the consumer and his or her family shortly after admission to determine strengths and concerns in the areas listed below:

1. Family, marital, and social relationships.
2. Money concerns.
3. Vocational and leisure needs.
4. Accessibility of the environment.
5. Discharge plans and options.
6. Drug and alcohol use.
7. Emotional reactions and coping.
8. Personal history.

In general, the social worker helps the consumer and family sort out these issues and find ways to manage them. The remainder of this chapter will go into more detail about these eight areas. The

reader can use the information as a guide to what types of questions a social worker can answer.

- ***Family, Marital, and Social Relationships***

The suddenness of a SCI can be disruptive, confusing, and frightening. The social worker helps the consumer and family cope with this crisis and other stresses. Everyone can talk open about the impact the SCI has had on all important relationships. A family conference is usually scheduled soon after admission. This meeting should include key family members and the rehabilitation team. The family will learn the consumer's medical status and the likely course of recovery. The information replaces fantasy and the unknown with reality. This is an important issue for the consumer because successful rehabilitation depends on remembering and understanding many new skills. At this time the social worker begins to help the consumer and family examine and perhaps redefine the role the consumer now plays in the family. These roles might include, but are not limited to, wage earner, parent, and sexual partner.

- ***Money Concerns***

As the consumer enters the rehabilitation phase, she or he usually has financial concerns. There may be uncertainty about health insurance, medical equipment and supplies, lost wages, and mounting bills. The social worker will go over different resource options with the consumer and family including those listed:

1. Social Security
2. Worker's Compensation
3. *Medicare*\*
4. *Medicaid*
5. Private health insurance policies
6. Disability Insurance Protection, offered on policies and some credit cards.
7. School Coverage Insurance, for injuries at school or during school activities or sports.
8. Credit Life and Health Policies, available on mortgages, credit cards, and auto loans.
9. Victims of Crime--if a person was injured during a criminal act. Check with your state's attorney general's office and inquire about a compensation program.

This is just a list to remind people what social workers can talk about.

- ***Vocational and Leisure Needs***

Early in rehabilitation, the social worker will talk to the consumer about referral to the Department of *Vocational Rehabilitation Services* (VR). A VR counselor screens the consumer and looks at the extent of disability, expected recovery, and the consumer's past vocational experience and future interests. Vocational Rehabilitation can also provide vocational testing and training. In addition, the VR counselor can also determine eligibility regarding funding for equipment including a wheelchair.

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

- ***Accessibility of the Environment***

Being able to move about the home and community is an important part of overall planning. Members of the rehabilitation team will visit the home to evaluate accessibility and to recommend solutions. The social worker can refer the consumer to contractors who can make changes at the consumer's home.

The social worker also has information about the American's With Disabilities Act (ADA). This act is designed to eliminate discrimination against persons with disabilities in the areas of employment, public accommodations, programs and activities, or state and local government including public school and public transportation, telecommunications, and public transportation. If needed, the social worker can also work with the consumer to find accessible and affordable housing. Ask the social worker about the nearest *center for independent living* (see Chapter 11). These agencies provide a wide range of services including independent living skills training, advocacy, peer counseling, and information and referral. The consumer may also want to inquire about a license plate or placard for people with disabilities so he or she can park in accessible parking spaces.

- ***Discharge Plans and Options***

It is important for the consumer and family to consider discharge needs soon after they become oriented to rehabilitation and can think about re-entry into the community. Through family conferences and education, his or her needs can be anticipated and the resources capable of meeting them can be identified. Likely, they will continue therapy after discharge and there will be medical follow-up. The social worker becomes the discharge planner who will make referrals to agencies such as outpatient clinics, home-health providers, and others as required. Some consumers have special discharge needs. For example, a consumer who is in school will need to meet with school officials to coordinate school re-entry.

Some SCIs include a blow to the head, which can cause mild brain injury. The consumer may not be aware of subtle changes in memory and thinking. It may be necessary for the family to share these concerns with the rehabilitation team and to ask about having the consumer evaluated by a *neuropsychologist*. This specialist can test for brain damage and help the consumer and the family learn how to deal with thinking and memory problems.

- ***Drug and Alcohol Use***

Several studies have shown there is a strong connection between the use of drugs and alcohol and SCI. A high percentage of SCI survivors were under chemical influences at the time of the injury. The social worker will assist the consumer and family in deciding if substance abuse treatment is needed. He or she will also provide the names of counselors and treatment programs.

- ***Emotional Reactions and Coping***

SCI is different than some other major life changes because it comes without planning. No previous experience compares to this injury, and there is usually a high sense of loss of control. The emotions surrounding this injury create feelings of powerlessness in the consumer and family. They

have little knowledge and are uncertain about how to deal with the health care system. Since SCIs usually occur with young adults, the injury happens at a time when the survivor is in the process of preparing to leave home or has been independent for only a short period. The injury can create physical, emotional, and financial needs that produce greater dependency on families and social services. The social worker can support the consumer and family's efforts to grapple with these needs. Counseling may be recommended to help the family see the difference between the consumer's initial physical dependence and intact mental and psychological skills. It is important that the family understand that while the consumer has lost some physical abilities, he or she still has other strengths and abilities that can help them compensate for what was lost.

- ***Personal History***

Part of the social worker's early *intervention* is to learn how the consumer dealt with life prior to the SCI. It is important for the rehabilitation team to know how the consumer coped with life stresses and how these skills can be used to deal with the SCI. A person's coping history may indicate the need for a mental health professional to deal with more serious emotional problems such as suicidal thoughts or mood disorders.

### **Working With Insurance Case Managers**

Over the years, commercial insurance companies have turned to a 'managed care' or 'case management' approach to help control costs and to assure the appropriate use of medical and rehabilitation interventions. It may not be long before government payers such as Medicaid, Medicare, and the Department of Veteran's Affairs also begin to use some form of managed care. If your health insurance company uses a case management approach, a case manager will be assigned to monitor progress, covered services, length of stay, and costs. It is likely the rehabilitation social worker will have made contact with this person to verify benefits for rehabilitation.

It is common for the rehabilitation facility to send the case manager a copy of the consumer's weekly team conference reports. These show the physical improvements and *discharge planning* activities. The case manager may attend team conferences, family conferences, discharge planning meetings, and even therapy sessions. If the case manager is not in the area, telephone conference calls can be used to include the manager in all of these important meetings. The consumer and family should feel free to ask the case manager questions about the following issues: length of time that inpatient and outpatient services will be covered; the coverages for equipment and nursing or *attendant care* in the home; transportation allowances; mental health services; and information about the appeal process if the consumer needs services beyond standard coverage. The Paralyzed

Veterans of America has a packet of educational materials available to anyone with a SCI. This packet includes the booklet, "A Guide to Managed Care." It is an excellent resource and can be obtained by calling the telephone number listed at the end of this chapter.

### **How to Find a Social Worker**

If the rehabilitation team does not include a social worker, someone will be assigned to cover many

of the same duties. This person may be called a discharge planner or case manager. These people will have similar skills as a social worker and can provide many of the same services. The consumer may request a social work consultation if there are specific needs not being met by the rehabilitation team. After leaving the rehabilitation setting, it is possible to locate a social worker near the consumer's home. Take the following steps to find a social worker:

1. Contact your local hospital and ask for the Social Work or Discharge Planning Department.
2. Use the telephone directory and look under Social Work or Rehabilitation Services.
3. Contact the nearest independent living resource center.
4. Call the area Community Mental Health Center.
5. Contact your state's social services office and ask for a chapter of the National Association of Social Workers. It can give you a list of local social workers.

When using any of these resources, be clear about the type of help you need so that the agencies can refer you to someone who best meets those needs free of charge.

**See Resources:**

- *Support/Self Help*
- *Advocacy*

## Chapter Five The Physical Therapist

Kenneth A. Gerhart, M.S., RPT

*Physical therapists*\* (PT) use their understanding of anatomy and physiology, physics, exercise principles, psychology, and health to treat people who have injuries, chronic problems, and pain. They help their customers regain lost strength, flexibility, stamina, and coordination. And, perhaps most important to you, PT's use their skills to help people with disabilities learn ways of adapting and compensating. These new ways will help them be as physically independent in their day-to-day lives as possible.

Physical therapists who treat people with spinal cord injuries (SCI) often have different skills, philosophies, and experiences than physical therapists who treat people with problems like back pain, knee injuries, and shoulder strains. All have graduated from an accredited college or university program and have about the same education and medical training. But the skills they have developed since leaving college are those that matter most to you as a *spinal cord injury* survivor. In fact, while most PTs focus on making people's problems go away, physical therapists that work with SCI survivors typically must help their clients cope with, adjust to, and compensate for disabilities that may never go away.

While PTs are pretty easy to find, PTs who understand spinal cord injury are a little harder to come by. This chapter will provide you with the information you need to find the right physical therapist for you.

### Rehabilitation

Almost all people with new, severe spinal cord injuries will need to and want to go to a rehab program where they will need several weeks, perhaps even several months, of in-patient care. Here a team of professionals will teach you the skills you need to care for yourself, move about, and return to your old life with as much independence, confidence, and enjoyment as possible.

A PT is an important member of this team. Different teams in different rehabilitation hospitals may define the professionals' roles differently. For example, between PTs and *occupational therapists*, in particular, there can be much overlap (see Chapter 5). This overlap is not a problem, and it almost always benefits you. The more these professionals overlap, the better they can work together and complement one another. What's important is that they work with you toward the same larger goals: those goals are your goals. More information about rehabilitation programs and about how to find the right program can be found in Chapter 3. This chapter specifically looks at physical therapy and physical therapists, and at a PT's role in a more general sense. The information here will be

especially useful if you need to go "shopping" for a PT for outpatient therapy, for training in your

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

home, or in a rural area that does not offer a comprehensive team rehab program.

## **The PT of Your Dreams**

If a spinal cord injury physical therapist had to be described in just one sentence, it would be: “A PT is someone who helps you figure out how to get from point A to point B quickly, safely, efficiently, and happily.” Let’s take this definition apart.

First, getting from point A to point B means a lot of things. Basically, it refers to all the different skills and activities your PT should be able to teach you or help you master. It could mean getting from a lying down position to sitting up or from sitting to standing. It can be going from the bottom of the stairs to the top or into and out of a car. It can be getting across a room, or a lawn, or a college campus, or even from your house to the airport and onto an airplane. It could also mean going from being discouraged and overwhelmed (point A), to being satisfied, confident, and ready to move on with life (point B).

Because spinal cord injury often means muscle weakness or paralysis, a wheelchair is a likely part of the picture. Teaching you how to get around using a wheelchair and how to get in and out of that wheelchair should be a big part of the therapist's job. Moreover, a really good PT can "put it all together." If your physical therapist knows and understands what it is you need to do, he or she should be able to teach you how to get from point A to point B and every place in between. For example, a good PT can teach you how to get from a wheelchair (point A) into bed (point B). A really good PT will know that "getting into bed" means you probably also want to go to sleep. The PT will anticipate all of the other pieces: getting undressed, preparing your bladder management system, pulling up the covers, setting up a telephone you can use from the bed, and even turning off the light. Hopefully, he or she will know how to work with other team members like occupational therapists and rehabilitation nurses to teach you all these things. If you're in a setting where these other professionals are not available, the PT alone will be able to help you problem-solve these things.

Spinal cord injury often means wheelchairs and other types of equipment will be involved, so “quick,” “safe,” and “efficient” enter the picture. For example, a loss of sensation is part of a spinal cord injury so, your PT needs to teach you to care for your skin, avoid potential problems, and use equipment like cushions, padding, and specialized beds to protect that skin. Your PT will need to know which type of wheelchair (lightweight, wide, tall, power-driven, or reclining) is best for your needs. The PT will work with other team members, or independently if there is no team, to get your chair and teach you to use it.

Quick, safe, and efficient also implies that your PT is realistic. If your muscles are weak and you're likely to fall while trying to get into your wheelchair, your PT needs another plan. It may take you too long to complete a task or you won't be able to give your skin the relief it needs. Your PT should not only tell you, but should be ready with a fall back plan. Of course, quick, safe, and efficient also has to do with all those little things such as turning out the lights and pulling up blankets. These movements are easy to forget, but important to know.

Finally, we get to the "happily" part of that first statement. "Happy" sounds a little too simple, but



it's there to remind you of an important characteristic you need in a PT: he or she needs to be committed to helping you meet your agenda, not his or hers. The PT of your dreams needs to realize that your agenda always means accomplishing a specific skill or addressing a specific need in a way that makes you happy. His or her goals should match yours. If your PT is determined to teach you how to get across the college campus, but your goal is to figure out a way to go fishing, then the "happily" is missing: Find a new PT!

### **Here Are Some Key Characteristics to Look for in a PT:**

- ***A PT who works with spinal cord injured people should be practical.***

Many people with spinal cord injuries have spent weeks, months, or even longer in physical therapy gyms where they strengthen muscles, stretch, and "work out." This may all be worthwhile, but all the strength in the world doesn't count for much if you can't use it in some way. Think of the child who wants to learn to play baseball. Does he stretch his shoulders, lift weights for his arms, and do leg exercises for the entire season? Or does he get in there and start to throw, bat, and run? You need both the exercise and the practice, but you need more of the practice, especially if you're trying to become more independent. Make sure you know what skills you want to learn, so that with every PT session you can see yourself getting closer to reaching those goals. Ask yourself and your therapist: "How does all this fit with my goal?" "How long should it take me to get there?"

- ***Your PT should have lots of experience specifically with spinal cord injury survivors.***

The PT's experience should be with people with all levels of injury and with varying degrees of paralysis or weakness, both *paraplegia* and *quadriplegia*. That experience should also be with people in all stages of their rehabilitation. Perhaps the most important type of experience PTs need, however, is with spinal cord injury survivors who have been injured many years. These people have creative solutions and clever tricks to deal with their own needs, and they're able to give therapists a sense of what works in the real world. It is their experiences that give answers to questions like "How do I turn off the light after I've gotten myself into bed?" "How do I push my wheelchair when it's icy?" "How will I carry my books to class if I need to have both of my hands on crutches?"

These longer-injured people also help therapists get good at "envisioning" the future. From them, PTs learn to anticipate the long-term results of decisions and choices you make, and to take steps to prevent potential or future problems as well. For example, they learn to ask questions: Will changing the location of the axle on your wheelchair now decrease the odds of future shoulder pain? Will altering the way you transfer out of your bed lessen your chances of wrist pain ten years from now?

Here are some questions to ask your potential PT: How many people with spinal cord injuries do you work with over the course of a year? How long have they been injured? What happens to them after they leave you?

- ***You and your PT should know how machines and equipment fit into the big picture.***

High-tech exercise equipment, electrical stimulators, massage tables, machines that are used for various heat and cold treatments, whirlpools, and other types of equipment are often found in PT clinics. Should you be impressed by their number, size, expense, or newness? Not really. These machines can be useful if you have a specific injury that needs to be treated, such as a sprained shoulder, an injured elbow, or an aching neck. But as aids to becoming and staying independent, learning new skills, or adapting to and compensating for your disability, they're probably not so useful.

More often the equipment to practice the skills you need can be found in the real world: beds, bathtubs, kitchens, car seats, airplane aisles, stairs, ramps, escalators. It's all the things you encounter day-to-day that create the obstacles and barriers between you and "point B." You'll find real-world things to practice with in good rehab hospitals. You probably won't find them in the typical free-standing PT clinic, but you should find a willingness in your potential PT to seek them out. Will he go to your home? Your workplace? Will she run across the street to the restaurant to help you practice getting into a restroom or into a booth? Is he willing to borrow a friend's pick-up truck to help you learn how to get in? Will she track down a shopping mall that will let you sneak in and practice riding escalators with her? Ask your PT: What treatment areas will you use for me?

- ***Your perfect PT should have a good working knowledge of the equipment that spinal cord injury survivors do rely on.***

He or she should be well-versed in the devices and tools that will help you. These can include low-tech transfer boards, cushions, and modified footrests, and high-tech power wheelchairs, environmental control systems, and specialized *orthotics*. These will help make your *activities of daily living* easier. Your PT may not deal with these things on a daily basis but your PT should know where to go to find out more about them, how to obtain ones for you to try out, and where to purchase them. Ask: What resources do you have for evaluating and ordering specialized equipment for me?

Finally, your PT should listen to what you need and see you as a whole person. He or she should acknowledge that you have a partner, a parent, or a friend in your life and this person also wants to be included in your treatment plan. Your PT should teach these people what you are learning.

Your PT also should accept that you have a mind of your own and should respect the things that you value. Your PT should not let his or her ego override your wishes. This is important. Suppose you were hurt a few years ago, and you've decided that pushing a manual chair hurts your shoulders. It slows you down. You're always late, and you're tired all the time. Even though you can push your own chair, you've decided you would like a power wheelchair, so you can make it around your college campus or to your job quickly, safely and efficiently. Moreover, you can pay for this new chair.

Your therapist tells you, "Sorry, but what you really need is to strengthen your muscles, build your endurance, and get motivated." When you get a comment like this, you need to know you can trust your therapist's judgment. You need to know when your PT is telling it like it is, and when his or her own ego is in the way. Is your PT afraid that switching to an "easier" chair will make him or her look less skilled as a therapist than those who get their people to push chairs that are more difficult? Will it challenge her belief that less equipment is always better? Will he or she be threatened by a client who "calls the shots?" There really isn't a specific question to ask here. Instead, try to get a gut feeling about your potential PT. Does she seem like someone you can talk to easily? Do you think he could treat you like an equal partner in your care?

### **Back to Reality**

Guess what? There's no such thing as the Perfect PT, just like there's no such thing as the Perfect Spinal Cord Injured Person! So then, which professional characteristics are vital and which can you let slide? Here's some advice:

- If you can't find a PT with specific spinal cord injury experience, find one who has worked extensively with people who have had these types of *neurological* problems: strokes, developmental disabilities, or head trauma. PTs with this experience tend to focus more on teaching than on healing or curing.
- A PT with creativity and flexibility is more important than one with a shiny new clinic and lots of high-tech machines.
- Often, PTs who have worked with clients in their homes and communities and who have helped them find practical solutions to every day problems will have skills to apply to your needs.
- A PT who is willing to listen to you and who is interested in your insights and experiences will be better able to meet you halfway. He or she will problem-solve with you more than someone who already has all of the answers.

Obviously you can't always get everything you want. If you're an inpatient in a rehabilitation hospital, or even an outpatient, you may have little say regarding which PT is assigned to you. Few, if any, hospitals will encourage you to "test drive" all of their PTs. That's not the most efficient, effective, and fair way for them to deliver, and for you to receive, rehabilitation services. However, know that you do have options. If you truly don't think you're getting what you need, talk to your therapist. If that doesn't work, talk to his or her supervisor. Be specific about your own goals and needs; focusing on personalities is not likely to get you far.

If you are shopping for a PT in your community, call several and ask if you can stop by some time for a 15-minute tour. As you're being shown around, try to ask some of the questions mentioned earlier. Compare different therapists with respect to experience, philosophy, and how well you seem to connect. Pick the one that seems like the best fit.

