

Respiratory Management Following Spinal Cord Injury: What You Should Know

**A Guide for People
with Spinal Cord Injury**

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This guide has been prepared based on scientific and professional information found in *Respiratory Management Following Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals* published in 2005. Users of this guide should periodically review this material to ensure that the advice herein is consistent with current reasonable clinical practice.

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**A Guide for People
with Spinal Cord Injury**

**Consortium for Spinal Cord Medicine
and Paralyzed Veterans of America**

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Introduction

Immediately after a traumatic injury to the upper spinal cord, most bodily functions are compromised by nerve-associated damage. Some functions may improve with time, whereas others, including the ability to breathe, may remain impaired. Consequently, many people who have suffered upper spinal cord injuries are unable to breathe on their own.

Fortunately, medical technologies enable an injured person to breathe with the assistance of various devices and/or treatments, such as diaphragm-pacemakers, antibiotics, physical therapy, and ventilators. As the injured person adjusts to the nerve damage incurred with the injury, some spinal cord functions *may* return (some people recover the ability to breathe for varying periods of time).

It is essential that people with spinal cord injury (SCI) work closely with their health-care team to determine the extent to which respiratory assistance will be needed and to choose the assisted breathing program that best fits their needs. The medical team will work with the injured person to ensure that breathing is carefully and continuously monitored. If required, breathing equipment can be installed and operated in the home for short- or long-term use. People with SCI are often more susceptible to such conditions as pneumonia or a collapsed lung; therefore, ongoing monitoring and education will allow for greater security, comfort, and independence.

This guide will answer many of the questions about respiratory health that may arise after a spinal cord injury. It will describe a variety of specialized treatments that people who have sustained a spinal cord injury may require to accommodate their respiratory needs.

Additionally, it is hoped that this guide will reassure people who are newly injured or have ongoing difficulties with breathing post-injury that there are safe and reliable methods available for dealing with these difficulties. It is always important for a person with SCI and their caregivers to talk with their doctors, nurses, and therapists to make sure all questions are answered satisfactorily.

Why Do People with SCI Need Assistance to Breathe?

A spinal cord injury involves damage to the nerves in the spinal column or backbone. High cervical injuries (in the neck) are injuries that are closer to the head and tend to cause more impairment than lower injuries because more of the body is paralyzed. High injuries to the spinal cord may damage the nerves that control breathing.

The chest muscles, the upper abdomen, and the diaphragm (the flat muscles across the bottom of the rib cage) work to move air through the lungs where the blood absorbs fresh oxygen and flushes out carbon dioxide. Air enters the respiratory system through the mouth and nose and passes through tubes in the lungs, called bronchi, which empty oxygen into small sacks called alveoli. As air passes through these sacks, the blood absorbs oxygen and eliminates carbon dioxide.

Breathing, like all bodily functions, is controlled by the brain. The brain is connected to the body by nerves that travel down through the spinal cord. Breathing is controlled by the “autonomic nervous system,” which means it is something people without SCI do automatically (without having to think about it). The nerves that carry breathing signals start in the upper part of the spinal column, in the back of the neck. If these nerves are injured, this “automatic” ability to breathe is lost. A person who has lost this ability must use technology to fill in for the damaged nerves to enable healthy breathing.

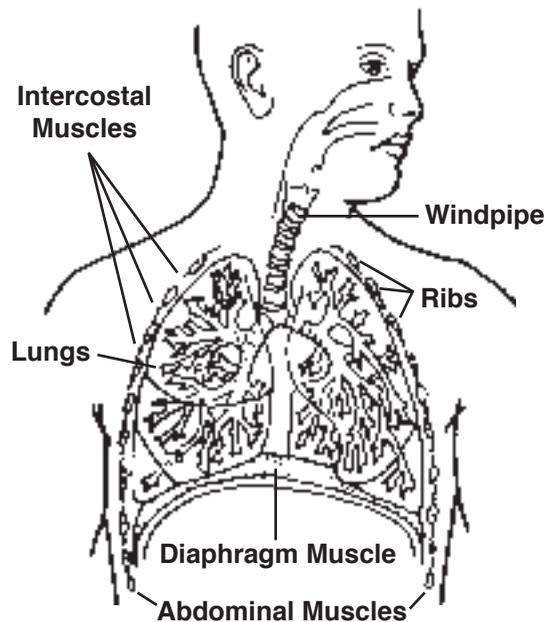
Many people with high-level injuries may recover some or all of their ability to breathe. How much is recovered and how long recovery will take depends on the extent of the injury and on how well the person responds to treatment.

