



Paralyzed Veterans
of America

Yes, You Can!

**A Guide to Self-Care for Persons
with Spinal Cord Injury**

FOURTH EDITION

EDITED BY:
Stephen P. Burns, MD
Margaret C. Hammond, MD



Paralyzed Veterans of America

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[Yes, You Can!]

**A Guide to Self-Care for Persons
with Spinal Cord Injury**

FOURTH EDITION

Here's to Your Independence!

The goal of rehabilitation is to help you design a lifestyle that will allow you to function as independently as possible within the realm of your ability. This manual has been put together to help you. It covers many things you learn while you are in the hospital. When you get home, the manual will serve as a resource for what you have learned. The information is there to answer any questions that may arise about caring for yourself. This manual does not replace your SCI clinic or physician. If you really get in a jam, call your nearest SCI center.

Foreword

Paralyzed Veterans of America is honored to present the 4th edition of *Yes, You Can!* Since its 1986 debut, *Yes, You Can!* has been a work of dedication and advocacy by the Spinal Cord Injury Service at the VA Puget Sound Health Care System in Seattle. The outcome of that dedication shows in this new edition with additional chapters and updated information, but shows most of all in the fact that *Yes, You Can!* is the most successful publication ever produced by Paralyzed Veterans. Literally, we can't keep a supply.

This new edition also was edited by Stephen P. Burns, MD, staff physician, and Margaret C. Hammond, MD, chief of service for the Spinal Cord Injury Service, VA Puget Sound. We must acknowledge this team for managing to secure returning authors and for soliciting new authors, more than 40 professionals. Even though Drs. Burns and Hammond were the editors for the 3rd edition, this new effort called for their steadfast hand through concept, solicitations, writing, editing, and the design process. Their stewardship and effort kept all the information focused on what helps a person with a spinal cord injury and his or her family live with this condition. The goal of full community integration following SCI hinges directly upon accessing and sharing knowledge and personal diligence. The principal goal of *Yes, You Can!* is to facilitate knowledge sharing.

This 4th edition has a new look and organization. Rather than the 27 chapters as appear in the previous edition, the 4th edition has four primary sections—How SCI Affects Your Body; Maximizing Your Function; Coping and Living with SCI; and Staying Healthy after SCI. Each section enumerates specific aspects that we know individuals frequently ask their clinicians about. All sections contain up-to-date information and supporting references so readers can pursue further discussion with their clinicians or support network. *Yes, You Can!* is a handy introduction and reference for life with spinal cord injury. This guide will help people with SCI expand their personal awareness and knowledge. And, finally, *Yes, You Can!* applies to all of levels of injury as well as time since injury. Our goal is that you will use this guide often and find the answers you seek to help you learn to live and thrive.

Paralyzed Veterans of America
February 2009

Acknowledgments

We first wish to thank all of the contributors to this fourth edition of *Yes, You Can!* Most authors of the current and prior editions have been members of the Spinal Cord Injury Service staff at the Veterans Affairs Puget Sound Health Care System (VAPSHCS) in Seattle, Washington. We also want to thank those individuals from outside VAPSHCS who wrote or edited chapters for this edition: Rosemarie Rossetti, Teresa Valois, Theresa Boyd, and Daniel Jones. Also, many of the chapters in the current edition contain information that has been modified from earlier versions written by different authors. For all but the new chapters, it would be unfair to attribute authorship to any single individual, and we thank those prior contributors.

Much of what we know about spinal cord injury (SCI) comes from our experience treating patients on our SCI unit over the past 25 years, and we wish to acknowledge those veterans with SCI who have contributed to the knowledge and expertise of the authors. We also acknowledge the continuing support of patient education and health promotion for persons with SCI that has been provided by VAPSHCS and the Department of Veterans Affairs. The views expressed in this work are those of the authors and do not necessarily reflect the views or opinions of the Department of Veterans Affairs.

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Because so many people and organizations have contributed to the current and three prior editions of *Yes, You Can!*, we apologize if we have inadvertently failed to recognize someone's contribution. Finally, we would like to acknowledge the tremendous support and guidance that have been provided by Paralyzed Veterans of America for the three prior editions of this book, as well as for this new edition.

- Stephen P. Burns, MD, Editor, 4th edition
- Margaret C. Hammond, MD, Editor, 4th edition

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How SCI Affects Your Body

What happens to the body when the spinal cord is injured? The first thing most people notice is that muscles in the legs or arms become weak or completely paralyzed. This happens because the spinal cord normally carries signals from the brain to the muscles, allowing you to move. However, spinal cord injury [SCI] affects much more than the strength of arm and leg muscles. The spinal cord carries signals of feeling from the body to the brain. It also helps control parts of the body that work automatically, like the bladder, bowel, and even the heart. When these things do not work correctly, serious medical problems can develop. Because all these body functions rely on the spinal cord, you need to understand how your SCI has affected your body and become an expert on how to take care of yourself so you can maximize your function, enjoy life, and stay healthy.

1.a | Anatomy, Physiology, and Research

Even though the brain controls the activities of the whole body, it only extends down to the top of the neck. Below that, the spinal cord carries messages between the brain and your body. Your face has a direct connection to the brainstem, so it is independent of your spinal cord.

The spinal cord looks like a long rope about the width of your little finger. It runs from the base of your brain down to the lower part of your back, and it is fragile. Spinal cord injury [SCI] can lead to loss of movement and feeling. It can also affect how your brain controls your internal organs. When your spinal cord is injured, parts of your body below the level of the injury are affected.

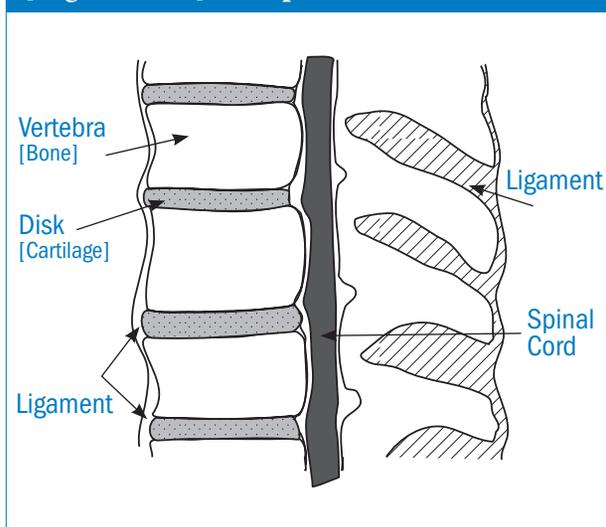
The spinal cord is protected by your backbones [your spine]. The backbones are 29 small bones stacked on top of each other. These bones are called vertebrae. To allow your back to bend and to lessen jarring, each vertebra is cushioned from the next by disks. Disks are made of a spongy material and act like shock absorbers. Ligaments hold the vertebrae together and allow your neck and back to twist and bend.

Each vertebra has a hole in it—a hard, bony tunnel through which the spinal cord passes. This is the spinal canal. It protects the spinal cord from damage. The vertebrae and disks, held together by ligaments, are called the spinal column [SEE FIGURE 1.a.1].

Your spine has four sections. The top is the *cervical section*, which is your neck. The next down is the *thoracic section*, which extends from your lower neck to your lower ribs. The *lumbar section* is your lower back, and the *sacral section* is your tailbone [SEE FIGURE 1.a.2]. Your sacral section is really only one bone, with five nerve pairs coming out through holes in it.

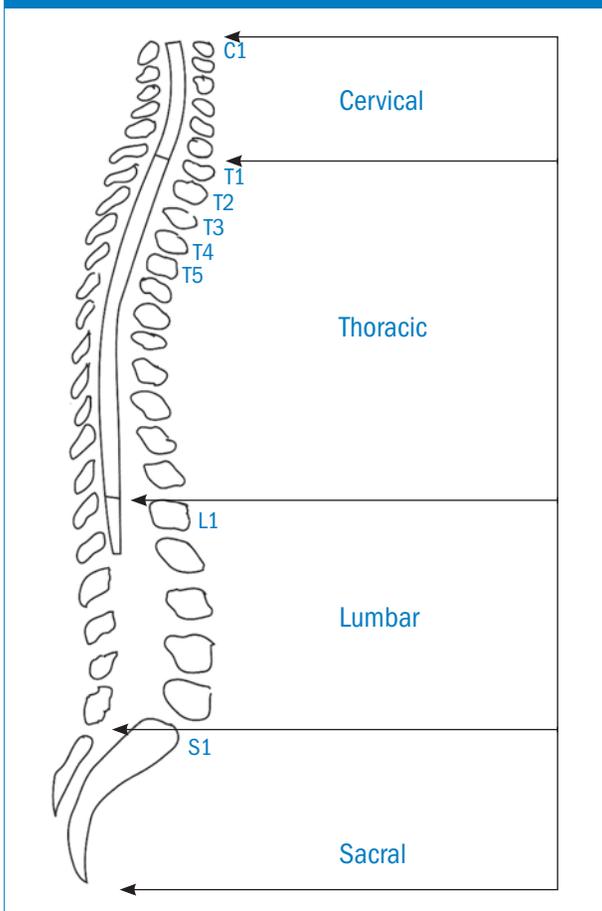
The cervical section contains eight pairs of nerves and seven vertebrae. The nerves numbered C1 through C7 exit from the spine above the corresponding numbered vertebrae, and the C8 nerve pair exits between the C7 and T1 bones on each side. For the thoracic and lumbar sections, each of the numbered nerves lies below the corresponding numbered vertebra. There are 12 thoracic nerves and 5 lumbar nerves on each side.

[Figure 1.a.1] The Spinal Column



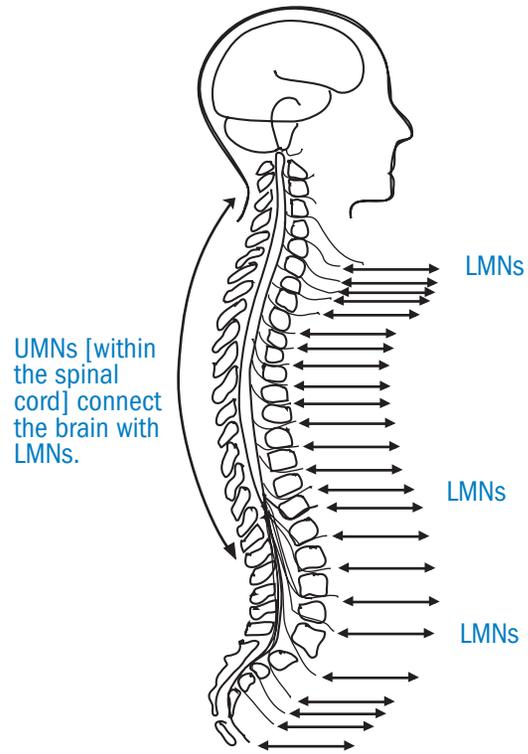
At the lower end of your spinal cord [below the second lumbar vertebra], the nerves travel long distances before they exit the spine. This is because the spinal cord itself ends much higher, at about the level of the L1 vertebra. The lower lumbar and sacral nerves look like a horse's tail inside the spinal column. In fact, this area is known as the *cauda equina*, which means “horse's tail” in Latin.

[Figure 1.a.2] The Spinal Cord



[Figure 1.a.3] Spinal Nerves

LMNs connect the spinal cord [UMNs] with muscles, blood vessels, glands, organs, etc.



How the Spinal Cord Functions

The spinal cord is the communicating link between the spinal nerves and the brain. The long nerve fibers inside the spinal cord are called the upper motor neurons [UMNs]. They run between the brain and the spinal nerves. The spinal nerves branch out from the spinal cord into the tissues of your body. Spinal nerves are called lower motor neurons [LMNs] [SEE FIGURE 1.a.3].

In movement, the brain sends messages through the spinal cord [UMNs] to the spinal nerves [LMNs]. The LMNs then carry these messages to the muscles to coordinate movements, such as walking. In this way, the brain controls movement.

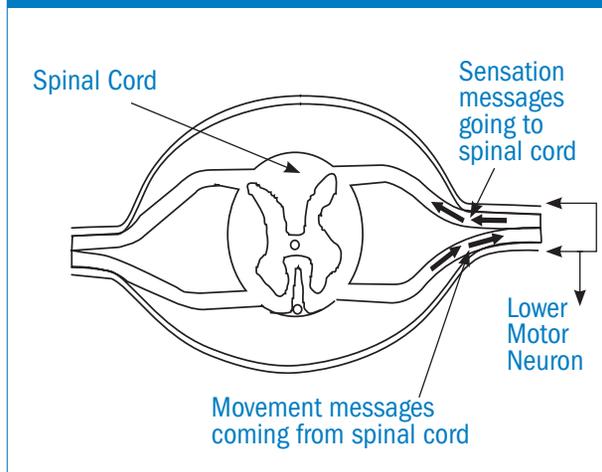
In sensation, nerves in your body collect information and send it up the spinal cord to the brain. This allows you to be aware of feelings, such as heat, cold, touch, or pain.

You may wonder how the spinal cord keeps these messages from getting confused, with all the running back and forth between brain and body. The motor nerves and the sensory nerves carry messages in different nerve fibers. Within the spinal cord, the nerve fibers are combined into groups called spinal tracts. Each tract carries messages one way, either up for sensation or down for voluntary movement. They are similar to the lanes on a freeway [SEE FIGURE 1.a.4].

What Is a Spinal Nerve and What Does It Do?

Each spinal nerve has two main parts. One part carries information related to movement from the spinal cord to the muscles. It is called a motor nerve. Each motor nerve connects to a specific muscle. Each level of the spinal cord causes movement in a certain group of muscles.

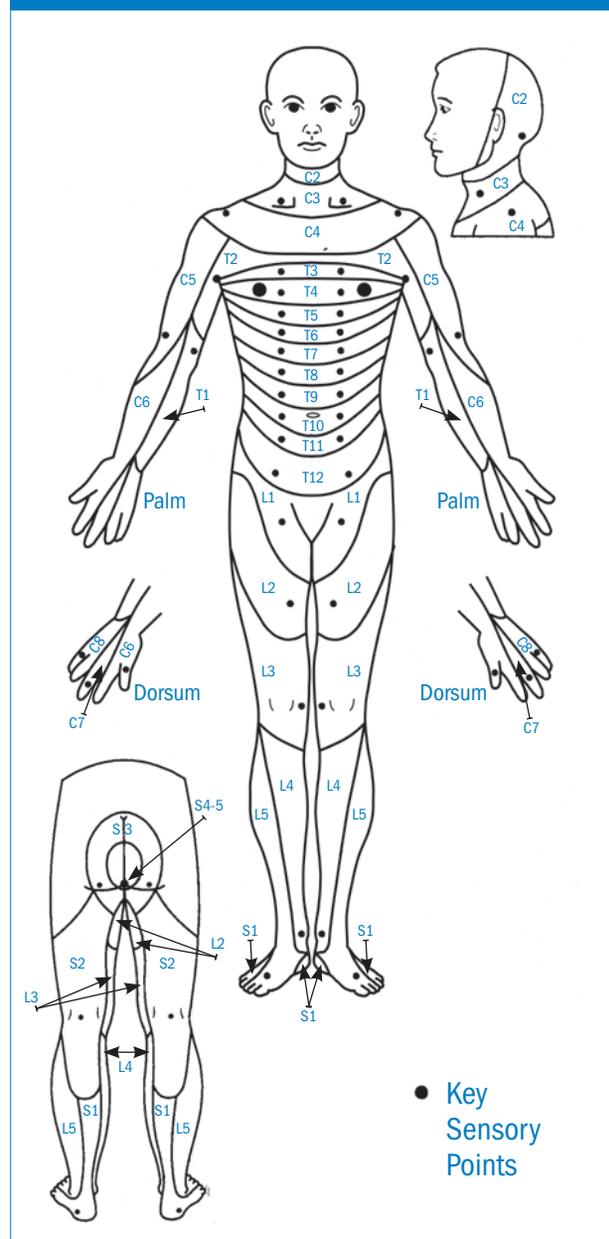
[Figure 1.a.4] Spinal Tracts for Nerves



The other part of the spinal nerve carries messages of feeling, such as heat and cold, from the body to the spinal cord. It is called a sensory nerve. Different types of sensation or feeling are carried up the spinal cord to the brain. These include pain, touch, heat, cold, vibration, pressure, and knowing where a body part is located in space without looking at it.

Each sensory nerve collects information about feelings from a given body part or area of skin. Each skin area is called a dermatome and matches a specific spinal cord level [SEE FIGURE 1.a.5]. Try to identify areas where you have normal sensation and where you do not.

[Figure 1.a.5] Map of Dermatomes



Spinal Cord Injury

Many types of injuries and diseases can cause spinal cord injury or dysfunction. If the space for the spinal cord [spinal canal] becomes narrowed, the spinal cord can become injured. This can happen when bones in your back or neck are broken, or when ligaments are torn and the vertebrae move in different directions.

Gunshot wounds, stab wounds, or fragments from explosions can directly damage the cord without much breaking of the bones. Infections and tumors near the spine can compress the spinal cord. Sometimes, arthritis can affect the bones and slowly compress the cord. Finally, the blood supply to the spinal cord can be blocked, causing part of the spinal cord to die. [This is similar to how a stroke affects the brain.]

Damage to your spinal cord can cause changes in your movement, feeling, bladder control, or other bodily functions. The changes depend on where and how badly your spinal cord was injured. The main problem is that the connection between your brain and your body below the injury is impaired or broken.

A numbering system is used to name levels of injury. It's the same as the system used to name bone and nerve levels in your back. A spinal cord injury is named for the lowest level of the spinal cord that still functions the way it did before the injury. It is important to your rehabilitation that you know your level of injury and how it affects your body. The level of spinal cord injury is not always the same level as where the spine was injured. When the spinal cord injury is at a cervical level, it is called "tetraplegia" or "quadriplegia." When it is at a lower level [thoracic, lumbar, or sacral], it is called "paraplegia." Most of the nerve supply to the arm and hand comes from cervical nerve roots. This means that people with tetraplegia have some numbness or weakness in their arms or hands. Paraplegia does not affect the arms or hands.

Complete and Incomplete SCI

If there is no voluntary movement [spasms don't count—they are involuntary] and no feeling below your spinal cord injury level, you have a complete injury. If you have some feeling or

voluntary movement below your injury, you have an incomplete injury. This happens when there is only partial damage to your spinal cord; that is, some nerve fibers are still working across your spinal cord injury site.

UMN and LMN Injuries

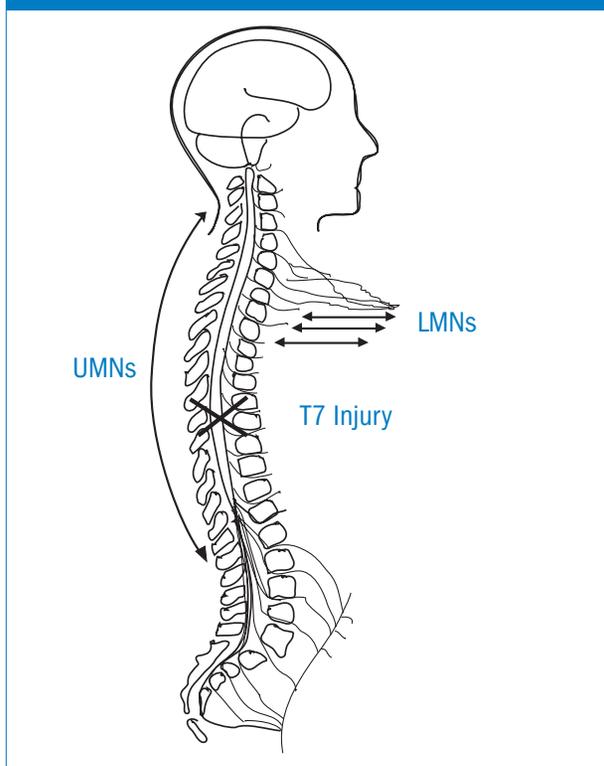
Earlier in this section, we discussed the difference between upper motor neurons [UMNs] and lower motor neurons [LMNs]. A complete injury cuts or affects all the UMNs running down the spinal cord. This disrupts the connection between the brain and the parts of the body below the injury. However, the LMNs below your spinal cord injury are not damaged. Because LMNs carry reflex actions, the reflexes below the level of injury are still working. This is a UMN injury [SEE FIGURE 1.a.6].