## **The Perfect Patient**

Everything said so far puts all of the responsibility on the PT. However, as in love and marriage, it takes two to make a relationship work. The reality is, it's you, the spinal cord injury survivor, who has most to lose if the relationship is not a good one. So it's fitting to end with a few thoughts on what makes you the perfect client.

- ***Do your homework.***

If your injury is new, send family members on a fact-finding mission. Have them find out where others in your area go for rehabilitation and other services. They can check with other spinal cord injury survivors and their families and other health care professionals, or they can check with some of the national information centers like spinal cord injury "hotlines," various Internet sites, or the National Spinal Cord Injury Association.

If you've been injured longer, find out how other survivors have tackled problems similar to the ones you're facing. Ask them about therapists they've worked with or have heard good things about. Ask who they know who is skilled in the area that you're interested in or needing help with. Ask who they think would be a good "fit" for you.

- ***Know what you want and accept responsibility.***

Present your PT with specific goals you want to accomplish; don't leave it to him or her to tell you what you need. Give your therapist information, even if it's not asked for. Don't think it's his or her job to know everything, and don't assume he or she remembers everything. The truth is that it doesn't really matter whether you're right and the therapist is wrong. Because in the end, it is you and you alone who reaps the benefits and suffers the consequences of anything that happens during your therapy.

- ***If your therapist offers you choices, take them.***

Don't assume the professional always knows best; don't defer decisions back to the therapist. It's your life. People who don't make choices soon find that they aren't offered any to make.

- ***Be assertive.***

State your wants and needs. The squeaky wheel really does get the oil!

- ***Be realistic.***

Work on what's possible; save the impossible for tomorrow. Therapists can only work with the muscles, functions, and abilities you have. The most tremendous PT in the whole world cannot cure a spinal cord injury.

- *Be yourself; be open with your therapist; and let him or her really get to know you.*

You probably have a lot to offer. Those "old timers" who teach so much to their PTs all started where you are now. Don't sell yourself short!

### **Parting Thoughts**

If you're in the market for a physical therapist, try using some of these ideas to find the right PT for you. Once you've found the PT of your dreams, re-evaluate your relationship with him or her regularly to make sure you're getting what you really need. Most important, don't underestimate your own role and responsibilities in that relationship. It takes two to make a relationship work!

### **See Resources:**

- *Rehabilitation*
- *Spinal Cord Injury & Disability Information*
- *Spinal Cord Injury Foundations/Organizations*

## Chapter Six

### What is Occupational Therapy? How Will it Help Me?

Lorie Richards  
Allied Health, Occupational Therapy Education  
University of Kansas Medical Center

Human beings are doers. Everyday people do many activities: those that are necessary, such as eating, to those that are fun, such as sports and hobbies. When you have a *spinal cord injury*\* (SCI), you suddenly find yourself unable to do what you used to. Your *occupational therapist* (OT) will help you identify those activities that will help you learn new ways of doing those things you now find hard to do.

The OT is the member of the rehab team who determines how your spinal cord injury is affecting your ability to accomplish what you need and want to do in your life. The OT will look at everything that makes you unique, and will try to help you continue to have a meaningful life, one in which you see yourself as successful in your activities. The OT will do this by understanding what is important to you and helping you figure out a way to keep those things in your life by working around the barriers resulting from your spinal cord injury.

#### Where and When Would I Expect to Receive Occupational Therapy?

You will probably meet an OT early in your recovery from spinal cord injury, probably while you are still in the Intensive Care Unit. You will also work with OTs during inpatient and outpatient *rehabilitation* or as part of home healthcare. You may even work with an OT many years after your spinal cord injury. Whenever you are faced with an activity that you need or want to do, but are unable to accomplish because of SCI, an OT can help you find a way.

#### What Kinds of Things Will the Occupational Therapist Want to Know About Me?

The OT wants to help you get back to your life, so he or she wants to understand what you do and what is important to you. The therapist wants to know how you and your family did things before your injury and how all of you are managing now. The table below gives you some examples of the questions that the OT may ask you and your family members:

- How did you take care of your personal needs such as bathing, feeding yourself and getting dressed?
- Do you prefer to take a shower, a tub bath, or a sponge bath?
- Do you prefer pull-over or button-down shirts?
- How do you prefer to spend your days?

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

- Did you work before your injury? Do you plan to return to work?
- Did you go to school? Do you plan to return to school?
- Did you do housework? Do you plan to resume housework?
- What did you do for fun or leisure? Do you plan to resume these activities?
- How did you get from place to place?
- Do you plan to resume these modes of transportation?
- What were your family relationships and friendships like? Have there been changes since your injury?
- Are you satisfied with how these relations are going now?
- How have you met your needs for romance, intimacy, and sexual needs since your injury?
- Do you find that your social support system is helping you get things done?

Depending upon where you are in your recovery from your spinal cord injury, you may not have thought about the answers to all of these questions. Just remember that your OT will be ready to discuss these activities and relationships with you and to help you discover ways to accomplish and work on these when you are ready.

Your emotions affect your ability to do the things you want and need to do. The OT will want to know how you feel about your spinal cord injury and your abilities to accomplish tasks you want and need to do. The OT understands that you have family and friends who may also be affected by your injury. The injury may have changed your relationships with them, at least temporarily. So, the occupational therapist will also want to know how you, your family, and your friends are coping with your injury. The OT wants to help you, your family, and friends adapt to your spinal cord injury so that all of you can get on with the task of living a satisfying life.

Lastly, the OT will want to know how the injury has affected your ability to accomplish the activities you want and need to do. She may ask you to do a task, so she can assess if your strength or your ability to feel sensation, such as touch and temperature, interfere with your doing the task. He may measure how much your joints move or how strong your muscles are. She will want to know this information so that you, your family and she can design *interventions* that will help you return to your activities.

### **What Will Occupational Therapy Look Like?**

The things you do with the OT will be different depending on when in your recovery you see your therapist. At first, you'll not be allowed to move much. So, the OT will spend most of the time determining what activities you want to work on. The OT will move your arms and legs to keep your joints mobile. You may be given splints, which are devices like removable casts, to keep your joints in a good position. The OT also will teach your family how to keep your joints mobile. You may begin to work on those activities you can do while in bed without further damage to your spinal cord. The OT will also provide you with information about spinal cord injury and explore what your injury may mean in your future.

As soon as your physician says it is safe for you to move about in bed and to sit up, the OT will begin working with you on your desired activities. Some activities often worked on first are basic

self-care activities such as feeding yourself and washing or dressing. However, you may have other activities that are more important to you and your family. **Be sure to discuss your priorities with your OT.**

Occupational therapists will help you accomplish your desired activities in several ways. She or he will have you engage in your activities again, because performing your everyday activities will strengthen your muscles. The stronger the muscles you can control, the easier it will be for you to perform the activities you want and need to do.

You will need to learn new ways of doing some things. For example, you may dress in bed rather than stand or sit as you did before. The OT will explore possible techniques and strategies for accomplishing your desired activities. She will teach you techniques and will coach you as you practice them. Learning new ways of doing activities takes lots of practice. Because the occupational therapist will not always be able to be there each time you practice, he will teach the nursing staff and your family how to assist you during practice.

Many of the activities you will be learning to complete in new ways you once did quickly, easily, and with little thought. Learning new ways to perform these activities may be frustrating. You may be frustrated with how difficult things are and how long it takes to complete even one step in these activities. You may be angry that you have to learn new ways to do things at all. We all feel frustrated when we are faced with changes and challenges we did not expect. These feelings are normal and need to be expressed and acknowledged. Talk to your OT about them. She will help you work through those feelings so you can create a meaningful life.

While you are learning new techniques for your activities, the OT will have you try assistive devices. *Assistive technology* is just a fancy name for tools that help you accomplish a task. People use such tools everyday. Before your spinal cord injury, you probably used an electric can opener. Your OT will show you special tools that may help you. These range from simple, inexpensive tools, such as loops at the tops of your pants that let you pull them up, to sophisticated, expensive tools, such as computers with special switches that will enable you to turn on lights and answer the phone. The OT will let you explore many of these assistive devices and practice with those that interest you. Again, learning how to use an assistive device is learning a new skill, and learning takes lots of practice.

The OT will teach you how to use the tool and will coach you while you practice with it. But he cannot be with you every time you practice, so he will teach your nurses and family how to coach you during practice. Some of the more sophisticated assistive devices need the expertise of specialists with advanced knowledge about their particular tools. If you want to explore more sophisticated tools, the occupational therapist will arrange meetings with these vendors and will help you select tools that match your needs and abilities. If you have a problem with a device, talk to your OT. She will be able to help you solve the problem.



You and your OT will not have time to work on every activity you want to resume after your injury. Also, new situations will arise that may pose barriers to your performing activities that are important to you. So, in addition to helping you discover how to perform some of activities you want to do, your OT will teach you strategies for performing activities that you can apply to new situations.

The OT will help you plan how you will live in the community. She will help you plan modifications to your home to make it more accessible. If modifications are impossible, she will help you identify the characteristics you need in a new home. Together, you and your therapist will plan how you will grocery shop, do laundry, houseclean, or take out the garbage. Sometimes, you will perform these activities using the techniques you learned and the assistive devices you selected during your inpatient rehabilitation. Often the chance to try some of these activities will not arise until you leave the medical center. So, you may continue to work with a therapist in your home and community to learn new ways to perform more of these community activities and to explore other *assistive technology* devices to help you. (See Resources section)

At times, you may be unable to perform certain activities or you may decide you want to use your energy and time on other things. You also may decide to hire a personnel assistant. Hiring a personnel assistant means you are now an employer, and you will supervise this person in the accomplishment of some very personal tasks. The OT can help you plan how to hire and supervise someone. The OT can help you identify the characteristics of the person you would want working for you, how to give good instructions, and how to fire someone who does not meet your needs.

When you are ready to return to work, you may again work with an occupational therapist. Your OT can help you complete a detailed analysis of the tasks required in your job and help you match the job requirements and your abilities. He can work with your employer to help her make the accommodations that will enable you to return to work. This may involve some simple modifications of your workspace so that it is accessible. It may involve the purchase of equipment to assist you in performing your tasks. It may involve the occupational therapist working with you on the job, as a job coach, for a short period of time. The OT may also help you negotiate some different job tasks that better match your current skills.

Your OT should also help you learn how to be your own *advocate*. He will help you learn how to effectively tell others your needs. She can often recommend community resources that you can use to help you meet your needs. Your OT should also help you learn about your rights and responsibilities according to the Americans with Disabilities Act.

### **How Do I Find Occupational Therapy Services if I Have Been Out of the Rehabilitation Loop?**

If you are currently under the care of a physician, you may contact him or her, explain your need, and request a referral to an OT.

Occupational therapists work in a variety of settings: hospitals, rehabilitation centers, outpatient clinics, and home health agencies. Depending on your specific need, a therapist from any one or several of these settings may be able to assist you. Home health therapists typically see people in

their homes and would be able to help you adapt your home for easier living and to perform those home activities that are important to you. If you require an adjustment or a splint or other assistive device, a visit to an OT in a rehabilitation unit or outpatient clinic might be most helpful.

It is important for you to understand how your insurance plan covers occupational therapy services and what services it pays for. Each plan is different, and some restrictions may apply. Insurance plans may restrict access to occupational therapy in some cases or limit the amount of therapy. Some plans also restrict the kinds of assistive devices they will pay for. Therapists will work within the plan's restrictions. They also may talk to the insurance company about your needs and negotiate for additional services. If payment is denied, the therapist may be able to help you find alternative payment sources or suggest other solutions. You can also choose to pay for the therapy services and assistive devices on your own.

Another avenue for finding an OT is through a *center for independent living* (see Chapter 11). These agencies have been established to assist persons with disabilities live quality lives in the community. They will either employ OTs directly or can refer you to one. Centers for independent living are typically found in urban rather than rural areas. Because there usually are few centers for independent living in a geographic area, they typically do not have their own listing in the yellow pages of your phone book. You may find them listed under Social Services and Welfare Organizations, Disability Services, Consumer Support Groups, or Self-Help Groups, or on the Internet under "Independent Living Centers."

If you have activities you need and want to do, but are unable to do because of your spinal cord injury, you may also be eligible to receive assistance from a *vocational rehabilitation* counselor at the Office of Vocational Rehabilitation. Counselors help people establish a quality life and return to work. The vocational rehabilitation counselor can also refer you to an occupational therapist. Each state has an Office of Vocational Rehabilitation and often regional offices. Their telephone numbers can be found in the white or blue pages under state government offices.

A final way to find some help is through a college or university in your area that offers a degree in occupational therapy. These programs are often looking for people with disabilities who are willing to volunteer to have students work with them.

### **How Can I Tell if I Am Receiving Good Occupational Therapy Services?**

You are the only one who understands the importance of the activities for your life. Thus, you will be the one who makes the ultimate decision about the activities you will work on. **A good OT values your priorities and can explain the steps necessary for you to meet your goals.**

For this reason, a good OT will listen to you. She will make suggestions and bring up the issues you should think about regarding your plans. However, she will accept your decisions about the kinds of activities and the kinds of health care practices you will perform. She will also accept your decisions about how you will accomplish the activities you need and want to accomplish. A good therapist is one who works with you on your priorities. She is not just giving you exercises for your muscles or splints for your arms or legs. **You should be spending time with your OT discussing how to perform activities and perhaps practicing those activities with the therapist coaching**

**you.**

It is important to realize, however, that the OT does not know everything. A good OT knows that. If a situation arises that the OT does not feel qualified to address, she or he will refer you to other professionals who can better meet your needs in a particular area.

If you are dissatisfied with the OT services you are receiving, the best thing you can do is to share your concerns with your therapist. If you still are dissatisfied, talk to a supervisor or agency. You may also end your services with that provider and ask your physician for a referral to another therapy provider. But, before switching to another occupational therapy provider, check with your case manager or insurance company. Many insurance companies limit your choices of service providers. If you live in an urban area, chances are you will have many OTs to choose from. If you live in a rural area, your choices will be more limited as there are typically fewer therapists in rural areas.

Several regulatory boards make sure that occupational therapists provide ethical practice within the practice laws of the states and the country. If you think that your occupational therapist has acted unethically or illegally, you should contact the regulatory board in your state. You can find your state's regulatory board by calling the state's occupational therapy association.

**See Resources:**

- *Rehabilitation*
- *Spinal Cord Injury & Disability Information*
- *Spinal Cord Injury Foundations/Organizations*

## Chapter Seven

### Recreational Therapy

James P. Verbout, C.T.R.S., Lead Therapist  
Mayo Medical Center, Rochester, MN

Recreational therapy is a key part of the *rehabilitation*\* of those with a spinal cord injury (SCI). This therapy helps restore or improve function and independence and can help reduce or eliminate the effects of illness or disability. The primary purpose of recreation services is to use recreation as a way to improve overall health and well being. Professionals trained in recreational therapy are part of the multi-disciplinary team that works with people with SCI.

In the rehabilitation unit, the recreational therapist may:

- Provide daily treatment.
- Conduct an assessment to determine the person's recreational interests, lifestyle, family support system, as well as his or her social and emotional needs, and mental and physical abilities.
- Devise a treatment plan in cooperation with the person with SCI.
- Identify goals specific to the person's recreational interests and to his or her current abilities.
- Document weekly progress as well as monitor the daily changes that may occur and shape that information with the patient, family, and members of the rehab team.
- Communicate the person's progress in required care conferences.
- Provide additional resources and equipment when the person returns home.

Within the private or group therapy sessions, the therapist will expose the injured person to a variety of experiences. These may include the following activities or equipment:

- Adaptive recreation techniques that develop new interests or renew past interests.
- Practice of these new techniques to improve or become familiar with new skills.
- Small and large group activities that use newly learned wheelchair skills and *functional* ability, and that include social interaction with peers.
- Adaptive sports equipment.
- *Assistive technology* that may include computers.
- Ways to constructively use time after discharge from rehabilitation.
- Resources for help in using newly learned rehabilitation skills.
- Activity list for things to do at home and in the community.
- Follow-up visits with current recreational therapist or a referral to a therapist closer to home.
- Help to practice learned skills in the community and discussions about safety issues, architectural barriers, public attitudes, use of adaptive equipment, assertiveness training, and adjustment to disability issues.
- Information about travel resources: local, state, national and international.

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

## **Beneficial Outcomes**

Most people with a recent SCI know little about recreational therapy or its benefits. Most often they don't realize how much it can impact their lives and improve their physical and mental health. They don't see recreational therapy as a way to improve and maintain their overall health and to learn functional skills that will be useful both at home and in the community. Recreational therapists can also help to educate family members, work to improve a person's fitness and reduce their stress, and help them find sports and activities that will improve their quality of life.

Research has shown that recreational therapy can help in a number of ways. It can:

- Improve short- and long-term physical health.
- Reduce secondary health issues, such as skin breakdown and *urinary tract infections*.
- Improve a person's mental and social health, including decreased depression, improved body image, and adjustment to disability.
- Reduce a reliance on health care.
- Decrease social isolation.
- Improve management of barriers to buildings and improve ability to get around the community.
- Improve stress management and identify coping strategies and activities.
- Increase self-assertiveness and improve ability to develop social relationships.
- Return to past recreational interests with new adaptive recreation skills and resources.

## **Recreational Therapy and Meeting Basic Needs**

Most often, people who are newly injured or who have been asked to see a recreational therapist for the first time are unsure about what to ask or look for from this new person in their lives. The newly injured person and the family are unsure and anxious about the person's physical abilities and new hospital surroundings. Also, the change from the acute medical floor to the rehabilitation unit or the first visit for recreational therapy adds to the list of adjustments. So what can someone with SCI expect from a recreational therapist? How can this person help? The therapist's services or skills include, but are not limited to the following:

- Flexibility to meet and work with the person and family in the hospital room, rehabilitation rooms, or quiet area.
- Certification experience, and training in working with SCI.
- Assessment of recreational interests, skills, and options that are in line with the person's current abilities and a willingness to look at all options and personal interests.
- Suggestions, printed or video materials, assistive technology to practice adaptive recreation, and cooperation with other rehabilitation professionals to coordinate the return home.
- Good listening skills and patience to explain a person's options.
- Recreational therapy spaces and time for use of adaptive equipment, social interaction with peers, introduction to new interests, and resource materials.
- Age-appropriate activities, from children to mature adults, with a clear idea of the goals behind each activity.
- Positive manner and realistic options at various phases of rehabilitation.

- Resourceful link to facility-based activity and community.

## **Communication and the Recreational Therapist**

Communication is one of the most important aspects of a good rehabilitation experience. Everyone involved needs to be on the same page, so to speak, and to share a close working relationship. The following list may help the injured person, family members, and recreational therapist accomplish their goals.

