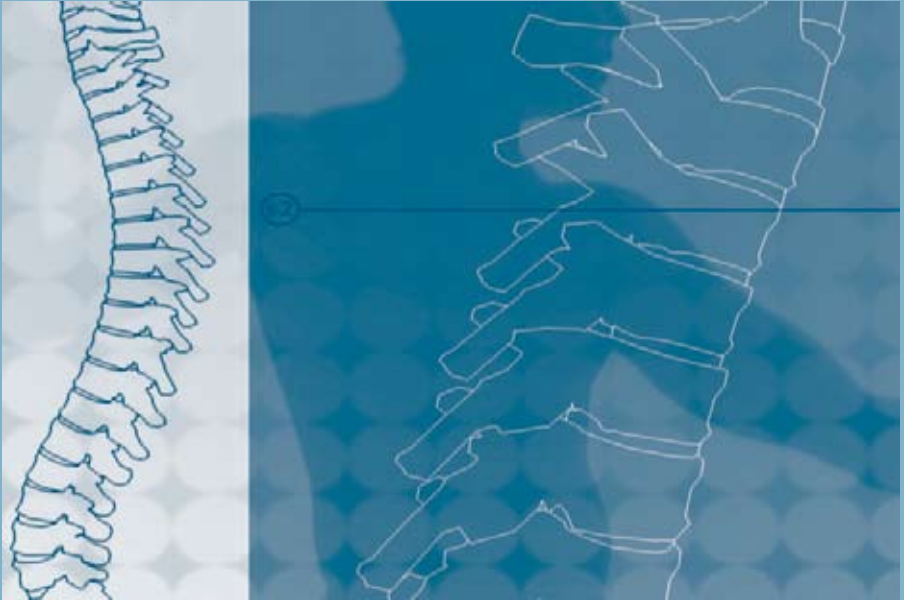


# **SPINAL CORD COMPRESSION (SCC)**

Information for adults with cancer  
and their caregivers



**If you're an adult with cancer,  
you are at risk for  
Spinal Cord Compression**

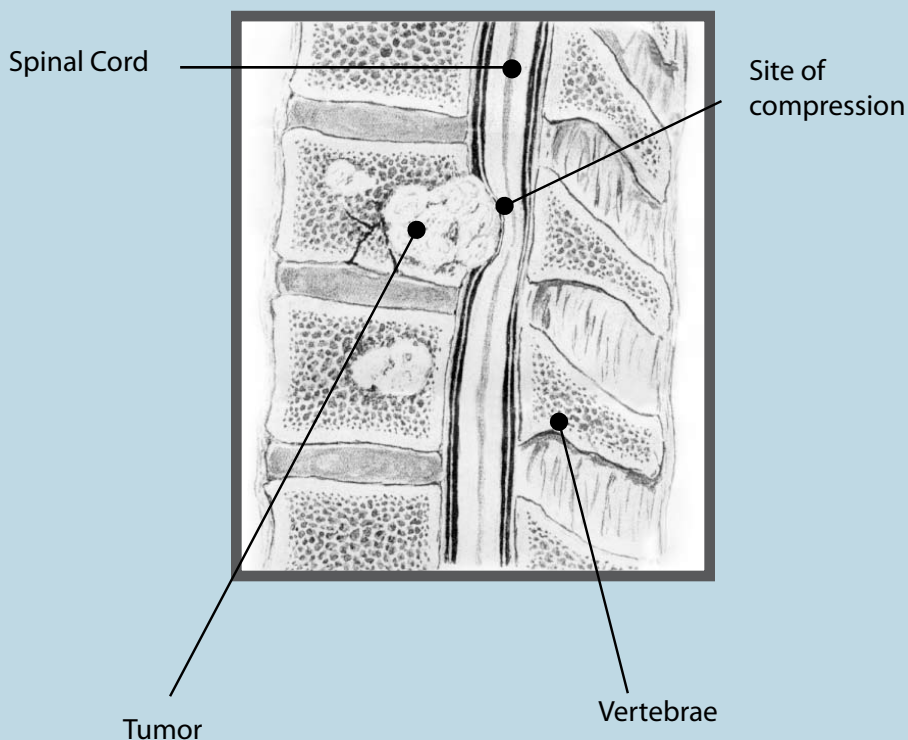


*This booklet will help you learn about SCC, its symptoms, diagnosis and treatment. Any adult who has been diagnosed with cancer is at risk for SCC.*



## What is Spinal Cord Compression (SCC)?

Spinal cord compression occurs when a tumor growing within the spinal canal presses the spinal cord against the bone. When this happens, nerves can be permanently damaged causing some patients to lose mobility or bladder control.