So the LMNs are still carrying out reflex actions below the level of injury, but this may cause a problem. In reflexes, the brain normally controls how much your nerves react. In a UMN injury, messages from the brain can't get past the point of injury, so the LMNs act by themselves, which may cause reflexes without limit. One example is spasticity, which is uncontrolled movement of your arms or legs. [For more about spasticity, see section 1.g, *Muscles and Bones.*]

LMN injuries are a different story. This kind of injury is usually at the lower tip of the spinal cord [the cauda equina]. The cauda equina is made up entirely of LMNs, so damage to it impairs reflex actions, although other UMNs and LMNs above the injury are still working [SEE FIGURE 1.a.7]. Spasticity does not occur with LMN injuries because the muscles no longer have any nerve contact to stimulate them.

Stated simply, a UMN injury is one in which the UMN pathway is broken, the LMNs below the injury are intact, and spasticity usually occurs.

[Figure 1.a.6] Upper Motor Neuron Injury



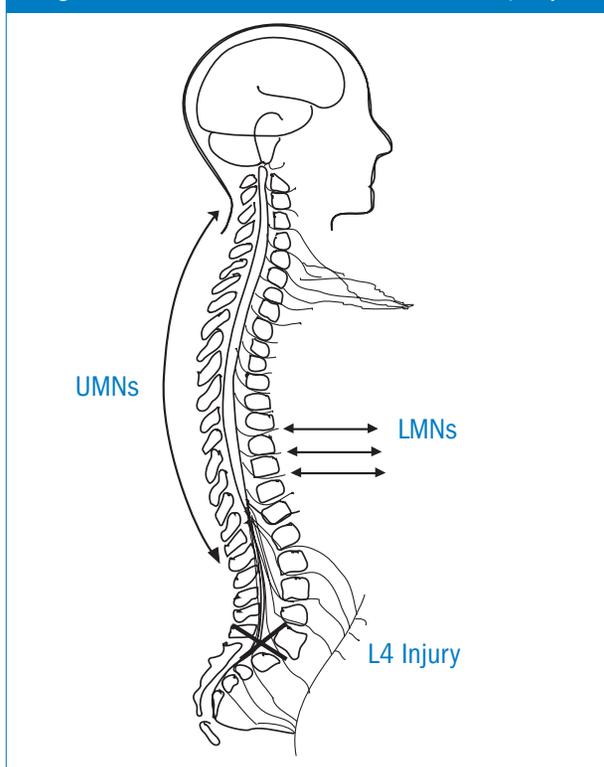
An LMN injury, usually at the cauda equina, blocks nerve activity in muscles controlled below the injury, and no spasticity develops. It is important to know which kind of injury you have because that will determine how it is managed.

Recovery

Immediately after a spinal cord injury, the spinal cord stops doing its job for a period of time—this is called “spinal shock.” All the reflexes below the level of injury are absent during this period, which may last for a few days to several weeks. The return of reflexes below the level of injury marks the end of spinal shock. Often with an LMN injury, reflexes never return.

If you have an incomplete injury, some feelings and movement may come back. Will this happen to you? No one can say. If you do regain some feeling and movement, it will likely start happening in the first few weeks after your injury.

[Figure 1.a.7] Lower Motor Neuron Injury



Rehabilitation begins immediately. You will learn strengthening exercises, new ways to use the muscles that are still moving, and how to use special equipment to achieve more function. If you recover more feeling or movement, your rehabilitation team will develop new goals with you.

Regeneration Research

The dream of spinal cord clinicians and researchers is to regenerate the injured spinal cord. Much progress has been made in the past 25 years, and some partial regeneration is possible in animals with spinal cord injury. Spinal cord nerve fibers can regrow if they have the proper stimuli to make the nerves grow and to guide where they go. But these treatments are not yet available for humans. Nerve cells would have to regrow for much longer distances in humans than they do in rats. Even after axons regrow in animals, they

have difficulty making new connections. And some research animals that receive experimental regeneration treatments develop severe nerve pain [neuropathic pain].

Some physicians outside the United States offer experimental treatments to people with SCI. Many of these involve cells and treatments that seem to help small animals recover after SCI. One treatment involves injecting olfactory ensheathing glia [cells that help nerve cells in the nose] or stem cells into the spinal cord, in a surgical procedure that costs tens of thousands of dollars. There is little or no scientific support for using these treatments in humans. Some complications, like spinal infections, happen frequently after some of these surgeries, and some surgeons do not explain these complications in advance to patients. You should consider waiting until the treatments have a better chance of helping you and less of a chance of causing harm. What are the chances you will lose strength and sensation or develop severe pain? Also, if you receive one of these treatments now, you may not be eligible to have other treatments in the future. When you hear of a new treatment, gather as much information as you can and then discuss it with an SCI physician or SCI researcher to determine whether it is something you should consider. *[See the ICORD resource at right for a list of factors to consider before participating in an experimental treatment or a clinical trial.]*

RESOURCES

The International Collaboration on Repair Discoveries [ICORD] has a free booklet titled *Experimental Treatments for Spinal Cord Injuries*. It contains a summary of experimental approaches to treat SCI, as well as information that you should know if you are thinking about participating in a clinical trial [www.icord.org/iccp.html].

Leading research journals require scientists to register their clinical trials before they begin. ClinicalTrials.gov provides regularly updated information on federally and privately supported clinical research using human volunteers. The website gives you information on a trial's purpose, who may participate, locations, and phone numbers for more details. Enter the search term "spinal cord injury" to find studies of spinal cord regeneration, spasticity, pain, and other conditions. www.clinicaltrials.gov

1.b | Skin Care and Pressure Ulcers

What Skin Does

The three main functions of your skin are protection, sensation, and temperature regulation. Your skin performs these functions for all your body structures and tissues, including layers of fat, muscles, and bones [SEE FIGURE 1.b.1].

Your skin serves as a shield against most chemical and physical agents, such as bacteria, dirt, foreign objects, and ultraviolet rays from the sun. The sensations of touch, pain, pressure, and temperature travel from nerve endings in your skin through the spinal cord to your brain. A major function of the skin is to regulate your body temperature. Sweat glands are always producing water and salts, changing the fluid content of your body. When liquid from your sweat glands evaporates, it helps maintain a stable body temperature. Your body can change the amount of blood that goes to your skin, and this also helps to control body temperature.

Table 1.b.A shows how these skin functions are affected by SCI and what you need to do to prevent problems. It also shows how edema [excess fluid in the skin layers] occurs after SCI and how it can be minimized.

Skin Care

Nutrition for the Skin

Protein, calories, vitamins, and minerals are all needed to maintain healthy skin. These nutrients can be obtained by eating a well-balanced diet and a variety of foods. [For tips on how to eat a well-balanced diet, see section 4.b, *Nutrition and Weight.*]

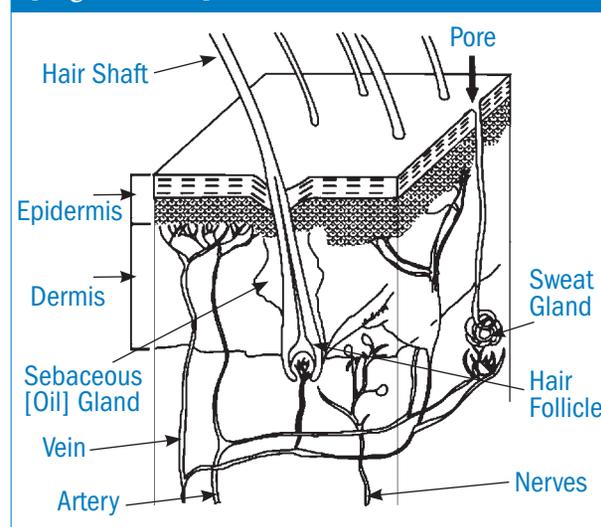
Weight Control

Weight control is another area of concern for skin care. Maintaining an appropriate weight for your height may help lower the risk of skin breakdown. [See section 4.b, *Nutrition and Weight*, to get an idea of the right weight for you.] How can being overweight cause skin problems? You might have difficulty protecting your skin when you're moving between your bed and your wheelchair, or it may be more difficult to relieve the pressure on your skin. If you've gained weight, your wheelchair or other equipment may no longer fit you correctly. Being underweight can also cause problems. You might have less padding over bony areas where pressure ulcers most commonly form. Being underweight may mean you are malnourished, which makes it easier to injure your skin and harder to heal skin problems.

Basic Hygiene

Daily bathing is encouraged during your younger and middle years. As you age, your skin becomes drier, so daily whole-body cleaning is not recommended for older people with SCI. Of

[Figure 1.b.1] Skin



[Table 1.b.A] How Skin Is Affected by SCI and How to Prevent These Problems

FUNCTIONS	CHANGE	YOU NEED TO
Protection	No change.	Avoid breaks in your skin.
Sensation	Decrease in or no feeling of touch, pain, pressure, and temperature below the level of your SCI.	Substitute specific protective habits to prevent injury to skin and underlying tissues; for example, perform pressure releases when sitting in your wheelchair, avoid applying hot packs to skin that doesn't have feeling, wear appropriate clothing outside when it is cold.
Temperature Regulation	Less sweat to evaporate and cool you below the level of your SCI.	Control temperature of your environment [stay out of sun, use air conditioning]. When in the sun, drink plenty of fluids.
	May have excessive sweating above the level of your SCI.	Bathe more frequently. Possibly take medication to control sweating and/or use antiperspirant in skin folds.
Fluid Regulation	Lack of voluntary muscle action below the level of your SCI can produce edema, swelling of the tissues due to pooling of fluids	Elevate swollen parts to reduce/control. Wear compression stockings.

course, skin should be washed any time it is soiled, and such areas as armpits and groin need daily cleaning.

Hygiene Tips Specific to SCI

Sitting in a wheelchair all day long with your legs close together doesn't allow air to circulate in the groin and buttocks areas. Also, unusual sweating patterns and poorly controlled bowel and bladder function may cause excess skin moisture. The following are some hygiene tips:

- Wash your groin area twice a day, in the morning and again before going to bed at night.
- Air out your groin area at least once a day by getting into the frog position [heels together, knees apart] for at least 20 minutes.
- Always thoroughly dry your groin area after bathing.

- If you use powder, *lightly* dust some on your groin area. Too much powder can cake and lead to irritation and splits in your skin.
- You might try using a stick antiperspirant along your groin creases to control excess moisture. If you have trouble with groin rashes, talk to your health-care provider about prescription-strength antiperspirant and antifungal medicine.
- Clean your urine-collecting equipment every day. [For more information, see section 1.d, *Bladder Management.*]
- Apply lotion daily to areas of dry skin, except between your toes. Dry skin can crack open.
- Dry carefully between your toes after bathing.
- Keep your toenails short to prevent them from catching on things or scratching your other leg. But don't trim too far down the sides of the nail. If you're developing ingrown toenails, ask your health-care provider or see

a podiatrist for recommendations on how to cut your nails.

- It may be easier to trim your nails after soaking them for 15–20 minutes or after taking a shower.
- Thick nails may need to be cut by a podiatrist or nurse.

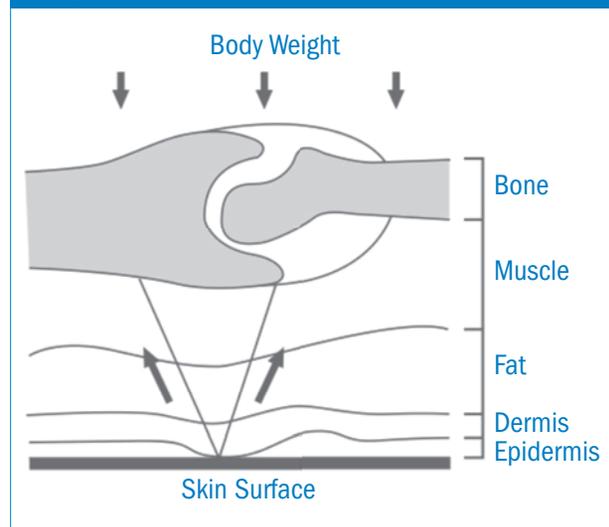
Why You Should Worry about Pressure

You need adequate blood circulation to keep the cells of your skin and body tissues alive. When your circulation is cut off for a prolonged time, cells die and pressure ulcers develop. Pressure ulcers are also called pressure sores, decubitus ulcers, or “decubes.” Pressure ulcers can be caused by a large amount of pressure applied to the skin for a short period of time or less pressure on the skin over a longer period. Sometimes people with other medical problems—like poor nutrition, diabetes, peripheral vascular disease, or an illness that requires hospitalization—develop pressure ulcers very quickly with only a small amount of pressure.

The harmful pressure usually comes from sources outside your body, such as the seat of your wheelchair or the mattress on your bed. The pressure of your weight compresses the blood vessels, especially in areas where bones normally stick out somewhat, like the pelvis or the heels. The blood vessels become pinched between the outside surface and your bones and get closed off [SEE FIGURE 1.b.2]. Blood, which carries oxygen and nutrients, cannot get past that point. Unless the pressure is relieved, the cells that are fed by those blood vessels will die and a pressure ulcer will form. This can happen very quickly.

Regular pressure releases when you’re up in your wheelchair and position changes when you’re lying down will allow the blood vessels to open and will prevent skin breakdown. Fortunately, pressure often causes changes in your skin that

[Figure 1.b.2] Pressure on Skin

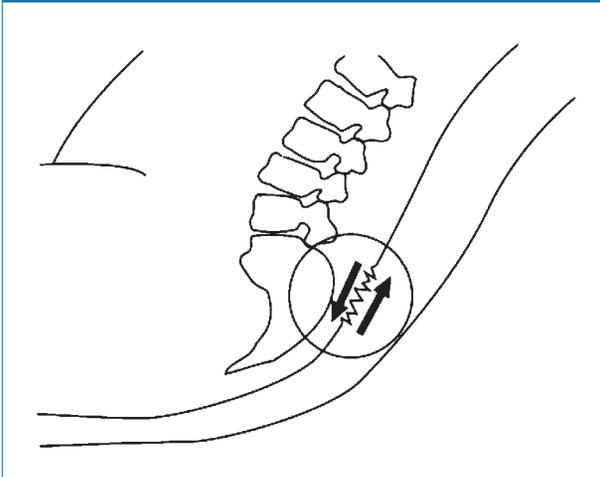


provide early warning signs that the cells are not getting adequate circulation. These early signs of damage include both color and texture changes. For example, redness can develop after excessive pressure. Color changes may not be as visible in people with darker skin.

Shearing and Friction

Shearing occurs when two layers of tissue right next to each other are pulled in opposite directions. The blood vessels in the layers of the skin are closed off by the pulling. This can lead to skin tears, blisters, and more serious breakdown [SEE FIGURE 1.b.3]. Shearing can happen if you slip down in your wheelchair or while you’re sitting in bed—if the head of your bed is raised, you might slide down and shear the skin over your tailbone [sacrum and coccyx]. Shearing can occur when you drag any body part across a bed, toilet, or other surface during a transfer. Shearing plus direct pressure from the weight of your body increases your risk of getting pressure ulcers. Friction is what happens when a part of your body rubs against another object or body part. An example would be ankle bones rubbing against each other when you lie on your side at night. Repeated friction can cause blisters and can

[Figure 1.b.3] Shearing



make existing wounds worse. Spasticity also can increase the risk of damaging your skin because it may pull you out of good alignment in your chair or in bed.

Daily Skin Care

You need to give your skin special attention every day because of the decrease in circulation, lack of feeling, and lack of movement in your body below the level of your injury. Pressure ulcers can develop quickly, so prevention is essential. If a wound does develop, it's important to recognize and treat it promptly. Examine your skin for possible problems:

- Check your skin twice a day. Before you get out of bed, inspect the areas that had pressure while you were lying down. After you get into bed, inspect the areas that had pressure while you were sitting [SEE FIGURE 1.b.4].
- Check all the bony places [ankles, elbows, heels, hips, tailbone] below the level of your injury. Use a mirror to see the bony areas behind you, like your sit bones [ischial tuberosities].
- If you can't use a mirror or check your skin yourself, get someone [your attendant or a family member] to check those areas for you.

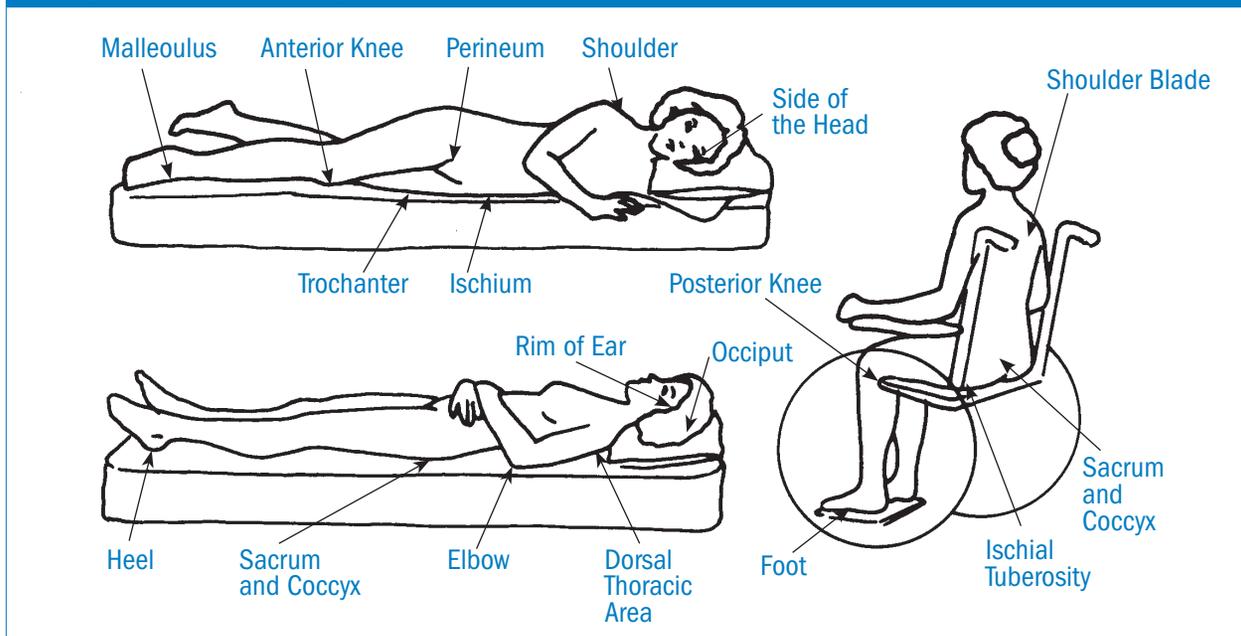
- Look for reddened areas, cuts, scrapes, blisters, and bruises. Carefully check anything that seems different.
- If you develop skin redness after having pressure on a bony area of your body, see how long the redness takes to fade. If it takes longer than 15–20 minutes or doesn't fade at all, the pressure was too much for your skin and you must take action: First of all, *do not massage red marks*. Don't put pressure on the area until the redness fades completely. The next time you sit or get into the position that caused the red mark, reduce the time you spend there. Make sure your wheelchair cushion and mattress are functioning correctly. Make sure you're doing pressure releases and position changes correctly and frequently. Talk with your health-care provider about these problem areas.
- Feel the bony areas on your body for lumps or spots that are firmer than the surrounding skin. If the tissue feels either extra firm or mushy, talk with your health-care provider.