- Let the recreational therapist know how you feel each day: How are you sleeping? Have your emotions or medications changed?
- Be assertive, not aggressive, if you disagree with the treatment plan or have concerns about how well you and the recreational therapist get along.
- Utilize the five interrogative pronouns (who, what, when, where and why) when a treatment *intervention* is going to start.
- Ask what is improved or better today than yesterday or earlier in the week of treatment.
- Don't be afraid to ask questions unrelated to recreational therapy. A recreational therapist will refer you to the right professional, identify a resource within or outside the facility, or tell you when he or she doesn't have an answer.
- After an initial assessment or consultation, the recreational therapist should offer a treatment plan, goals, and intervention that are explained to the person with SCI, agreed upon, and then begun.
- If conflict or disagreements arise between the recreational therapist and the person, try to resolve it. If that attempt is not successful, speak with the treatment team leader or the therapist's immediate supervisor. If you still are unsuccessful, it may be better to switch to another recreational therapist.
- Ask many questions. A well-informed person is less anxious and is able to move forward and progress in his or her rehabilitation.
- Challenge yourself and the recreational therapist. Push for higher skill levels, practice in different social situations, and try community outings. What you practice in a secure, accessible environment may not be helpful once you leave the hospital and must confront the attitudes of friends, access to buildings, or transportation options.
- Ask for a peer mentor. This person, who has experienced the type of injury you have and is living independently, will give you insight into the future on how effective and efficient you will be after hospitalization.
- Take time in personal sessions to discuss what is working and what is not. Provide suggestions. Remember, no matter what the outcome, attempts to become more independent are a worthwhile learning experience.
- Put together your list of questions, concerns, and ideas, so you can be proactive at regularly scheduled conferences with your rehabilitation team, as well as with your recreational therapist.

## **Recreational Activities and Sports Choices**

People with SCI *paraplegia* or *quadriplegia* are often concerned about return to an active life and past recreational interests. The recreational therapist will help you find resources, identify

equipment, and expose you to alternative recreational pursuits. Ever-changing technology such as sports chairs and power wheelchairs; personal and family assistance and support; and the growing awareness of people with disabilities, opens up many possibilities for returning to recreational and leisure pursuits.

People with SCI can participate in team sports, such as:

- basketball
- sled hockey
- quad rugby
- softball
- soccer

Or outdoor recreation such as:

- hiking
- handcycling
- fishing
- hunting
- park exploration

You can also choose competitive sports like:

- paralympics
- road racing
- weight lifting
- sports competitions
- volunteer opportunities

Your options should not be limited by the physical components. Instead, look at the social, emotional, and psychological impact a particular sport or recreational event may have. Return to recreational activity and sports is only limited by your lack of willingness to try. Recreational pursuits and sports is not a question of *if* but *when*.

**See Resources:**

- ***Rehabilitation***
- ***Recreation/Travel/Sports Resources***

## Chapter Eight

# The Rehabilitation Psychologist

Timothy R. Elliot, Ph.D., ABPP  
Spain Rehabilitation Center  
University of Alabama at Birmingham

The rehabilitation psychologist is a vital member of the *rehabilitation*\* team. This psychologist has training to ensure that the unique needs and abilities of each person with a disability are addressed in therapeutic activities. In this chapter, the role, functions, skills, and services of the rehabilitation psychologist will be explained.

### What is a Rehabilitation Psychologist?

Typically, a rehabilitation psychologist has a doctoral degree from an accredited training program. Most earned their doctorate in either clinical or counseling psychology; some now have more specialized doctorates in health or rehabilitation psychology. These professionals have taken coursework and supervision in areas common to all psychologists. *To practice as a professional psychologist, they are licensed by a state board that oversees and regulates the practice of psychology in that particular state.*

But, rehabilitation psychologists take their training one step further. They have participated in clinics and hospitals where they have learned to work with persons who have physical and sensory disabilities. This experience gives them special expertise in working with people who have disabilities. In fact, the American Board of Professional Psychology now provides board certification for rehabilitation psychologists. According to this board, a rehabilitation psychologist works with people who have an illness or injury and with their families. They help the injured person achieve the highest levels of physical, mental and personal function possible. The rehab psychologist provides services that meet a person's level of impairment and his or her wishes, needs, and resources. The psychologist works with others as part of a rehabilitation team. He or she assesses the person's physical and mental health, social needs, home and workspace, and personal politics as a way to help the injured person reach his or her goals. Rehabilitation psychologists usually work with accredited rehabilitation programs.

### What Do Rehabilitation Psychologists Do?

Rehabilitation psychologists are sensitive to the unique aspects of the disabling condition. They look at a person's unique characteristics, and at the problems the person may face in the home and community. So, a rehabilitation psychologist must learn as much as possible about a person in a brief period of time and usually in a hospital setting. A rehabilitation psychologist may visit a

person's bedside soon after the person arrives at a rehabilitation hospital. Or he or she may

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\* All italicized words appearing in this chapter can be found in the Glossary Section.



interview a person in more detail in between rehabilitation therapies at an inpatient program.

Sometimes a *vocational rehabilitation* counselor may ask a client to visit a rehabilitation psychologist for an evaluation. A person can also ask the vocational counselor for a referral to a rehabilitation psychologist, or request a list of psychologists from the approved provider plan used by their insurance company to find a suitable referral. In these situations, the person may have to justify their request by stating a need to see a psychologist who is qualified to work with the unique needs of persons with disabilities.

Usually the psychologist will ask the person to complete several questionnaires. The psychologists will carefully examine the answers and compare them with those from others with similar conditions. In this way the extent of the person's abilities, assets, habits, and difficulties may be better understood.

The rehabilitation psychologist wants to gather this information to help the person with a spinal cord injury (SCI). But he or she knows that others also may ask to see this information: the health team, the person's lawyer, or another agency, such as a vocational rehab center. The psychologist must explain to the injured person how his or her answers to the questionnaire will be used and who will see them. At that time, the person has the option to consent to the release of this information or to refuse to answer the questions. The person's comfort and confidence is most important. When the evaluation is over, the person has the right to learn the results and what they mean and what will be reported to others.

A rehabilitation psychologist can help identify problems a person may have in adjusting to a disability or in working with self-care programs suggested by a rehabilitation team. The psychologist should point out ways in which these problems may be eased. He can explain to the person how the individual's unique strengths, skills, and talents may be used to deal with any problem. Based on information from the interview and from questionnaires, the rehabilitation psychologist can help the team recognize and use the person's strengths and assets. In this way the rehab team can make the best use of the therapy time and increase the chance that the team and person will achieve their goals.

The rehabilitation psychologist is also often in the best position to work directly with problems the person experiences. She might provide individual counseling, marital or couples' counseling, or group counseling, or refer the person to someone else for this service.

### **When Do I Need to See a Rehabilitation Psychologist?**

When we have problems, it sometimes helps to talk with someone who is trained and objective. But we need to know we can trust this person to show us respect and to have our best interests at heart. Before a rehabilitation psychologist can help you, you must have some sense of your problems. You must also feel like your psychologist is sensitive, understanding, and respectful.

A rehabilitation psychologist can address a wide array of problems. These may include stress, anger, or pain management; assertiveness training and social skills; problem solving; or time management. He can also focus on habits or patterns that harm a person's health and well-being. A psychologist can help someone stop smoking or quit the use of alcohol or other substances. She can look at why a person has many problems with *pressure sores* or infections or constant arguments with others. If a person persists in being unhappy, anxious, sad, sleepless, or lonely, a psychologist can help figure out why and find ways to address these feelings. Remember, if a problem interferes with someone's ability to have satisfying relationships and to participate in life, then most likely a psychologist might be someone who can help.

### **How Do I Find Help After Leaving the Hospital?**

When people with recent physical disabilities leave the first inpatient hospital program, they will face considerable stress as they try to adjust to life at home and in the community. It might help at this time to meet with a psychologist for counseling or therapy. However, a person may not know how to find a psychologist with the special skills and expertise of a rehabilitation psychologist. Because this is a fairly new specialty, the American Board of Rehabilitation Psychology is developing a listing of rehabilitation psychologists for national distribution. Until this list becomes available, here are a few options to consider.

Talk with consumer or support groups to learn if there is a psychologist who has worked with some of their members. Could they recommend someone? You may hesitate to let others know you are looking for a psychologist, but being open could prove valuable. For example, you may learn of a particular psychologist with a good reputation in working with persons with spinal cord injury. You might also contact the state vocational rehabilitation service to see if it has a psychologist to recommend. This agency often uses psychologists for assessment and counseling, and it will likely have a list of psychologists it has worked with. Many rehabilitation psychologists are affiliated with rehabilitation departments at hospitals, medical schools, and universities. So a search of staff psychologists at these facilities might be useful. If you can't find a rehabilitation psychologist, psychologists who specialize in health psychology or behavioral health may have experience working with those who have health problems or chronic limitations. These persons can also be found in medical centers and hospitals. Mental health centers are listed in the phone book, and someone there might suggest a rehabilitation psychologist.

You may be concerned about paying for psychological services. Many insurance plans cover a certain number of sessions with a psychologist who may be on their approved list of providers. People sponsored by state vocational rehabilitation agencies may have access to a psychologist as part of their rehabilitation program. If you are using such an agency, talk with the vocational rehabilitation counselor managing your case. Others may be covered under a state *Medicaid* program. Some of these programs cover psychological services; others do not. In most cases, the psychologist will know if Medicaid or a particular insurance company or health maintenance organization (HMO) will cover services. If a *co-payment* is involved, this should be discussed prior to a session. Some psychologists charge an hourly rate set either by the psychologist or negotiated with a client. Some psychologists will often make arrangements with a client who is unable to pay so that the person can receive the help they request and need.

**See Resources:**

- *Mental Health*
- *Support/Self Help*

## Chapter Nine

### Finances: Rehabilitation and Beyond

Barbara Bradford Knowlen  
Barrier Breakers  
Oriskiny Falls, NY

#### Introduction

When a serious, and often sudden, crisis of a disabling illness or injury occurs to you or a family member, money is often the last thing on your mind. Finances are also a low priority to the doctors, nurses, and therapists who are giving urgent and important medical treatment. By the time you are ready or forced to deal with medical costs and income, you may find that some decisions have already been made. Actions may have been taken, or not taken, which could threaten eligibility for disability benefits and access to Medicaid or Medicare, or that could limit earnings upon returning to work later.

This chapter will serve as a road map, with warning signs posted to prevent financial pitfalls. Much of what I share in the next few pages are answers to a question I am asked all too often: "Why didn't somebody tell me that?"

You have often heard it said, "Hope for the best, and prepare for the worst." This statement is true in dealing with disability. So much is unpredictable. People have emerged from months-long comas to return to leading normal lives. Others face seizures and short-term memory loss from a blow to the head so slight that they didn't even seek medical attention. Your hope and belief in yourself or your family member is an important part of recovery. But while you hope, start making plans for the possibility that you may not be able to do the same things. You may not live in the same place, work, or continue education. Substantial support, including financial support, and technology and accommodations may be needed. Being prepared won't make the medical or *functional*\* damage any less, but it can greatly increase your ability to cope with it.

So in dealing with financial issues, start with the assumption that the disability will be severe and long lasting. Again, this is not a "bad attitude." It does not show lack of faith or giving up, instead it uses common sense in being prepared.

#### Social Security

Two programs are available to people with disabilities for health care and income when the individual is unable to work. Both are obtained through the Social Security Administration, and you are applying for both when you apply for Social Security disability. Of the two programs run

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

by Social Security, one is an insurance program, the other a public assistance program. They are very different in how they define disability and work, and they follow different regulations. Social Security will decide if you get one, both, or neither.

**Early application can be critical.** As soon as possible, pick up the phone, or have somebody do it for you, and make an appointment to apply for disability benefits with Social Security. Realistically, it could be months before you could actually keep an appointment and make application. But the importance of making that call to Social Security, 1-(800)-772-1213, is that your subsequent application can be backdated to the day you made the call. It is called your "protected filing date." Keep rescheduling the appointment until you are actually able to make it. Making this call as soon as disability is even mentioned as an outcome, instead of several months later when the disability is definite, could mean thousands of dollars.

The insurance-type program has two parts: Social Security Disability Income (SSDI) and Retired and Survivors Disability Income (RSDI). Social Security Disability Income is based on your having paid into the Social Security system through the FICA payroll deductions when you worked. Retired and Survivors Disability Income is based on a parent or spouse, who is now retired, disabled, or deceased, having paid into the system. Your benefits are drawn on that person's Social Security credits. The amount of the benefit check is based on the amount of work done, and the amount of money paid into Social Security. You may have any amount of assets or unearned income, and still receive SSDI or RSDI. Here are the criteria for RSDI and SSDI: First, you, a parent, or a spouse paid enough into the system while working. Second, your disability prevents you from earning income through work for at least a year. If you go back to work and earn more than \$700 a month (as of 7/1/99) in the first year of disability, you could end up owing back all the Social Security benefits you have been paid. If you are found eligible for SSDI or RSDI, benefits begin six months after the disability. The health care program that goes with SSDI and RSDI is *Medicare*.

The other disability program is Supplemental Security Income-SSI, a public assistance program. A person must be poor, as well as disabled, to receive SSI. He or she must have under \$2,000 in assets, not counting the house he or she lives in, and one vehicle. The person cannot have unearned income, such as disability checks, gifts, or dividends exceeding the current amount of a monthly SSI check plus \$20.

*Medicaid* is the health care program that goes with SSI. SSI and Medicaid can begin one month after the onset of disability. But coverage can't go back further than the date you apply for it, or your protected filing date. The important thing about getting SSI started as soon as possible is that it carries Medicaid coverage with it. This coverage is much more important than the benefit check.

### **Medicaid and Medicare—They're Not the Same**

Medicare, which goes with SSDI or RSDI, has *co-pays* and *deductibles*. It also doesn't cover a lot of things, including medications, and therapies and supplies that would be considered medical maintenance. Medicare, and most health insurance companies, only pay for medical care that is expected to "improve or restore function." They will cover, up to a point, physical, occupational, and respiratory therapies, medical supplies, and nursing services. But when these therapies,

supplies, and services become ongoing medical maintenance for a permanent disability, the coverage runs out. Medicare coverage does not begin until two years after the onset of the disability.

What Medicaid covers varies from state to state. It usually has no co-pays or deductibles. To find out what Medicaid covers in your state, call your state's department of Health and Human Services. Few, if any, states have one document explaining Medicaid coverage in general. The best you can usually get is an answer as to whether a particular service is covered. In general, Medicaid is the only third-party payer that covers ongoing medical maintenance, the therapies, supplies, and attendant services needed by a person with a permanent disability.

The first step is to apply for benefits at the local Social Security office. If you or a family member is hospitalized, ask the hospital social worker to help start the process.

### **Dealing With "The System"**

Once you enter the system, follow these three habits every time you interact with people in the system:

1. **Record and document EVERYTHING**, and keep all records in orderly files. Don't ever throw away medical records or Social Security letters and records, no matter how old. If you made a phone contact, record the name of the person, the agency, date, and time, and a brief summary of what was said. At the end of a phone conversation, repeat back what you believe was said, and ask if that is correct. Use the template below to make additional copies for your own use. Keep a copy of all written correspondence you send or receive. Having quick access to medical records or Social Security communications could be worth thousands of dollars later on. Start a file drawer now.

<b>Date:</b>	<b>Time:</b>
<b>Name of Person Contacted:</b>	
<b>Name of Agency:</b>	
<b>Address:</b>	<b>Telephone Number:</b>
<b>Notes:</b>	

2. Keep calling people who are supposed to be doing something (filling out papers or working on a claim) until it gets done. Don't ever assume something will be done because someone said it would

be. Always ask for an estimate of how much time the task will take, and stay in touch until it is done. Don't be discouraged if the person called is irritated at your frequent calling or complains of a heavy work load. Your goal is not to be liked by him or her. It is to secure money and health care. Don't be hostile with your calls, just extremely persistent.

3. Appeal any decisions with which you disagree, from your medical treatment and bills to your Social Security claim. In the majority of appeals, decisions are reversed or amended. In some cases, you may end up needing a lawyer, but file the appeal immediately. Just ask the hospital, insurance company, or Social Security what to say, what form you need to say it on, and where you need to send it.

### **Settlements, Lawsuits, and Inheritance Money Could be Hazardous to Your Health**

In some cases of disability caused by injury, a settlement or an award from a lawsuit may arrive a few months or years down the road. Some may be in line for an inheritance. If anything like this is a possibility, it can do you more harm than good if you depend on Medicaid for health care and medical maintenance services. When you get the money, you will be cut off from Medicaid until all the money but \$2,000 is gone, probably mostly on health care costs. If you anticipate money, you can do several things ahead of time before the Estate giveth, and the State taketh away.

First, get referred to an attorney who will set up a needs-based trust. This trust will shelter the money from being counted as income or assets in determining SSI or Medicaid eligibility. Another is to generate debt to family members or friends you can trust for their services to you, such as physical care, rides, housekeeping, or things they buy you. By the time the money gets there, you will have a paper trail showing you owe your relative or friend thousands of dollars. When you pay them, the money goes into an account under their control. But you agreed that all or part of the money is to be spent on you. Another option is to have a plan for spending the money immediately: pay your debts or buy a house, a vehicle, furniture, clothes, electronics, or adaptive technology. If you choose this route, have your list ready of what to buy and where, so you can spend it as soon as possible. Get proof of all expenditures. Social Security or county workers don't care what it was spent on, as long as it was spent, and you can prove it. These methods, alone or in combination, will help you make sure that you and not the state benefit from your money.

Here's an example of what I discussed: Nancy sustained a disabling injury in an auto accident and was awarded a lump sum of \$200,000. She used \$50,000 immediately to pay off her debts, buy new furniture, a car, visit her aunt in Iowa, and buy the purebred dog she always wanted. She had \$10,000 in bills from her brother for cleaning her house, doing her shopping, mowing the lawn, shoveling snow, and walking the dog she already has. She paid her brother \$10,000. The money went into an account in her brother's name. She and her brother agreed this is her money for future needs. The other \$140,000 she placed in a needs-based trust, also under her brother's control. Needs-based trusts can also be administered by attorneys or *conservators*. The lesson: Nancy made the money disappear in the calendar month in which she received it. She did not get an SSI check for that month. She could, but probably didn't, lose that month of Medicaid coverage. Supplemental Security Income and Medicaid resumed the next month. She may have had to reapply for Medicaid the following month.

If you are dependent on SSI or Medicaid, any gift of money, or payment by others, of life essentials like your rent, mortgage, utilities, clothing, or food will be deducted from or cause denial of SSI and also Medicaid. If you need financial help, have your friend or family member lend you the money, not give it to you. Document the loan with an IOU. Reality may be that the IOUs will have to be collected in the hereafter, but as long as you technically owe the money, it will not be counted as income. A friend or relative may directly pay non-survival expenses for you, such as phone, cable TV, car payments, repairs, insurance, computers, electronics, or pet expenses.

If, however, you receive a settlement or inheritance, you can't just give it to others. Giving away money or something of value can make you ineligible for SSI and Medicaid. It can only be "given" to friends or relatives in the form of payment for money you owe them. So generate a paper trail of money owed to friends and relatives for the value of what they have done or bought for you.