***Spinal cord compression is serious and requires immediate action.***

## Who gets SCC and why does it matter to you?

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If you are an adult with cancer, you are at risk for SCC. More than 25,000 people in the United States develop SCC each year. SCC can occur with every major type of cancer, especially prostate, breast and lung cancer. Any cancer can spread or **metastasize** to the spinal column, including non-Hodgkin's lymphoma, multiple myeloma, kidney and colorectal cancer. Most cases of SCC occur in patients who already have cancer. For some people SCC is the initial sign of cancer.

### Getting your Questions Answered

This booklet helps answer questions about spinal cord compression and discusses:

**Symptoms, diagnosis and treatment of SCC**  
**What you can do to protect your health**  
**How to find the support you need**

A glossary beginning on page 19, defines terms that may be new to you. These terms will appear in **bold**.

# SPINAL CORD COMPRESSION (SCC)

- 1**      **What are the symptoms of SCC?**
  - New back pain*
  - Pain*
  - Weakness*
  - Loss of bowel and bladder control*
  - Sensory changes*
  
- 3**      **What you can do**
  
- 5**      **Diagnosing spinal cord compression**
  
- 6**      **Treatment for spinal cord compression**
  
- 7**      **Stories about spinal cord compression**
  
- 13**     **Finding the support you need**
  
- 14**     **Symptom journal**
  
- 15**     **Understanding your spinal cord**
  
- 19**     **Glossary**

### **What are the symptoms of SCC?**

Spinal cord compression is a major source of suffering in cancer patients. You should know the warning signs and symptoms of SCC because early **diagnosis** is important. Treatment may stop SCC from getting worse. It is less common for treatment to restore a patient's lost function. Early treatment may prevent loss of **bladder** and **bowel** function and **paralysis**.

*New back pain is the most common warning sign of SCC.*

While back pain is the most common sign of SCC, other signs relate to the area of the **spinal cord** that is being compressed. Patients may have weakness in their arms and legs and **sensory** changes. These symptoms can progress to loss of bowel and bladder control, and loss of **sensation**. Paralysis or loss of movement may also occur. Symptoms can appear and get worse rapidly.

## ***Pain***

Most patients have pain by the time they find out that they have SCC. Typically pain increases in intensity over time. It may be worse when lying down. The pain may be different depending on what part of the spine is involved. For example, a gripping chest or abdominal pain is more common when the cancer involves the **thoracic spine**.

## ***Weakness***

A decrease in muscle strength is common. This kind of weakness is usually felt in the legs. The person may not have the strength to move one or both legs. A change in the ability to walk is common. Many patients have difficulty walking at the time of diagnosis.

## ***Loss of Bladder and Bowel Control***

Problems with bladder and bowel functions tend to happen later in SCC. Unfortunately, because SCC is often diagnosed at a late stage, about half of patients are **catheter** dependent at diagnosis. **Urinary retention** is the most common problem.

## ***Sensory Changes***

SCC may cause decreased sensation, numbness or tingling.

***Other symptoms*** include **erectile dysfunction** (impotence).

## WHAT YOU CAN DO

It is important for cancer patients to recognize the early warning signs of SCC and to discuss them with their healthcare providers in order to prevent or minimize the effects of SCC. You can do this *before* you experience symptoms of SCC. **If you experience any of the symptoms associated with SCC (see pages 1-2), report these immediately to your healthcare provider.**

**If you have cancer, you are at risk for SCC.**

**Talk about SCC with your healthcare team.**

**Be suspicious of SCC warning signs.**

**Don't wait! Report symptoms immediately.**

**Early treatment is *critical!***

**MRI is the best way to diagnose SCC.**

**Give this booklet to your healthcare team.**

## TAKE CHARGE

Keep your healthcare provider's phone number handy, including the number for after-hour emergencies. If you develop signs or symptoms of SCC and are unable to contact your healthcare provider, *go to the Emergency Room*. Spinal cord compression must be treated immediately to prevent permanent damage.