It's important to check the fit of your clothes, shoes, and equipment to make sure nothing is too tight. Avoid the following:

- Thick seams, especially on blue jeans.
- Binding in the groin area with pressure on your scrotum.
- Tight shoes, especially if you have swollen feet.
- Socks with elastic tops that bind around your lower leg.
- Straps holding your urine drainage system that are too tight or too narrow.
- Condom catheters that have been applied too tightly.
- Sitting on urinary tubing.

Consider these factors in choosing clothing and wearing adaptive equipment:

[Figure 1.b.4] Skin Inspection Points



- Wash new clothes before you wear them and check your skin after one or two hours for redness or chafing.
- Buy jeans that have low-profile seams [not bulky]. Consider removing back pockets or buying jeans that don't have them.
- Buy jeans and slacks a size larger than your usual size to prevent constriction.
- Wear clothes made of "breathable" fabric, such as cotton.
- If you are male, adjust your scrotum after you transfer to your chair. Be sure you're not sitting directly on your scrotum.
- Unless your doctor has prescribed compression socks, wear socks that are neither too tight nor too loose.
- Check the fit of shoes carefully and watch your feet for signs of edema [swelling]. After you've worn your shoes for six months or more, recheck the interior cushioning to make sure the padding isn't wearing down.
- Change the position of your urine drainage system from side to side every day.

Positioning/Turning

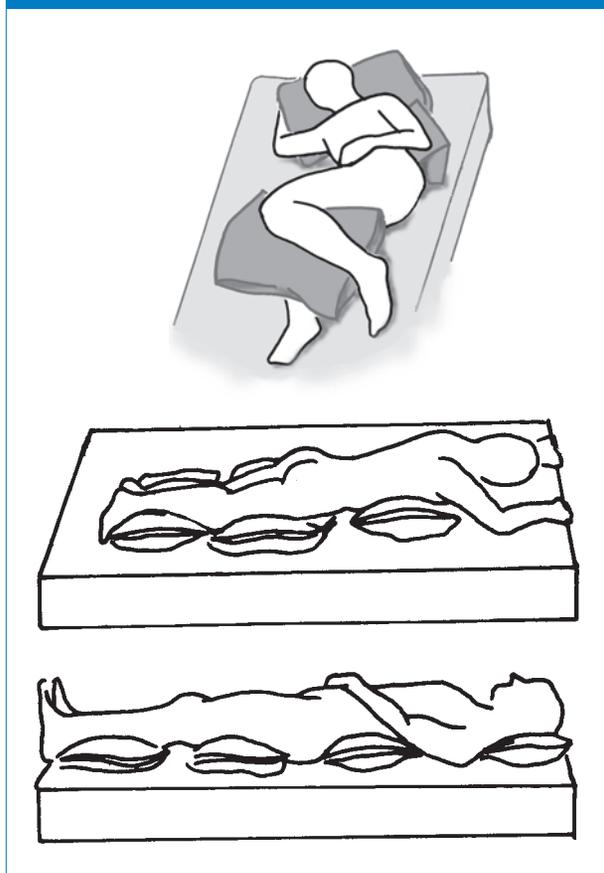
Changing your body posture takes pressure off your bony prominences. Here is some guidance for positioning/turning:

In Bed [SEE FIGURE 1.b.5]

- Change your position according to your skin tolerance level. Use the routine of side-to-side-to-back for turns. If possible, spend some time sleeping on your stomach [prone].
- Avoid pressure on your heels and ankles by "floating" them over the edge of a pillow. Some people wear special foot splints to protect the skin over the ankles or heels.
- When side-lying, turn only part of the way. The side-lying position should put pressure on the fleshy part of your buttock, not your hip bone [trochanter].
- If the head and knee portions of your bed elevate, try raising the knee portion first. This helps prevent shearing at your tailbone area when the head of the bed is raised.

- Sitting in bed for prolonged periods is hazardous to the skin over your tailbone. Raise the head of the bed for short functional activities only.
- Use an alarm clock to wake you for turns during the night. After a while, turning in bed may become automatic for you.
- Get someone else [like your attendant] to turn you if you can't do it by yourself.
- You may need a special mattress to distribute pressure over your bony parts. Discuss this with your health-care provider.

[Figure 1.b.5] Positioning/Turning in Bed



In a Wheelchair

- Do pressure releases every 15 minutes to take the pressure off your tailbone and sit bones. Different kinds of pressure releases are

described below. Work with your therapist to find which is best for you. If you can do more than one type of pressure release, vary them. This can minimize the stress on your upper limbs.

- > Push up out of the seat of your wheelchair and hold for 30–60 seconds.
- > Lean side to side, staying in a side-leaning position for 30–60 seconds per tilt.
- > Bend your chest forward onto your knees and hold this position for 30–60 seconds.
- > Tilt your wheelchair back or use your recliner if you have one. Follow your therapist's instructions about how far back the chair should be tilted. Usually, you'll have the lowest pressure if you tilt or recline the chair as far as it goes. Stay reclined for 1–2 minutes. Some people develop skin problems from remaining in a tilted or reclined position for more than 30 minutes, so don't stay in that position long.
- Shift your position as much as possible. It doesn't come automatically, but moving changes the pressure points and allows the blood to continue flowing. Don't get distracted by other activities and forget to relieve pressure.
- Do pressure releases routinely throughout the day. If you're forgetting to do them, consider using an alarm [like a watch alarm or a kitchen timer] to remind you.
- Check your posture by looking at yourself in a full-length mirror after you're up in your wheelchair. Make sure that your ankles, the sides of your knees, and your hipbones are not leaning against parts of your wheelchair. Your body has a natural balance and symmetry. Your knees and feet should appear to be "even." Spasticity and muscle

strength imbalances can disrupt your balance and cause a change in your posture. Tight muscles in your trunk and legs can do the same. Pay attention to these things:

- > Curving or twisting in your back [spine].
- > Tightness in your legs or trunk that prevents your body from keeping its normal balance.
- > One knee looking “higher” than the other.
- > Any appearance of slumping or leaning to one side of the wheelchair or the other.
- > Make sure your foot pedals are adjusted for your height.
- > Sit up as straight as possible in your wheelchair.
- > Always use a *well-maintained* cushion. [See section 2.b, *Equipment.*]
- > Be aware that any change in your positioning to ease pressure in one area will affect the pressure on other areas.

Preventing Injury

Before your SCI, sensations warned you to move away from harm. Now that you’ve lost some or all of the ability to feel and/or move below your level of injury, your skin is at risk for injury.

- Always be aware of how close your paralyzed body parts are to possible hazards around you. Are you too close to a heater, fireplace, campfire, or exposed hot water pipes? After transferring to an overstuffed chair, are your feet squarely on the floor?
- When transferring or moving around, be careful not to bump into things. Use your eyes to check out distances and obstacles. Remember that when you’re in your wheelchair, your feet stick out farther than the rest of you, so wear shoes to protect your toes.

- Don’t do fancy or new maneuvers in your wheelchair until you’ve been trained.
- Spasms can lead to skin trauma. For example, a spasm during a tilt back can result in your ankle hitting a calf rest pad and causing injury.
- Don’t sleep in your wheelchair. You can’t do a pressure release if you’re asleep.

Potential Hazards to Skin

Many problems from inside and outside your body can affect skin health and wound healing. Some examples of internal problems are anemia [not enough red blood cells], poor nutrition, diabetes, lung disease, and problems with circulation. Emotional and psychological problems like drug or alcohol use or depression can have a negative effect on your ability to practice good skin care.

Cold Injuries

Loss of skin sensation puts you at risk for injury from things that are too cold:

- Prevent frostbite by wearing warm socks and sturdy shoes when you’re outside. Cover your head, ears, and hands when you go out. If your ears are getting cold and tingling, your feet probably are too, so go inside.
- If you’re using ice or a chemical cold pack for swelling, wrap it in a towel. Don’t ice longer than 10 minutes at a time.
- Beware of holding frozen foods on your lap. Use a protective pad under frozen items.
- Wheelchairs and their parts can get cold enough to cause injury if they’re used or stored in a cold place. Wear gloves to push your manual wheelchair during cold weather. Exposure to the cold parts of your wheelchair can dry your skin, causing cracks and splits that are hard to heal. Some wheelchair cushions with gel packs have caused injury after being stored outside.

Heat Injuries

Things that are too hot can also cause injuries.

- Check the water temperature by putting a part of your body with normal sensation into the water and holding it there for five seconds. If you feel comfortable, the water temperature is safe. If you don't have good sensation in your hand, have someone else check the water temperature or use a thermometer. Water temperature should typically range between 100 and 104 degrees Fahrenheit for bathing.
- Be sure your hot water heater is not set higher than 120 degrees F. Scalding burns occur very rapidly at temperatures above 120 degrees.
- Don't use a heating pad or chemical hot packs on skin you can't feel.
- Make sure your feet are not too close to the heater in a car.
- Don't use electric blankets.
- Don't move too close to fireplaces, radiators, hot water pipes [especially under a sink], or campfires. If your equipment [such as your wheelchair] gets too hot, it may cause a burn.
- Don't carry hot fluids or foods in your lap without a tray. If you carry hot foods, use a sturdy board that supports the entire surface of the dish or pan to keep it from touching your legs.
- Use cup holders on your wheelchair.
- Don't fill cups too full.
- Keep pan handles over the stove surface to avoid bumping them and spilling the contents.
- Be careful reaching across hot stove burners.

If you burn yourself, apply first aid immediately. Apply cool water. Do not use ice, other frozen things, or butter on a burn. If you spill hot food or fluids on yourself, you may not be able to detect

all the places it came in contact with. Pay close attention to your groin and buttocks area.

Ingrown Toenail

If the area around the nail is red and you see pus when you press on the edge of the nail, it may be cutting into the skin.

- Soak your foot in soapy water, wash it well, rinse, and blot dry.
- Place a small piece of cotton under the nail to keep the edge of the nail away from the skin. Change the cotton daily.
- If it does not begin to heal in two or three days, call your health-care provider.
- Make sure your socks and shoes leave plenty of room for your toes.
- Keep your feet clean and dry. Keep your toenails trimmed following the curve of the toe [not straight across].

Moisture

Anything that makes your skin wet—including sweating, urine incontinence, or diarrhea—puts you at risk for skin infections.

- Keep your skin clean and dry.
- Pay special attention to cleanliness in areas where you sweat.
- If you have skin folds, clean and dry well under them.
- Apply antiperspirant in moist skin folds.
- Use ointments or preparations with lanolin, petroleum jelly, or zinc oxide as barriers against moisture. If you develop a reddened area due to moisture, try one of these. As you would with any other reddened area, pay close attention to it. If the redness doesn't go away in a week, call your health-care provider.
- If you think you might have a skin infection, call your health-care provider.

Scar Tissue

A scar is a mark or change in skin that remains after a wound has healed. Scar tissue has fewer blood vessels and is less elastic than normal skin. It can't withstand the same amount of pressure or stretch. When scar tissue forms in a weight-bearing area, there's a high risk that it will break down again.

- Prevent wounds that result in scar formation.
- Do careful skin inspections of areas with scars.
- Not all scars will turn red as the first sign of a problem; they may get white and feel hard to the touch. If the scar area starts getting red or becomes whiter for a long period, keep pressure off of it.
- If you have a significant amount of scar tissue in a weight-bearing area, you may need to limit the time in that position to prevent recurrent breakdown.

Sun

Your SCI has not changed your sensitivity to sunburn.

- Use a sunscreen with a sun protection factor [SPF] of 15 or greater.
- To avoid burns, check sun-heated plastic, vinyl, or metal surfaces before you put any part of your body on them.
- Wear protective clothing when you're out in the sun; for example, a hat and a long-sleeved shirt.
- Certain medications, such as antibiotics, can make your skin more sensitive to sunburn. The pharmacist will usually discuss this with you when you get the medicine.

Pressure Ulcers

Skin breakdown is more likely with certain medical conditions [like diabetes or poor arterial blood supply], from trauma [like burns or skin tears], or from excess moisture.

A pressure ulcer [pressure sore, decubitus ulcer, or decube] is an injury to the skin and the tissues underneath. It is caused by excessive or prolonged pressure. When pressure is applied for too long, the blood supply is cut off. This deprives the cells of oxygen and nutrients, which leads to skin breakdown. Pressure ulcers can form in two ways—from the outside of the skin downward [these are shallow when they start] or from the bone outward toward the skin [these are quite deep by the time they reach the surface of the skin]. The pressure is always greatest on the deep tissues that are near the bone. Your tailbone [sacrum and coccyx], hips [trochanters], sit bones [ischials], and heels are the main places to watch. Tissues here get squeezed between a “rock” [the bone] and a “hard place” [your chair or mattress, for example]. Before your injury, your body signaled you to squirm around in a chair or change positions to get blood to an area. After your SCI, you may not have the same warning system. Unless you think about it and move yourself by doing a pressure release, the blood supply to an area can be cut off. Pressure is greatest at the bone, so the most damage is done there. A pressure ulcer may look small on the surface but can be much larger underneath. Think about an iceberg: what you see is only a small part of what's really there.

It's always better to prevent pressure ulcers. Even after a wound heals, especially if it's deep, the skin and soft tissue below will never be as strong and elastic as they were. And each time you have skin breakdown in the same place, it becomes weaker and less elastic when it heals. Your equipment

[Figure 1.b.6] Pressure Ulcer CPG



should help relieve and distribute pressure over your bony areas—you can use special bed surfaces and wheelchair cushions that help prevent pressure ulcers. But the most important prevention is to *move your body often*.

If you do develop a pressure ulcer, *get off it and stay off it* until it's healed. There are many ways to manage pressure ulcers. All of them take a long time to work and require you to keep pressure off the area. Talk with your health-care provider. Successful treatment of pressure ulcers requires you to do the following:

- Remove all pressure. This may require bed rest, with no sitting.
- Stay off the pressure ulcer.
- Keep the area around the pressure ulcer clean and dry.

You may need a referral to a visiting nurse agency to help you heal your wound, and some pressure ulcers require surgical repair.

Pressure Ulcer Classification

Health-care providers use a rating system to describe the severity of pressure ulcers [SEE FIGURE 1.b.6]. The deeper the pressure ulcer, the more serious the problem. The rating system has four main levels:

- **Stage 1.** An area of redness that does not fade or blanch. In darker-skinned people, it may look dark red, blue, or purple. The skin

is intact [unbroken]. The soft tissue may feel either extra firm or mushy. The skin may feel warmer or cooler than other skin close by.

- **Stage 2.** If the skin is broken at all, the wound is at least a stage 2. It will look like a scrape, blister, or shallow crater with pink tissue at the base of the wound. An intact water-filled blister or a popped blister is also classified as a stage 2 wound.
- **Stage 3.** This wound will be a deeper crater, going through the skin layer into the soft tissue below. Yellow slough [dead tissue] may be present. This wound may have undermining or tunneling into deeper tissue layers.
- **Stage 4.** This wound is deep enough to extend to a tendon, bone, or muscle. Tunneling and undermining are common.

Two more categories are used to describe skin damage:

- **Suspected deep tissue injury.** Even though your skin is still intact, there may be significant soft tissue damage underneath. This may look like a deep bruise or feel like a large swollen area. Even with pressure relief, it can turn into a deep pressure ulcer.
- **Unstageable.** If your ulcer is covered with black, tan, yellow, gray, or brown tissue, you can't tell how deep the pressure ulcer is. The dead tissue must be removed to stage the wound.

[Table 1.b.B] Time and Process for a Pressure Ulcer to Heal

STAGE	WHAT HAPPENS IN THIS STAGE
First Stage of Healing	The wound area gets red and hard to the touch. This happens because red and white blood cells are sent to the area to clear away dead tissue and fight infection.
Second Stage of Healing	New blood vessels are formed to provide oxygen and nutrition to the area. This looks like bumpy, red tissue. At the same time, new cells are laid down at the bottom of the wound. After the first layer is formed, other cells grow underneath, filling in the wound. This is an extremely slow process. The sides of the wound are building layers in the same way. The wound gets smaller, and scar tissue forms on the skin surface. In deep wounds, it is very important that the sides do not close in first. If they do, a pocket may remain in the middle of the wound and form an abscess. This space can become larger and may reopen the wound from the inside out.
Third Stage of Healing	Scar tissue becomes stronger and may fade in color. The tissues “remodel,” but scar tissue is never as strong as skin. The remodeling can take up to two years.

Complications of Pressure Ulcers

Pressure Ulcer Worsens

The pressure ulcer can get longer, wider, and deeper. In deep wounds, tunneling or “tracking” between layers of muscle, fat, or bone can occur. You can usually keep a pressure ulcer from getting worse by immediately getting off it and following the guidance of your health-care provider. A pressure ulcer will not heal if pressure is still being applied.

Infection

Skin and wound infections can occur with pressure ulcers. In deep wounds, the bone can also become infected. This bone infection is called osteomyelitis; it can spread into your bloodstream and make you very sick. Symptoms of wound infection include increasing redness around the wound, pus draining from the wound, and fever. Follow the recommendations of your health-care provider to prevent such infections.

Scarring

All but the most superficial ulcers heal by forming scar tissue. In the future, this scar tissue will break

down faster than normal skin because scars have poor blood supply. Scar tissue is also less elastic and may not stretch enough as your body gets into different positions. Scarring of the skin and soft tissue can even decrease your range of motion in nearby joints. The best way to avoid scarring is to prevent deep pressure ulcers altogether. It’s important not to let a superficial pressure ulcer [which is likely to heal without a scar] turn into a deeper one.

Healing Skin Breakdown

Healing a pressure ulcer can take from just a few days for a very superficial wound to many months for a deep wound. All ways of treating pressure ulcers require keeping pressure off the area [SEE TABLE 1.b.B].

Pressure Management

The most important part of treating a pressure ulcer is removing the cause. To treat a pressure area at any stage, remove pressure and shearing. For example, if the pressure ulcer is on an area that gets high pressure when you’re sitting, don’t sit until the ulcer heals. If your ulcer is on a pressure area related to lying down [like the tailbone or hip bones], don’t lie in that position

again until the ulcer heals. If you're on bed rest, don't sit in bed. If it is a heel problem, eliminate pressure by wearing a special splint or suspending your heel over the edge of a pillow. Your health-care provider can advise you about your options.

Management of Other Body System Problems

Other problems can increase your risk of developing a pressure ulcer. Think carefully about factors in your environment that may have contributed to the development of your pressure ulcer. For example, urine leakage that causes the skin to be wet for long periods of time can lead to skin breakdown. Find a way to manage urine leaks. Spasticity that pulls you out of alignment in your chair might cause uneven weight distribution and a higher risk for skin breakdown. Correct your sitting posture so you have even weight distribution over your sit bones.

Healing a wound requires good nutrition. If you're anemic or malnourished, healing will be slow. The pressure ulcer itself may add to problems of anemia and malnutrition, especially if there's a large amount of drainage. Your health-care provider can give you advice about treating your anemia or low body proteins. You may need help from a dietitian to get a well-balanced diet. You may need extra calories, protein, vitamins, and minerals.

Smoking impairs your skin's ability to heal because it constricts blood vessels and limits the absorption of some nutrients. If you have a pressure ulcer, try to stop using nicotine in any form. Ask your health-care provider to help you stop smoking. Do whatever it takes to stay nicotine-free even after your wound heals.

Other medical problems, such as diabetes and chronic lung disease, can add to the challenges of healing a wound. Your health-care provider can guide you in the best management of those problems.

Problems associated with pressure ulcers aren't always physical. Emotional and social issues can have a big impact on your skin health. Depression, for example, can get in the way of protective skin care. Unreliable caregivers can make it difficult to manage your skin well. Do everything you can to remedy the physical, emotional, and social problems that contribute to pressure ulcers. You may need the assistance of one or more members of the rehabilitation team to solve these problems: doctor, nurse, occupational and physical therapist, psychologist, social worker, or vocational counselor.