How to Make Sure the Injured Person Can Breathe

When SCI prevents automatic breathing or the ability to cough hard enough to keep the lungs clear of mucus, a physician will prescribe mechanical methods to move air through the airways and lungs. To use a machine to breathe, a tube or a mask is required to carry air to the lungs. These breathing techniques can be somewhat complicated and will, at least initially, require full-time supervision. Only a physician can prescribe the correct breathing apparatus to achieve optimal oxygen intake and avoid medical complications. Likewise, only a physician will know if or when it is safe for a person who has had impaired breathing ability to breathe without mechanical assistance and when tubes and ventilators should be reconnected.

A ventilator (also known as a “vent”) is a type of air pump that gently pushes air into the lungs. A ventilator has controls that adjust how much air goes in and how much pressure is used.

Depending on the type and severity of the injury, the air from the ventilator might go through a mask or through a tube. A tube may go to the lungs through the mouth or through a tracheostomy (often called a “trach,” pronounced “trake”), which is an opening in the neck that leads directly to the trachea (commonly called the “windpipe”), which is located below the vocal cords. The health-care team will describe the process of getting a tracheostomy and caring for it so that it works correctly and is maintained properly.



**Anatomical Components
of the Respiratory System**



Breathing Using a Trach Tube

Some people can breathe well enough to use a mask instead of having to have a tracheostomy. In this case, the ventilator is adjusted so that it provides just enough pressure to allow the person to breathe in and out comfortably. The pressure to inhale can be set differently than the pressure to exhale depending on a person's needs.

If a person with SCI is unable to cough hard enough to keep the lungs and throat clear of mucus (or food or other objects), a suction catheter (a narrow tube used to remove mucus from the airway) or bronchoscope is needed to clear the airways.

A bronchoscope is a tube that a physician can use to reach into the airways and remove secretions that the suction catheter cannot reach.

What Is Assisted Coughing?

Assisted coughing, also known as “quad coughing,” is a method to help people with SCI clear their airways. Assisted coughing is extremely important, and anyone who assumes responsibility for monitoring the safe breathing of a person with SCI must be taught how to properly perform this function. Often, after injury, a person may not have the muscle strength to cough effectively or clear the breathing airways, which can lead to choking and even death. Therefore, it is extremely important for caregivers to get instructions from a health-care professional who is familiar with techniques for assisted coughing.

When looking for someone to teach effective assisted coughing, find a nurse or other professional who knows how to do it using the correct amount of force. Understandably, some people are afraid to use too much force for fear of hurting the

person with SCI. However, with practice, assisted coughing can be effective without causing harm. Caregivers should practice assisted coughing in the presence of a professional before trying it alone. Done properly, assisted coughing can be one of the most important aspects of helping a person with SCI who may be choking.

For more information about assisted breathing, see *Respiratory Management Following Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals*, Consortium for Spinal Cord Medicine, 2005. This publication is available at www.pva.org/cpgs.

Living with a High-Level Cervical Injury

High-level cervical spinal cord injuries (injuries near the base of the skull or neck) can be particularly dangerous and even life threatening, in part because of the resulting breathing problems. If breathing is not properly maintained or if effective coughing is not achieved, complications will occur. Therefore it is important to maintain ongoing discussions with health-care providers and to ensure that there is always adequate assistance available for effective breathing and coughing.

In the hospital, people with SCI depend on health-care professionals to monitor interruptions in breathing. For many people, these kinds of complications are less likely to occur as the body recovers and adjusts to changes in breathing. However, watchful monitoring of breathing patterns in a person with SCI is always important.

Some potential complications to discuss with the doctor include the following:

COLLAPSED LUNGS

When an individual has a high-level spinal cord injury, his or her breathing may be so weak that the air sacks (alveoli) in the lungs start to close. When the lungs do not fully expand, they lose the moisture and flexibility they need to work properly. If lungs dry out, they cannot expand; this can potentially cause a collapsed lung. Doctors may prescribe beta-agonists to open the tiny air passages in the lungs, thus helping to keep them moist and flexible and reducing the risk of a collapsed lung.