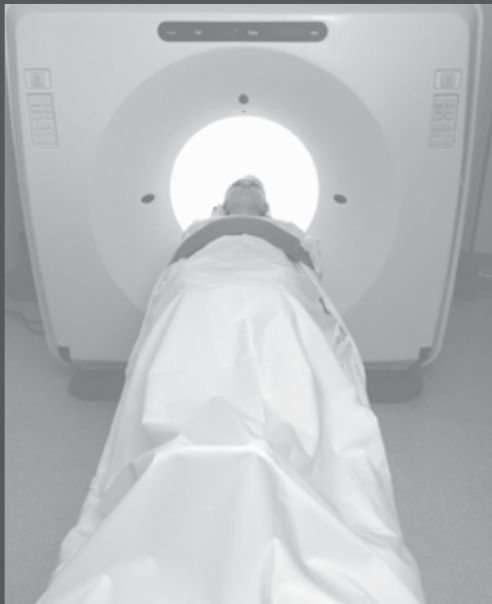
***Don't wait for your doctor to mention SCC; bring up the topic yourself.***



### **How is spinal cord compression diagnosed?**

If your doctor suspects that a spinal cord compression may be present, a **magnetic resonance image (MRI)** scan of the spine will be performed. If the MRI confirms a spinal cord compression, prompt treatment options will be presented by your doctor. Studies have shown that an examination and plain **x-rays** are inadequate in SCC diagnosis.

*The best possible treatment planning requires MRI diagnosis.*



## TREATMENT FOR SCC



Magnetic Resonance Imaging indicating SCC

( images contributed by Lubdha M. Shah M.D. )

Treatment may include surgery, **radiation therapy**, and **steroids**.

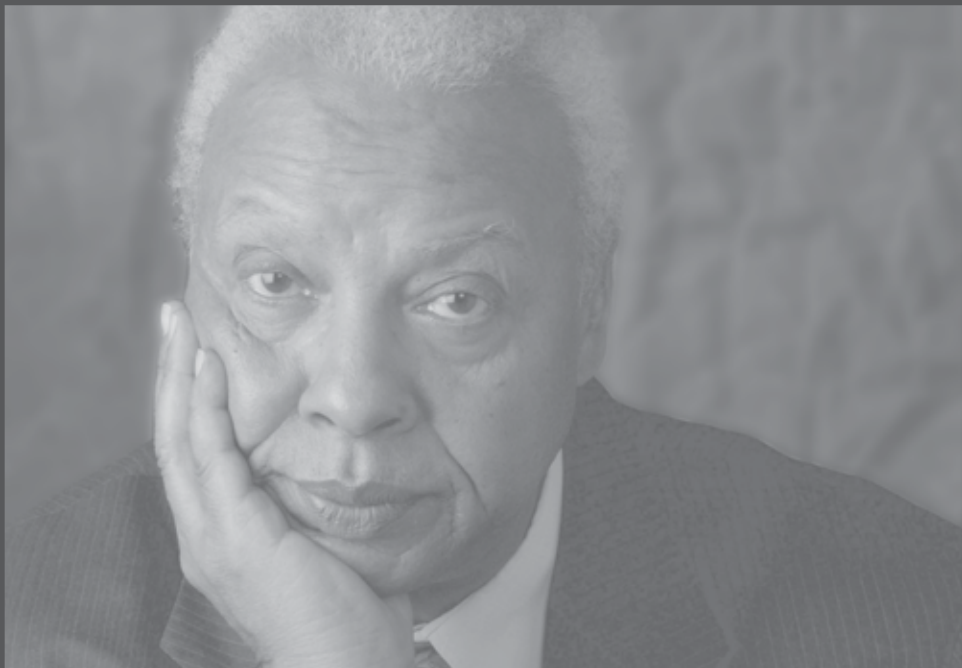
A neurosurgeon may recommend removal of the **tumor** pressing on the spinal cord. There are some factors that affect the decision to have surgery. If surgery is an option, radiation therapy may be given after surgery. If surgery is not advisable, **external beam radiation therapy** may be used to treat the tumor. Steroids may be used to decrease the swelling and pressure on the spinal cord.