Wound Care

If you develop a pressure ulcer, take immediate action. But before we talk about what to do, you should know *what not to do*:

- Don't massage areas of redness.
- Don't clean your wound with soap, iodine [e.g., betadine], hydrogen peroxide, alcohol, vinegar, or bleach solutions. These solutions are toxic to your exposed tissues.
- Don't soak in the bathtub.
- Don't try to dry your wound with a heat lamp or hair dryer.
- Don't put sugar, vitamins, or antacids into your wound.
- Don't use antibiotic ointments in your wound unless they're prescribed by your health-care provider.
- Don't use creams or ointments unless they're prescribed by your health-care provider.

Dressing changes are based on the principles of moist wound healing. If you have a minor skin breakdown, simple wound care at home may be enough. Healing is promoted by keeping your wound moist [not wet] and covered. Irrigate your wound with normal saline solution or by taking a shower and letting the water run down over the wound. Blot the area dry and then cover it with a

film, foam, or hydrocolloid dressing. Your wound will make “soup” under these kinds of dressings. Don’t be alarmed if there’s a puddle of smelly drainage when you take off the old dressing—this is normal! If your ulcer doesn’t heal or start to heal within a week, call your health-care provider for guidance. A home care nurse may be needed to help you manage your wound care.

If you have a deeper wound; if the wound has black, yellow, or gray tissue in it; or if the skin around the wound keeps getting redder, call your health-care provider right away.

Surgery

Sometimes total pressure relief and good wound care are not enough to heal a pressure ulcer. In these cases, surgery may be needed. The surgical procedure depends on the location and severity of the pressure ulcer. Some procedures involve moving muscle and skin from somewhere near the ulcer to close the ulcer and provide padding. Sometimes the bone under a pressure ulcer needs to be removed because it is infected. Each pressure ulcer is evaluated for the most effective surgical procedure. There are limits to the number of times repair surgery can be performed. It’s much better to prevent a serious ulcer.

Getting Ready for Surgery

Before surgery, the pressure ulcer must be well cleaned. This can take several weeks and may involve frequent dressing changes and/or surgically removing all the dead tissue from the wound. If your pressure ulcer is infected, your doctor may prescribe antibiotics. Signs of infection include redness and swelling around

the wound, foul-smelling drainage, and fever. Your nutritional health will be evaluated to see if you need more protein, vitamins, or minerals to improve the chances of a successful operation. Most surgeons will insist that you be nicotine-free for three to six weeks before and after your surgery. Ask your health-care provider for assistance in stopping your nicotine habit.

After Surgery

After surgery, you’ll stay in bed [usually a special bed] for three to six weeks to allow the surgical site to heal. It’s very important not to put pressure on the surgical site and not to pull or stretch the skin in that area. You’ll need help with turning. After healing, you’ll learn range-of-motion exercises for the nearest joint. Next, there will be a gradual buildup of weight bearing or pressure on the site by lying or sitting on it in carefully timed sessions. The process of building pressure tolerance should be very slow. Follow the guidance of your health-care team.

This surgical area will need special care for the rest of your life. It will never be as strong as it was before you had the pressure ulcer. Transfers and pressure tolerance need regular evaluation. Your seating system and how you do pressure releases may need to be reevaluated as you age or after you’ve had a pressure ulcer in a seating area. Often, modification of wheelchairs and cushions can reduce pressure and decrease the chance of developing new ulcers.

The most important part of healing, whether by conservative methods or surgery, is to determine what caused the pressure ulcer and to have a plan for prevention in the future.

RESOURCES

Publications

Pressure Ulcers: What You Should Know: A Guide for People with Spinal Cord Injury
www.pva.org/consumerguides

Pressure Ulcer Prevention and Treatment Following Spinal Cord Injury: A Clinical Practice Guideline for Health Care Professionals
www.pva.org/CPGs

Website

National Pressure Ulcer Advisory Panel
www.npuap.org

1.c | Respiratory Care

Breathing is the voluntary or automatic movement of air in and out of the lungs, through the mouth or nose. Breathing moves oxygen from the air into your blood and to all cells of the body, and moves carbon dioxide out of your body. Without a steady supply of oxygen and the removal of carbon dioxide, all parts of the body will begin to stop working. Coughing is the forceful movement of air out of the lungs. Coughing moves secretions or mucus out of the lungs.

The exchange of oxygen and carbon dioxide takes place in the lungs. Air tubes [bronchi] come down from your windpipe into your chest like a tree growing upside down [SEE FIGURE 1.c.1]. These tubes keep branching until they are very tiny. At the end of the smallest branches are air sacs that look like little clusters of balloons. These balloons are located next to the blood vessels in the walls of your lungs. When you inhale, air is sucked into the balloons to inflate them.

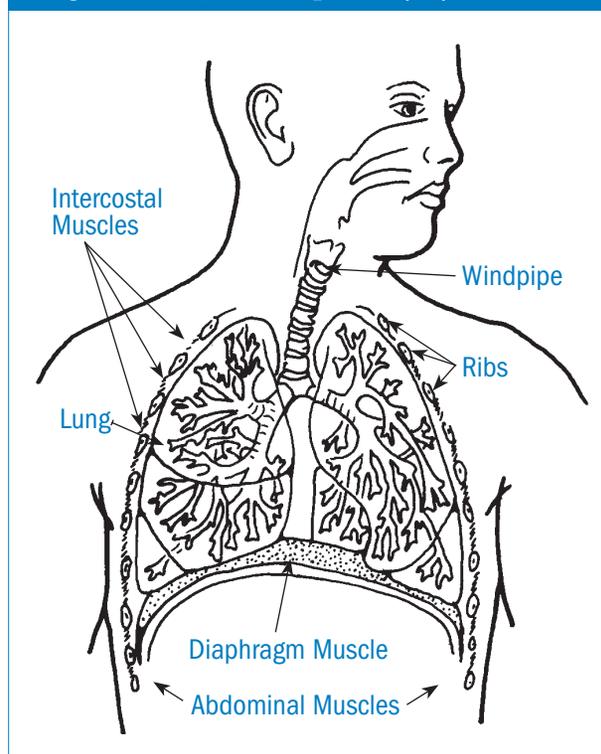
Breathing and coughing require different muscles [SEE TABLE 1.c.A].

Ventilators and Tracheostomies

Almost half of people with complete tetraplegia [cervical injury level and complete paralysis of lower muscles] will have difficulty breathing right after their injury. If there is severe weakness of the diaphragm, a breathing machine called a ventilator is required to move air in and out of the lungs. The ventilator pushes air into the lungs through a tube that usually goes through the mouth and down the throat.

For many people, diaphragm strength improves in a few days and the ventilator is no longer necessary. Some people take much longer to get

[Figure 1.c.1] The Respiratory System



enough strength back to breathe. About 1 out of every 25 people with SCI never get back enough strength to breathe without a ventilator or other device. If a person needs to use a ventilator for more than a few days, a physician makes a small hole in the front of the neck [tracheostomy or tracheotomy]. A tube [tracheostomy tube] is placed in this hole, and the ventilator is connected to the tube. This allows the tube to be removed from the mouth and throat. Most people with SCI can learn to speak and swallow food after a tracheostomy. If the ventilator is no longer needed, the tube is removed and the hole in the neck closes up.

Respiratory Problems

Problems that affect the lungs are the most common cause of death after SCI. Pneumonia, an infection of the lungs, causes most deaths.

[Table 1.c.A] Some of the Muscles Used in Breathing and Coughing

RESPIRATORY MUSCLES	FUNCTION	SPINAL CORD INJURY LEVEL AND ITS EFFECT ON BREATHING
Diaphragm	The main muscle of breathing. It is found just underneath your lungs.	An injury above C5 may require the use of a ventilator [breathing machine] for a while or permanently, because the diaphragm and most other muscles may not work.
Intercostals	These muscles run in between your ribs. They are used in coughing and deep breathing.	An injury above T8 will reduce the strength of these muscles, but diaphragm and neck muscles can help you breathe.
Abdominals	These muscles help you cough. They run between your ribs and hips.	An injury above T12 will reduce the strength of these muscles, but intercostal, diaphragm, and neck muscles can help.

The risk of death from pneumonia is highest in people with high-level injuries and more complete paralysis. Other serious respiratory infections also can occur, and they can lead to pneumonia if too many secretions build up in the lungs.

Why is pneumonia so common and so severe after SCI? The main problem is that for many people, the coughing muscles are extremely weak. It's difficult to get secretions up and out of your lungs without a strong cough. Because of this, you need to know about different ways to get the secretions and mucus out of your lungs.

You may experience any or all of the following symptoms of respiratory infection:

- Shortness of breath.
- Rapid breathing.
- Increased congestion or secretions from your lungs.
- Lower reading of air flow through your incentive spirometer.
- Early morning headache, fever, or unusual drowsiness.

Treating Respiratory Problems

The following are some ways to treat respiratory problems:

- Quad coughing [manually assisted coughing] can increase the effectiveness of your cough. This is done by having someone push your abdomen at the same time you cough. [Note: Do not attempt this until it is demonstrated to you.] This method works best if you take a very deep breath. If you know how to do glossopharyngeal [“frog”] breathing, do that right before you receive a quad cough. Self-assisted coughing can be done by bracing your arms, leaning forward, and putting pressure on the abdomen.
- Drink more fluids to thin your secretions, which will make it easier to cough them up.
- If you have a machine that helps with your cough [a mechanical insufflator-exsufflator; CoughAssist], increase your use of it for a few days until the secretions diminish.
- Change your position more frequently by moving from sitting to lying and by turning from side to side. This will change the areas of your lungs that get air and will help keep all areas of your lungs working.
- Increase the number of times you do your breathing exercises. Do them every two hours.
- Do postural drainage after your breathing exercises whenever the time and place allow,

but only if you've been taught how to do it properly. If you put your head and chest down, gravity helps the secretions drain toward the upper lung. They can then be coughed up more easily.

- Chest percussion can also aid in the removal of secretions. Lie with your head lower than your feet and get someone to clap their hands on your chest. You must be taught how to do this properly.
- Take a warm [not hot!] bath or shower. This warms and humidifies the air, and the steam can help liquefy secretions so they become easier to cough up. Do this once or twice a day.

If your symptoms don't go away in 5–10 days, if they get worse, or if your treatments don't seem to help, call your health-care provider. Fever, chills, or a cough associated with shortness of breath should be evaluated by a health-care provider as soon as possible. Some respiratory infections may need antibiotics to kill bacteria or medications to help you breathe easier. Serious breathing problems like pneumonia often require treatment in a hospital. Make sure the hospital staff understands what needs to be done to get the secretions out of your lungs. They may not know how to do this if they don't usually take care of patients with SCI. Your family or caregivers might need to discuss this with hospital staff if you're too sick to do it yourself.

Sleep Apnea

People who have sleep apnea stop breathing for at least 10 seconds at a time while they're sleeping. This can happen for two reasons. Most commonly, the soft tissue at the back of the throat or the back of the tongue blocks the flow of air into the lungs when you inhale. Less commonly, your brain temporarily stops trying to breathe. These short pauses in breathing can happen up to 400 times

a night. When your breathing stops, you might wake up slightly from deep sleep. If you're waking up often all night long, your sleep will not be restful, and you'll be tired all day. Also, sleep apnea can cause problems with the heart and lungs.

How do you know if you have sleep apnea?

- You may notice daytime sleepiness [falling asleep at work, while driving, or when talking] and irritability or fatigue. But remember that many medications taken by people with SCI also can cause sleepiness.
- You may notice that you have morning headaches, forgetfulness, or mood changes.
- A person you sleep with or a caregiver may notice heavy snoring or long pauses in your breathing during sleep.
- Your doctor can diagnose sleep apnea by ordering special breathing tests while you sleep. The tests are usually done by specialists in sleep medicine.

You can take some steps to help you sleep better:

- Stop all use of alcohol and sleep medicines.
- If you're overweight, lose weight.
- Sleep on your side or stomach if possible, instead of on your back.
- Ask your doctor if he or she recommends that you use a machine [called a CPAP [continuous positive airway pressure] or BiPAP [bilevel positive airway pressure]] that blows air into your nose [or your mouth and nose] through a small mask while you sleep. The flow of air from the machine keeps your airway open by adding pressure to the air you breathe.
- If these options don't work, a surgeon can remove the extra tissue in your throat. This is helpful for some types of sleep apnea.

Keeping Your Lungs Healthy

- Stop smoking. Smoking increases secretions and your likelihood of getting infections.
- Do breathing exercises regularly if you have a cervical or high-thoracic level of injury and if the exercises have been recommended to you. If you have an incentive spirometer, use it at least two or three times a day. If you don't have one, take as deep a breath as you can. Hold it for a count of three; then push all the air out. Do that 5–10 times at least two or three times a day.
- Learn “frog breathing” [glossopharyngeal breathing] to help you increase the amount of air in your lungs. This breathing exercise is usually taught by a speech therapist.
- Try to stay away from pollutants, such as smoke, dust, and dangerous chemicals.
- If you get a cold or sore throat, do more breathing exercises. If you have bronchitis or a cold and have secretions in your lungs, do quad coughing two or three times a day. This should help prevent the buildup of secretions and the risk of pneumonia. Take it seriously. If a cold or sore throat doesn't go away in 5–10 days, contact your SCI clinic or your doctor for further instructions.
- An abdominal binder can increase respiratory capacity by substituting for a paralyzed abdominal wall. Use one while you're seated in your wheelchair if it's recommended by your health-care provider.

Smoking

The nicotine in tobacco products causes the blood vessels to constrict, and smaller blood vessels reduce the amount of blood, oxygen, and nutrients that gets into the tissues of the body, including the skin. Lack of oxygen and nutrients increases the likelihood of skin breakdown. In addition, hot ashes from cigarettes can fall on your skin and burn you.

The only way to prevent the harmful effects of nicotine is to stop using it in any form. Medication is available to help with nicotine craving. Stop-smoking classes are available. Contact your health-care provider for help. Strategies to help with quitting include these:

- Set a quit date, ideally within two weeks.
- Get support from your family, friends, and co-workers.
- Review any past attempts to quit—what helped and what led to relapse.
- Anticipate challenges, including nicotine withdrawal, especially during the first two weeks.
- Write down your reasons for quitting and the benefits of quitting.
- Call 1-800-QUIT-NOW for additional information.

If you continue to smoke, use a cigarette holder if you have impaired use of your hands. Knock the ashes off into an ashtray frequently. Hold the cigarette away from your body. Never smoke in bed. Drape a fire-retardant cloth over your lap to keep ashes from burning you and your clothes. Install and maintain a smoke alarm in your home.

RESOURCES

Publication

Respiratory Management Following Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals
www.pva.org/CPGs

Websites

For information on the use of the CoughAssist mechanical insufflator-exsufflator for lung secretions, go to www.coughassist.com.

For information on managing breathing problems with various nerve and muscle diseases, including SCI, go to www.doctorbach.com.

1.d | Bladder Management

Before your spinal cord injury [SCI], you probably didn't pay much attention to your urinary system. During the first few months after your injury, you and your SCI team will be spending what seems like a great deal of time establishing and managing your bladder program. Eventually, the program will become routine.

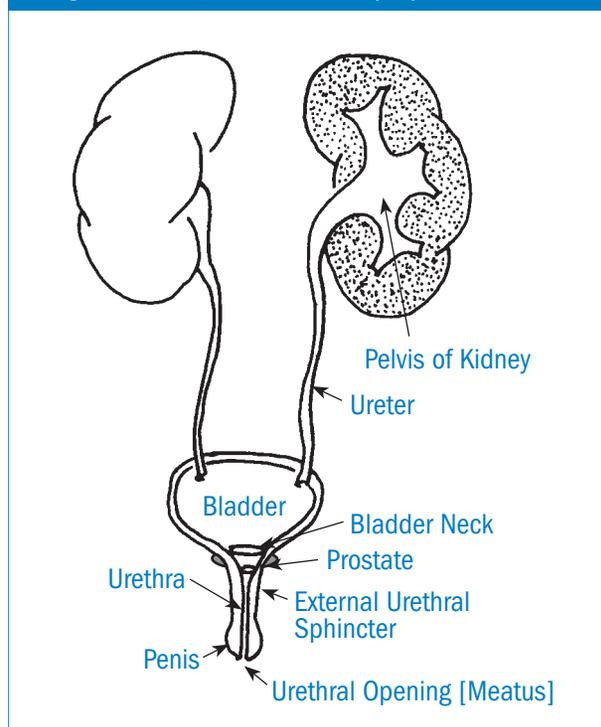
The Urinary System

The urinary system consists of the kidneys, ureters, bladder, and urethra [SEE FIGURES 1.d.1 AND 1.d.2]. The primary differences between the male and female urinary systems are the length of the urethra and the presence of a prostate in the male. Otherwise, the systems are the same.

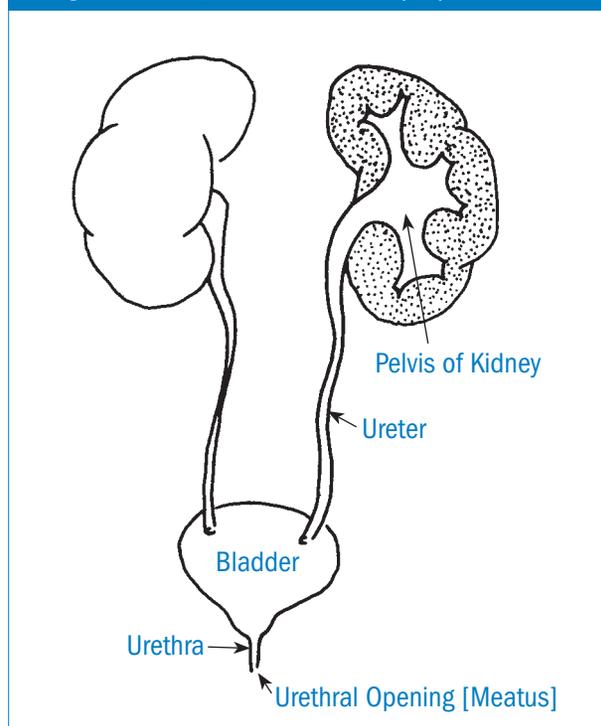
The kidneys filter your blood. They remove waste and excess water from your bloodstream and process them into urine. The urine then flows down the ureters [which are small tubes] to your bladder. The bladder is a muscular sac that stretches to hold urine until you are ready to void [urinate]. When you void, the bladder [also called the detrusor muscle] contracts, the sphincter [a circular muscle that acts as a gate] opens, and urine passes through the urethra.

Urination requires a finely balanced coordination of bladder and sphincter muscles. This coordination involves both voluntary and involuntary [or automatic] control by the nervous system. When your bladder becomes full, nerve impulses are sent to the sacral level of the spinal cord and then to your brain. At that time, you can decide to urinate or to hold the urine. This is the part under voluntary control. If you want to void, the brain will send messages back to the urinary system. The involuntary part involves the opening of the sphincter muscle and the bladder muscle contraction.

[Figure 1.d.1] Male Urinary System



[Figure 1.d.2] Female Urinary System



Changes in Bladder Function after SCI

After a spinal cord injury, nerve impulses from the bladder may no longer tell your brain that your bladder is full or allow you to voluntarily void. Depending on the level of your injury and whether your bladder contracts or not, two general kinds of bladder dysfunction can occur. These are described below, but don't just depend on labels to understand how your own bladder works. The term "neurogenic bladder" refers to any of these changes in bladder function following SCI.