### **Living at Home and Getting SSI**

In most cases after the onset of a person's disability, he or she lives in a shared living arrangement. Most often the person lives in the family home or with a family member. Most likely, this will not be a public assistance household. Because the person lives in a nice home that is supported by a steady income, the family does not think that the person with the disability is eligible for SSI.

If the person is living with his or her spouse, and that wife or husband has a job or assets, the person with the disability is probably not SSI eligible. But in almost all other situations, such as living with parents, siblings, grandparents, aunts and uncles, or grown children, it only needs to be shown that the person with the disability is paying his or her "fair share" of household expenses. Or it must be shown that the person could pay his or her fair share with an SSI check. "Household expenses" is defined strictly as rent or mortgage and other shelter expenses, utilities, and food. "Fair share" is that sum of the household expenses divided by the number of people in the household.

For example, Tom is spinal cord injured at the age of 25. He is discharged from the hospital to his parents' home, whose household also includes two younger sisters. Tom's parents both work. The family income is \$80,000 a year. The mortgage is \$1,200 a month, utilities run \$250, and food costs about \$400 a month. His family also pays car payments and insurance, phone, cable TV, and the parents have saving toward their retirement. However, they are looking at heavy medical expenses for Tom. They have never been involved in public assistance and are not looking at it now but they should be.

Medicaid could be paying all Tom's medical costs. None of their assets will be counted as Tom's, unless his name appears on the title or account. None of the car, phone, or cable counts as a household expense, because these are not basic to survival.

<b>“Fair Share” Example:</b>
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Costs for Mortgage, Utilities, and Food	\$1, 850
Number of people in Tom's household	5
Tom's fair share (total divided by 5)	\$370
<b><i>A SSI check is \$512 in 1998. Tom is SSI eligible.</i></b>	

Another way to make him eligible, if the fair share approach doesn't work, is to consider Tom a household of one, renting a room in the house. With this approach, it must be shown that Tom pays fair market value for the room or rooms. A statement from a realtor would establish fair market value. Why is it so important for Tom to get SSI? Because Medicaid goes with it and will pay many, if not all, of Tom's medical costs. In some states, when someone gets SSI, the Medicaid is automatic. In others, you have to apply for it through the county after becoming SSI eligible.

### **Accessing Medicaid if You're Not SSI Eligible**

A person can be ineligible for SSI and Medicaid—regardless of the living situation—if an SSDI or RSDI check exceeds a full SSI check plus \$20. Not being eligible for SSI usually means not being able to access Medicaid coverage. In cases like this, some states have spenddown, through this mechanism a recipient with too much unearned income to be SSI eligible, can spend some of that income on health care. When the person has spent down to a base amount set by the state, Medicaid then will cover the rest of the health care costs.

For example, if Joe gets an SSDI check of \$685 a month, he is ineligible for SSI and for Medicaid. But Joe lives in Minnesota, which says that if he spends \$245 of that \$685 on medical costs "spending down" his check to a \$440 base, then Medicaid will pay all of his other medical expenses past that \$245. These expenses, however, must be items or services covered by Medicaid. Ask an intake person at your county public assistance office if spenddown is used in your state, sometimes medical bills may be used for a spenddown.

The only way for a person to go from an SSDI/RSDI and Medicare program into the SSI and Medicaid program is with a PASS, Plan for Achieving Self Support. PASS is a Social Security work incentive program, and it's a plan a person writes and submits to Social Security. The plan states the person's vocational goal and the time it will take to reach that goal. The plan also includes the costs for any equipment and services needed to achieve the goal. The person also states what money he or she will put into the PASS. Social Security must approve the written plan before it goes into effect.

A person who is not eligible for SSI can get a PASS only by putting into the PASS the income, usually from a disability check, or assets that make the person ineligible for SSI. The PASS then shelters that income and assets from being counted against SSI eligibility.

Let's use Joe's example again. Joe writes a PASS stating that he wants to be an accountant. He says he will need three years to do this, and he will need to attend college for two years. He will

purchase his own computer and get a car to get to and from school and to the job. To pay for these things, he will put \$665 of his \$685 SSDI check into a separate account for the PASS. He keeps \$20, because \$20 of unearned income is disregarded in figuring an SSI check. When he puts the \$665 into the PASS account, he becomes SSI eligible. He gets an SSI check of \$494 a month, plus the \$20 he kept, to live on during the PASS. But during the PASS, Joe gets Medicaid along with the SSI, and he gets it without a spenddown. If he is in a state where he can't access Medicaid with a spenddown, becoming SSI and Medicaid eligible will probably pay the medical costs Joe has been paying out of pocket. If Joe can lose the SSDI check by working within 12 months after his PASS ends, he will continue to be SSI and Medicaid eligible. He will retain Medicaid even after making too much money to get an SSI check. To get information about the PASS, call Social Security and ask someone to send you a form SSA 545. Sometimes the people at 1-(800)-772-1213 are not well informed about the PASS, and they will tell you that you have too much money to have a PASS if you get SSDI or RSDI. This is not true. If you are told this, tell them that the POMS (Procedure Operations Manual System) in sections SI SIE00870.003 A.3a and SI E00870.003B.1 says you can put SSDI or RSDI into a PASS and become SSI eligible. Ask for a supervisor if you get more argument.

For the most part, the PASS is for people with disabilities who are medically stable, and who have resolved day-to-day living issues to the point where they can consider education and work. But I know of two cases where a PASS was written for a person who was anything but medically stable.

The PASS I wrote was for a 20-year-old man, who six months earlier had been spinal cord injured at C-5. He was still in rehab. His family's car insurance had a rider that paid \$1,000 a month, for a two-year period, to anyone disabled in a covered accident. The money was being entirely paid into the spenddown to access Medicaid. Assuming the young man would need a decent wheelchair, a computer, and an adapted vehicle, I wrote a PASS for these items. The job goal was to be a computer programmer. The income going into the PASS was the \$1,000 a month from the car insurance, and later his RSDI check. He got SSI to live on during the PASS, and he got Medicaid with no spenddown. A year later he went to school. The PASS rescued \$18,000 for his own needs; he did not lose it to the state to access Medicaid.

My colleague wrote a PASS for a man who was desperately ill and in need of a life-saving liver transplant. He lived in a state where his \$1,200 a month SSDI check prevented him from accessing Medicaid. The private insurance he had retained from his job would not cover the transplant. He was not disabled long enough (two years) for Medicare to start. My colleague submitted a PASS with a temporary job goal of vocational evaluation. He was then covered by Medicaid, which covered the transplant in his state.

Writing a PASS is complex, and getting it approved by Social Security can be difficult. Consult with a professional PASS preparer, *vocational rehabilitation*, or your local *center for independent living*.

### **Centers for Independent Living**

Income and medical coverage can vary state to state, and the system is complex. Getting accurate information and useful advice is nearly impossible. Each agency speaks in its own terminology and

abbreviations. The staff assumes you understand their language as well as they do. It seems as if most of what they tell you is what you can't have and what they can't do. It is from exactly this frustration and from the desire of people with disabilities to control their own lives and services that the independent living movement was born. There are now over 400 centers for independent living (CILs) in the country (see chapter 11). An up-to-date list of them can be obtained from ILRU Research and Training Center on Independent Living at TIRR, 2323 S. Shepherd, Suite 1000, Houston, TX 77019. The phone is (713) 520-0232. Your nearest CIL can refer you to resources and benefits counseling relevant to your area. Most of the people working at a CIL are people with disabilities. So instead of being trained to deal with the system as something that affects other people, they also live dealing with the system. They have first-hand knowledge of how to access services and how to make the system work to the advantage of people with disabilities.

**See Resources:**

- *Benefits/Financial*
- *Support/Self Help*

## Chapter Ten

### The Family and The Individual

Sandra A. Wicina, MS, LPC, NCC  
Counseling, ETC., Stillwell, KS

Spinal cord injury (SCI), from impact to *rehabilitation*\* to reentry, is a family affair. The family can be the single most important resource in dealing with a devastating trauma, and as such, plays a central and crucial role in the social and emotional stabilization of someone with SCI.

The sudden impact of SCI places overwhelming stress on the family, which has had no time to prepare. It can throw off the equilibrium and balance of even the strongest families.

Families face various changes and must meet many crises over their life times. How successful they have been will help determine how they will meet the crisis of SCI.

At the time of injury, the family enters into an interdependent partnership with the injured person and becomes an integral and contributing part of the clinical team. The family provides support, empathy, and resilience. The family passes through stages to re-establish its balance after trauma. During the *acute* stage, the family gets to respond to meet the threat of injury. At this time, the family is overwhelmed, fearful, confused, out of control, powerless, and numb. It needs emotional support itself so it can support the survivor. The family needs clear and accurate information because, in most situations, the family has not had a previous experience with a catastrophic injury; it has no reference points to build from and must rely on strangers speaking in medical terminology. The family must assess its strengths and work from those strengths. One member may be good at finances, another at research, another at care-giving. Maximize those strengths and nurture them.

The family responds by temporarily decreasing its own personal goals. It works out new role patterns, develops mutual goals, and invents new solutions. It looks to previous successes in meeting crises. The family will need both physical and emotional support from other family members, friends, and community.

During the adjustment or rehabilitation stage, the family actively works with the injured family member and the rehab team to become educated about SCI. The family members become learners and teachers, coaches and boosters to the survivor as he or she struggles to rebuild a life.

During the accommodating or reentry stage, the family works with a professional team of therapists, physicians, and social workers to make a constructive reentry into the outside world. Family members must learn body-handling skills, how to purchase and maintain equipment, get *attendant care* and community resources, keep records, learn about legal issues, and how to find leisure and *vocational rehabilitation*. These skills and knowledge need to be imparted to the survivor. If this does not occur, then it creates dependence. Survivors are greatly affected by the manner in which

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

their family treats them. If accepted as a valuable, important, and capable family member who must be involved in decision-making, he/she will feel strong and worthwhile. This sense of importance in the family will spread over to other relationships. Making a survivor feel dependent deprives him/her of the opportunity to be successful and feel good about him/herself. The survivor, in order to maintain maximum independence in controlling his/her life, must be able to direct the manner of personal care, social life, home management, school/business and transportation.

As the family and the injured person move through phases of therapy, they also move through a healing process. They pass through stages of emotional trauma and growth in an attempt to re-establish the family's equilibrium. These stages are not necessarily linear and may occur differently in each family. The family experiences set backs, some skip stages, some become trapped on specific issues. The survivor and the family may not go through these stages at the same time, which often creates conflict. Each person has his or her own calendar for grieving and healing. Progress from one stage to another is uneven, unpredictable, and unique in each individual.

But some stages are common to all. Usually the initial stage is shock and disbelief upon impact. Denial is a part of the shock stage and it may take the form of unrealistic expectations or refusal to cooperate in treatment. Although usually temporary, denial is a natural reaction. But it can become destructive when the survivor and co-survivors refuse to accept the implications of the injury and refuse to cooperate with the treatment team. When prolonged, denial can become pathological and a deterrent to healing.

Loss is part of a devastating injury that brings deep and significant changes and disruption to both the individual and the family. The sense of that loss often leads to depression, grieving, guilt, anger, frustration, and exhaustion. The pile up of losses becomes overwhelming as survivor and co-survivors deal with the reality that rehabilitation is not necessarily total recovery. It is crucial that the survivor be able to grieve his/her losses resulting from SCI. If the grieving does not occur early on, it will occur years later increasing the stresses and the emotional impact and will result in starting the process over again. If the survivor has no family to air in this process, it is important to seek out support groups and counselors who can help in dealing with the loss.

Central to this healing process is adaptation, the ability to be flexible, to creatively use resources. The adaptive phase requires an increase in tasks and time commitments, setting up a home attendant care and home modifications and seeking community resources. The primary purpose of this stage is to support the survivor's efforts at independence.

Each stage involves loss, grief, and internal pain. Equally each stage is an opportunity for growth and healing. For the family to develop a sense of competence, it needs information, training, referral services, and resources at all stages. It is imperative that the family recognizes the need for the survivor to become as independent as he or she can and to rebuild a life in a connective and supportive atmosphere. As the family and survivor move from shock, crisis, isolation, anger, and intermittent depression, they also move forward to reconstruction and renewal as they learn to create their own tomorrow.

When the situation becomes overwhelming, the family members need to know how to seek outside help. Because the family is sharing the same grief, it is too difficult and unrealistic for families

themselves to provide all the support each one needs. Resources are available in the community to help meet the emotional, spiritual, physical, social, and financial needs of individuals and families. Family support groups, individual professionals, and educational resources can be found through word of mouth, through rehabilitation hospital personnel, resource manuals, community agencies, and SCI organizations. There are national caregiver groups listed in this directory that are available to help you to start your own support group if none exists.

Family adaptation to SCI is not a single event, and it is more than a linear outline of stages. It is a lifelong process and a search for meaning. It is a process that involves the challenge to dream a new dream.

**See Resources:**

- *Caregivers*
- *Peer Support*
- *Support/Self Help*

## **Chapter Eleven**

### **Independent Living: History and Philosophy**

**Mike Oxford, Executive Director**  
**Topeka Independent Living Resource Center, Topeka, KS**

The history of independent living stems from this independent living philosophy: people with disabilities have the same rights, options, and choices as anybody else. This includes both civil rights and the right to make bad choices and mistakes, to learn from mistakes, or not, and basically to live like everyone else, as imperfect people in an imperfect world.

The history of independent living is closely tied to the African American civil rights struggle of the 1950s and 1960s. The issues (disgraceful treatment based on bigotry and mistaken stereotypes in housing, education, transportation, and employment) the strategies, and the tactics are all similar, but are focused on a different minority group. This history is also allied with the general social movements of the country in the late 1960s and early 1970s, such as the women's movement.

Independent living, or disability rights philosophy, is an outcome of political and social transformations amongst people with disabilities that took off in the 1970s. People began to view themselves as powerful and self-directed, or in control, as opposed to passive victims, objects of charity, or cripples. An important piece of this philosophy is that this transformation entailed people viewing the problem not as the disability, but as an inaccessible environment, populated by narrow-minded thinkers. Under this model, disability is a natural, not uncommon experience in life and not a tragedy.

Ed Roberts, considered the "Father of Independent Living," became disabled at 14 from polio. After a period of denial in which he almost starved himself to death, Ed received his high school diploma. He wanted to go to college, but the California Department of Rehabilitation rejected his application for financial assistance. It said he was "too disabled to work." He went public with his fight and within one week was accepted for services. There are two lessons to learn from Ed's experience. The first is that advocacy works and never give up without a fight. The second lesson is that there is no such thing as "too disabled." Fifteen years after Ed's initial rejection by the State of California as being too disabled, he became head of the California Department of Rehabilitation, which had originally rejected him!

After Ed earned his associate degree at the College of San Mateo, he applied to go the University of California at Berkley. After initial university resistance, Ed was accepted. The university let him use the university hospital like a dormitory, because there was no accessible student housing. Ed uses both a power wheelchair and a respirator/iron lung.

Ed received attendant services through a state program called "Aid to the Totally Disabled." This is an important note, because these were consumer-controlled, personal assistance services. The attendants were hired, trained, and fired by Ed. This type of program is still not available to all who need it, in spite of some thirty years of proven success, pioneered by Ed and others. In 1970, Ed and other disabled students founded a Disabled Students' Program on the Berkley

campus. They quickly realized, however, that there was much greater need beyond the university's walls. Because of these needs, a general community entity was started and called a *center for independent living* (CIL)\*, the first in the country. It became the primary model for every such center in the country. It rejected the medical model and focused on consumerism, peer support, advocacy for change, and needed direct services.

The early 1970s were a time of awakening for the disability rights movement in a related, but different direction. While Ed Roberts and others were establishing that people with disabilities did not need to be "homebound" and that participation in society, in school, in work, and at play was a realistic and proper goal, others were realizing that the system of institutionalizing people was wrong. The inhuman and degrading treatment of people in state hospitals and schools and other residential institutions, such as nursing facilities, was coming to light, and the financial and social costs were beginning to be seen as unacceptable. This awakening within the independent living movement is exemplified by another leading disability rights activist, Wade Blank.

Wade began his lifelong struggle in civil rights activism traveling with Dr. Martin Luther King, Jr. to Selma. It was during this period that he learned about the stark and rampant oppression that occurs against those people considered outside the "mainstream" of society. By 1971, Wade was working in a nursing facility, Heritage House, trying to improve the quality of life of some of the younger residents. These efforts, including taking some of the residents to a Grateful Dead concert, ultimately were bound to fail. Institutional services and living arrangements, and personal liberty and life with dignity, are incompatible.

In 1974, Wade founded the Atlantis Community, a model for community-based, consumer controlled, independent living. The Atlantis Community provided personal assistance services primarily under the control of the consumer in a community setting. The first consumers of the Atlantis Community were some of the young residents who were freed from Heritage House by Wade after he was fired. Initially, Wade provided personal assistance services to nine people by himself for no pay so that these individuals could integrate into society and live lives of liberty and dignity.

In 1978, Wade and Atlantis realized that access to public transportation was a necessity if people with disabilities were to live independently in the community. This was the year the American Disabled for Accessible Public Transit (ADAPT) was founded. On July 5-6, 1978, Wade and nineteen disabled activists held a public transit bus "hostage" on the corner of Broadway and Colfax in Denver. ADAPT eventually mushroomed into the nation's first grassroots, disability rights, activist organization.

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\* All italicized words appearing in this chapter can be found in the Glossary Section.



In the spring of 1990, Secretary of Transportation Sam Skinner finally issued the regulations mandating lifts on buses. These regulations implemented a law passed in 1970, the Urban Mass Transit Act, which required lifts on new buses. The transit industry had successfully blocked implementation of this part of the law for twenty years, until ADAPT changed their minds and the minds of the nation!

In 1990, after passage of the Americans With Disabilities Act (ADA). ADAPT shifted its focus to a national system of community-based, personal assistance services and the end of the apartheid system of segregating people with disabilities into institutions. The acronym, ADAPT, became American Disabled for Attendant Programs Today. The fight for a national policy of attendant services and the ending of institutionalization continues to this day.

Wade Blank died on February 15, 1993, while unsuccessfully attempting to rescue his son from drowning in the ocean. Wade lives on in many hearts, and his struggle for the rights of people with disabilities continues.

These two leaders in the disability rights movement, Ed Roberts and Wade Blank, provide poignant examples of the modern history, philosophy, and evolution of independent living in the United States.

### **What is a Center for Independent Living (CIL)?**

Centers for independent living are private, not-for-profit, charitable, organizations that advocate for the civil rights and service needs of people with disabilities. In this regard, CILs are primarily agents of societal change. Centers for independent living also provide direct services. For example, a CIL may assist people using a wheelchair, or a CIL may assist someone with asserting her employment rights under the Americans with Disabilities Act. All centers for independent living must also meet other requirements to be considered a center for independent living. These requirements include the following:

The center must be governed by a Board of Directors composed of a majority of people with disabilities.

A majority of staff members must be people with disabilities.