## STORIES ABOUT SCC

### Ray, age 69, prostate cancer

Ray was diagnosed with prostate cancer two years ago. He noticed pain in his back which was unusual for him. At first, the pain wasn't too bad and he thought he probably pulled a muscle when he was playing in the yard with his grandchildren. But the pain persisted.

The pain didn't go away over several weeks time. In fact, it seemed to be getting worse, not better. Ray felt intense pain. It was worse when he was lying down. Ray didn't think his back pain had anything to do with his cancer, so he put off making an appointment with his doctor.



One morning when Ray woke up, his legs felt weak. He had tingling and numbness in his toes and lower legs. By the afternoon he was having trouble walking. That night he went to the emergency room where the physician ordered an MRI. From the MRI, doctors could see that Ray had a tumor in his **spinal canal** pressing his spinal cord against the bone.

After discussing treatment options with his physician, Ray decided to have surgery to remove the tumor. Ray was not able to regain his lost **mobility**, but he was able to retain bladder and bowel control. Ray's nerve damage may have been much less severe if he had seen his doctor at the first sign of back pain.

## WHAT YOU CAN LEARN FROM RAY'S STORY

Ray wasn't suspicious that his back pain was SCC.

Ray hadn't talked to his physician about SCC.

Not telling his physician about his symptoms right away may have resulted in more nerve damage for Ray.

## STORIES ABOUT SCC

### Susan, age 55, breast cancer

Susan was diagnosed with breast cancer at age 52. From the time of her diagnosis, she educated herself on the complications of cancer. She was aware of SCC and had discussed it with her **oncologist**. When she woke up with a sharp, gripping pain in her abdomen she paid attention, and although she was worried about what she might discover, she immediately made an appointment to see her doctor.

At her doctor's office, her health team conducted a thorough examination. After hearing her symptoms, Susan's doctor decided to order an MRI.



The MRI showed that she had spinal cord compression from a tumor in her thoracic spine. Surgery was not an option for Susan, but she had radiation therapy that was successful in alleviating her pain and preventing permanent **neurologic dysfunction**.

Susan did not lose mobility or suffer from severe nerve damage. She continues to have some sensory changes, but her quick actions have helped her.

## **WHAT YOU CAN LEARN FROM SUSAN'S STORY**

**Susan took a proactive approach to her health.**

**She discussed SCC with her oncologist before symptoms were present.**

**Both Susan and her oncologist were suspicious of the symptoms she reported.**

**Susan's physician made her diagnosis using MRI.**

**Susan took action and sought help at the first sign of her symptoms.**

## STORIES ABOUT SCC

### Cindy, age 42, lung cancer

Cindy lives in rural Virginia. At the time she was diagnosed with lung cancer, she was working part-time as a waitress in a local diner.

Cindy had just completed her last **chemotherapy** treatment cycle. Twice in one week, she stumbled and dropped trays while clearing tables at work. The second time this happened, she noticed that her legs felt numb. Her boss insisted she go to the emergency room and so a co-worker drove her there. The ER was busy and Cindy waited a long time to see the doctor. An MRI was not done, but an **x-ray** of her spine did not show any signs of a problem. Relieved, Cindy went home and took it easy for a few days.



Soon, Cindy experienced more weakness and numbness in her legs, along with back pain. She wondered if these symptoms had to do with her cancer. After a week, she made an appointment with her family doctor. At the visit, she talked about her symptoms and the trip to the emergency room. Her doctor was able to review her x-rays and agreed that everything looked normal. Cindy's doctor thought some of her symptoms might be **side effects** from her cancer treatment.

Within a month of her doctor's appointment, Cindy was unable to get out of bed. Her doctor had her transported to a larger city to have an MRI. There, a diagnosis of SCC was made. Sadly, by this time, Cindy had lost her ability to walk as well as her bladder and bowel control.