Hyperreflexic [overactive, reflex, or spastic] bladder

The hyperreflexic bladder tends to hold less urine than it did before the injury. Just like your other muscles, your bladder muscle may spasm and contract on its own. The result is that you may have frequent, small urinations with varying amounts of voluntary control, depending on the severity of your injury. Although the bladder may contract more frequently than it did before your injury, it does not necessarily empty with each contraction. This type of bladder is common with SCI above the sacral level.

Areflexic [flaccid] bladder

The areflexic bladder has lost its ability to contract and can be easily stretched, allowing large amounts of urine to accumulate. Because the muscle does not contract, the bladder can overflow and leak—the urine "spills over" like a glass that's too full of water. This bladder activity is common when SCI affects the cauda equina, or the spinal nerves in your sacral spinal cord.

In either type of bladder, it may be impossible for you to tell if your bladder is full.

Bladder Function Tests

A number of tests can evaluate the structure and function of the urinary system. Your kidney function should be checked during routine annual checkups. You may have one or more of these tests.

Imaging Procedures

KUB [kidneys, ureters, bladder]

X-ray image of the abdomen. This test is sometimes used to look for stones in the urinary tract.

Ultrasound

Sound waves are bounced off tissue surfaces and then picked up by a probe to form an electronic picture on a screen. This test is useful to identify kidney stones or blockage of urine drainage. It's also used to check other organs in the abdomen.

Renal scan

In a renal scan, a radioactive substance is injected into a vein and the radioactivity in the kidneys is measured. The level of radioactivity used is extremely low. The scan shows the filtering function and the blood supply to the kidneys.

Intravenous pyelogram [IVP]

An IVP is an x-ray study in which a contrast dye is injected into your vein. The contrast is filtered by the kidneys and shows up on the x-ray. A series of films is taken to show the size, shape, and working order of the kidneys, ureters, and bladder. It can also show kidney stones. [Note: If you have ever had an allergic reaction to IVP dye, be sure to tell your health-care provider.]

Cystogram

In a cystogram, contrast material is injected into the bladder through a catheter. This test shows the size and shape of the bladder, and whether urine moves from the bladder back up to the kidneys [reflux].

Bladder-Filling Studies

Cystometrogram

A cystometrogram [CMG] shows how your bladder reacts when it's filled. A catheter is used to fill your bladder with either carbon dioxide or water. This mimics the way it would usually react when filled with urine. The test measures the amount of pressure that builds in your bladder.

With this information, your practitioner can help plan a bladder program suited for you.

Urodynamics

Urodynamics refers to a combination of tests used to evaluate the bladder. The tests may include a cystometrogram, cystogram, and electromyography [EMG, a test of muscle activity] of the external sphincter. This comprehensive study will assist in planning the best bladder management program for you. If there are changes in your bladder function over time, this study can be repeated.

Cystoscopy

Cystoscopy allows the urologist to look at the inside of your urethra and bladder through a lighted, hollow telescope inserted through the urethra. This test is used to diagnose and sometimes to treat problems inside the bladder or urethra.

Other Laboratory Tests

A number of tests are available to evaluate your blood and urine, and to show how your urinary system is functioning:

Serum creatinine and blood urea nitrogen [BUN]

These blood tests are the best routine measure of kidney function.

Creatinine clearance

This test involves collecting all your urine for a 24-hour period. Chemicals in the urine are measured and compared with chemicals in your blood. These measurements can be an indicator of kidney function.

Urine cultures

A urine specimen is sent to a laboratory to look for bacteria. When a sensitivity test is also ordered, specific antibiotics that kill these bacteria can be determined.

Urinalysis

Urine is analyzed for a number of different chemical and cellular products.

Bladder Management

The primary goal of bladder management is to protect kidney function. If the bladder does not function well, the kidneys may stop filtering the blood. A secondary goal of bladder management is to avoid incontinence. Incontinence makes the skin wet, which can promote pressure ulcers. Also, it is not socially acceptable for adults to be incontinent.

There are two general guidelines for bladder management. First, have a good bowel program. Constipation will impair bladder function and put you at higher risk for a urinary tract infection. Second, keep your genital skin as dry as possible.

If you have an incomplete injury, you may eventually regain some or all voluntary control of your bladder. Your bladder management may change over time. If you have a complete injury, one or a combination of the following bladder-emptying techniques will become part of your bladder management program.

Bladder-Emptying Techniques

To preserve kidney function, these principles should be followed when choosing a bladder-emptying technique:

- The bladder should be emptied regularly and completely. If this cannot be done with spontaneous voiding, catheterization, either intermittent or continuous, should be used [see descriptions that follow].
- In general, bladder emptying should not make you dependent on someone else. For example, intermittent catheterization is beneficial because it reduces some medical complications. However, it takes good hand

function to do it independently. The benefits aren't as great if someone has to do it for you, and that person would have to help you whenever you needed to empty your bladder. So, if you can't use your hands or you can't remember to empty your bladder on a regular schedule, intermittent catheterization may not be the best method for you. If you use a leg bag to collect your urine, someone will show you how to empty it. If you don't have enough strength in your hands to empty the leg bag, you can use an electric leg bag opener.

Intermittent catheterization

A small rubber or plastic tube is inserted into the bladder to drain urine several times a day. This is called the intermittent catheterization procedure, or ICP. At first the nursing staff will do this for you, but you'll learn how to do it so you can continue at home. If you're managing your bladder with ICP, you'll want to limit your bladder volume to around 300–500 mL. More than 500 mL in your bladder overstretches your bladder muscle and makes you prone to infection or reflux [see *Avoiding Infections*]. You should adjust the frequency and interval of catheterizations, as well as your fluid intake, to produce at least 1,500 mL/day of urine output. And you should catheterize at least four times a day. If your fluid intake is greater, you may need to catheterize more often.

Indwelling catheter

Two types of continuous drainage are urethral [Foley] and suprapubic [SP] catheters. A Foley catheter is a hollow tube with a balloon on the end that goes inside you. When the catheter is placed inside your bladder and the balloon is inflated, it will stay in your bladder. The catheter is inserted through your urethra and is usually changed about once a month. A suprapubic catheter is placed in your bladder through a small opening in your lower abdomen. A surgical procedure is required to place the tube for the first time. This catheter also has a balloon to keep it in your bladder. After

the first catheter is changed by a physician or nurse, it should be changed about once a month.

Stimulated voiding

Some bladders can be mechanically stimulated to empty. Just as a spastic muscle might move when it's tapped or brushed, so might a bladder. "Reflex voiding" can be induced by tapping over the lower abdomen or tugging on pubic hairs. This is not a very efficient method of bladder emptying.

Spontaneous voiding

Some bladders spontaneously contract. If your bladder triggers on its own or you've had a sphincterotomy to open the sphincter muscles and allow urine to flow, wearing an external collecting device [a condom catheter] will keep you dry. There are many different types of condoms, and your SCI team will work with you to find the best device for you.

Avoiding Infections

- Maintain a consistent fluid intake to wash out bacteria and limit stone formation.
- Empty your bladder routinely and prevent overfilling. Consistently having more than 500 mL of urine in your bladder can weaken your bladder muscle in two ways. First, the bladder lining can't fight off infection as well. Second, the bladder muscle can't contract as tightly, so a pool of urine is left behind, in which bacteria can grow.
- Maintain a good bowel program to avoid constipation [see *section 1.e, Bowel Management*].

Keeping Your Skin Dry

The best way to keep your skin dry is to carefully follow your bladder management program.

- Routinely empty your bladder using the method that works best for you.

- Manage your fluid intake.
- Wear appropriate appliances, such as condoms, external devices, or padding.
- Avoid infections. Infections can irritate your bladder and cause incontinence between intermittent catheterizations or leakage around Foley or suprapubic catheters.
- Change your clothes as soon as they get wet.

out when the bladder is drained. Three sites of infection common to SCI are the kidney, bladder, and, in men, the testicles. A kidney infection is called pyelonephritis; a bladder infection is called cystitis; and an infection involving the testicles is called epididymitis. Table 1.d.A will help you understand these infections and the diagnostic tests and treatments that may be required.

Problem Solving

Urinary Tract Infections

Having an SCI can put you at risk for infection because you're using mechanical methods to empty your bladder. Bacteria are more likely to enter the bladder, and these bacteria often don't get flushed

Kidney Damage and Kidney Failure

Kidney failure is a complex combination of conditions. Basically, it means that your kidneys no longer function properly and cannot properly filter the blood. Infections, stones, or reflux can damage your kidneys. Kidneys can also be damaged by medical conditions, such as diabetes.

[Table 1.d.A] Types of Infection

TYPE OF INFECTION	SIGNS AND SYMPTOMS*	DIAGNOSTIC TESTS	TREATMENT	OTHER CONSIDERATIONS
Kidney [pyelonephritis]	<ul style="list-style-type: none"> • Chills • Fever • Flank pain • Hematuria [bloody urine] • Urinary frequency • Cloudy, thick urine • Foul-smelling urine • Sediment • Burning upon urination • Increased spasticity • Autonomic dysreflexia 	<ul style="list-style-type: none"> • Urinalysis • Culture + sensitivity [C+S] 	<ul style="list-style-type: none"> • Increased fluid intake • Antibiotics • Foley catheter possible 	Reevaluation of bladder management
Bladder [cystitis]	Same, although you may not have a fever & chills	<ul style="list-style-type: none"> • Urinalysis • Culture + sensitivity [C+S] 	<ul style="list-style-type: none"> • Increased fluid intake • Antibiotics • Usually not necessary to insert Foley 	Chronic attacks require reevaluation of bladder management
Testicles [epididymitis]	Any of the above, plus: <ul style="list-style-type: none"> • Hot, red swollen scrotum • Testicular pain in incomplete lesions 	<ul style="list-style-type: none"> • Urinalysis • Culture + sensitivity [C+S] Plus: <ul style="list-style-type: none"> • Scrotal ultrasound 	<ul style="list-style-type: none"> • Increased fluid intake • Antibiotics • Foley possible • Bed rest • Scrotal support to elevate scrotum • Hot & cold compresses to scrotum 	Reevaluation of bladder management

*You may not have all of the signs and symptoms.

[Table 1.d.B] Urinary Stones

SIGNS AND SYMPTOMS	DIAGNOSTIC TESTS	TREATMENT	OTHER CONSIDERATIONS
<p>[You may not have all of them.]</p> <ul style="list-style-type: none"> • Excruciating pain in lower back or lower abdomen, which may radiate to groin [for those who have sensation] • Nausea • Vomiting • Anxiety because you may not know why you are uncomfortable • Frequent infections • Fever and chills • Bloody urine 	<ul style="list-style-type: none"> • Blood specimen • Urinalysis • IVP • Cystoscopy 	<p>Care is individualized depending on stone, but may include:</p> <ul style="list-style-type: none"> • Increased fluids • Straining urine • Taking medication • Having surgery 	<p>Reevaluation of bladder management</p>

Note: If you see blood in your urine, call your doctor or the SCI clinic. This often happens if the catheter irritates the urethra or bladder. If there is enough bleeding, blood clots can block the catheter or prevent you from emptying your bladder. Blood can also be a sign of a more serious problem in your urinary tract.

Autonomic dysreflexia

If your SCI is at the sixth thoracic level [T6] or above, you may develop autonomic dysreflexia. The most common cause of autonomic dysreflexia is overfilling of the bladder, although anything that irritates the urinary tract can cause it. It is important that you read *section 1-i, Autonomic Dysreflexia*. You need to know the symptoms and how to take care of this condition immediately, as it can be a serious problem.

Urinary stones

Stones can develop in the kidneys, ureters, or bladder. They are mineral deposits that develop because of infection, high calcium levels, or an increase of certain chemicals in the blood and urine. They are usually small enough to pass through the urinary system and appear in the urine as sediment that looks like sand. If they get large, they may block the urinary system and

can damage your kidneys or cause a severe kidney infection. Table 1.d.B will help you understand urinary stones. You may have the symptoms listed in the table, or the stones may develop without symptoms—your yearly evaluation will check for them.

RESOURCES

Publication

Bladder Management for Adults with Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Providers

www.pva.org/CPGs

1.e | Bowel Management

The bowel, also called the colon, is the large intestine, the last part of your digestive system. The waste products of digested food are stored in it until you have a bowel movement.

How the Digestive System Affects Bowel Movement

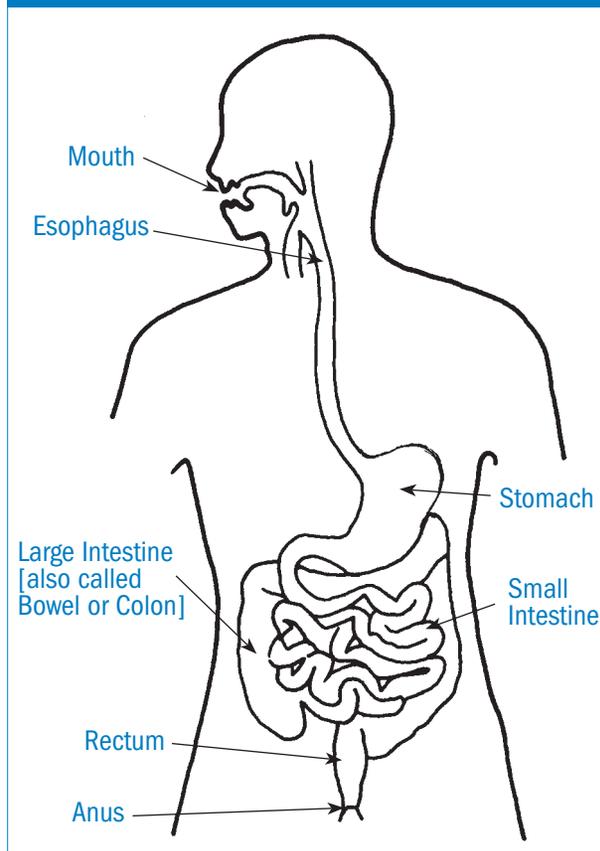
Your diet, the amount of exercise you do, and the regularity of your bowel movements play an important role in keeping you healthy. The following is a description of the digestive system and how some parts can affect your bowel movements [SEE FIGURE 1.e.1].

- *Mouth:* As you chew, saliva mixes with broken-up pieces of food. If you eat a well-balanced diet high in fiber, there will be enough bulk to make passage through the system run smoothly.
- *Esophagus:* This is a hollow passageway through which food reaches the stomach.
- *Stomach:* Digestive juices break down the food into carbohydrates, fats, proteins, and other end products. [See section 4.b, *Nutrition and Weight*, to find out why these things are important.]
- *Small intestine:* As the watery mixture moves through, nutrients are absorbed into the bloodstream.
- *Bowel [large intestine] or colon:* Water is absorbed back into the body as the remaining by-products of digestion move through the bowel. When these by-products move too quickly, your bowel movements are very watery [diarrhea]. When the by-products remain in the bowel for prolonged periods, water continues to be absorbed into the body. This results in hard stools that are

difficult to pass [constipation]. SCI may affect the last half of the large intestine, causing slow, uncoordinated passage of stool.

- *Rectum:* When stool reaches the rectum, you get the urge to have a bowel movement. If you lack feeling in your rectum, you won't get this urge.
- *Anus:* The anus, or rectal opening, is controlled by the sphincter muscle. When you relax this muscle, you can have a bowel movement. When you tighten it, you can prevent one. If you're unable to relax or tighten the sphincter, your bowel movements cannot be controlled.

[Figure 1.e.1] The Digestive System



As you can see, the colon, rectum, and anus can be affected by SCI. The term “neurogenic bowel” is used to describe these alterations and their consequences.

of your bowel program are to prevent accidents [unplanned bowel movements], to produce bowel movements at regular and predictable times, and to minimize bowel-related complications.

Bowel Program

A bowel program involves diet, exercise, fluids, medication, and scheduled bowel care. The goals

Bowel Care

Bowel care is one part of the bowel program. It’s the scheduled process of helping your body have

[Table 1.e.A] Bowel Medications

TYPE OF MEDICATION	MEDICATION NAMES	WHAT THEY DO
ORAL LAXATIVES		
Stimulants	Bisacodyl, Cascara, Castor Oil, Senna	Increase the wave-like action of peristalsis to move stool through the bowel faster and keep it soft.
Osmotic laxatives	Lactulose, Magnesium Citrate, Magnesium Hydroxide, Magnesium Sulfate, Sodium Biphosphate, Sodium Phosphate	Increase stool bulk by pulling water into the colon. You need to drink extra fluids with these.
Bulk-forming laxatives	Hydrophilic Muciloid, Methylcellulose, Psyllium	Add bulk to stool. You will need to drink extra fluids with these.
Stool softeners	Docusate Calcium [DOSS], Docusate Potassium, Docusate Sodium, Mineral Oil	Help stool retain fluid, stay soft, and slide through the colon.
Prokinetic agents	Metoclopramide	Stimulate bowel peristalsis.
RECTAL STIMULANTS		
Suppositories	Bisacodyl	Increases colon activity by stimulating the nerves in the lining of the rectum.
	Carbon Dioxide	Produces carbon dioxide gas in the rectum, which inflates the colon and stimulates peristalsis.
	Glycerin	Stimulates peristalsis in the colon and lubricates the rectum to help pass stool.
Enemas	Mineral oil	Lubricates the intestine.
	Mini-enema	Stimulates the rectal lining and softens stool.

Adapted from *Neurogenic Bowel: What You Should Know*, Consortium for Spinal Cord Medicine, March 1999, p. 27. www.pva.org/consumerguides.

a bowel movement. The goal is to regularly empty your bowel to prevent chronic overdistention. Some people find that an abdominal support binder is helpful. To stimulate peristalsis [the wave-like tightening of the intestines], you can use a rectal suppository, mini-enema, or digital stimulation of the rectal muscles. Bowel care can be done on a commode chair, on a toilet, or in bed with pads—whatever works best for you.

Your bowel management program will depend on the type of bowel you have following your SCI: reflexic or areflexic. The rehabilitation nurse and your health-care provider will work with you to establish the most effective routine. The following is a description of tools, medications, and techniques that are commonly used in bowel care regimes. Table 1.e.A lists some medications that may be prescribed as part of your bowel program.

Do:

- Establish a regular time for bowel care that will fit into your daily schedule. Your bowel care can be every day or every other day. In the first weeks after your injury, it will be every day.
- Eat a well-balanced diet with high-fiber foods.
- Have privacy.
- Be comfortable.
- Exercise regularly [range-of-motion exercises].
- Drink as much liquid as your bladder management allows.

Don't:

- Use large enemas, because they can stretch the bowel. Mini-enemas may be prescribed.
- Take strong oral laxatives routinely.

Supplies:

- Suppository inserter [if you need one]
- Suppository or mini-enema
- Scissors if using mini-enema
- Lubricating jelly
- Waterproof pads
- Gloves
- Antibacterial soap and warm water
- Toilet paper or moist wipes for cleansing

How to Perform Bowel Care

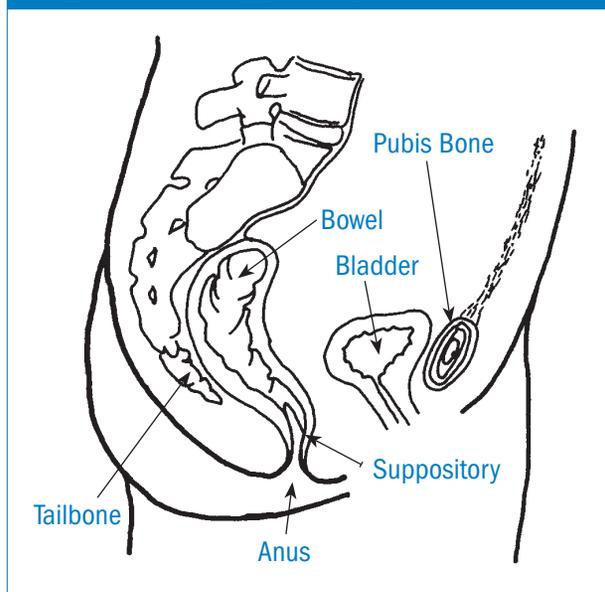
If you have sufficient arm and hand function, you'll learn to do your own bowel care. If you're not able to do your own care, you'll learn how to instruct others in the process.