All CILS must provide these core services:

- *Independent Living Skills Training (ILST)* teaches people how to budget, comparison shop, use public transit, and other everyday skills.
- *Peer counseling and support* for people with disabilities provide role modeling, information, ideas, encouragement, and other types of support to people with disabilities. Assisting someone with adjusting to a newly acquired disability is one example.
- *Information and referral* offers an array of services ranging from answering a simple question, such as the phone number to the bus service, to detailed technical assistance, such as

accessibility standards and ADA compliance requirements.

- *Advocacy (Individual and Systems)* works with or on behalf of individuals or groups of people with disabilities to gain equal rights, justice, entitlements, and needed services. Examples include assisting someone with appealing a Social Security claim, filing an employment discrimination complaint, or passage of a civil rights law such as the Americans with Disabilities Act.

### **How Can the CIL Benefit People With Disabilities?**

Generally, a CIL is a place where a person with a disability, any type of disability, should feel "at home." Since CILs are made up of people with different disabilities, a person should be able to benefit from a strong feeling of peer support. After all, peer relationships are what CILs are all about, not to mention peer counseling.

### **Individuals Should Benefit From a Center for Independent Living Through the Independent Living Plan.**

The independent living plan should specify the type, amounts, and duration of any services an individual elects to receive. Further, services should be what the individual wants, as opposed to what the agency wants the individual to do. All independent living plans have to be approved and signed off by the individual requesting the assistance. For example, a new person in town may want assistance learning how to use the public transit system. Because of classes at the university, the best time to learn the transit system is Wednesday at 3:00 pm. This is when the transit training should take place, and this is what should appear on the independent living plan and be approved.

### **Other Examples of Services CILs Typically Provide Include the Following:**

- assistance with locating accessible, affordable housing
- assistance with procuring or maintaining social security benefits
- assistance with living skills, such as balancing a checkbook or comparison shopping
- assistance with training or locating an attendant
- assistance with alternate formatting, such as brailing
- assistance with locating a sign language interpreter
- almost any other community service or product

Besides creating an independent living plan that meets the consumer's needs, each CIL should also provide a grievance procedure to follow if the consumer is unhappy in any way with the agency, its services, or staff. Additionally, each consumer of an CIL should be given information about the Client Assistance Program (CAP). The CAP is a federally-mandated function meant to provide advocacy assistance to people who are facing problems with CILs or *vocational rehabilitation* (VR).

Centers for independent living exist to benefit people with disabilities who wish to maximize their independence and remove barriers in society that exist for people with all kinds of disabilities. If

you don't need anything from a CIL, maybe there is something you can offer or contribute. To find out more about CILs in your area, look in the phone book under human or social services. Ask other agencies in town or contact the regional Rehabilitation Services Administration (RSA) office nearest you.

**See Resources:**

- *Advocacy*
- *Support/Self Help*

## **Chapter Twelve**

### **How Vocational Rehabilitation Helps the Consumer**

**John A. Chappell, Jr., Deputy Commissioner**  
**MRC IL & Consumer Involvement Program, Boston, MA**

#### **Introduction**

This chapter deals with the many benefits of vocational rehabilitation (VR) and how people with disabilities who qualify for services can get the most out of their VR Program. A number of different and important issues face people with disabilities as they approach the VR system. These include: developing good communications with their VR Counselor; common questions consumers should ask their VR counselor; communicating the consumer's concerns, if any, about his or her progress; learning how to access VR services in rural areas; and using independent living services and centers to further the success of a VR goal.

For many people with disabilities, the issue of work is both intimidating and new. Nearly 80 percent of people with disabilities of working age is unemployed, according to National Organization on Disability/Harris Survey 1998). In addition, over two-thirds of those unemployed want to go to work. These two statistics clearly indicate there is both a need and a desire to go to work.

The obstacles to making this transition to work are even more complicated when the person receives Social Security benefits. The disincentives inherent in both SSI and especially SSDI are real obstacles to making a transition to work. The VR system and the VR counselor can help a move into a work setting.

#### **What Types of Services are covered by Vocational Rehabilitation?**

Vocational Rehabilitation Services are generally any type of service that assists a person with a disability to achieve his or her Individual Plan Employment (IPE). Thus, services to attend a vocational training program, a college or university, or any other type of training program including the cost of books and supplies, personal assistance, transportation, and other associated costs, would be covered. Also covered is any type of assistive technology that is needed to assist an individual to complete their training program.

In addition, the cost of a vocational assessment, or vocational test to determine one's vocational interests and abilities, are covered. Other services might be: durable medical equipment, the modification of one's home, or even the cost of modifying a van or automobile for transportation.

All of these services and many others can be part of an IPE, but it is important to note that VR agencies are usually the payer of last resort; that is, they pay for only services that are not covered by any other agency. So, if Medicaid will pay for a wheelchair then the VR agency will not cover that expense. It must also be noted that VR only pays for time-limited services. Thus, even if an individual needs personal assistance after completing their IPE, VR would only cover that service

for a limited period of time, usually 60 to 90 days after an individual goes to work.

### **Developing Good Communications With the VR Counselor**

The VR counselor has experience in helping persons with disabilities develop an appropriate plan (an Individual Plan for Employment: IPE) to go to work. The Rehabilitation Act, as amended in 1998, emphasizes work in an integrated setting; so the plan will focus on accessing an individual's vocational abilities and developing a career objective. The plan also lays out the necessary training to achieve that career objective.

It is important from the first meeting with the VR counselor to establish a good relationship. The counselor is a tool toward achieving the goal of going to work. The best approach is to see the VR process as a team effort with the consumer as the coach. Some times the counselor and the consumer disagree on the best approach to take, but the best way to resolve this disagreement is to go back to the counselor and state the needed approach. A good coach seeks a consensus. If this cannot happen, it is important to understand that there are many ways to remedy this disagreement. These issues will be covered elsewhere in this chapter.

In summary, establishing good communications from the start is important. If possible, the consumer should have some training in how to be a good *self-advocate*<sup>\*</sup> and in how to feel comfortable in an advocacy role that will move their VR Program to a successful conclusion. This type of training is available at many CILs (see Chapter 11). It may be a good strategy to make a referral to the local CIL as part of the VR program.

### **Common Questions Consumers Should Ask Their VR Counselor**

Consumers face many different issues as they use the VR System and begin meeting with their VR counselor. Which questions to ask depends on the needs of the consumer, but some questions seem to apply to many individuals as they approach VR for the first time.

- *Does the agency have a consumer handbook of rights and responsibilities?*

This handbook can be a very useful tool in informing new consumers to the way VR works and the types of services available. Most handbooks also cover consumer rights when disagreements occur.

- *Does the state have an order of selection?*

The Rehabilitation Act requires a state to serve every eligible consumer. If it cannot, it must establish a priority system of providing services first to those with the “most severe disability.”

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\* All italicized words appearing in this chapter can be found in the Glossary Section.

- *Does the agency practice person-centered planning?*

This question is especially important when the consumer has significant disabilities. The variety of needs and the strategies for approaching the development of the VR program are enhanced when a team includes different professionals and the consumer.

- *Is there a waiting list for services?*

Some states have implemented a waiting list for services because there are not enough resources to provide services to all consumers who apply.

- *Is the Rehabilitation Advisory Council active?*

This question helps the consumer determine the extent to which the VR Agency practices consumer involvement in the development of policy. How does the agency resolve disputes between the consumer and the agency?

Many states have formal and informal methods of resolving differences and of making sure the consumer knows about the Client Assistance Program. The Client Assistance Program is mandated under the Rehabilitation Act to assist individuals who have complaints about their VR services.

- *How do I get in touch with the Client Assistance Program if I need it?*

The Rehabilitation Act requires that VR agencies notify consumers of their rights and how to contact Client Assistance (see "State Offices" in local phone book).

- *What types of career choices do I have?*

The Rehabilitation Act requires that VR agencies provide services to qualified individuals with disabilities to obtain competitive employment, if possible. The extent to which services are provided are based on individual negotiations with one's Rehabilitation Counselor. This is often a difficult issue to resolve in that advocates feel that VR should provide any services necessary to achieve an individual's career goals. VR agencies sometimes feel that given their need to serve as many consumers as possible, they help persons with disabilities enter competitive and not maximize their employment potential. The latest amendments to the Rehabilitation Act are somewhat ambiguous on this point. So the best answer is to build a case for what you think your career goals are and then begin your collaboration with your VR Counselor.

### **Effectively Communicating Consumer's Concerns About the Progress of the VR Program**

This issue is important to the ultimate success or failure of the consumer's VR program. One-on-one meetings with the VR counselor may intimidate some people with disabilities. They may have a problem with disagreeing with some of the counselor's recommendations or with expressing their own views about their progress in the VR program. The VR counselor must discern potential obstacles in the development and ultimate success of the VR process. Passive behavior is a clear

sign that the consumer is not an active participant in the implementation of their work plan. This behavior occurs most often because the individual with the disability has not been in the position of controlling his or her own life. Perhaps their parents, spouse, or significant others have made most of the decisions. When people with disabilities are put in the position of having to control their own life, they are not always comfortable with this new role. Many times a referral to a *center for independent living*, where consumer control is part of the overall philosophy, is a good strategy. Not only does the individual become better able to participate in the *rehabilitation* program, the chance of going to work is increased.

### **Learning How to Access VR Services in Rural Areas**

Vocational Rehabilitation services in rural areas are difficult in the best of circumstances and are further compounded by the fact that states with large land areas usually have smaller populations. So these states are negatively impacted by the formula that provides funds through the Rehabilitation Act, because the formula is directly related to a state's population. Many states use itinerant rehabilitation counselors who travel state-wide. It is extremely important to connect to the rehabilitation agency and set up an appointment either for a home visit or an office visit with the VR counselor, depending on how the state provides services in rural areas.

Most rehabilitation agencies have agreements with many different community rehabilitation programs. It is important to identify in advance, if possible, programs that are close to home. Nearby programs will help in identifying potential training opportunities and, if necessary, supported employment options. In rural areas, where transportation is difficult to access, rehabilitation programs close to home work best.

This rural issue affects persons from different cultures, such as Native Americans, because they live in states with large land areas and rural populations. Also different cultures may perceive disabilities in a different way. For example some cultures may consider a disability as a punishment or as the responsibility of the family. Thus, it is important to respect the culture while developing strategies that helps the person access VR services.

### **Using Independent Living Services and Centers to Further the Success of a VR Goal**

In many states, centers for independent living have developed cooperative agreements with the state VR agency. The centers provide skills training, peer counseling, and information and referral. These services help the consumer develop better skills related to making a decision, choosing a career, and accessing the community for training and potential job development. In Massachusetts, for example, each CIL has a contract to provide these services to referrals made from the local VR Office. Consumers meet with the peer counselor from the center and begin to address basics such as decision making, using public transportation, and any other IL skills necessary to go to work. The program has been in effect for five years and has demonstrated some real success, especially for those struggling with the development and implementation of their VR Program.

**See Resources:**

- *Rehabilitation*
- *Support/Self Help*



## **Chapter Thirteen**

### **Personal Assistants: How to Find, Hire, and Keep Them**

**Cindy Higgins**  
RTC/IL at the University of Kansas

Many people with disabilities require assistance in daily living tasks to live in the community. Assistance is often provided by a hired worker. In the past, an outside agency provided and supervised personal care assistants (PCA's). In recent years, many consumers have been taking full responsibility for their own care services. In consumer-directed assistance, the consumer recruits, hires, trains, supervises, and pays his or her own assistants. By managing personal care, consumers gain independence and reduce the cost of attendant care.

#### **Needs Assessment**

The first step in setting up assistant services is deciding what type of assistance you need. Typical needs include: bathing, dressing, housekeeping, medications, exercises, meal preparation, shopping, bowel program, bladder program, transfers, errands, etc.

Everyone has different needs, abilities, and support. For one person, needs might be a morning bath, help with dressing, and breakfast in the morning; lunch; help getting to bed; and a few turns at night to prevent bed sores. Another person may only need help with housecleaning and errands.

#### **Recruiting**

Before you hire an assistant, you have to find one. Of course, you can hire assistants through a home health care agency. But you may be trading control for convenience.

If you are not taking the home health care agency route, a good idea is to contact the local center for independent living to see whether it keeps a PCA register. Asking around or telling others of your quest works well, too.

Often, advertising is the ticket to finding candidates. By all means, make your ad clear. Give specific hours, geographic location (Not your address: you don't want people showing up at your door), needed qualifications (for instance, a driver's license), typical duties, and contact information. An example is: *Aide to assist student with disability. Duties include bathing, meal preparation, driving, and light housekeeping. 6 hrs/day. \$8.50/hr. Hillsboro area. Call Ann at 555-5555.* Run the ad in newspapers, do an Internet posting, or place it on a flyer on bulletin boards at college campuses, churches, medical facilities, and elsewhere.

#### **Interviewing**

Do a pre-interview over the phone to narrow choices. Explain your situation and specific job requirements. Be ready when callers respond and have set questions for applicants. You might ask

about relevant job experience, education level, transportation, and other attributes. At the conclusion of the conversation, tell them you will call back to schedule a personal interview.

Once the interview is scheduled (you might want to ask applicants to bring two personal references), don't be disappointed if the applicant doesn't show. Many won't. Greet the ones that do, make small talk, and be upfront about your disability. Describe specific duties, pay rate, hours, and other job details. Once done, continue conversation to get a feel for the candidate. Find out their attitude toward people with disabilities, past work history, reliability, other responsibilities, and special skills. Ask yourself, "Am I compatible with this person? Could we have a good working relationship?"

Show candidates around your house. Before leaving, ask them to fill out a written application. You may also want to demonstrate some tasks in a trial run. Encourage candidates to go home and think about the job and their willingness to do it. Don't let over enthusiasm on either part turn into a disappointment later on.

## **Selection**

Check personal references, and eliminate candidates who need more money than the job pays or have time conflicts. People who need the money often prove to be better assistants than people who "want to help others."

Think twice about hiring a friend or relative. They may feel it is their duty or want the job so you don't have to be cared for by an "outsider." This can cause resentment later. Some consumers like to keep the role of family member or friend and caregiver separate.

Ask others for advice, but you make the decision about who will provide your care. Certain types of people may work out better than others. College students are available in early morning and evening hours when services are often needed. Students in special education and therapy also may be looking for practical experiences, and you can benefit from their training.

If you are thinking about hiring one assistant, think of possible future scenarios that might require you to have back-up care. Once you have made your selection, inform the applicant. On the first day of work, have the employee fill out a W-4 form reporting tax withholding status and Social Security number. At this time, some may want the employee to sign a contract detailing hourly rate, cancellation procedures, dismissal grounds, acceptable social behavior (swearing, smoking, drinking, overnight guests), notice needed of changes, termination (number of absences, conditions, etc.), and other policies.

## **Training Assistants**

Ideally, an experienced helper can demonstrate techniques. Then, the new PCA can try the task a few times. Be sure to concentrate on one activity at a time, and when giving instructions, be specific. "Prepare bath water, check water temperature, make sure soap and washcloth are ready, ensure privacy, and have large towel for drying" is more enlightening than "Help me take a bath." Encourage questions. Developing a personalized checklist that PCA's can use each day can help

you get the care you need.

During training, provide positive feedback. For example, say what the PCA has done well. Research shows that job performance improves and remains high when employees receive positive feedback.

Positive feedback has two parts: Praise (“*Good job*”) and saying exactly what was done well (“*I feel so clean; You really did a good job with today’s bath.*”) Praise is usually expressed in adjectives. Be careful not to use the same one repeatedly because the feedback loses effectiveness.

Corrective feedback, also essential in training, is telling why something was done incorrectly and giving specific instruction how to correct the problem (“*Next time, cook the eggs a few minutes longer, so the yolk is not runny.*”). The best time to give any feedback is immediately after the task. If the PCA did most of the task well, first mention what was done correctly before giving instructions on the part not done well. Being angry and yelling is not productive. It will only make the PCA frustrated and confused about expectations.

At the start of employment, a daily feedback session at the end of day will keep communication lines open. Preventing bad work habits is better than correcting them.

## **Supervising**

Because of the personal nature of duties, you, the boss, have an unusual dependence on the employee and your relationship will have a delicate balance if the goal is not to oppress each other. Obviously, both of you should treat each other with respect. No one should feel like a second-class citizen or a slave.

If a problem is getting out of hand, don’t be fearful of angering the PCA or being abandoned. Express concerns in a calm tone of voice. Tell the PCA what the problem is, your feelings, and consequences. No one can read minds.

If lateness is a problem, you might say, “Pam, this is the second day in a row that you have been late without an excuse. When you are late, I am late, too. I feel frustrated and apprehensive when you are late. If this happens again, I will have to let you go. You are such a good assistant, I really don’t want to do that. Are you having any problems getting here that I don’t know? What will it take to fix those problems? Let’s not let this happen again, okay?”

When something goes wrong or you are not happy, it is up to you to fix it. Be specific in instructions. If you need help, contact someone at the local center for independent living. Staff there has experience in PCA management.

## **Record Keeping**

It’s not fun, but it is necessary: Records. One type of record might list current helpers, phone numbers, alternate phone numbers, addresses, start dates, current pay rates, and Social Security numbers. Another record could be solely pay history for each employee. Yet another may be a

personal schedule for employees, and another for sick days, paid vacation, fill in days, etc.

Not only do you need records for personal organizations, but the government wants them, too, because you have to pay taxes, Social Security, and worker's compensation. In Massachusetts, the state withdraws taxes directly from PCAs' paychecks. In the past, workers were paid directly and were responsible for paying state unemployment insurance and Social Security taxes. The 1999 changeover happened when PCA's filed for unemployment benefits, government workers found that many people with disabilities were not paying unemployment insurance.

Each year, the government will want you to fill out Internal Revenue Service (IRS) unemployment tax forms, Social Security forms, state tax reports, etc. Your employee will need to file IRS forms reporting cash wages paid, income tax withheld, and payment for taxes. In some states, employees are considered self-employed, so they are responsible for IRS records.

## **Payment**

You can pay PCA's out of your own pocket or you can receive funds from another source, such as the Veteran's Administration, Medicaid, etc. Programs vary from state to state. Understand the source's policies, procedures, and limitations before you hire assistants. Some sources have only a set amount of money they will pay out for assistants or require certain records (see, there they are again) to be kept.

Before you hire, too, determine your base rate and pay increases. Often, a pay raise might be warranted after six months if all works out. Do you have enough? Maybe you do if you have something to barter, such as room and board for services. Or maybe you can pool your financial resources with others for a shared-assistant care pool.

Once you have regular employees, consider expressing your appreciation non-financially. For instance, if you have a garden, share produce. Remember birthdays. Pay on time. Write recommendations. Tutor. Individuals in each working partnership are different, thus, so are tokens of appreciation.

At the time of this writing, disability groups have been advocating for the passage of the Medicaid Community Attendant Services Act (MiCASA). This act would change the present allocation of Medicaid long-term care dollars. Instead of 75% of long-term care dollars paying for institutional service, while the remaining 25% covers optional programs and community-based wavers, MiCASA calls for people with disabilities and their families to be able to choose where and how they receive services. In actuality, a lot of money currently used for nursing home care will be used to pay PCA's. For information, see <http://www.adapt.org/casaintr.htm>.