PNEUMONIA

Pneumonia is a bacterial infection of the lungs. Without good air circulation through the lungs, secretions accumulate, creating an environment in which bacteria can grow. Physicians may prescribe mucolytic medicines to moisten mucus secretions, making it easier for people to clear their lungs. Antibiotics may be prescribed to help fight off infection. Anyone with SCI should check with his or her health-care team to determine if and when pneumonia and/or flu shots are needed.

PULMONARY EMBOLISM

A pulmonary embolism is a blood clot that blocks an artery and stops blood from getting to part of the lungs. If a physician determines that there is a risk of a pulmonary embolism, blood-thinners may be prescribed to help blood flow more easily, thus reducing the risk of a clot.

ASPIRATION

“Aspiration” means inhaling something other than air; for example, when a person chokes on a piece of food that “went down the wrong way.” If a paralyzed person begins to choke on saliva, liquids, food, or vomit, and cannot clear the mouth and throat, these objects can get into the lungs where they will cause serious problems. People at risk of aspiration who cannot cough on their own may need a caregiver nearby at all times to induce coughing, and should check with their health-care team to determine the level of care that is needed.

Important Topics Related to Assisted Breathing

LEVEL OF INJURY

The extent to which a person with SCI will recover the ability to breathe without the use of a ventilator or with intermittent ventilator use depends largely upon where and how badly the nerves that control breathing were damaged:

- Above C3 – If the spinal cord injury is at a very high cervical level, all or most of the nerves that control the breathing muscles may be damaged. Unless a

diaphragm pacemaker (a device which is surgically implanted to help with breathing by using electrical stimulation) can be used, the ventilator will likely always be required.

- C3-C5 – A mid-cervical injury may leave some of the nerves needed to breathe intact. A person with this type of injury may be able to breathe without the ventilator—at least part of the time.
- Below C5 – With a low-cervical injury, people may not require a ventilator but may be at risk for future respiratory complications, thus making careful observation and regular follow-up care essential.

The decreased ability to cough and clear secretions from the airways puts people with SCI at increased risk of choking and pneumonia. This is something that always needs to be monitored—anyone with SCI should work with his or her medical team *before* making any changes to his or her breathing management program.

WEANING

In general, it is helpful for a person with SCI to try to breathe unassisted as much as possible, but always in **accordance with a doctor's instructions**. At first, breathing unassisted is usually only recommended for brief intervals until the muscles are strong enough to do the job without mechanical assistance. Working the breathing muscles for brief intervals may speed recovery. The more endurance the breathing muscles develop the less dependence the individual with SCI will have on machines.

In some cases, a ventilator may only be necessary for the first few weeks or months after injury because many people are able to wean off the ventilator after the spinal cord nerves have had time to heal. Weaning from the ventilator is hard work because strength and endurance must be rebuilt in muscles that have not been working on their own for some time.

The weaning process can be very frightening. People who have been depending on the use of a ventilator may feel like they will not be able to breathe or get enough air without the ventilator. It is very important to openly express any such concerns or fears. At this critical time, when trying to breathe without assistance, receiving support and understanding from health-care providers, caregivers, friends, family, and peers is especially important. It can be especially helpful for individuals to talk with others who have gone through the weaning process and who can share their experiences and provide pointers.

WEANING PROGRAM

Weaning is accomplished by breathing unassisted for short periods of time and gradually building up to longer periods of unassisted breathing if possible as the individual with SCI develops strength and endurance. An individual's medical team will prescribe the specific weaning program appropriate for that person. When the ventilator is off, the muscles used to breathe are exercised so they will gain strength. When the ventilator is turned on again, the breathing muscles can rest and recover. With practice, unassisted breathing can become possible for longer and longer periods of time. For some people, with enough time and effort, the ventilator may not be needed at all or may be needed for only specified periods of time.

PARTIAL WEANING

Some people with SCI are able to breathe on their own for specific periods of time, but still need to use a ventilator at other times. For example, a person might be able to breathe without assistance during the day and use the ventilator at night while sleeping or resting. In some cases, people may only be able to do without the ventilator for brief intervals during the day—this is still an advantage because it makes communication easier and provides a degree of safety in case something goes wrong with the ventilator (for example, if a tube becomes disconnected from the tracheostomy).