## WHAT YOU CAN LEARN FROM CINDY'S STORY

**Cindy sought medical attention promptly, yet her doctor failed to diagnose SCC.**

**An x-ray is not adequate to diagnose SCC. MRI is the best way to diagnose SCC.**

**Neither Cindy nor her family doctor were suspicious that her symptoms were SCC.**

**The extent of Cindy's suffering may have been decreased by early detection of SCC.**

Many patients have found these actions helpful: ***Ask friends or loved ones for support.*** Asking for support can be hard for some people. It may be easier to start by asking a friend or family member for specific help, such as going to your healthcare provider's office with you while you are learning about your choices in testing and treatment.

*Experiencing the symptoms of SCC can be scary.*

***Help your healthcare team to support you by asking questions.*** If you are confused by something, always ask for an explanation.

Remember that **primary care** doctors don't see many cases of SCC. ***Your family doctor may not suspect SCC*** even when you are experiencing SCC symptoms. Because oncologists see more SCC, they are more likely to suspect it.

# SYMPTOM JOURNAL

Immediately reporting signs and symptoms of SCC to your healthcare team is critical. Some people have found that keeping a symptom journal, or diary, can help. Here is an example to get you started.

PCP PHONE: \_\_\_\_\_

ONCOLOGIST PHONE: \_\_\_\_\_

EMERGENCY PHONE: \_\_\_\_\_

DATE: \_\_\_\_\_

SYMPTOMS I'M EXPERIENCING TODAY:

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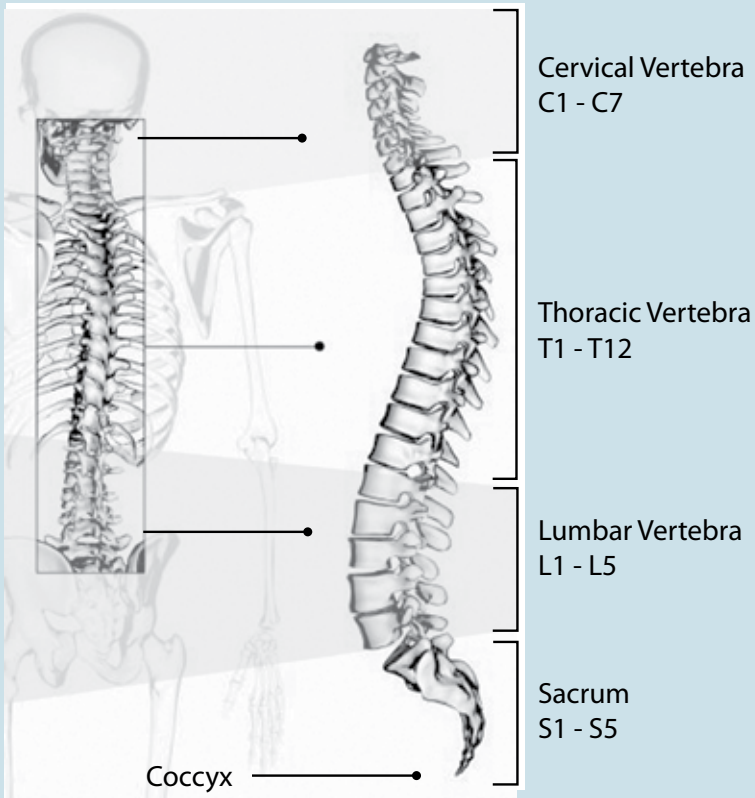
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# UNDERSTANDING YOUR SPINAL CORD



## REGIONS OF THE SPINAL COLUMN

The spine is an intricate set of bones, muscles, nerves and discs. The backbone (or vertebral column) is a stack of more than 30 small bones called **vertebrae**. These vertebrae are held together by muscles, tendons and ligaments. Between the vertebrae are intervertebral discs.

The discs are in the front part (anterior) of the spine. They allow movement, cushion shocks, and create a bony canal that surrounds and protects the spinal cord. The spinal cord begins at the base of the brain and runs down the spine to the lower back.