Do your bowel care 30–45 minutes after a meal or hot drink because this stimulates peristalsis to promote stool movement in your colon. Most people choose to do bowel care as part of their morning routine or in the evening after dinner. If you use the intermittent catheterization procedure [ICP] to empty your bladder, do that before bowel care.

1. *Wash hands:* Wash your hands and put on a clean pair of exam gloves. Hand-washing is important to maintain a clean environment and reduce the risk of infection from stool contamination.
2. *Setup and positioning:* Arrange all the supplies you'll need so they're within easy reach. Many people sit on a commode chair for bowel care, as gravity may help with emptying the bowel. Some transfer to the commode chair after the medication insertion [step 4]. Others do their care in bed, for a variety of reasons. If you're lying on your side, the left-side-down position is usually recommended.

3. *Check for stool:* Lubricate a gloved finger. [Be sure to use a water-soluble lubricant.] Check your rectum for stool and gently remove any stool that may be there.
4. *Insert stimulant medication:* If you need stimulant medication, insert a well-lubricated suppository high into your rectum with a gloved finger or adaptive device. Place it next to the intestinal wall [SEE FIGURE 1.e.2], so it comes in contact with all surfaces of the rectal wall to provide optimal stimulation. Another medication choice may be an enema. Gently insert the enema tip into the rectum to the neck of the container. Squeeze the container and wait 5–15 seconds before removing the tip.

[Figure 1.e.2] Suppository Placement



5. *Waiting period:* Wait 5–15 minutes after inserting any stimulant medication.
6. *Digital stimulation:* Digital stimulation is a technique that can both start and enhance the strength and frequency of peristalsis. Gently insert a lubricated gloved finger or adaptive device into your rectum. With a firm circular motion, rotate your finger, maintaining contact with the bowel lining all the way around until

it relaxes [15–60 seconds]. You may need to do digital stimulation every 5–10 minutes to promote and prolong peristalsis while the anus relaxes. This allows stool to pass through the anus until gas and stool flow have stopped.

7. *End of bowel care:* Do a final check with a lubricated gloved finger or adaptive device to determine if your rectum is empty. Other signs that bowel care is complete are no more stool after two digital stimulations or mucus coming out without stool.
8. *Clean up:* Wash and dry the anal area and your hands.

Autonomic Dysreflexia

If you experience symptoms of autonomic dysreflexia [AD] during bowel care, you may need to use an anesthetic cream for medication insertion and digital stimulation. Ask your health-care provider for a prescription. [See section 1.i, *Autonomic Dysreflexia.*]

Things that Can Affect Your Bowel Program

- Exercise stimulates peristalsis. Try doing range-of-motion exercises before bowel care or after inserting the suppository and before digital stimulation. Your routine use of your wheelchair, even a power wheelchair, is also exercise.
- Some medications can affect peristalsis. For example, many narcotics [such as oxycodone or methadone] and anticholinergics [such as oxybutynin [Ditropan] or amitriptyline] can slow peristalsis and cause constipation.
- Emotional stress can cause either constipation or diarrhea.
- A change in the time of your bowel care can lead to a bowel accident.

[Table 1.e.B] Dietary Effects on Bowel Management

FOOD GROUP	FOODS THAT HARDEN STOOLS	FOODS THAT SOFTEN STOOLS
Milk	Milk, yogurt made without fruit, cheese, cottage cheese, ice cream	Yogurt with seeds or fruit
Bread & Cereal	Enriched white bread or rolls, saltine crackers, refined cereals, pancakes, waffles, bagels, biscuits, white rice, enriched noodles	Whole grain breads and cereals
Fruits & Vegetables	Strained fruit juice, apple sauce	All vegetables except potatoes without the skins
Meat	Any meat, fish, or poultry	Nuts, dried beans, peas, seeds, lentils, chunky peanut butter
Soups	Any creamed or broth-based without vegetables, beans, or lentils	Soups with vegetables, beans, or lentils
Fats	None	Any
Desserts & Sweets	Any without seeds or fruits	Any made with cracked wheat, seeds, or fruit

- Your diet can harden or soften your stool [SEE TABLE 1.e.B].

Problem Solving

Diarrhea

Diarrhea [loose or watery stools] may cause unplanned bowel movements and accidents.

Causes:

- Spicy foods or foods containing caffeine, such as coffee, tea, cocoa, and many soft drinks.
- Medications such as antibiotics, or an increase or decrease in medications you're already taking.
- Overuse of laxatives or stool softeners.
- Severe constipation. [See the fourth item under Solutions.]
- Flu or intestinal infection.
- Psychological stress.

Solutions:

- Eat the recommended foods for when you have diarrhea [SEE TABLE 1.e.B].
- Stop laxative use until diarrhea clears up.
- Stop using stool softeners. After the diarrhea stops, adjust the dose to get the stool consistency you want.
- Evaluate whether there is a chance that you have a blockage—no stools, hard stools, or small, hard bowel movements. Blockage is a common cause of diarrhea, since only liquid and soft stool can get past it. Call your health-care provider.
- After the diarrhea clears up, reevaluate your bowel program, use of stool softeners, diet, and so on.
- When you take antibiotics, eat yogurt with active cultures to help restore the normal bacterial flora in your bowel.
- Call your health-care provider if diarrhea lasts more than 24 hours.

Constipation

Constipation is a common condition in which stool does not pass as often, as fast, or as completely as we expect. The stool may be hard and dry. It is sometimes hard to determine if you are constipated until you have had incomplete results or no results after two or more episodes of bowel care. Be sure to check the amount of stool produced with each bowel movement.

Causes:

- Lack of regularly scheduled bowel care.
- Incomplete emptying during bowel care.
- Diet that is low in fiber.
- Bed rest or low levels of physical activity.
- Certain medications—narcotics, anticholinergics, iron, or aluminum hydroxide—or an increase or decrease in medications you're already taking.
- Dehydration.

Solutions:

- Perform bowel care on a schedule. You may need to do it more often.
- Eat high-fiber foods. *[See section 4.b, Nutrition and Weight.]*
- Increase physical activity and range of motion.
- Take psyllium hydromucilloid [Metamucil].
- Take docusate sodium [DOSS].
- Drink as many fluids as your bladder program allows.
- Try milk of magnesia or senna the night before scheduled bowel care.
- Talk to your health-care provider about trying a rectal stimulant medication or a stronger one if you're already using one. Also discuss whether any of your medications might be causing constipation and, if so, whether they can be changed or stopped.

Impaction

An impaction is a partial or complete blockage in the intestine by stool.

Causes:

- Same as for constipation.

Solutions:

- Manually remove stool in rectum.
- Call your health-care provider for advice.

Rectal Bleeding

Rectal bleeding appears as bright red blood on your stool, toilet paper, or glove.

Causes:

- Hemorrhoids.
- Hard stools [constipation].
- Rectal fissures [cracks or breaks in the skin].
- Trauma during digital stimulation of the anus [for example, damage from long fingernails].
- Bleeding from higher up in the gastrointestinal tract.

Solutions:

- Soften stools with DOSS, psyllium powder, or increased fluid intake.
- Do gentle digital stimulation using a lot of lubrication.
- If bleeding occurs during two or three consecutive bowel care episodes, consult your health-care provider.
- If bleeding does not stop between scheduled bowel care episodes, consult your health-care provider immediately.

[Table 1.e.C] Foods that May Cause Gas

VEGETABLES

Beans [kidney, lima, navy]
Broccoli
Brussels sprouts
Cabbage
Cauliflower
Corn
Cucumbers
Kohlrabi
Leeks
Lentils
Onions
Peas [split or black-eyed]
Peppers
Pimientos
Radishes
Rutabagas
Sauerkraut
Scallions
Shallots
Soybeans
Turnips

FRUITS

Apples
Avocados
Cantaloupe
Honeydew melon
Watermelon

Autonomic Dysreflexia

[See section 1.i, Autonomic Dysreflexia.]

Causes [bowel-related causes only]: Anything that can cause pain, such as

- Hemorrhoids or fissures.
- Full or overdistended bowel [constipation, skipped bowel care, impaction].
- Rough digital stimulation.

Solutions:

- Regularly scheduled bowel care with adequate emptying. You may have to increase the frequency of your scheduled bowel care.

- Comfortable positioning during bowel care.
- Anesthetic ointment applied to the anal area 5–10 minutes before suppository insertion and digital stimulation.

No Bowel Movements for Two or Three Scheduled Bowel Care Episodes

Causes:

- Constipation.
- Impaction.
- Not eating.

Solutions:

- Try to determine the cause.
- Call your health-care provider.

Excessive Gas

Causes:

- Gas-forming foods [SEE TABLE 1.e.C].
- Constipation.
- Swallowing air while eating or drinking.
- More than normal bacterial breakdown of bowel contents.

Solutions:

- Eat slowly, chewing with your mouth closed; avoid gulping food.
- Certain foods may give you gas. Try omitting certain foods one at a time to determine which ones cause you to have excess gas.
- Follow your scheduled bowel care regime.

RESOURCES

Publications

Neurogenic Bowel: What You Should Know: A Guide for People with Spinal Cord Injury
www.pva.org/consumerguides

Bowel Management Programs: A Manual of Ideas and Techniques

Accent Press

Accent Special Publications

Cheever Publishing, Inc.

P.O. Box 700

Bloomington, IL 61702

[309] 378-2961

Taking Care of Your Bowels—The Basics

Taking Care of Your Bowels—Ensuring Success

Northwest Regional Spinal Cord Injury System

University of Washington

Department of Rehab Medicine

1959 NE Pacific

Seattle, WA 98195

[800] 366-5643; [206] 543-3600

Download: sci.washington.edu

Home Care Manual for Spinal Cord Injury

Santa Clara Valley Medical Center

751 S. Bascom

San Jose, CA 95128

[408] 885-5000

Preventing Secondary Medical Complications:

A Guide for Personal Assistants to People with Spinal Cord Injury

Research Services

University of Alabama at Birmingham

Department of Physical Medicine and

Rehabilitation

619 19th Street South, Room 529

Birmingham, AL 35249-7330

[205] 934-3334

Download: www.spinalcord.uab.edu

Fact Sheet #10: Bowel Management in Spinal Cord Injury

Arkansas Spinal Cord Commission

1501 North University, Suite 470

Little Rock, AR 72207

[800] 459-1517

Download: [www.spinalcord.ar.gov/Fact%20](http://www.spinalcord.ar.gov/Fact%20Sheets%20html/bowelmanagement.html)

[Sheets%20html/bowelmanagement.html](http://www.spinalcord.ar.gov/Fact%20Sheets%20html/bowelmanagement.html)

Neurogenic Bowel Management in Adults with a Spinal Cord Injury

www.pva.org/CPGs

Videos

Accidents Stink! Or Bowel Care 202

Production of this 50-minute video was supported by the Paralyzed Veterans of America

Education Foundation.

Available through www.conceptsinconfidence.com

SCI Video Access, a lending program of information videos

Spinal Cord Injury Network International

3911 Princeton Drive

Santa Rosa, CA 95405-7013

[800] 548-2673; [707] 577-8796

www.spinalcordinjury.org/videos.htm

1.f | Sexual Health and Reproduction

Sexuality is much more than just gender [male or female] or the act of sex. People show their sexuality in many ways, such as the way they present themselves in interactions with others, clothing, body image, hobbies and interests, and grooming habits. Sex, on the other hand, is the physical interaction between two people. It may or may not be a very intimate experience. It may or may not be with someone of the opposite sex. It does, however, express sexuality.

For many people with SCI, both male and female, the change in or loss of genital sensation has a great impact on sexuality. However, many people with SCI say that sex can be much more intimate and spiritual than it was before the injury—instead of orgasms being just physical and focused on the genitals, they can be more a state of mind.

These people have found pleasure in discovering their own and their partners' bodies in new ways: touching, caressing, and exploring each other. This kind of intimacy and pleasure require open and willing communication. This means talking about what feels good and how and where to touch, as well as things like bladder and bowel function. Ongoing discussions about sexual functioning help both partners know what to expect.

In the past the assumption was that people with SCI were no longer capable of or interested in sex. Today, we know this is not true. It is recognized and increasingly accepted that sex, marriage, and parenthood can be a part of anyone's life, with or without a disability. A physical disability does not eliminate sexual feelings. Persons with SCI experience the same sexual feelings as those without SCI. You can lead a sexually active life and maintain intimate relationships if you choose to do so. This section provides information that will help you accomplish these goals. The topics

include myths and misconceptions about sexuality and disability, anatomy of sexual functioning, changes in sexual functioning after SCI, and effects of SCI on fertility and pregnancy.

Myths and Misconceptions About Sexuality and Disability

Myth: It is not appropriate for persons with SCI to discuss sex with health-care providers.

Fact: Sex is a natural part of life. It deserves attention in your rehabilitation program. Sex and sexuality are health issues and should be discussed between you and your health-care providers.

Myth: People with disabilities are no longer sexual beings.

Fact: We are all sexual beings. This does not change after SCI. After you're discharged from the hospital, you may find that people on the outside don't react to you the same way they did before you were injured, and that new people you meet might seem a little uncomfortable or anxious around you. They may not know what to say or how to relate to you. You may not be seen as a sexual person or a potential sex partner. For a time just after your injury, you may react to yourself that way.

If you already have a sex partner, you may notice that he or she does not approach you sexually in the same way as before. Likewise, you may be somewhat timid about initiating sex with your partner. If you are, it may come from fear and anxiety about being able to perform sexually with a "new" body. You may not know how to begin or what to expect, which can be very frightening. SCI sex education is one way to start working out those fears. Education, along with good social and

communication skills, can help you approach sex without anxiety or confusion.

The onset of paralysis will likely affect your genital function. This does not erase your ability and desire to sexually please and be pleased. Through education, exploration, and experimentation, mutual satisfaction is possible. You will get to know your body much better than you did before you were injured. You are also likely to learn how to perform some sexual acts in new ways. This is discussed in more detail in the next section.

Myth: Marriage and parenting are not options for people with SCI.

Fact: People with SCI fall in love and marry. Men and women with SCI become parents, raise children, and manage happy households.

In the long run, the effect of SCI on your sexuality has a lot to do with how you feel about yourself—your self-esteem. Your skill and confidence in close relationships will affect your ability to function sexually. You must accept yourself as a sexual being and use your learned skills. You need to explore your body for sensation, movement, and reaction. To successfully guide your partner, you need to know the territory. Keep the following in mind:

- The presence of SCI does not mean the absence of desire or romance.
- Inability to move does not mean inability to please or be pleased.
- Absence of sensation does not mean absence of emotions.
- Loss of genital function or sensation does not mean loss of sexuality.

Anatomy of Sexual Functioning

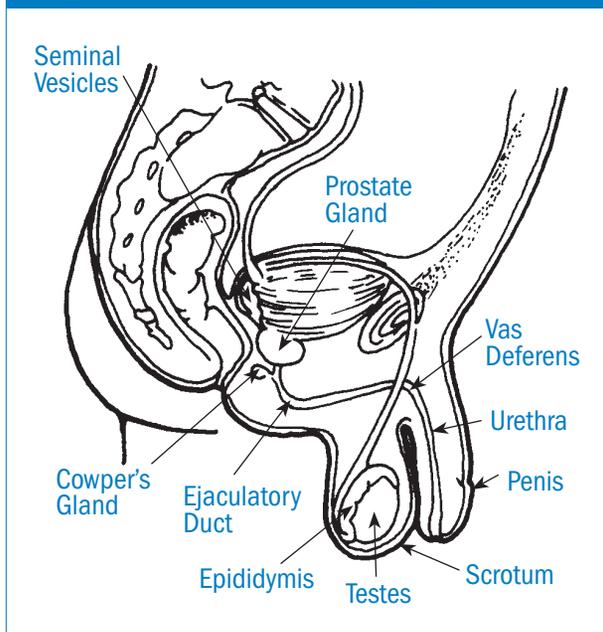
This section identifies and describes areas of the body involved in sexual functioning.

Male Sex Organs

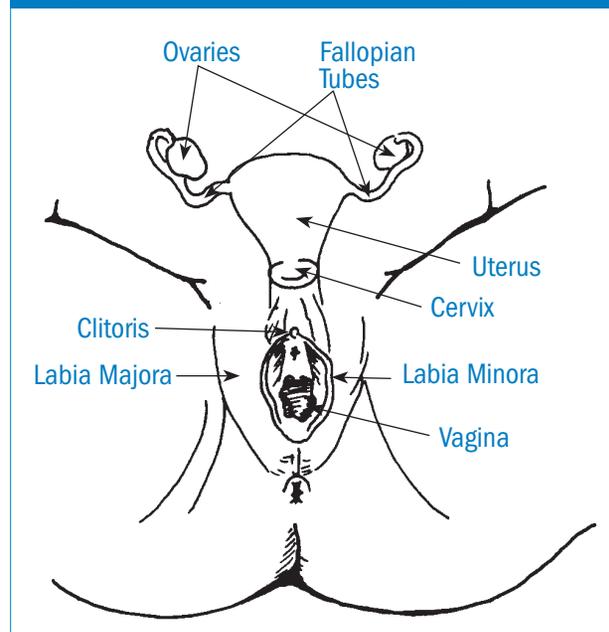
[SEE FIGURE 1.f.1]

- *Scrotum:* A sack of thin muscle and skin that houses and protects the testes.
- *Testes:* Egg-shaped organs that produce and secrete the male sex hormone testosterone and produce sperm.
- *Epididymis:* A storage place for sperm.
- *Vas deferens:* One of the narrow tubes through which sperm travels to exit the body.
- *Seminal vesicles:* Two small glands that add fluid to the sperm.
- *Prostate gland:* A small gland shaped like a walnut that adds fluid to the sperm to make semen. This gland is just below the bladder. The urethra passes through it.
- *Ejaculatory duct:* A small passageway in the urethra through which semen [both fluid and sperm] moves close to the time of ejaculation.
- *Cowper's gland:* Two pea-sized glands that secrete a small drop of fluid after a man becomes sexually excited to lubricate the urethra.
- *Urethra:* A tube that is a passageway for the sperm to exit the body during ejaculation. It also carries urine out of the body.
- *Penis:* The organ that contains the urethra, through which sperm and urine pass. It becomes erect during sexual stimulation, which enables it to enter the vagina during sexual intercourse.

[Figure 1.f.1] The Male Sex Organs



[Figure 1.f.2] The Female Sex Organs



Female Sex Organs [SEE FIGURE 1.f.2]

- *Labia majora* ["large lips"]: The larger of the skin folds that surround and protect the vaginal area.
- *Labia minora* ["small lips"]: The smaller skin folds inside the larger ones. These lie directly beside the vaginal opening.
- *Clitoris*: The organ located just above the urinary opening and just below where the tops of the labia minora meet. It is made of the same type of tissue as the penis. Unlike the penis, the only purpose of this organ is for sexual excitement.
- *Vagina*: A tube leading from the labia to the uterus. The penis is inserted into the vagina during sexual intercourse. During childbirth, the baby passes through the vagina from the uterus.
- *Cervix*: The opening into the uterus from the vagina. Through it, sperm enter to fertilize an egg and a baby exits to be born.
- *Uterus*: A thick, hollow muscle in the lower abdomen. Its purpose is to carry and nurture a fetus.

- *Ovaries*: Two small organs that take turns every month producing eggs. They also produce the female sex hormones estrogen and progesterone.
- *Fallopian tubes*: Two tubes attached to the top of the uterus. On the outer ends of the tubes are fingerlike pieces of tissue that catch the eggs from the ovaries and pass them down the tube to the uterus. It is within these tubes that eggs are usually fertilized by sperm.