## **Termination**

You may be the one to want the employee to find new employment or it may be the employee's decision. Sometimes the decision is mutual. At times, a PCA may be getting tired of the job, and you will know because the PCA is increasingly lazy, leaving early, and displaying another form of apathy. Try talking with the PCA first to see whether he or she may be having an unrelated personal

problem.

If it is the job, fix the problem or find a new attendant. If the employee does quit, have an exit interview. Find out why they are leaving, their complaints, and suggestions for improvement. You might learn something. *From Home Health Aides: How to Manage the People Who Help You*, the top ten reasons care assistants quit their jobs:

1. The initial job description was incomplete and changed too often.
2. Duty organization is illogical, inefficient, and time wasting.
3. The work environment is messy and disorganized.
4. Pay is inefficient or lack of appreciation.
5. Another assistant is preferred.
6. The employer is too passive or aggressive.
7. The employer is dishonest about salary, hours, etc.
8. There are unreasonable duties.
9. Intolerant employer.
10. Lack of respect for assistant's personal life.

### **Conclusion**

Being in charge of a PCA isn't a walk down Easy Street. Turnover is high. Power plays can lead to emotional or physical abuse. You can even be robbed if you leave valuables around or allow PCA's to manage your bank account and use your credit card. Yet, considering the alternatives, PCA's are a support and integral to community living.

### **See Resources:**

- *Spinal Cord Injury & Disability Information*
- *Spinal Cord Injury Foundations/Organizations*
- *Support/Self Help*

## **Chapter Fourteen**

### **Medical Expenses: You and Your Insurance Company**

**Cindy Higgins**  
**University of Kansas**

Health insurance comes in a variety of packages. Plans can cover the whole gamut of expenses or only pay out for a specific need. Typical health insurance covers medical bills, surgery, hospital expenses, and prescription drugs.

#### **Types of Insurance**

Today two types of health insurance predominate: fee-for-service and managed care. In the first type of coverage, the patient chooses a doctor and receives treatment. A claim is submitted to an insurance company. The company pays only for “covered” medical expenses, those listed in the plan’s benefits summary. A patient is reimbursed for the service cost, but also usually pays a portion of the covered medical expenses known as “coinsurance.” Sometimes this is 20% of the total cost. Or it could be the difference between the prevailing rate and the provider’s charge. Deductibles, the amount of covered expenses a patient must pay each year before the insurer provides reimbursement, range in fee-for-service plans. The rule-of-thumb is: The higher the deductible, the lower the regular payments (“premiums”). Policies also have lifetime limits on some benefits (e.g., mental illness services) or total dollar amounts. Experts think that any policy less than \$1 million dollar in lifetime benefits may be inadequate.

Managed care has many names, including health maintenance organizations (HMO), preferred provider organizations (PPO), and point-of-service (POS) plans. Instead of paying separately for each managed care service, coverage is paid in advance (“prepaid care”). Premiums are the same if patients use the plan or not. Generally, these plans do not have deductibles nor coinsurance. They do have some out-of-pocket fees, notably “co-payments.” These token amounts may run \$10.00 for every office visit or \$5.00 for each prescription.

Physician selection is limited with managed care plans because an individual chooses a primary care physician who coordinates care and refers patients to selected specialists when necessary. PPO and POS combine fee-for-service features in their plans and therefore offer more flexibility than traditional HMOs.

Besides the broad coverage policies of fee-for-service and managed care, other medical insurance options exist. Hospital-surgical policies provide “first-dollar” coverage (no deductible or extra expenses) for hospitalization, testing, and surgery costs only. Catastrophic coverage kicks in when hospital and medical expenses rise above a certain deductible, providing additional protection with inadequate limits. Deductibles for catastrophic insurance can be high (\$15,000 or more). Dread disease policies provide benefits for a specific disease, such as cancer, but tend to have limited benefits.

Government health insurance, already covered in *CHOICES* (see Chapter 9), includes Medicare and Medicaid. To supplement Medicare, the federal medical insurance for people age 65 and over, individuals can use MedSup or Medigap, private insurance that covers gaps in Medicare coverage.

Other health insurance, besides Medigap, that pays for health care costs not covered by Medicare are employee or retiree coverage from an employer or union, Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) coverage, or Programs of All-Inclusive Care for the Elderly (PACE). Long-term care policies cover medical care, nursing, and other assistance needed for chronic illness or disability. Most health insurance policies do not include long-term care benefits, which must be purchased separately. Those who have more than one insurance plan, often have a designated plan order payment (“coordination of benefits”) that determines which plan pays costs first, second, and so forth.

One type of insurance that individuals do not have to pay for directly but can receive benefits from is Workers’ Compensation. Most on-the-job injuries are covered by Worker’s Compensation. Exceptions are injuries caused by an employee’s intoxication, illegal drug use, self-infliction (including the person who starts a fight), or crime participation. Injuries that occurred when an employee was not on the job or that violated company policy are also not covered. When a worker is injured, his or her claim is filed with an insurance company that pays medical benefits according to a state-approved formula. This form of insurance does not provide benefits to independent contractors, domestic employees in private homes, farm workers, and unpaid volunteers. Each state also may have certain occupation exclusions.

Medical insurance policies list the services they will pay for and those they will not. Make sure you are familiar with covered services. And, if your primary care physician refers you to a specialist, get permission in advance (“preauthorization”) for service. Your plan book list contains guidelines on getting services pre-authorized. If you are in any doubt, call your insurance customer service department.

As you may refer to your insurance policy later, keep it in a safe, handy place. Your insurance company will issue you a card that you may want to carry with you. This card tells the insurance company name, address, and policy number. When contacting the insurance company, refer to this insurance identification card.

### **Claim Filing**

If you obtained services for a medical need, file a claim quickly to receive benefits (“claim check”). Insurance companies have a wide range of time limits for filing claims. This period can be as long as six months or as short as 24 hours. If you do not file within the time limit, your benefits claim could be declined or your benefits reduced. Your policy will tell the filing time limit. It will also tell you how to file the claim by mail or telephone. Workers’ Compensation claims usually must be done within two to 30 days following an injury. Injuries that happen over time such as carpal tunnel syndrome should be reported as soon as they are discovered.

After you visit a doctor (often provided by the company) and receive treatment, follow the doctor’s instructions before filing a claim with Worker’s Compensation. For instance, you fall out of your wheelchair, fractured your right arm, and were taken to the local hospital for treatment. Contact the

insurance company by phone or letter as soon as possible. Give your name, address, policy number, and injury details. Your insurance company will furnish the proper claim form and filing instructions.

### **Claim Submission**

Usually, medical service providers submit their bills directly to your insurance company. However, providers may not know that you have insurance. The first time you receive a bill from any service provider, contact that provider, ask whether the bill was submitted to your insurance company for payment and submit it if the bill was not already submitted. Make sure the provider knows the name and address of your insurance company. Also offer your policy number.

Insurance companies typically need the following information to process a claim: Insurer's name and address, patient's name and address (if different), patient birth date, insured's identification number (usually a Social Security number), service billed and proper service code, service date, place service performed, itemized charges, diagnosis, and provider's name, address, and tax identification number.

### **Medical and Customary Charges**

Service providers provide services and receive an average fee ("reasonable and customary charges") from your insurance company. The insurer derives this fee by using statistical data in specific zip code areas. Most companies will not pay more than the reasonable, customary charge for service provided. Depending on the plan, you may or may not be expected to pay the amount that exceeds the set fee.

For instance, remember that fractured arm from the wheelchair fall? The physician charged you \$900.00 for his services. The average charge in his postal code area was \$850.00. So the insurance company only approved \$850.00 in benefits and will not pay more. You then have to pay the physician the amount not covered by the company. With this in mind, you may want to ask service providers in advance if you will have to pay charges above those in the postal zip code area. If so, you may want to shop around for treatment.

### **Claim Payment**

Insurance companies receive claim notifications, statements, and bills before processing claim checks. Benefits are mailed to respective providers with a benefits explanation. If you want to know whether a claim has been processed or do not understand how the pay amount was derived, contact your insurance agent or insurance company.



## Claim Disputes

If you think your claim was underpaid or overpaid, contact your insurance company and discuss your claim so the problem can be resolved. Reasons why claims are not paid could be:

- **Outdated or missing claim form.** Most insurance carriers require a completed claim form each year even if the information is the same as previous years.
- **Additional information.** Often, more documentation is necessary to process a claim. For instance, a doctor's office may have more than 100 codes, and one of them, the service you want paid, has a code the processor does not know. The more complete the claim, the less time wasted trying to decipher or hunt information.
- **Insufficient cause.** If the claim is for an accident or injury, an insurance carrier may not pay it if the company suspects the liability may be some other company's responsibility. This may be the case if you get hurt at work, because a private insurer may want to pass the claim to Worker's Compensation. If the injuries had to do with an automobile, medical expenses may be the liability of auto insurance. Determining who is liable before claims are submitted gets claims paid off quicker.
- **Non-coverage.** If an item or procedure (e.g., cosmetic surgery or infertility) is not listed in a plan's benefits section, then the insurer is not going to pay for it. If this is the case, check your policy again. Medical claims processors can make mistakes. Even if they are right, you still can appeal the decision.
- **Pre-existing conditions.** In some plans, if you had a condition that the plan said it would not pay for if it was in existence before you purchased the insurance ("pre-existing condition"), then the plan does not have to pay for the condition's treatment. Once again, you can appeal the decision.
- **Filing time.** Remember the warning earlier about timely filing? If you file after the claim expiration date, the claim will not be considered. Extenuating circumstances can be the loophole to this decision. If you can provide a reason why you could not file the claim in time, appeal the denial. The decision could be reversed.
- **Injury extent.** Some Workers' Compensation carriers deny coverage on the charge that you were not injured or do not have a serious injury. Private investigators are often hired to photograph a person in strenuous physical activity to dispute a claim. If denied, file an appeal with the state appeal agency or hire an attorney.

If the customer service representative still denies your claim, call another representative. The first one may have misinterpreted guidelines or the guidelines may be open to interpretation. If the claim is still denied, call the claims supervisor. This person may be better at explaining why the claim was denied or may be the person to reverse the decision.

If denied at each step, consider writing a letter of appeal. Tell why you are requesting the appeal, offer possible denial errors, and include your attempts to get the claim paid. Be detailed, focused, and leave emotions by the wayside. The appeals process may take months. The appeal committee is comprised of upper level management, an attorney, and medical representatives that meet to discuss appeals.

After trying all these measures and documenting your attempts, call the State Insurance Commission, a government agency that examines insurance complaints, listed in the blue pages of your phone book. Or you could use legal action as a last resort. Remember, insurance companies may have several in-house attorneys and outside help well-seasoned in defense techniques.

**See Resources:**

- *Benefits/Financial*
- *Legal*

## Glossary on SCI and Rehabilitation Terminology

(NOTE: Those words with \* indicate use within the text of the manual.)

**Acute:** The early stages of an injury. In SCI, for example, early management of acute trauma and acute medical and surgical care. Also may refer to level of rehabilitation care. The opposite of acute is chronic or long-term.

**ADL:** Activities of daily living, such as eating, dressing, grooming, or shaving. Nurses, occupational and physical therapists are the main coaches for ADL, which is sometimes called DLS or daily living skills.

**Advocate:** Someone who represents your best interest; works on your behalf. Often, people with disabilities become their own advocates.

**\*Anesthesia:** Medication that blocks pain sensations. Some anesthesia causes a person to also fall asleep, while others may simply numb an area while the injured person is conscious.

**\*Angiogram:** A diagnostic procedure done in the X-ray department to visualize blood vessels following introduction of a high-contrast dye injected into an artery.

**Assistive Technology:** The utilization of technology, strategies, and methods in enabling individuals to master tasks at home, school, work, increase independence, and quality of life—use of computers, toys, controls, equipment, communications, modifications, etc. Usually done by OT or PT. Some centers for independent living provide assistance on assistive technologies.

**\*Associated Injury:** An injury that occurs at the same time as the spinal cord injury. Injuries such as broken limbs or ribs or internal bleeding are not directly related to the spinal cord injury, but add to the medical problems of the person with a new SCI.

**Attendant Care (Personal Assistance):** Assistance given for personal care by a hired, trained assistant or personal care attendant hired by the person with SCI as part of his or her self-directed care.

**\*Attending Physician:** The medical doctor who oversees all of a patient's hospital care, no matter how many specialists or therapists are involved in the person's care.

**Autonomic Nervous System:** The part of the nervous system that controls involuntary activities, including heart muscle, glands, and smooth muscle tissue. The autonomic nervous system is subdivided into the sympathetic and parasympathetic systems. Sympathetic activities are marked by the flight or fight emergency response, initiated by way to the transmitter norepinephrine (adrenaline). Parasympathetic activities are known by lowered blood pressure, pupil contradiction, and slowing of the heart.

**\*Bedsore:** See Pressure Sore

**Bladder Training:** Method by which the bladder is trained to empty (micturition) without the use of an indwelling catheter. Involves drinking measured amounts of fluid, and allowing the bladder to fill and empty at timed intervals. See intermittent catheterization.

**Bowel Program:** The establishment of a “habit program” or a specific time to empty the bowel so that regularity can be achieved. Stool softeners might be recommended as well as laxatives. The main side effect of both softeners and laxative is diarrhea. Suppositories are useful to start elimination; however, an ideal management program doesn't rely on suppositories. Enemas relieve fecal impaction, but should not be used routinely.

**Catheter:** A flexible rubber or plastic tube for withdrawing or introducing fluids into a cavity of the body, usually the bladder.

**Cauda Equina:** The collection of spinal roots descending from the lower part of the spinal cord (the conus medullaris—T11 to L2), occupying the vertebral canal below the spinal cord. These roots have some recovery potential.

**\*Center for Independent Living (CIL):** Not-for-profit, charitable, organizations that advocate for the civil rights and service needs of people with disabilities so that they can live independently in the community.

**Central Nervous System (CNS):** The CNS includes the brain and spinal cord. The prevailing theory is that CNS cells won't repair themselves. Experiments show, however, that CNS nerves can re-grow and reconnect to appropriate targets. A clinical “cure” for spinal cord injury has not yet been found.

**Central Cord Syndrome:** A lesion occurring almost exclusively in the cervical region that produces sacral sparing and greater weakness in the upper limb than the lower limbs. It indicates injury to the central structures of the spinal cord.

**Cervical:** The upper spine or neck area of the vertebral column. Cervical injuries often result in quadriplegia, also known as tetraplegia.

**Complete Lesion:** An injury with no motor or sensory function below the zone of cord destruction at the site of primary trauma.

**\*Co-Payment:** A fee set by an insurance company that a person pays each time she or he receives service for health care.

**\*CT Scan:** A special radiographic technique that uses a computer to assimilate multiple X-ray images into a 2-dimensional cross-sectional image.

**\*Decubitus Ulcer:** See Pressure Sore

**\*Deductible:** An amount up to a certain limit that is set by an insurance company and that shows how much a client must pay toward his or her health-care costs. Under most insurance policies, the insurance company will pay the full cost of care once the client has met his or her deductible.

**Discharge Planning:** Preparation for life after rehab, including insurance and legal issues, home adaptation, and community support issues.

**\*Elective Surgery:** Surgery that does not involve a medical emergency and that can be done at the convenience of the patient or medical staff.

**\*Endotracheal Tube:** A tube that runs from the mouth into the windpipe and that allows air into the lungs.

**Extension:** Movement that brings the body or limbs into straight position.

**Fecal Impaction:** Blockage of bowels resulting in severe constipation.

**Flexion:** Movement that brings body or limbs into a bent position.

**Foley Catheter:** A rubber tube placed in the urethra that extends into the bladder and empties it. It is held in place with a small fluid-filled balloon.

**Functional:** The ability to carry out a purposeful activity.

**Functional Level:** Motor level in patients with spinal disease or injury indicative of activity performance capability.

**Gait Training:** Instruction in walking, with or without equipment.

**Halo Traction:** The process of immobilizing the upper body and cervical spine with a traction device. The device consists of a metal ring around the head, held in place with pins into the skull. A supporting frame is attached to the ring and to a body jacket or vest to provide immobilization.

**Heterotopic Ossification:** Extra bone growth, typically located in the hip area.

**Incomplete Lesion or Injury:** A spinal cord lesion in which some sensation or muscle function below the level of injury is preserved.

**Incontinence:** Lack of bowel and/or bladder control.

**Indwelling Catheter:** A flexible tube retained in the bladder, used for continuous urinary draining to a leg bag or other device. The catheter can enter the bladder via the urethra or through an opening in the lower abdomen (suprapubic ostomy). It is important for those using this method of bladder management to drink lots of water, up to six quarts a day. A sterile procedure should be used when changing an indwelling catheter.

**Intermittent Catheterization (ICP):** Use of a catheter for emptying the bladder on a regular schedule. See self-catheterization.

**\*Interventions:** In layman's terms, this means using some type of treatment or variable to see if it has any positive or negative effect upon a specifically identified condition. For example, one could do a comparison test to see if one type of wheelchair cushion is more helpful in preventing pressure sores from developing than another type of wheelchair cushion.

**\*Intravenous:** Within a vein. For example, intravenous medications are put directly into the vein.

**Lesion:** An injury or wound, any pathologic or traumatic injury to the spinal cord.

**\*Lower Motor Neurons:** Nerve cells that are located in the spinal cord and that provide the connection from the brain's upper motor neurons to the skeletal muscles which move joints and limbs.

**Lumbar:** Pertaining to that area immediately below the thoracic spine; the strongest part of the spine, the lower back.

**\*Medicaid:** State health care programs that cover the health care costs of those with low incomes. The level of one's income, not age or amount paid in to Social Security, is the qualifying factor. Although partially funded federally, each state's Medicaid program is different.

**\*Medicare:** The federal health care program that goes along with Social Security for those over 65 and for those receiving Social Security Disability after two years.

**Motor:** Referring to motion/movement

**Magnetic Resonance Imaging (MRI):** A high-tech diagnostic tool to display tissues unseen in X-rays or by other techniques.

**Myelin:** A white, fatty insulating material produced in the peripheral nervous system necessary for rapid signal transmission along nerve fibers. Loss of myelin accompanies many central nervous system injuries. The process of remyelination is very important in spinal cord injury research.

**\*Neuropsychologist:** A specialist who tests for brain damage and helps people find ways to adjust and compensate for thinking and memory problems.

**\*Neurosurgeon:** A medical doctor who specializes in operating on any part of the nervous system, including the spinal cord.

**\*Non-penetrating Injury:** An injury to the spinal cord that comes when bones to the spine or vertebrae are damaged. This injury also is known as a *closed injury*, because the injuries are internal and not visible.

**\*Nutritionist:** A person who helps others nourish their bodies with foods that promote health and healing.

**Occupational Therapist (OT):** The member of the rehabilitation team who helps maximize a person's independence. OTs teach daily living activities, health maintenance and self care, and consult on equipment choices.