SPIROMETER

Individuals with some ability to breathe can exercise and strengthen their breathing muscles with a device called a “spirometer.” A spirometer is a plastic bottle with a ping-pong ball inside. The ball goes up when a person breathes into the bottle, giving an indication of breathing strength. The goal is to encourage people with SCI to work their lungs and breathing muscles as much as possible. The more the breathing muscles can do the less the risk of complications.

ABDOMINAL BINDER

Another helpful tool is an abdominal binder. An abdominal binder is a supportive belt-like device (similar to a girdle) worn around the abdomen to provide extra support where muscles are weak as a result of injury. An abdominal binder helps support the weight of the organs to relieve pressure on the diaphragm. This extra support makes it easier for the person with SCI to sit up. In time, the muscles may recover some of their strength and a person may be able to function without the binder. Abdominal binders are also used to stabilize blood pressure. It is important for people with SCI to talk to their health-care providers to be sure they understand how the abdominal binder is being used in their particular case.

FROG BREATHING

Frog breathing (also known as “glossopharyngeal breathing”) is breathing with the tongue and mouth muscles. This type of breathing requires getting a mouthful of air and “squeezing” it into the lungs. It is not something that is easy to *tell* somebody how to do, but it can be learned by watching as someone else demonstrates. However, when a person has an open trach tube, this type of breathing may not be possible.

DIAPHRAGM OR BREATHING PACEMAKER

Some people with paralyzed breathing muscles can use a diaphragm, or breathing pacemaker, instead of a ventilator during the day. The pacemaker is a battery-powered computer that sends signals to stimulate the diaphragm muscles. The placement of a breathing pacemaker requires a surgical procedure. After an appropriate training period, the diaphragm muscles may get strong enough to allow breathing without the ventilator during the day. Going back on the ventilator at night lets the diaphragm muscles rest during sleep. Pacemakers cannot be used in all cases; only a physician can determine if a pacemaker is a viable option depending on each individual's injury and the related nerve damage. If the lungs are healthy but the muscles needed for breathing are not strong enough to start weaning, doctors may test the phrenic nerves (nerves used to control breathing) to see if a pacemaker is an option.

Leaving the Hospital

Medical facilities that treat patients following SCI should have access to specially trained staff and a network of professionals and agencies that can help ease the transition from hospital to home. Homes often have to be modified to accommodate new equipment and to make it easier to move around in a wheelchair. Some items that will be needed in the home are an electric hospital bed, a power wheelchair, and a lift device for transferring between a bed and a wheelchair. Anyone using a ventilator should make sure there is sufficient respiratory equipment and supplies available at home. The array of devices and equipment depends on a person's particular physical condition and the level of help that will be received from family, friends, paid caregivers, and other support systems.

Respiratory equipment typically includes two portable ventilators and a variety of additional equipment:

- Emergency power supply—in case of a power outage
- Alarm systems—in case the ventilator fails or becomes disconnected
- Emergency call systems—to allow the person with SCI to call for help without a voice



Traveling Outside with Equipment

- Oxygen—to enrich inhaled air, if necessary
- Suction equipment—to clear the breathing airways
- Tracheostomy hygiene supplies—to properly maintain tracheostomies

An “insufflator/exsufflator,” often called a cough machine or coughlator, can be helpful for people with high spinal cord injuries. The cough machine blows air gently into the lungs and then sucks the air out quickly to clear the airways. It is more effective and less invasive than suction with a catheter. Use of a cough machine may reduce the risk of pneumonia by drawing mucus out of the throat and lungs. Cough machines can also be used to dislodge food or mucus lodged in the throat (when combined with assisted cough).

If a ventilator interferes with eating, additional equipment may be needed to help with nutrition (a doctor can explain the types of devices that may be available to help ensure proper nutrition).

Anyone who depends on ventilators and/or other mechanical devices to maintain the ability to breathe will probably need round-the-clock assistance. If friends or family members plan to be caregivers, they must be trained to operate the ventilator and other equipment. If friends or family are not available full time, a personal care attendant or a nurse will be needed in the home.