Sexual Functioning after SCI

If you have some or no feeling below the level of your injury, you may wonder what sex will be like now. Genital sensation is one [but only one] part of the sexual experience. You can feel full sexual sensations above the level of your injury, which includes your ears, neck, face, and mouth.

Areas that are particularly sensitive and produce sexual arousal are called "erogenous zones." Many people with SCI discover that areas other than the genital areas and nipples are sexually exciting when touched. Use them and your other senses to heighten sexual feelings with the help of the

largest sex organ of all: your brain. Sexual function requires a fine-tuned coordination of different parts of the nervous system. Think about people working together as a team on some goal. If some team members don't do what they're supposed to do, the goal may be only partially achieved or not achieved at all—or the remaining team members can work harder and fully achieve the goal. The same thing happens with SCI: some nerves can't do what they used to do, but that doesn't mean everything stops functioning.

In males, the changes after SCI are typically related to erection, ejaculation, and orgasm or climax. In women, changes in sexual function include decreased ability to lubricate and reach orgasm. Changes in feeling and movement will change the sexual experience for both men and women.

Male Sexual Function

Erections

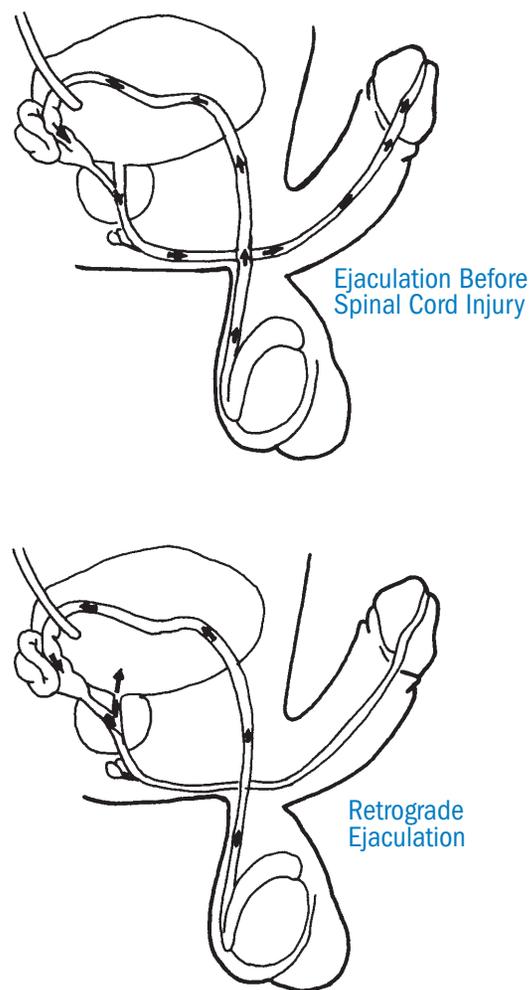
There are two types of erections—psychogenic and reflexogenic—and they involve different parts of the spinal cord. The extent to which each is affected depends on where and how complete or incomplete your injury is.

- Psychogenic erections. These erections occur from sexually related thoughts [fantasy], seeing a physically attractive person, looking at erotic pictures, reading sexually exciting material, or hearing sounds that are sexually stimulating. If your SCI is in the lower lumbar or sacral area and is incomplete, you may be able to have a psychogenic erection. If you have an incomplete injury above the T12 level, psychogenic erections may still sometimes occur.
- Reflexogenic erections. These erections occur through a reflex mechanism in the sacral part of your spinal cord. Your brain plays no part in this type of erection. All you need is an intact, functioning reflex system at the S2, S3, or S4

segments of the spinal cord. This is present in cervical, thoracic, and lumbar [upper motor neuron] SCI. In this case, any stimulation to the scrotum, penis, or anus may cause an erection. Maybe you've noticed this when you wash or apply your condom catheter.

If having a partial or full erection is not easy and you consider it a major part of your sexual activity, you do have some options. See the section below on adaptive equipment and medications to enhance male sexual functioning, and feel free to discuss these options with your health-care provider or other rehabilitation team members.

[Figure 1.f.3] Ejaculation



Ejaculation

Ejaculation is the mechanism that allows semen to be discharged. In normal ejaculation, muscle contractions cause spurts of semen to be forced outward from the penis. Part of the process that allows normal ejaculation is closure of the bladder neck, so the semen can flow past the bladder and out the urethra.

Some men with SCI experience retrograde ejaculation. This happens when the bladder neck stays open and semen travels into the bladder instead of out the urethra [SEE FIGURE 1.f.3]. Most men with complete SCI do not have orgasms or ejaculations. If you have an incomplete injury, you may be able to ejaculate. The best way to learn your ejaculatory status is to try it out. Be patient—give yourself a few chances to see if this system still works.

Orgasm

Orgasm is the pleasurable release of sexual tension after achieving a peak of sexual stimulation. It is associated with rhythmic contractions of the pelvic floor muscles [ejaculation] and expulsion of semen.

Female Sexual Function

Lubrication and arousal

In women, sexual stimulation causes lubrication of the vagina. SCI may result in a lack of lubrication. With an injury above the sacral spinal cord, stimulation to the genitals and vagina will most likely cause reflex lubrication. You may also have psychogenic lubrication if you were injured around or below the T12 level of your spinal cord. Women who are not able to lubricate may wish to use a water-soluble jelly to enhance lubrication. It's not advisable to use an oil-based product like Vaseline or any perfume-based material because these don't dissolve in water and can cause an infection.

Orgasm

Orgasm is the release of sexual tension after achieving a peak of sexual stimulation. Little information is available regarding orgasm in women with SCI. Some women with complete SCI are able to reach orgasm, although the experience is typically different from the pre-injury orgasmic experience. This is an area of continued investigation.

Adaptive Equipment and Medications to Enhance Sexual Functioning

Male

Vacuum pump

Vacuum erection/constriction devices are the least invasive and least expensive of the current treatment options. The devices produce an erection by creating a vacuum around the penis. This triggers blood flow into the corpora cavernosa, a part of the penis that fills with blood to cause an erection. The erection is maintained by placing a tension band or ring around the base of the penis. Although this is a fairly simple method, it's important to receive instruction from your health-care provider.

Penile injection

This treatment involves injecting the FDA-approved drug alprostadil [Caverject] into the penis about 20 minutes before sexual activity. The dose is individualized, so testing and training are necessary.

Transurethral therapy

MUSE is a urethral suppository containing alprostadil. It's important to receive specific training if you want to use this form of therapy.

Phosphodiesterase 5 inhibitors

PDE5 inhibitors, such as sildenafil [Viagra], vardenafil [Levitra], and tadalafil [Cialis], help restore penile blood flow and erection in response

to sexual stimulation. These medications act by dilating the blood vessels in the penis. They are generally safe, although men who are taking medications with nitrates should not take PDE5 inhibitors. PDE5 inhibitors also can interact with some blood pressure medications, especially alpha blockers.

Penile prostheses

These silicone devices are surgically implanted in the penis. They have fluid chambers to simulate a true erection. An important consideration for patients and partners is that this is an invasive procedure [surgery] and is considered irreversible. You should investigate all other feasible options before you consider penile implant surgery.

Final note

For any treatment to be successful, it's advisable to include your partner in research and learning sessions.

Female

Treatment options are limited for women with sexual dysfunction. With partial loss of genital sensation, self-stimulation or the use of a vibrator can enhance the sexual experience. As with men with SCI, lost erogenous sensation cannot be restored, but stimulation can focus on the areas of the body above the level of injury that are still capable of sexual response, as well as from audiovisual stimulation.

Both men and women with SCI ask questions related to how they can have a satisfactory and fulfilling sexual experience. The answers and solutions often come from personal exploration alone or with a partner.

SCI and Intimacy

Compared with before your SCI, sexual activity now requires some planning. At the same time, many people like sexual spontaneity and the

freedom to explore themselves and their partner. This can happen if you first take the time to explore your new self, both in body and mind. Your health-care provider may have suggestions for more reading material. *[For information on sexual relationships and counseling, see section 3.b, Psychosocial Adjustment.]*

Things to Think About before Sexual Activity

Preparation will enhance, not destroy, the moment.

Autonomic dysreflexia

In some persons, sexual activity can trigger an episode of autonomic dysreflexia [AD]. You should be able to recognize AD and know how to treat it. *[See section 1.i, Autonomic Dysreflexia.]*

Bladder management

If bladder control is a problem or concern, and you've planned to have sex at a certain time, reduce your fluid intake for three to four hours before sex. Emptying your bladder just before sex is the best insurance against incontinence. You may choose to remove catheters and other urinary equipment before sex. If you don't want to remove them, the following are some things to consider:

- You can use longer connective tubing with a larger volume "night bag." This will allow for a greater area of movement. Check once in a while to make sure the tubing is not pinched or kinked.
- Men can bend a Foley catheter against the shaft of the penis and place a condom over it. If you do this, you may need extra lubrication around the tubing coming into contact with the penis to prevent chafing the skin.
- If you wear an external collecting device [a condom], you can remove it and then replace it after sex. Have the supplies ready to replace the catheter following sexual activity.

- Women who do not want to remove their Foley catheter can tape the tubing to the stomach or upper thigh area.
- If you have an ostomy, you may want to use extra tape to prevent leakage. Avoid direct pressure against the ostomy bag during sexual activity.
- If you have a suprapubic catheter, tape the tubing out of the way. Be sure to use a tape that will not pull on your skin.

Leaks and accidents are not the end of the world. They can happen even with all proper preparation and planning. People without SCI sometimes have problems with incontinence, too. You may want to place a waterproof pad over your mattress and keep towels around the bedside in case of an accident.

Bowel management

To avoid accidents with your bowels, plan ahead for bowel care. You may want to perform your bowel care in the morning or just before intercourse, so it won't be a problem.

Preparation as foreplay

A bath or shower can be part of foreplay and eliminate unpleasant body odors at the same time.

If you require assistance to transfer, position, undress, or handle hygiene, and your partner is willing and able, these activities can be part of your foreplay. Positioning yourself for sex will depend on the type of sexual activity you wish to engage in. Check with your health-care provider, physical therapist, or occupational therapist for any possible limitations on positioning.

Surroundings

Sexual activity is always better in a comfortable setting. Think about your surroundings. Where are you most comfortable having sexual activity—in your wheelchair, a bed, a couch? At

home, in a hotel? Environmental barriers may limit accessibility for sexual activity. For example, you may have an accessible residence, but your partner's home may not be accessible.

Spasticity

Many men with spasticity are able to achieve reflexogenic erections. However, limb spasticity can be a hassle during sex for both men and women. Spasticity can prevent certain sexual positions. Your best bet is to maintain your range of motion as outlined by your therapist. During your therapy process, you may learn to position and move your body in ways that will minimize spasticity.

Diseases

Sexually transmitted diseases [STDs] can affect sexually active persons with SCI as easily as anyone else. Activities that involve the exchange of semen, genital secretions, or blood may place you at risk of contracting diseases such as herpes, genital warts, gonorrhea, chlamydia, hepatitis, or HIV. Always practice safe sex. In general, using a condom will reduce the risk of disease. Contact your health-care provider, the local AIDS hotline, or the local health department for more information. If you notice any abnormal discharge or abnormalities of the skin on your genitalia, consult your health-care provider for an examination.

Fertility and Reproduction

Male

If you can ejaculate or you have any mucus-like fluid from your penis during sexual activity, you should use birth control if you don't want your partner to get pregnant. Any fluid from the penis might contain sperm. However, two problems are very common in males with SCI: inability to ejaculate and poor semen quality. So if

pregnancy is the goal, you'll probably need to have a consultation with a fertility clinic. Both the male SCI patient and his partner should be evaluated to optimize the chances of pregnancy.

If you can't ejaculate, or you can but your partner has not gotten pregnant, have a semen analysis. If ejaculation is the problem, most major medical centers will have techniques to help you. For example, a vibrator can be applied to the head of the penis; it causes stimulation that eventually sets off ejaculation. If your SCI is at T7 or below, you can learn how this works at the medical center or clinic and then do it yourself at home. [Note: If your SCI is at T6 or above, vibratory stimulation may cause AD.]

Electroejaculation involves using a probe through the rectum to apply electrical stimulation to the prostate and seminal vesicles to cause ejaculation. In special cases, sperm can be retrieved directly through the skin by a fertility clinic, using a needle and syringe.

Once sperm are obtained, there are many ways to use them to achieve pregnancy—these methods are called assisted reproductive techniques [ARTs]. For specific information, get a referral from your health-care provider.

Female

It may be a few months after the injury before a woman with SCI has a period [menstruates] again. Once menstruation returns, your fertility is similar to what it was before your injury, so pregnancy can occur easily if you are of child-bearing age. If you don't want to get pregnant, discuss all birth control options with your health-care provider. If you're considering becoming pregnant, talk

with your gynecologist about special medical considerations related to your SCI. In pregnancy, you will face increased risks of blood clots, premature labor, AD, urinary tract infections, and pressure ulcers. Some women decide to have a Caesarian section to avoid some of the complications of labor.

Both ARTs and adoption are options for women and men with SCI who want to raise children.

RESOURCES

Website

www.scisexualhealth.com

This site covers topics related to sexual health and fertility after spinal cord injury.

1.g | Muscles and Bones

Many conditions can affect your muscles and bones after spinal cord injury. This section describes some of the most common conditions.

Spasticity

When a muscle contracts [tightens] in response to stimulation—like when a doctor taps your knee—it’s called a reflex. Spasticity is the name for increased muscle reflexes or muscles moving on their own when you don’t want them to. Before SCI, the brain sent messages down your spinal cord to keep your reflexes minimal. After SCI, these messages may be blocked, and your reflexes can become overactive. Some people don’t get spasticity until a month or more after their injury; others never get it.

Many things can trigger a muscle spasm. Even simple things like touching your skin, changing body position, stretching your muscles, or letting your bladder fill with urine can cause a muscle contraction that you can’t control. One common type of reflex muscle contraction after SCI is *extensor spasms*—rigid straightening of the arms or legs. Another is *flexor spasms*—bending of the joints. During a spasm, many people have *clonus*, a rapidly repeating muscle contraction that shakes the limb.

The pattern and amount of spasticity can change over time, especially in the first year after SCI. Sometimes a significant increase in spasticity may be a sign that something is wrong in a part of your body where you do not have sensation; for example, a urinary tract infection, a pressure ulcer, a kidney stone, appendicitis, an ingrown toenail, or almost any problem. Notify your health-care provider if you notice a significant increase or decrease in spasticity.

Possible Benefits of Spasticity

- An increase in spasticity can warn you of pain or a problem in areas where you do not have sensation.
- Spasticity may help maintain some of your muscle size and bone strength.
- Spasticity helps promote circulation of your blood from your legs back up to your heart.
- You may be able to learn to use your spasticity functionally; for example, using extensor spasms to move paralyzed legs when you’re transferring.

Disadvantages of Spasticity

- Spasticity can interfere with transfers, bathing, dressing, staying positioned in a wheelchair, driving a vehicle, walking, and other activities.
- Spasticity may be uncomfortable or may interfere with sleep.
- Spasticity may cause scraping or shearing of your skin, which contributes to skin breakdown.
- Spasticity may cause you to lose joint movement [range of motion] because it’s hard to move the joint through its full range. *[See Contractures.]*

What to Do

Spasticity needs to be treated only if it’s causing a problem; for many people, it causes no problems. The goal of treatment is to keep spasticity from interfering with activities or causing health problems, not to completely eliminate it. Here are some ways to minimize spasticity and its effects without medications or surgery:

- Perform daily range-of-motion exercises. *[See section 2.c, Limb Preservation and Posture.]*
- Avoid stimulation that aggravates the spasticity, such as fast movements or certain body positions.
- During a spasm, protect your feet and legs from striking sharp or hard objects, like hitting your wheelchair during a transfer. Ask your therapists about the use of padded straps and splints to help control spasticity.
- Take a warm [not hot!] bath or shower.
- Talk to your health-care provider about wheelchair options, such as shock absorbers.
- Talk to your health-care provider about other treatment options.

For spasticity that can't be controlled with those treatments, other options include the following:

- Oral medications [but, like all medications, each one has side effects].
- Injection of a specific medication into a muscle or nerve to reduce spasticity.
- Intrathecal medication—medication delivered directly to the spinal canal from a pump implanted under your skin by a surgeon. The pump is refilled with medicine at regular intervals by a health-care provider.
- Surgery to nerve roots or to the spinal cord.

Muscle Atrophy

Atrophy is the shrinking of muscle size when a muscle is not used. Some people with SCI develop more atrophy than others. Atrophy generally is not a medical problem. However, if your muscles get smaller, you'll have less padding over bony spots where pressure ulcers can form—such as sit bones, heels, or shoulders—and you'll need to avoid long-term pressure on these spots. Spasticity may help decrease the amount of atrophy by keeping the muscles active. Atrophy

of paralyzed muscles can sometimes be partially reduced by using electrical stimulation treatments to make the muscles contract. However, each muscle must be stimulated, and if the treatments are stopped, atrophy will return. Electrical stimulation will not restore voluntary strength in completely paralyzed muscles. This treatment is usually very time-consuming and costly compared with the benefits.

Contractures

Contracture is tightness of tissues around joints and in muscle that limits joint movement and function. Contractures can be a serious problem, but they are preventable. If you neglect range-of-motion exercises, contractures can permanently limit your joint movement. Contractures can interfere with transfers and daily activities and can change your posture, which can lead to pressure ulcers.

In some persons with tetraplegia [*cervical injury level and weakness of arm muscles*], tightness of finger muscles is actually promoted to improve the grip. When the wrist is extended [raised backward], muscle tightness causes the fingers to bend down toward the palm and thumb. This method of adaptive grasp and release is called “tenodesis”—it can give a weak but functional grip to some people whose finger muscles are completely paralyzed.

Prevention

Contractures can be prevented by moving joints through their full range of motion regularly. Joints in body areas where the muscles do not work must be moved manually by you or your attendant. Shoulders, elbows, hips, knees, and ankles are the joints in which it is most important to prevent contractures. If you have severe spasticity, range-of-motion exercises may be particularly important and you may need to do them several times a day. *[See section 2.c, Limb Preservation and Posture.]*

Once a contracture happens, it's very hard to reverse. It may require skilled therapy or surgery to release or cut the muscle to regain flexibility. The longer the contracture is there, the less likely it can be reversed; eventually, the joint may become frozen. Even if a contracture has developed, a regular range-of-motion program can keep it from getting worse.

Heterotopic Ossification

Heterotopic ossification [HO] is the growth of a knot-like piece of bone in the soft tissues near joints. It typically occurs below the level of your spinal cord injury. Bone is formed most commonly around the hips and knees, in the space between muscles [SEE FIGURE 1.g.1]. The cause of HO is not known. Up to half of people with SCI will develop at least some HO. It can be seen on an x-ray 4–10 weeks after the injury. The growth stops on its own after 8–30 months, leaving behind a chunk of bone. It's just like any other bone in your body, except that it serves no particular function, and it can cause problems in joint movement.

Effects

The worst complication of HO is severely decreased range of motion. Like a contracture, HO can interfere with your self-care and mobility

tasks and cause problems with sitting, lower extremity dressing, transfers, bathing, and walking. Fortunately, most people don't develop a large enough piece of HO to cause problems.