**\*Occupational Therapy:** Treatment approach, which can include exercises, self-help skills, and adaptive equipment, designed to help people care for themselves.

**\*Orthopedic Surgeon:** A medical doctor who specializes in operating on or manipulating the skeletal system or on the muscles that enable movement.

**Orthotic:** A device applied to the exterior of the body to support and align the body and limbs; or to influence motion by assisting, resisting, blocking, or unloading part of the body weight.

**Ostomy:** An opening in the skin to allow for catheter drainage for urine, for elimination of intestinal contents, or for passage of air.

**\*Paramedic:** Medical emergency person who is often the first medical person called to assist someone at the accident site.

**Paraplegia:** Loss of function below the cervical spinal cord segments, wherein the upper body retains most function and sensation. Paraplegia results in paralysis of the lower limbs; however, the degree of loss depends on the level of spinal cord lesion.

**Paresis:** Weakness.

**\*Penetrating Injury:** An injury to the spinal cord that results from something such as a knife or bullet entering the body and damaging the spinal cord.

**Peripheral Nervous System:** Nerves outside the spinal cord and brain (not part of the central nervous system). If damaged, peripheral nerves have the ability to regenerate.

**Physiatrist:** A doctor whose specialty is physical medicine and rehabilitation.

**Physical Therapist (PT):** A key member of the rehabilitation team. The PT examines, tests, and treats persons to enhance their maximum physical activity.

**\*Physical Therapy:** Movements and exercises designed to improve mobility.

**Plegia:** Paralysis.

**Pressure Sore:** Also known as decubitus ulcer. A potentially dangerous skin breakdown due to pressure on skin resulting in infection and tissue death. Pressure sores usually occur over bony area and are subject to infection, which may move to the bone. Skin sores are preventable with twice daily checks for redness, weight shifts, and an appropriate seating system and cushion.

**\*Primary Care Physician (PCP):** The medical doctor who is a patient's first contact for medical help. Generally, the PCP manages the patient's care after he or she has left the hospital and has returned home or has gone to a rehabilitation setting.

**Prosthetic:** Replacement device for a body part, for example an artificial limb.

**\*Psychologist:** A mental health professional—not a medical doctor—who helps others deal with, manage and understand their emotions and behaviors.

**\*Pulmonary:** Pertaining to the lungs.

**Quadriplegia:** Loss of function of any injured or damaged cervical spinal cord segment, affecting all four body limbs.

**Range of Motion (ROM):** The normal range of movement of any body joint. Range of motion also refers to exercises designed to maintain this range and prevent contractures or spasms.

**\*Recreational Therapy:** Exercises and activity usually guided by a medical professional towards promoting a patient's physical recovery or rehabilitation.

**\*Rehabilitation Psychologist:** Someone who has training and experience to work with the mental health needs of someone who has a physical disability caused by injury or illness.

**Reflex:** An involuntary response to a stimulus involving nerves not under control of the brain. In some types of paralysis, reflexes cannot be inhibited by the brain and they become exaggerated, thereby causing spasms.

**Regeneration:** In brain or spinal cord injury, regeneration is the regrowth of nerve fiber tissue by way of some as-yet-unknown biologic process. In the peripheral system, nerves do regenerate after damage, and reform functional connections. Regeneration researchers are confident central nerves can be induced to grow, with the proper environment. The challenge remains to restore functional connections to effectively restore function.

**Rehabilitation:** A sequence of services built around the problems of a disabled individual and designed to restore optimum physical, psychological, social, and vocational levels of function.

**\*Respiratory Treatment:** Treatments, most often given in a medical facility, that help to keep the lungs breathing more freely.



**Sacral:** Refers to the fused segments of the lower vertebrae or lowest spinal cord segments below the lumbar level.

**SCI Care System:** An organized multi-disciplinary system of care including acute treatment, rehabilitation and lifetime follow-up services for spinal cord injured individuals.

**Self-Catheterization:** The process of emptying the bladder as needed, on one's own. This procedure minimizes the risk of infection, and is typically easier for men. Women need to use a mirror. People with tetraplegia may need help if hand function is impaired. Can be done “sterile,” with no touching of special cath equipment, or “clean,” which doesn't require time-consuming and more expensive sterile conditions.

**Sensory Level:** Feelings from the body: hot, cold, pain, touch.

**Spasticity:** Hyperactive muscles that move or jerk involuntarily. Spasms may be caused by bladder infections, skin ulcers, and any other sensory stimulus. Such uncontrolled muscle activity is caused by excessive reflex activity below the level of lesion. Some spasticity can be beneficial for circulation and muscle tone. If severe, though, spasms can interfere with normal activities, and can hasten contractions as muscles shorten.

**\*Speech Therapist:** Someone trained to help others improve their ability to communicate.

**\*Speech Therapy:** Field that works to improve people's communication skills, including their speech, listening and writing skills, and their ability to think, swallow, and problem solve.

**Spinal Cord Injury:** Impairment or loss of motor and sensory function in the cervical, thoracic, lumbar, or sacral neurologic segments secondary to damage of neural elements within the spinal canal.

**Spinal Shock:** Similar to concussion in the brain, spinal shock causes the system to shut down. In spinal cord injury, shock causes immediate flaccid (lack of muscle tone) paralysis, which lasts about three or four weeks.

**Suprapubic Catheter:** A catheter surgically inserted into the bladder by incision above the pubis, or the hipline.

**\*Tetraplegia:** Another word for quadriplegia, which is a spinal cord injury that affects all four limbs. The term is most often used outside the United States.

**Thoracic:** Pertaining to the chest, vertebrae, or spinal cord segments between the cervical and lumbar areas.

**Tone:** Refers to normal state of balance and tension in the tissues and muscles of the body.

**Tracheostomy:** Opening in windpipe to promote breathing.

**\*Transected:** Divided by cutting across.

**\*Trauma Center:** A medical facility that specializes in wounds or injuries caused by a sudden, physical blow.

**\*Traumatic Injury:** An extreme or acute injury that results from a major accident, such as a fall or car crash.

**\*Upper Motor Neurons:** Brain nerve cells that initiate voluntary movements by sending an electrical impulse down their axons lying in the spinal cord to stimulate lower motor neurons.

**\*Urethra:** The canal, extending from the bladder, through which urine leaves the body.

**Urinary Tract Infection (UTI):** Bacterial invasion of the urinary tract, which includes bladder, bladder neck and urethra.

**Ventilator:** Mechanical device to help facilitate a person with impaired diaphragm function to breathe.

**Vertebrae:** The bones that make up the spinal column.

**Vocational Therapy:** A special program designed to help those with a physical or mental impairment to obtain, prepare for, engage in, or retain a job. Services are provided through the division of vocational rehabilitation. This program is supported by federal and state funds.

**\*Vocational Rehabilitation:** Services that guide those with a physical or mental impairment with vocational therapy (see above definition) for the purpose of integration or reintegration into the workforce consistent with the individual's strengths, resources, priorities, concerns, abilities, capabilities, and informed choice.

**Weaning:** Gradual removal of mechanical ventilation as patient's lung strength and vital capacity increases.





## Resources: Index of Topics

**DISCLAIMER:** We have personally visited and selected all of the resources included in **CHOICES**. However, we cannot assure the accuracy of the resources and web sites. We hold no accountability for the content of these web sites. Moreover, web sites change hands, content and format may change on a daily basis, and telephone numbers are subject to change. The inclusion of a resource in **CHOICES** does not imply endorsement of the web site or resource. There are additional sources available that may not be included in this directory. **CHOICES** does not render medical or legal advice. The information provided through **CHOICES** should not be used for diagnosing or treating a health problem or for obtaining legal opinions. **CHOICES** is not a substitute for professional services. If you have health or legal questions, you should consult an appropriate professional.

**Accessible Housing/Modifications**

**Advocacy**

**Aging Issues**

**Assistive Technology**

**Benefits/Financial**

**Car/Van Modifications**

**Caregiver Support**

**Children's**

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**Job Resources/Employment**

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**Magazines/Books/Pamphlets**

**Mental Health**

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**Recreation/Travel/Sports**

**Rehabilitation**

**Research**

**Service Dogs**

**Secondary Medical Conditions**

**Sexuality**

**Spinal Cord Injury  
Foundations/Organizations**

**Spinal Cord Injury & General  
Disability**

**Support/Self Help**

**Wheelchair Information**

*The resources listed under each section may contain useful information on additional topics.*

*ACCESSIBLE HOUSING/MODIFICATIONS:*

**ABLEDATA**

Informed Consumer's Guide to Accessible Housing  
(800) 227-0216, (301) 608-8998; TTY: (301) 608-8912  
[www.abledata.com/text2/icg\\_hous.htm](http://www.abledata.com/text2/icg_hous.htm)

**Alpha One – Housing Information**

127 Main Street  
South Portland, ME 04106  
(800) 640-7200  
[www.alpha-one.org/housing.htm](http://www.alpha-one.org/housing.htm)

**The Center for Universal Design School of Design  
North Carolina State University**

Box 8613  
219 Oberlin Road  
Raleigh, NC 27695-8613  
(800) 647-6777  
[www.design.ncsu.edu/cud/](http://www.design.ncsu.edu/cud/)

**ADVOCACY**

**ADAPT – Americans Disabled for Attendant  
Programs Today**

Fighting so people with disabilities can live in the  
community with real supports instead of being locked  
away in nursing homes and other institutions.

PO Box 9598  
Denver, CO 80209  
(303) 733-9324  
[www.adapt.org](http://www.adapt.org)

**Advocacy Training/Technical Assistance Center of the  
National Association of Protection and Advocacy Systems**

900 2nd Street, N.E. #211  
Washington, D.C. 20002  
(202) 408-9514  
[www.protectionandadvocacy.com/atoh.htm](http://www.protectionandadvocacy.com/atoh.htm)

**NCIL - National Council on Centers for Independent Living**

1916 Wilson Blvd., Suite 209  
Arlington, VA 22201  
(703) 525-3406 [www.ncil.org](http://www.ncil.org)  
Email: [ncil@ncil.org](mailto:ncil@ncil.org)

**U.S. Department of Justice  
A Guide to Disability Rights Laws**  
P.O. Box 66738

Washington, D.C. 20035-6738  
(800) 514-0301  
[www.usdoj.gov/crt/ada/cguide.htm](http://www.usdoj.gov/crt/ada/cguide.htm)  
[www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)

*AGING ISSUES*

**Craig Hospital**

3425 South Clarkson Street  
Englewood, CO 80110  
(303) 789-8220  
Fax: (303) 789-8470  
[www.craighospital.com/](http://www.craighospital.com/)

*ASSISTIVE TECHNOLOGY*

**ABLEDATA**

8455 Colesville Road, Suite 935  
Silver Spring, MD 20910  
(800) 227-0216  
[www.abledata.com/Site\\_2/state\\_technology\\_assistance\\_proj.htm](http://www.abledata.com/Site_2/state_technology_assistance_proj.htm)

**The Alliance for Technology Access (ATA)**

2175 East Francisco Blvd., Suite L  
San Rafael, CA 94901  
(415) 455-4575  
[www.ataccess.org](http://www.ataccess.org)

**Rehabilitation Engineering and Assistive Technology  
Society of North America**

1700 North Moore Street, Suite 1540  
Arlington, VA 22209-1903  
Phone: (703) 524-6686  
[www.resna.org](http://www.resna.org)

*BENEFITS/FINANCIAL RESOURCES*

**Architectural and Transportation Barriers  
Compliance Board**

(800) 872-2253 [www.access-board.gov/](http://www.access-board.gov/)

**Health Care Financing Administration (HCFA)  
Information Clearinghouse**

(410) 786-3000 (800) 633-422  
[www.hcfa.gov/about.htm](http://www.hcfa.gov/about.htm)

**The Official U.S. Government Site for Medicare  
Information**

(800) 633.4227  
[www.medicare.gov](http://www.medicare.gov)

**Social Security Administration**

Social Security Online  
(800) 772-1213  
www.ssa.gov

**State Vocational Rehabilitation Services**

To locate the office in your area, look in the blue pages of your telephone directory under State Government or in the white pages under Government Agencies

trfn.clpgh.org/srac/state-vr.html

**CAR/VAN MODIFICATIONS****ABLEDATA**

8455 Colesville Road, Suite 935  
Silver Spring, MD 20910  
(800) 227-0216  
www.abledata.com/links.htm#Transportation

**Access Unlimited**

570 Hance Road  
Binghamton, NY 13903  
(800) 849-2143  
www.accessunlimited.com  
www.accessunlimited.com/vehicle\_modification.html  
www.accessunlimited.com/driver\_rehab.html

**Accessible Vans of America**

(888) AVA-VANS; (888) 282-8267  
www.accessiblevans.com

**Ford Mobility Motoring Program**

P.O. Box 529  
Bloomfield Hills, MI 48303  
(800) 952-2248; TDD: (800) 833-0312  
www.ford.com/default.asp?pageid=367

**GM Mobility Assistance Center**

100 Renaissance Center  
P.O. Box 100  
Detroit, MI 48265-1000  
(800) 323-9935  
www.generalmotors.com/ownership/service/mobility.htm

**Lifts For Free**

(800) 377-0799  
www.scooterdepot.com/reimbur.shtml

**CAREGIVER SUPPORT****National Family Caregivers Association**

10605 Concord Street, Suite 501  
Kensington, MD 20895-2504  
(800) 896-3650  
www.nfcacares.org

**CHILDREN'S RESOURCES****Easter Seals**

230 West Monroe Street, Suite 1800  
Chicago, IL 60606  
www.easter-seals.org/services/children.asp

**National Information Center for Children and Youth with Disabilities**

P.O. Box 1492  
Washington, DC 20013-1492  
(800) 695-0285  
www.nichcy.org

**The National Spinal Cord Injury Association**

8300 Colesville Road  
Silver Spring, MD 20910  
(800) 962-9629  
www.erols.com/nscia/resource/infoitwk.html

**Shriner's Hospitals for Children**

2900 Rocky Point Drive  
Tampa, FL 33607-1460  
(813) 281-0300  
www.shriners.com

**Social Security Administration  
Office of Public Inquiries**

6401 Security Blvd.  
Room 4-C-5 Annex  
Baltimore, MD 21235  
(800) 772-1213  
www.ssa.gov/pubs/11053.html

**Winner on Wheels**

2842 Business Park Avenue  
Fresno, CA 93727  
(800) WOW-TALK; (800) 969.8255  
Fax: (559) 291-3386  
www.wowusa.com

***DURABLE MEDICAL EQUIPMENT/SUPPLIES*****Care Catalogue Services**

1877 N.E. Seventh Ave  
Portland, OR 97212  
(800) 443-7091  
www.caremedical.com/ccs

**Health IQ**

750 The City Drive, Suite 210  
Orange, CA 92868  
(800) 866-4474  
www.healthiq.com/HealthcareResources/glossary/G51.htm

**Home Medical Equipment Answer Book**

11300 Rockville Pike, Suite 1100  
Rockville, MD 20852-3030  
(301) 287-2700  
www.ucg.com/health/hab.html

**Medship Direct**

P.O. Box 956848  
Duluth, GA 30095-9515  
(800) 633-1565  
www.medshipdirect.com

**National Healthcare Benefit Corporation**

767 E. Division Street  
Cadillac, MI 49601  
(231) 779-1079  
www.healthcarebenefits.com/durable.htm

***JOB /EMPLOYMENT RESOURCES*****Job Accommodation Network**

West Virginia University  
PO Box 6080  
Morgantown, WV 26506-6080  
(800) 526-7234  
www.jan.wvu.edu

**President's Committee on Employment of People  
with Disabilities**

1331 F Street, N.W., Suite 300  
Washington, DC 20004  
(202) 376-6200  
www.dol.gov/pcepd/

***LEGAL RESOURCES*****American Bar Association Service Center**

541 N. Fairbanks Court  
Chicago, IL 60611  
(312) 988-5522  
www.abanet.org

***MAGAZINES/BOOKS/PAMPHLETS*****National Spinal Cord Injury Association**

Help Line: (800) 962-9629; (301) 588-6959  
Fax: (301) 588-9414  
Email: nscia2@aol.com  
www.spinalcord.org



**New Mobility Magazine**

(215) 675-9133 ext. 108

[www.newmobility.com/magazine](http://www.newmobility.com/magazine)

**Paralyzed Veterans of America Publications**

(888) 860-7244

[www.pva.org/pubsandproducts/pubproductsindex.htm](http://www.pva.org/pubsandproducts/pubproductsindex.htm)

**PN/Paraplegia News**

(888) 888-2201

[www.pva.org/pn](http://www.pva.org/pn)

**Research & Training Center on Independent Living**

The University of Kansas

4089 Dole Center

Lawrence, KS 66045-2930

(785) 864-4095

[www.lsi.ukans.edu/rtcil/rtcil.htm](http://www.lsi.ukans.edu/rtcil/rtcil.htm)

**Spinal Network**

The Total Wheelchair Book

(800) 543-4116 ext.480; (310) 317-4522 ext.480

[www.newmobility.com/bookstore](http://www.newmobility.com/bookstore)

**SPORTS 'N SPOKES**

2111 East Highland Ave., Suite 180

Phoenix, AZ 85016-4702

Email: [snsmagaz@aol.com](mailto:snsmagaz@aol.com)

[www.pva.org/pn](http://www.pva.org/pn)

**Spinal Cord Injury Information Network  
The University of Alabama at Birmingham**

(205) 934-3283

Fax: (205) 975-8376

619 19<sup>th</sup> Street, S. SRC-529

Birmingham, AL 35249

[www.spinalcord.uab.edu](http://www.spinalcord.uab.edu)

**We Magazine**

(212) 931-6700

[www.wemagazine.com](http://www.wemagazine.com)

***MENTAL HEALTH RESOURCES***

**American Psychological Association**

Public Information Line

(800) 964-2000

[www.apa.org](http://www.apa.org)

**The Family Village Waisman Center  
University of Wisconsin-Madison**

1500 Highland Avenue

Madison, WI 53705-2280

[www.familyvillage.Wisc.Edu/lib\\_ment.htm](http://www.familyvillage.Wisc.Edu/lib_ment.htm)

[www.familyvillage.wisc.edu/map/s.html](http://www.familyvillage.wisc.edu/map/s.html)

**National Mental Health Services Knowledge Exchange  
Network**

PO Box 42490

Washington, DC 20015

(800) 789-2647

[www.mentalhealth.org](http://www.mentalhealth.org)

***PAIN***

**American Pain Society**

4700 W. Lake Avenue

Glenview, IL 60025

(847) 375-4715

[www.ampainsoc.org](http://www.ampainsoc.org)

**Pain Research Initiative  
The Miami Project to Cure Paralysis**

P.O. Box 016960 (R-48)

Miami, FL 33101-6960

(800) STAND-UP; (305) 243-6001

Fax: (305) 243-6017

[www.miamiproject.miami.edu/miami-project/pain.htm](http://www.miamiproject.miami.edu/miami-project/pain.htm)