In Case of Emergency

CONTACTING LOCAL EMERGENCY SERVICES

Before going home from the hospital, be sure to contact local providers of emergency services (for example, the local fire department, local hospital/emergency room, EMT services, volunteer organizations, etc.) explain that a person with SCI who is dependent on certain mechanical breathing equipment will be living in their service area. Give them the individual's name, address, phone number, details about the equipment that will be in the home, and any special or unusual characteristics of the individual's particular situation.

CONTACTING LOCAL POWER SERVICES/COMPANIES

Contact the local power provider and ask what special services they provide to people who use power operated equipment (such as ventilators) on a daily basis. They may be able to install special backup generators or devices that alert them to power-related emergencies.

CALLING 911

Always call 911 in case of an emergency. When doing so, be very specific when describing the situation to the 911 operator. The emergency response team may need to bring special equipment or send special personnel—most important, be sure to relate the urgency of the situation so that they will respond as quickly as possible.

PAYING THE BILLS

Everyone's financial situation is different. Private or public insurance or other benefits provided by organizations in the community, such as state social services, vocational rehabilitation programs, social workers affiliated with the hospital or other health-care organizations may be available. Veterans will likely be eligible for services provided by the

Department of Veterans Affairs. Be sure to discuss potential resources with health-care and insurance providers.

Money will be needed for medical bills, equipment costs, supplies, home modifications, transportation costs, and caregiver services. The medical facility where the person with SCI is treated has staff that can evaluate his or her personal needs and family situation and provide information about the variety of available resources.

You can learn more about dealing with financial issues following spinal cord injury from the booklet “On the Move,” (National Endowment for Financial Education, 2002) which is published by the National Endowment for Financial Education, the National Spinal Cord Injury Association, and Paralyzed Veterans of America. Medical facilities should be able to provide this booklet; you can also get a copy (as well as other free publications) by calling PVA at 800-424-8200 or visiting the PVA website: www.pva.org/publications.

In Conclusion...

Although currently there is no cure for a spinal cord injury, someday there may be a way to restore or regenerate the nerves that were damaged. Scientists are working hard to find solutions and, ultimately, to cure SCI.

Our advice is to maintain a positive attitude and stay informed about the research that may lead to future treatments for paralysis. As scientists look for ways to repair spinal cord damage and to make living with SCI easier, some of the abilities that have been lost may be restored or improved.

Living with paralysis requires healthy daily habits that prevent respiratory complications, such as pneumonia.

People with weak breathing muscles should not smoke! One should always check with his or her personal physician before getting any vaccinations; the doctor may recommend getting flu and/or pneumonia vaccinations.

Caregivers are encouraged to help maintain a positive attitude and share that hope with the person for whom they are caring. Both caregivers and persons with SCI should try their best to stay healthy—physically, mentally, and emotionally.

The Consortium for Spinal Cord Medicine

The Consortium for Spinal Cord Medicine (the Consortium) was founded in 1995 with the goal of improving the quality of life for persons with spinal cord injury by making their care more evidence based—and, through concerted outreach efforts, bringing this knowledge to the widest possible audience. The professional health-care, payer, and consumer organizations that comprise the Consortium work in partnership with PVA’s research and education team to develop clinical practice guidelines (CPGs) for health-care providers and companion consumer guides, such as this one.

Paralyzed Veterans of America is proud to fund and administer the Consortium. We are honored to partner with this esteemed group to continue to provide groundbreaking guidelines that consolidate recommendations from the highest level of experts in the field of SCI.

For more information about the Consortium and PVA, please visit www.pva.org.

Acknowledgments

The Consortium for Spinal Cord Injury extends its sincere thanks to Charles James and Amelia Rolfes for providing their photographs for use in this consumer guide.

Glossary

Abdominal binder—A supportive belt-like device (similar to a girdle) worn around the abdomen to provide extra support where muscles are weak due to injury. It helps support the weight of the organs so as to relieve pressure, allowing less effort for sitting up, thus allowing easier breathing. Abdominal binders are also used to stabilize blood pressure.

Aspiration—Inhaling foreign matter into the lungs that must then be expelled. For persons with SCI this can be very dangerous if they do not have the muscle strength to cough up the foreign matter in order to clear their airways. In such cases immediate assistance is necessary.