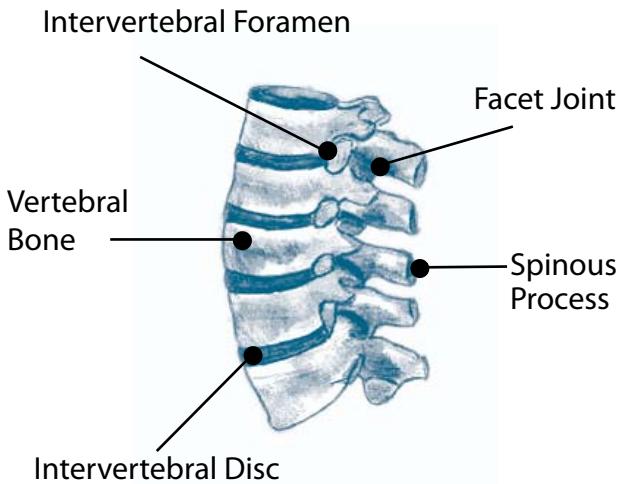
### The spine is divided into regions

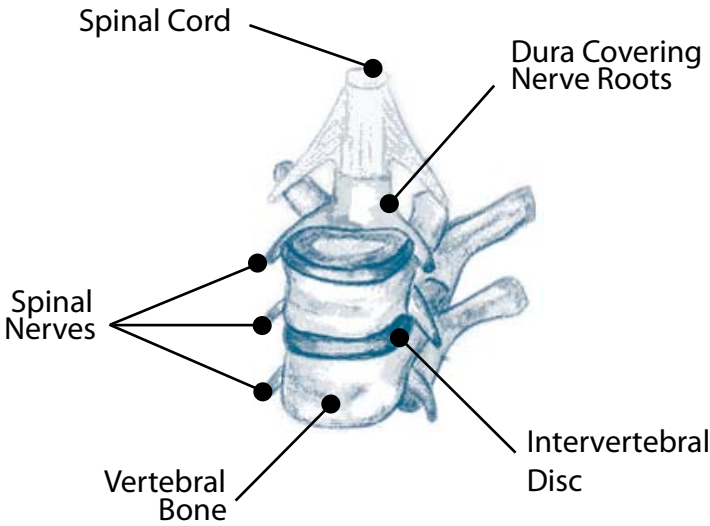
The spinal column consists of five regions: cervical (neck bones); thoracic (in the chest); lumbar (low back); sacral (attached to the pelvis); and, coccygeal (the tail bone).

The spine bones are often referenced with letters and numbers. C, T, L, and S refer to the cervical, thoracic, lumbar and sacral regions respectively. Within each region, the vertebral bones are numbered from the top down.

## UNDERSTANDING SPINAL CORD COMPRESSION

Spinal nerves exit the spinal cord through holes, called foramen, between the vertebrae. Each nerve goes to a specific area of the body. The nerves from the neck go to the arms. The nerves from the thoracic spine go to the chest wall and abdomen. The nerves from the lumbar spine go down the legs. The nerves control sensation and muscles. Some nerves regulate blood flow and internal organ functions.





If there is spinal cord compression the tumor may pinch a nerve. When a nerve is pinched the pain radiates along the path of the damaged nerve. If a nerve in the neck is pinched, pain in the arm is usually felt. If a low back nerve is damaged, there is usually leg pain. If a nerve is badly pinched, some of the muscles may become weak and there may be abnormal reflexes, loss of sensation, and even loss of bladder and bowel function.

**Bladder:** A hollow organ in the pelvis with flexible, muscular walls that stores urine as it is produced by the kidneys.

**Bowel:** One of the divisions of the intestines.

**Catheter:** A medical device that is a thin, flexible tube through which fluids enter or leave the body.

**Catheter dependent:** Requiring a catheter (tube) to drain urine.

**Chemotherapy:** Treatment with drugs to destroy cancer cells. Chemotherapy is often used with surgery or radiation to treat cancer when the cancer has spread, when it has come back (recurred), or when there is a strong chance that it could recur.