***PERSONAL CARE ATTENDANT/HOME  
CARE***

**American Disabled for Attendant Programs  
Today**

PO Box 9598

Denver, CO 80209

(303) 333-6698

[www.adapt.org](http://www.adapt.org)

**disAbility Resource Center**

607-S.E. Everett Mall Way, Suite 9B

Everett, WA 98208  
(425) 347-5768  
[www.wa-ilsc.org/index.html](http://www.wa-ilsc.org/index.html)  
[www.wa-ilsc.org/toc2ack.html](http://www.wa-ilsc.org/toc2ack.html)

#### **National Association for Home Care**

228 Seventh Street, S.E.  
Washington, DC 20003  
(202) 547-7424  
Fax: (202) 547-3540  
[www.nahc.org/Consumer/coninfo.html](http://www.nahc.org/Consumer/coninfo.html)  
[www.nahc.org/home.html](http://www.nahc.org/home.html)  
[www.nahc.org/Consumer/stassn.html](http://www.nahc.org/Consumer/stassn.html)

#### **NCIL - National Council on Centers For Independent Living**

1916 Wilson Blvd., Suite 209  
Arlington, VA 22201  
(703) 525-3406  
Email: [ncil@ncil.org](mailto:ncil@ncil.org)  
[www.ncil.org](http://www.ncil.org)

#### **Research & Training Center on Independent Living**

(785) 864-4095  
[www.lsi.ukans.edu/rtcil/rtcil.htm](http://www.lsi.ukans.edu/rtcil/rtcil.htm)

#### ***PREVENTION RESOURCES***

##### **Think First Foundation**

22 S. Washington Street  
Park Ridge, IL 60068  
(800) THINK56; (847) 692-2740  
[www.thinkfirst.org/home.htm](http://www.thinkfirst.org/home.htm)

#### ***RECREATION/TRAVEL/SPORTS RESOURCES***

##### **Beneficial Designs, Inc.**

5858 Empire Grade  
Santa Cruz, CA 95060-9603  
(831) 429-8447  
[www.beneficialdesigns.com/balans.htm](http://www.beneficialdesigns.com/balans.htm)

##### **Disabled Sports USA**

(301) 217-0960  
[www.dsusafw.org](http://www.dsusafw.org)

##### **National Sports Network**

P.O. Box 47799  
St. Petersburg, FL 33743-7799  
(800) 699-4494

[www.nsnsports.org](http://www.nsnsports.org)

##### **Paralyzed Veterans of America**

(800) 424-8200  
[www.pva.org/sports/Events/main.htm](http://www.pva.org/sports/Events/main.htm)

##### **Shake A Leg**

76 Dorrance Street, Suite 300  
Providence, RI 02903  
(401) 421-1111  
[www.shakealeg.org](http://www.shakealeg.org)

#### ***REHABILITATION***

##### **American Therapeutic Recreation Association**

(703) 683-9420  
[www.atra-tr.org](http://www.atra-tr.org)

##### **Allied Services**

475 Morgan Highway, P.O. Box 1103  
Scranton, PA 18501-1103  
(570) 348-1405  
Fax: (570) 348-2909  
[www.allied-services.org](http://www.allied-services.org)

##### **CARF – The Rehabilitation Accreditation Commission**

(520) 325-1044  
Fax: (520) 318-1129  
[www.carf.org](http://www.carf.org)

##### **Head Injury Rehabilitation Services**

4720 Lincoln Blvd., Suite 321  
Marina del Rey, CA 90292  
(800) 705-4477  
[www.neurorehab.com/links.html](http://www.neurorehab.com/links.html)

#### ***NATIONAL MODEL SCI CENTERS***

The Model Spinal Cord Injury System program, sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR), provides assistance to establish innovative projects for the delivery, demonstration, and evaluation of comprehensive medical, vocational, and other rehabilitation services to meet the needs of individuals with spinal cord injury. The following were model systems as of May 2000.

CHECK [www.ncddr.org/rpp/hf/hfdw/mscis](http://www.ncddr.org/rpp/hf/hfdw/mscis)  
FOR CURRENT LISTINGS or call

(800) 266-183; (512) 476-6861  
Fax: (512) 476-2286

**University of Alabama at Birmingham SCI Care System**

Amie B. Jackson, M.D.  
UAB - Spain Rehabilitation Center  
619 19<sup>th</sup> Street, S, SRC-190  
Birmingham, AL 35249-7330  
(205) 934-3330  
Fax: (205) 975-9754

**Regional SCI Care System of Southern California**

Robert L. Waters, M.D.  
Rancho Los Amigos Med Center, HB 121  
7601 East Imperial Highway  
Downey, CA 90242  
(310) 940-7161  
Fax: (310) 803-5623

**Northern California SCI System**

Peter C. Werner, M.D.  
Santa Clara Valley Medical Center  
751 South Bascom Avenue  
San Jose, CA 95128  
(408) 885-2000  
Fax: (408) 885-2028

**Rocky Mountain Regional SCI System**

Robert R. Menter, M.D.  
Craig Hospital  
3425 South Clarkson Street  
Englewood, CO 80110  
(303) 789-8220  
Fax: (303) 789-8470

**Georgia Regional SCI System**

David F. Apple, Jr., M.D.  
Shepherd Spinal Center  
2020 Peachtree Road, NW  
Atlanta, GA 30309  
(404) 350-7353  
Fax: (404) 350-7596  
[www.shepherd.org/sci/index.htm](http://www.shepherd.org/sci/index.htm)

**Midwest Regional SCI Care System**

Paul R. Meyer, Jr., M.D.  
Northwestern Memorial Hospital

250 East Superior, Room 619  
Chicago, IL 60611  
(312) 908-3425  
Fax: (312) 908-1819

**Boston University**

Mel B. Green, M.D.  
Boston University Medical Center  
88 East Newton Street, F-511  
Boston, MA 02118  
(617) 638-7300  
Fax: (617) 638-7313

**University of Michigan Model SCI System**

Theodore M. Cole, M.D.  
University of Michigan Medical Center  
300 North Ingalls  
Ann Arbor, MI 48109-0491  
(313) 763-0971  
Fax: (313) 936-5492  
Email: [tcole@umich.edu](mailto:tcole@umich.edu)

**Southeast Michigan Regional SCI System**

Bruce E. Becker, M.D.  
Rehabilitation Institute of Michigan  
261 Mack Boulevard  
Detroit, MI 48201  
(313) 745-1095  
Fax: (313) 745-1063  
Email: [drteton@aol.com](mailto:drteton@aol.com)

**Missouri Model SCI System**

Kristofer Hagglund, Ph.D.  
5R01 Rusk Rehabilitation Center  
1 Hospital Drive  
Columbia, MO 65212  
(573) 882-6271  
Email: [hagglk@pmr.missouri.edu](mailto:hagglk@pmr.missouri.edu)

**Northern New Jersey SCI System**

Joel A. DeLisa, M.D.  
Kessler Institute for Rehabilitation  
1199 Pleasant Valley Way  
West Orange, NJ 07052  
(201) 731-3600 ext.250  
Fax: (201) 325-7027

**Mount Sinai SCI Model System**

Kristjan T. Ragnarsson, M.D.  
Mt. Sinai Medical Center  
5 East 98th Street, B-17  
New York, NY 10029-6574  
(212) 241-9654  
Fax: (212) 348-5901

**Northeast Ohio Regional SCI System**

Frederick Frost, M.D.  
Department of PM&R  
MetroHealth Medical Center, 2500 MetroHealth Dr.  
Cleveland, OH 44109-1998  
(216) 778-3483  
Fax: (216) 778-5560  
Email: fsf@po.cwru.edu

**Regional SCI System of Delaware Valley**

John F. Ditunno, M.D.  
Thomas Jefferson University Hospital  
111 South 10th Street, Suite 9410  
Philadelphia, PA 19107  
(215) 955-6573  
Fax: (215) 955-3729

**Texas Regional SCI System**

R. Edward Carter, M.D.  
The Institute for Rehabilitation & Research  
1333 Moursund Avenue  
Houston, TX 77030  
(713) 797-5910  
Fax: (713) 799-7017

**Medical College of Virginia**

William McKinley, M.D.  
Medical College of Virginia, Box 980677  
Richmond, VA 23298-0677  
(804) 828-0861  
Fax: (804) 828-5074  
Email: wmckinley@gems.vcu.edu

**Northwest Regional SCI System**

Diana D. Cardenas, M.D.  
Department of Rehab Medicine, RJ-30  
1959 N.E. Pacific Street  
Seattle, WA 98195  
(206) 543-8171  
Fax: (206) 685-3244

Email: dianamac@u.washington.edu

**Medical College of Wisconsin**

Dennis J. Maiman, M.D., Ph.D.  
Froedtert Memorial Lutheran Hospital  
9200 W. Wisconsin Avenue  
Milwaukee, WI 53226  
(414) 259-3645  
Fax: (414) 259-7927

**National Rehabilitation Information Center**

1010 Wayne Ave., Suite 800  
Silver Spring, MD 20910-3319  
(800) 346-2742  
[www.naric.com/naric/search/t08.html](http://www.naric.com/naric/search/t08.html)

**National Spinal Cord Injury Association**

Help Line (800) 962-9629; (301) 588-6959  
Fax: (301) 588-9414  
Email: nscia2@aol.com  
[www.spinalcord.org](http://www.spinalcord.org)

**National Spinal Cord Injury Hotline**

2200 Kernan Drive  
Baltimore MD 21207  
(800) 526-3456  
[www.scihotline.org](http://www.scihotline.org)

**PointTIS - Point of Care, Teambased Information System**

<http://calder.med.miami.edu/pointis/handbook.html>

**Vocational Rehabilitation**

See local phone directory under state offices.

**RESEARCH**

**National Institute of Neurological Disorders & Stroke (NINDS)**

National Institutes of Health  
Bethesda, MD 20892  
[www.ninds.nih.gov](http://www.ninds.nih.gov)

**Spinewire**

(800) 850-0335

[www.spinewire.com/cgi-bin/templates/index.html](http://www.spinewire.com/cgi-bin/templates/index.html)

**SCI Research**

[www.cureparalysis.org/drs/index.html](http://www.cureparalysis.org/drs/index.html)

***SECONDARY MEDICAL CONDITIONS*****Rehabilitation Research & Training Center  
The University of Alabama at Birmingham**

619 19<sup>th</sup> Street S., SRC-529

Birmingham, AL 35249

(205) 934-3283

Fax: (205) 975-8376

[www.spinalcord.uab.edu](http://www.spinalcord.uab.edu)

**The Wound Care Institute, Inc.**

1541 NE 167th Street

North Miami Beach, FL 33162

[www.medicaledu.com/wndguide.htm](http://www.medicaledu.com/wndguide.htm)

***SERVICE DOGS*****Assistance Dogs International**

c/o Canine Partners For Life

334 Faggs Manor Road

Cochranville, PA 19330

[www.assistance-dogs-intl.org/memlist.html](http://www.assistance-dogs-intl.org/memlist.html)

**International Association of Assistance Dog Partners**

Post Office Box 1326

Sterling Heights, MI 48311

(810) 826-3938

[www.ismi.net/iaadp/](http://www.ismi.net/iaadp/)

**Service Dog Directory**

[www.wolfpacks.com/serviced.htm](http://www.wolfpacks.com/serviced.htm)

**Support Dogs, Inc. - Training Facility**

9510 Page Avenue

St. Louis, MO 63132

(314) 892-2554

[members.aol.com/maxidog1/support.htm](http://members.aol.com/maxidog1/support.htm)

***SEXUALITY*****Fertility and Adoption Resources**

[www.sexualhealth.com/index.html](http://www.sexualhealth.com/index.html)

[www.my.webmd.com/content/asset/chat\\_transcript.526826](http://www.my.webmd.com/content/asset/chat_transcript.526826)

Sandra Welner, MD Email: [Welnersmd@aol.com](mailto:Welnersmd@aol.com)

**The Miami Project to Cure Paralysis**

PO Box 016960 (R-48)

Miami, FL 33101-6960

(800) STAND-UP; (305) 243-6001

Fax: (305) 243-6017

[www.miamiproject.miami.edu](http://www.miamiproject.miami.edu)

**Sexual Health Network**

3 Mayflower Lane

Shelton, CT 06484

(203) 924-4623

[www.sexualhealth.com](http://www.sexualhealth.com)

***SPINAL CORD INJURY******FOUNDATIONS/ORGANIZATIONS*****Christopher Reeve Paralysis Foundation**

P.O. Box 277, FDR Station

New York, NY 10150-0277

(800) 225-0292

[www.paralysis.org](http://www.paralysis.org)

**Kent Waldrep National Paralysis Foundation**

16415 Addison Road, Suite 550

Dallas, TX 75248

(877) SCI-CURE; (972) 249-7100

[www.kwnpf.org](http://www.kwnpf.org)

**The Miami Project to Cure Paralysis**

PO Box 016960 (R-48)

Miami, FL 33101-6960

(800) STAND-UP; (305) 243-6001

Fax: (305) 243-6017

[www.miamiproject.miami.edu](http://www.miamiproject.miami.edu)

**The National Spinal Cord Injury Association**

8300 Colesville Road

Silver Spring, MD 20910

(800) 962-9629

[www.spinalcord.org](http://www.spinalcord.org)

**National Spinal Cord Injury Hotline**

2200 Kernan Drive

Baltimore, MD 21207

(800) 526-3456

[www.scihotline.org](http://www.scihotline.org)

**Paralyzed Veterans of America**

801 18<sup>th</sup> Street, N.W.  
Washington, D.C. 20006  
(800) 424-8200  
[www.pva.org](http://www.pva.org)

**Steve Palermo Chapter  
Kent Waldrep National Paralysis Foundation**

11350 Tomahawk Creek Parkway, Suite 200  
Leawood, KS 66210  
(800) 513-3700; (913) 451-3700  
[www.kwnpf.org](http://www.kwnpf.org)

***SPINAL CORD INJURY & GENERAL  
DISABILITY INFORMATION***  
**ABLEDATA**

8455 Colesville Road, Suite 935  
Silver Spring, MD 20910  
(800) 227-0216  
[www.abledata.com](http://www.abledata.com)

**American Association of People with Disabilities**

(888) 712-4672  
[www.aapd-dc.org](http://www.aapd-dc.org)

**The DRM Guide to Disability Resources on the  
Internet**

(516) 585-0290  
[www.disabilityresources.org](http://www.disabilityresources.org)

**Health Care Information Resources**

Spinal Cord Injury Links  
[www-hsl.mcmaster.ca/tomflem/spinalcord.html](http://www-hsl.mcmaster.ca/tomflem/spinalcord.html)

**National Center for the Dissemination of Disability Research  
Southwest Educational Development Laboratory**

211 East Seventh Street, Suite 400  
Austin, TX 78701-3281  
[www.ncddr.org/mscis/](http://www.ncddr.org/mscis/)  
[www.ncddr.org/mscis/map.html](http://www.ncddr.org/mscis/map.html)

**Paralysis Society of America**

801 Eighteenth Street, N.W.  
Washington, DC 20006-3517  
(888) 772-1711; TTY: (202) 973-8422

Fax: (202) 973-8421

[www.psa.org](http://www.psa.org)

**Paralinks**

[www.paralinks.net](http://www.paralinks.net)  
PoinTIS - Point of Care, Teambased Information  
System  
[www.calder.med.miami.edu/pointis/index.html](http://www.calder.med.miami.edu/pointis/index.html)

**Rehabilitation Research & Training Center  
The University of Alabama at Birmingham**

619 19<sup>th</sup> Street S., SRC-529  
Birmingham, AL 35249  
(205) 934-3283  
[www.spinalcord.uab.edu](http://www.spinalcord.uab.edu)

**Spinewire**

[www.spinewire.com](http://www.spinewire.com)  
[www.cando.com](http://www.cando.com)

**Warm Springs Resource Center for People with  
Disabilities**

[www.warmsprings.org/RCenter/informat.htm](http://www.warmsprings.org/RCenter/informat.htm)

***SUPPORT/SELF HELP***

Contact your local independent living center for  
information about independent living skills.

Centers for Independent Living (CILs) are programs  
of services for individuals with significant disabilities  
or groups of individuals with significant disabilities  
that promote independence, productivity, and quality  
of life. They are funded by the Rehabilitation  
Services.

**American Disabled for Attendant Programs  
Today**

PO Box 9598  
Denver, CO 80209  
(303) 333-6698  
[www.adapt.org](http://www.adapt.org)

**Friends' Health Connection**

(800) 483-7436  
[www.48friend.org](http://www.48friend.org)

**Independent Living Research Utilization**

2323 South Shepherd, Suite 1000  
Houston, TX 77019

(713) 520-0232

[www.ilru.org](http://www.ilru.org)

**International Ventilator Users Network (IVUN)**

(314) 534-0475

[www.post-polio.org/ivun.html](http://www.post-polio.org/ivun.html)

**NCIL - National Council on Centers for Independent Living**

1916 Wilson Blvd., Suite 209

Arlington, VA 22201

(703) 525-3406

[www.ncil.org](http://www.ncil.org)

Email: [ncil@ncil.org](mailto:ncil@ncil.org)

**National Spinal Cord Injury Hotline**

Hot Line and Peer Support

2200 Kernan Drive

Baltimore, MD 21207

(800) 526-3456

[www.scihotline.org](http://www.scihotline.org)

**Ventilator Use**

[www.familyvillage.wisc.edu/lib\\_vent.htm](http://www.familyvillage.wisc.edu/lib_vent.htm)

***WHEELCHAIR INFORMATION***

**Beneficial Designs, Inc.**

5858 Empire Grade

Santa Cruz, CA 95060-9603

(831) 429-8447

[www.beneficialdesigns.com/balans.htm](http://www.beneficialdesigns.com/balans.htm)

[www.beneficialdesigns.com/seatsys.htm](http://www.beneficialdesigns.com/seatsys.htm)

**The Family Village Waisman Center  
University of Wisconsin-Madison**

1500 Highland Avenue

Madison, WI 53705-2280

[www.familyvillage.wisc.edu/at/wc-seating.html](http://www.familyvillage.wisc.edu/at/wc-seating.html)

[www.familyvillage.wisc.edu/at/wheelchairs.html](http://www.familyvillage.wisc.edu/at/wheelchairs.html)

**A Guide to Wheelchair Selection: How to use  
ANSI/RESNA Wheelchair Standards to Buy a  
Wheelchair**

**Published by: Paralyzed Veterans of America**

SCI Education and Training Foundation

801 Eighteenth Street, N.W.

Washington, DC 20006

(800) 424-8200 ext. 609

**SpinLife**

(800) 850-0335

[www.spinlife.com](http://www.spinlife.com)

Name:	
Company:	
Address:	
City, ST, Zip:	
Work Phone:	Home:
Fax:	Mobile:
Other Contact:	Pager:
Phone:	Email:
Name:	
Company:	
Address:	
City, ST, Zip:	
Work Phone:	Home:
Fax:	Mobile:
Other Contact:	Pager:
Phone:	Email:
Name:	
Company:	
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Other Contact:	Pager:
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