Assisted coughing—Also known as “quad-coughing,” this is a method in which a caregiver assists the person with SCI to clear his or her airways by applying pressure below the ribs over the diaphragm while pushing upward. Assisted coughing is extremely important and must be taught by an experienced health-care professional.

Beta-agonist—A bronchodilator medicine that opens the airways by relaxing the surrounding muscles. Beta-agonists can be administered by inhalers or orally.

Bronchoscope—Flexible tube with a light that can be inserted into the trachea, allowing doctors to view the respiratory system.

Cervical spinal cord injury—A high injury (in the neck) that is closer to the head and tends to cause more impairment than lower injuries. High injuries to the spinal cord may damage the nerves that control breathing.

Collapsed lung—When lungs do not fully expand, they cannot retain the moisture and flexibility they require and the air sacks (alveoli) in the lungs start to close. If lungs dry out, they cannot expand—potentially resulting in a collapsed lung. Doctors may prescribe beta-agonists to reduce the risk of a collapsed lung.

Diaphragm pacemaker—A phrenic nerve stimulator that consists of surgically implanted receivers and electrodes connected to an external

transmitter by antennas worn over the implanted receivers. It provides ventilatory support for patients with chronic respiratory insufficiency. Also called breathing pacemaker.

Frog breathing, or glossopharyngeal breathing—a technique used to increase ventilation when respiratory muscles are paralyzed. Glossopharyngeal breathing coordinates movements of the tongue, cheeks, and pharynx to force air from the mouth into the lungs.

Glossopharyngeal—Relating to the tongue and pharynx.

Mucolytic—Capable of dissolving, digesting, or liquifying mucus.

Pulmonary embolism—A blockage of the pulmonary arteries, the arteries that carry the blood from the heart to the lungs, usually the result of a deep vein thrombus (blood clot from a vein) that becomes dislodged from and travels in one of the lungs.

Spirometer—A device used for measuring the volume of air inhaled and exhaled by the lungs. The spirometer records the amount of air as well as the rate of air that is breathed in and out over a specified period of time.

Suction catheter—Flexible tubes used to remove secretions from the airway and keep the airway clear of obstacles that would prevent breathing.

Tracheostomy—A tracheostomy is a surgical procedure that opens a direct airway through an incision in the trachea (the windpipe).

Ventilator—A ventilator (or “vent” for short) is a device that mechanically moves air into and out of the lungs. It provides the basic mechanism of breathing for patients who are unable to breathe or cannot breathe sufficiently.

Weaning—This is the stepwise process of slowly transferring the mechanisms of breathing from the ventilator back to the patient if his or her breathing muscles regain enough strength to inhale and exhale air without mechanical assistance or with limited mechanical assistance.

Resources

A. Books

Burns, S. P. & Hammond, M. (2009). *Yes You Can! A Guide to Self-Care for Persons with Spinal Cord Injury (fourth edition)*. Washington, DC: Paralyzed Veterans of America.

Dikeman, K. J. & Kazandjian, M. S. (2003). *Communication and Swallowing Management of Tracheostomized and Ventilator Dependent Patients (2nd edition)*. New York: Delmar Cengage Learning.

Tippett, D. C. (Ed.) (2000). *Tracheostomy and ventilator dependency: management of breathing, speaking and swallowing*. New York: Thieme Medical Publishers, Inc.

B. Organizations

American Association of Spinal Cord Injury Nurses (AASCIN)
www.aascin.org

American Association of Spinal Cord Injury Psychologists
and Social Workers (AASCIPSW)
www.aascipsw.org

American Paraplegia Society (APS)
www.aps.org

American Spinal Injury Association
www.asia-spinalinjury.org
404-355-9772

Association of Programs for Rural Independent Living
www.april-rural.org
330-678-7648

Canine Companions for Independence
www.caninecompanions.org
800-572-2275

Christopher and Dana Reeve Paralysis Resource Center
www.paralysis.org
800-225-0292

Disabled American Veterans
www.dav.org
859-441-7300

National Spinal Cord Injury Association
www.spinalcord.org
800-962-9629

Paralyzed Veterans of America

www.pva.org

800-424-8200 or 202-872-1300

Spinal Cord Injury Information Network University of Alabama
at Birmingham

www.spinalcord.uab.edu

205-934-3283

consortium for
 **SPINAL CORD
MEDICINE**
CLINICAL PRACTICE GUIDELINES



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