**Diagnosis:** Identifying a disease by its signs or symptoms, and by using imaging procedures and laboratory findings. The earlier a diagnosis of cancer is made, the better the chance for long-term survival.

**Erectile Dysfunction (ED):** A consistent inability to sustain an erection sufficient for sexual intercourse. Also commonly known as impotence.

**External beam radiation therapy (EBRT):** Radiation that is focused from a source outside the body on the area affected by the cancer. It is much like getting a diagnostic x-ray, but for a longer time.

**Metastasis/Metastasize:** The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.

**Mobility:** Capable of moving or walking.

**Magnetic resonance imaging (MRI):** A method of taking pictures of the inside of the body. Instead of using x-rays, MRI uses a powerful magnet and transmits radio waves through the body. The images appear on a computer screen as well as on film. Like x-rays the procedure is physically painless, but some people find it psychologically uncomfortable to be inside the MRI machine.

**Neurologic dysfunction:** Impaired or abnormal functioning of the nervous system.

**Oncologist:** A doctor with special training in the diagnosis and treatment of cancer.

**Paralysis:** Complete or partial loss of the ability to move a body part or loss of sensation usually as a result of nerve damage.

**Primary care physician:** The doctor that a person would normally see first when a problem arises. A primary care doctor could be a general practitioner, a family practice doctor, a gynecologist, a pediatrician, or an internal medicine doctor (an internist).

**Radiation therapy:** Treatment with high-energy rays (such as x-rays) to kill or shrink cancer cells. The radiation may come from outside of the body (external radiation) or from radioactive materials placed directly in the tumor (internal or implant radiation). Radiation therapy may be used to reduce the size of a cancer before surgery, to destroy any remaining cancer cells after surgery, or, in some cases, as the main treatment.

**Sensory/sensation:** Relating to the senses (hearing, sight, smell, touch, taste).

**Side effects:** Unwanted effects of treatment such as hair loss caused by chemotherapy, and fatigue caused by radiation therapy.

**Spinal canal:** Made up of bones, called vertebrae, which encircle and contain the spinal cord. Also called the vertebral canal.

**Spinal cord:** A thick cord of nervous tissue that is enclosed in the spinal canal. Pairs of spinal nerves go to the various parts of the trunk and limbs serving as a pathway for nervous impulses to and from the brain.

**Spinal cord compression:** When the spinal cord is pressed against the bone of the spinal canal. This can cause nerves to be permanently damaged.

**Steroids:** Any of numerous natural or synthetic compounds often prescribed by a physician to treat inflammation.

**Thoracic spine:** Refers to the 12 vertebrae located in the chest area. The ribs connect to the thoracic spine and protect many vital organs.

**Tumor:** An abnormal lump or mass of tissue. Tumors can be benign (not cancerous) or malignant (cancerous).

**Urinary retention:** Not able to urinate. This condition requires a catheter.

**Vertebra/Vertebrae:** Bony segments that make up the spinal column and enclose the spinal cord.

**X-ray:** One form of radiation that can be used at low levels to produce an image of the body on film or at high levels to destroy cancer cells.

## INFORMATION FOR PHYSICIANS

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*This booklet was first printed in August, 2006. The information presented here was drawn from the following literature:*

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## MORE INFORMATION

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The information contained in this booklet is not intended to constitute medical advice, diagnosis, or treatment. Decisions about medical diagnosis and treatment should *always* be made by a licensed healthcare provider. The SCC case examples presented here are the creation of the authors based on real-life stories about SCC. Any similarity of any clinical or personal description contained here to any identifiable person is unintended and entirely coincidental.



# SCC: TAKE ACTION FOR YOUR HEALTH

1

## BE AWARE !

If you have been diagnosed with cancer, you are at risk for SCC.

2

## TALK WITH YOUR DOCTOR

Don't wait for symptoms. Discuss SCC with your healthcare team *now*.

3

## BE SUSPICIOUS!

Immediately report any symptoms of SCC to your healthcare team.  
*Early detection is critical!*

4

## GET AN MRI DIAGNOSIS

*Don't rely on plain x-rays to diagnose SCC.*  
The best treatment planning requires MRI diagnosis.

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