Symptoms of HO

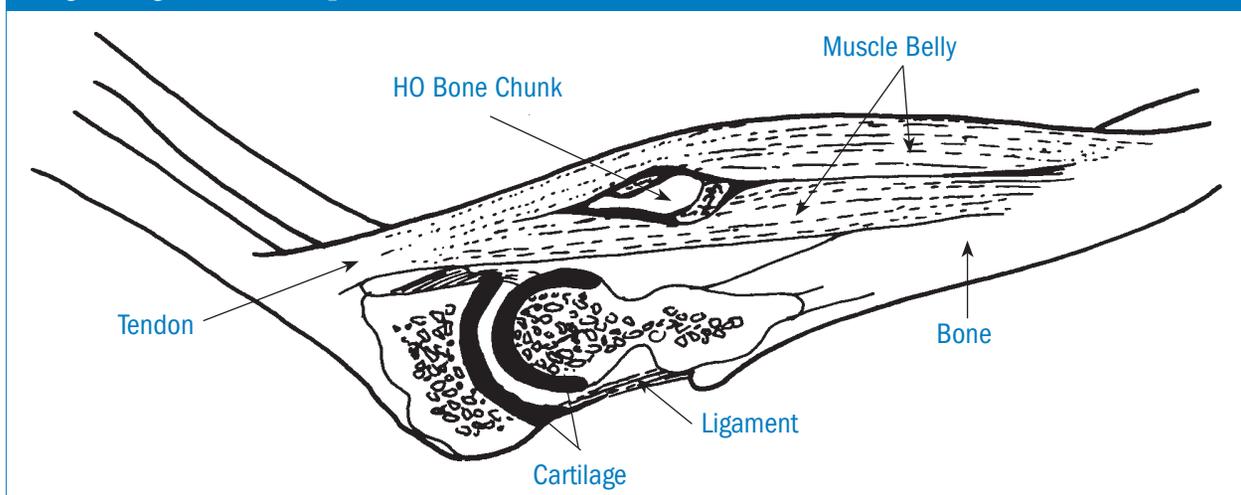
- Decreased joint range of motion—this may develop slowly or quickly.
- Swelling.
- Redness.
- Increased skin temperature over a swollen region.
- Pain or autonomic dysreflexia during joint movement.
- Changes in your positioning in your wheelchair.

Other Causes of These Symptoms

Other conditions can have the same symptoms as those for HO, so you should be evaluated if you have any of the following:

- Infection.
- Broken bone.
- Bleeding into the muscle.
- Blood clot [deep vein thrombosis, DVT].

[Figure 1.g.1] Heterotopic Ossification



Your health-care provider can do tests to find out which condition is causing the symptoms.

Testing for HO

Several tests are used to evaluate and follow HO:

- Blood tests, such as alkaline phosphatase.
- X-rays to confirm the location of the HO. An x-ray usually cannot tell how long the HO has been there, and it may not show it at the earliest stages.
- A bone scan, which can detect HO about four weeks before an x-ray can.

Treatment

Medications can be used in the first few months of HO development. They can reduce the amount of bone that forms but will probably not eliminate the bone after it begins forming. Medications are sometimes prescribed soon after injury to reduce the chance of developing HO. As with all medications, there are side effects, and one medication may not be the best one for everyone. Most people think that full, gentle range-of-motion exercises help rather than hurt. You should try to maintain the range you have. *[See section 2.c, Limb Preservation and Posture.]*

If HO is so severe that it prevents you from doing what you need to do, surgery is sometimes an option. For example, some people have so much HO around their hips that they can't sit upright in a wheelchair. Surgery is usually delayed until the HO has stopped growing. HO usually comes back after the surgery, so patients often receive medications or even radiation therapy. Fortunately, most people with HO do not need surgery.

Osteoporosis and Osteopenia

Osteoporosis and osteopenia cause bones to become weak and more likely to break. Both conditions commonly affect the leg bones after SCI. Bones are normally kept strong through

muscle activity and walking. The bones of people who are paralyzed do not bear as much weight or get pulled on as strongly by contracting muscles. Eventually, the bones lose some of the minerals that help them stay strong, leaving them much easier to break. The greatest bone loss occurs during the first five years after SCI. In addition to not bearing weight and not being pulled by contracting muscles, other factors probably contribute to osteoporosis after SCI, such as changes in hormone levels.

Medications that prevent or treat osteoporosis in people who stand and walk don't seem to work as well in people with SCI, so most experts don't advise everyone with SCI to take these medications. Some factors that contribute to osteoporosis are fairly easy to correct. For example, many people don't get enough calcium or vitamin D from the foods they eat. Most people with SCI should consider taking calcium and vitamin D supplements. Smoking weakens bones—one more reason to stop smoking. Follow your therapist's limb preservation and range-of-motion guidelines to avoid putting excessive stress or pressure on your bones. Walking with braces might help limit the amount of osteoporosis that develops in the legs. However, if you've been injured for more than a year, talk to your health-care provider about checking your bone density before you start a standing or walking program.

Fractures

When bones are affected by osteoporosis, they are much more likely to break. People with SCI have double the rate of broken leg bones as the general population. Most of these leg fractures are caused by low-speed, low-impact activities, such as twisting a leg during a transfer, hitting a leg on something while driving a power wheelchair, or a seemingly small fall from the wheelchair.

Fractures usually require at least some bed rest in a hospital. Without the correct treatment,

they can lead to pressure ulcers or DVT, a blood clot. Complications are very common with both surgical and nonsurgical treatment of these fractures, so be sure to request a health-care provider and a physical therapist who have experience treating people with SCI. Many leg fractures can be treated without surgery if they happen below the level of the hip joint.

Here are some things to keep in mind if you're being treated for a leg fracture:

- You should not have a cast or splint that can't be removed for skin checks. Many patients develop severe pressure ulcers as a result of leg swelling inside a cast.
- Someone should check your skin frequently to prevent breakdown from the splint.
- Someone should check your wheelchair and bathroom equipment setup, transfers, and safety after you get a brace. You may need to learn some new techniques to cope with the brace.
- You should get out of bed as soon as possible after your fracture.
- People with SCI who walk should generally receive the same fracture treatment as anyone else who walks.
- Your functional independence should be unchanged after the fracture heals, although you may need extra help while it's healing.

The goal of fracture care should be to return you to the same level of activity as before the fracture, with as few complications as possible. Another goal is to maintain the best possible alignment of the healing bone. An alteration in the shape of the bone can interfere with your posture and cause problems in your wheelchair seating. After the fracture heals and the brace is removed, have your equipment readjusted to ensure proper fit.

Spine Bones

Whether or not your SCI was caused by a traumatic injury to your back, the bones, discs, and ligaments of your spine need special care. When you have SCI, the muscles in your back and abdomen may be paralyzed along with your legs and arms. These muscles work together to hold you up against gravity and to protect your spine. If they're not working, or only partially working, you'll probably need external support. In addition to the lack of muscle support, you may have had stabilization surgery [with metal rods, wires, or plates] to fix the injury to the bones in your back. This surgery can cause a large segment of your spine to lose its flexibility. In response, the areas right above and below the surgery site may start to move excessively and become loose. This looseness can cause increased pain and arthritis in the spine. In addition, walking patterns that are not smooth and natural can increase stress to the lower back and can cause spinal problems later in life.

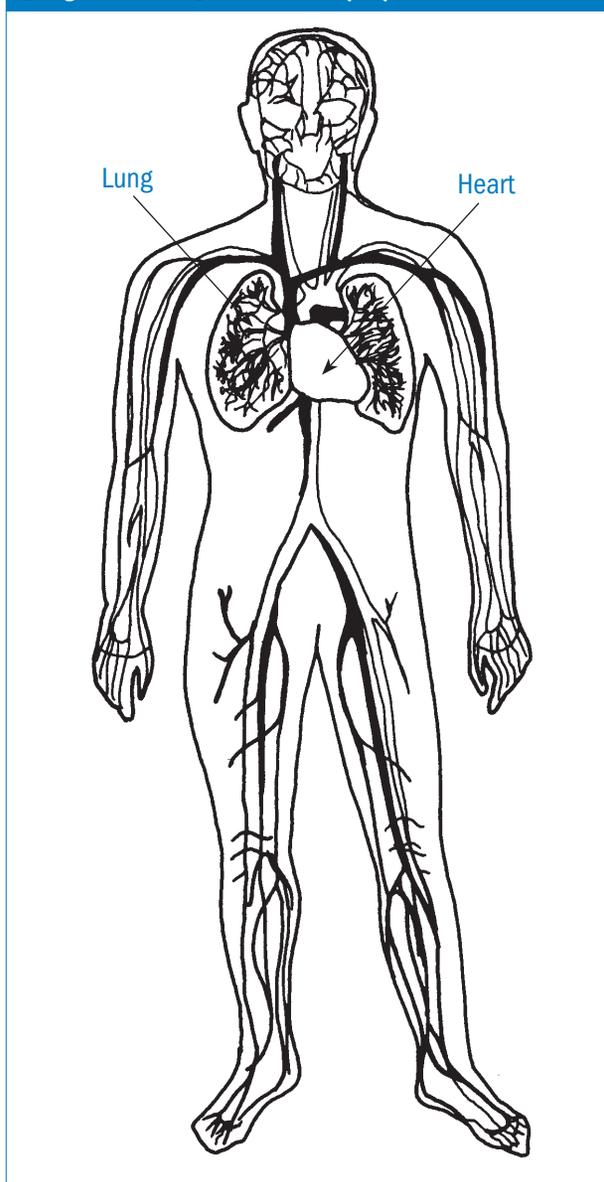
What to Do

- Work with a therapist who's familiar with SCI to make sure you're in the best possible position when you're sitting in your wheelchair.
- Avoid overstretching your spine during range-of-motion exercises.
- If you're walking, work with your SCI therapist to learn the best possible walking pattern. If your walking pattern is not great, consider using a wheelchair for long-distance travel to reduce stress on your spine. Also, look for alternative kinds of exercise besides walking or using a treadmill.
- Work with your therapist to use spine-protective techniques for all activities. [*See the recommendations in section 2.c, Limb Preservation and Posture.*]

1.h | Circulatory System

Your circulatory system is made up of your heart, arteries, capillaries, and veins. The circulatory system moves oxygen, carbon dioxide, and nutrients throughout your body. Blood travels throughout your body by way of this system [SEE FIGURE 1.h.1]. Spinal cord injury [SCI] causes some changes to the circulatory system. After a quick look at the basics, we'll describe these changes.

[Figure 1.h.1] Circulatory System



How the Circulatory System Works

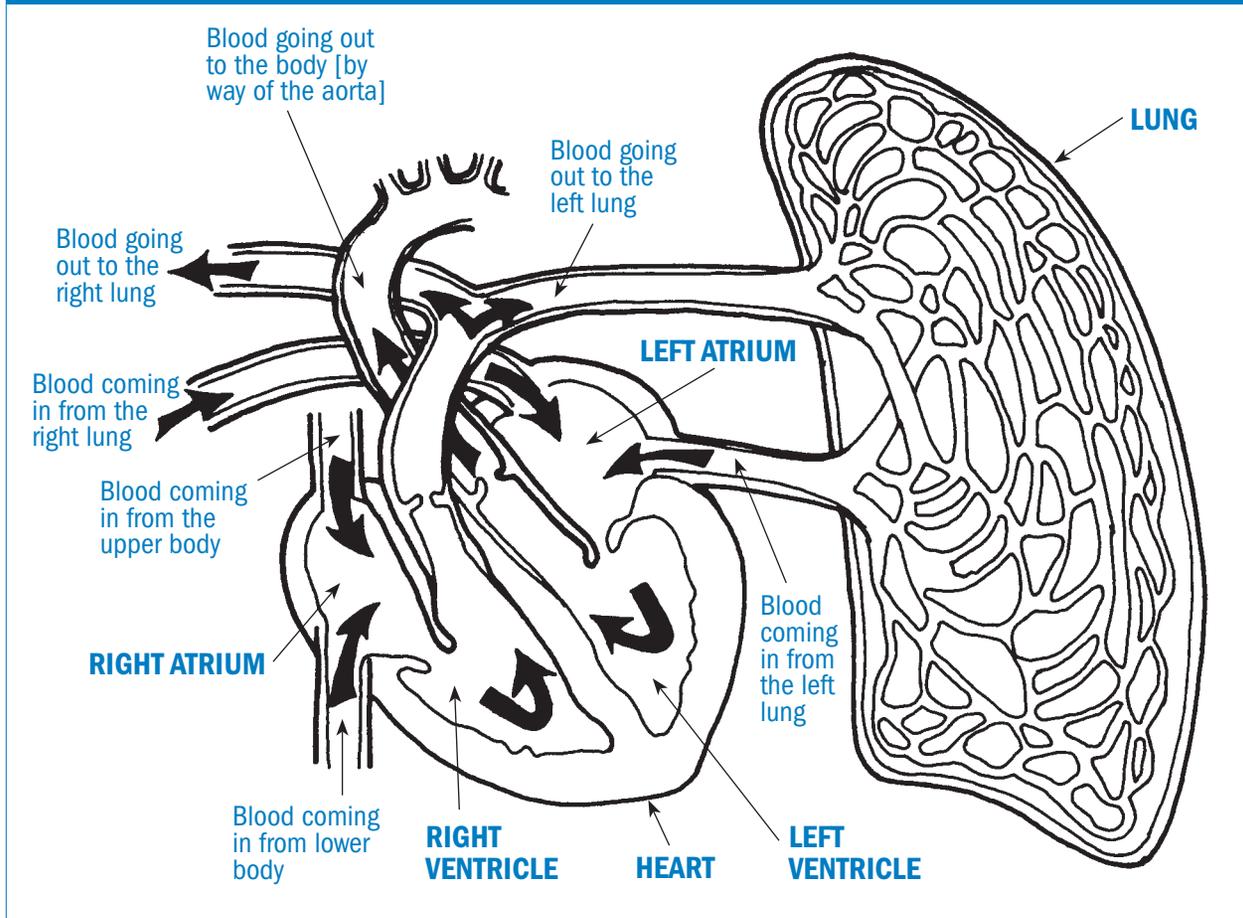
Getting blood to every cell in your body is the job of your heart. It acts as a pump, sending blood through a system of tubes [blood vessels]. Your heart pumps blood through the lungs, where it picks up oxygen. The blood returns to the heart and is then pumped to all the other parts of the body. It first travels through large blood vessels called arteries. The arteries carry it to tiny blood vessels called capillaries, which run through all the tissues of your body. They deliver oxygen and nutrients, and pick up waste products. The blood leaves the capillaries by way of the veins. Veins return the blood to your heart, where the cycle begins again [SEE FIGURE 1.h.2].

To make the blood move through the body, your heart and blood vessels keep the blood under pressure. Your nervous system controls the size or diameter of your blood vessels. The diameter is always adjusting, depending on your body position and level of activity. This helps keep your blood pressure stable. For example, when you move from sitting to standing, the blood vessels in your legs get narrower to force the blood up to your heart. Otherwise, the blood would pool in your legs.

How SCI Affects Your Circulation

SCI can change how your body controls blood pressure and how well your blood moves from your body back to your heart. Your nervous system adjusts the diameter of your arteries, so the arteries in the parts of your body affected by your injury will be affected. You need a stable blood pressure that is high enough to circulate nutrients and oxygen to your body quickly and efficiently but not so high that it causes problems. After SCI, your arteries tend to stay wide open. They can't

[Figure 1.h.2] How Circulation Works



get as narrow as they did before. The result is that your blood pressure may be lower than it was before your injury.

The action of your muscles, contracting and relaxing, helps keep your blood moving from your arms and legs back to your heart. The muscles affected by your injury can't do this any more [although spasticity can help somewhat]. These changes in your circulation increase your risk for developing the following conditions:

- Edema [swelling].
- DVT: formation of a blood clot in a deep vein, usually in the leg.
- Pulmonary embolism [PE]: a blood clot that has moved into the lung.

- Orthostatic hypotension [low blood pressure when you sit up].
- Decreased heart rate.
- Reduced control of body temperature.

Edema

Edema is a condition in which fluid collects in and around tissues, causing swelling. Depending on the level of your injury, your feet and legs, and perhaps your hands, may swell. Swelling occurs when fluid leaves your blood vessels and goes into the spaces between tissue cells. This swelling is called "dependent edema." [Dependent refers to any area that is below the level of your heart.] This edema is caused by muscle weakness in your legs or arms because muscle action and movement

normally help return blood to your heart. If the blood returns to the heart too slowly, more fluid will leak out of the blood and into the spaces between tissue cells.

To prevent your legs from swelling or to reduce edema, you can do the following:

- Wear compression stockings if they've been prescribed for you. These are tight elastic stockings that usually come up to the top of your thigh. They help move blood back up to your heart and keep it from pooling in your legs.
- Make sure your braces, splints, clothing, and urinary devices are not too tight.
- Elevate your hands, legs, and feet often if they are affected by edema. Elevate your legs up to or above the level of your heart for 10–15 minutes four to five times a day. Sleep with your legs slightly elevated, if possible.
- Do your range-of-motion exercises every day, and make sure you move your legs from one position to another every two to three hours.
- If you often have swelling, buy shoes one size larger. Make sure there's plenty of room from top to bottom in your shoe, not just from one end to the other.

If the swelling continues in your legs for more than a week despite your efforts to treat it or if you notice a sudden increase in swelling, contact your health-care provider. If the swelling is only in one leg, you may have a blood clot in your leg.

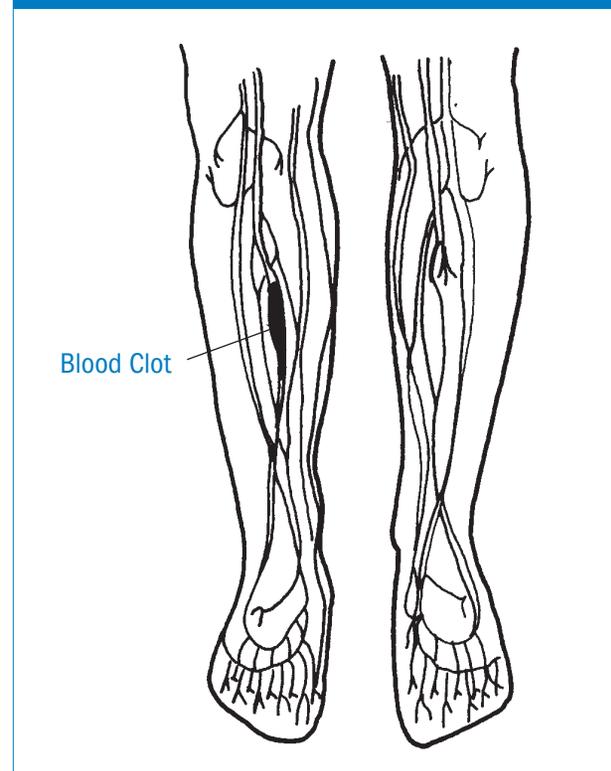
Blood Clots

Blood clots in your legs, arms, or lungs are serious medical problems. Blood tends to stick together and form a clot when it isn't moving at its usual steady pace. The lack of muscle contraction in your legs slows the blood and allows clots to form. Blood clots begin in veins, especially those in your legs. If it's in a vein deep inside your leg, it's called DVT [SEE FIGURE 1.h.3].

These blood clots can break free and travel to other parts of your body. A clot that stays in one place is called a thrombus. A clot that breaks free is called an embolus [plural = emboli]. The most common place for an embolus to go is the lung. This is called a PE.

Blood clots are very common after SCI, especially during the first two months after injury, when activity is suddenly decreased and the blood is moving slowly through the leg veins. Eventually the risk of blood clots goes down, but it's always a concern. People can't avoid some things that increase the risk—like having cancer or broken leg bones, needing surgery, being older, or having heart failure. But you should try to avoid risky conditions that you can control, like weight gain, cigarette smoking, dehydration, and unnecessary inactivity. Pregnancy also increases the risk of blood clots. And if you've ever had a blood clot, it's more likely that you will have another.

[Figure 1.h.3] Blood Clot [thrombus] in Leg



Doctors often use drugs and other treatments to try to prevent blood clots. They usually start by suggesting the same things that are used to treat swelling [see the list above]. Your doctor might also prescribe a “blood thinner” or anticoagulant to reduce the chance of clot formation. The most common of these is heparin. Sometimes doctors also use plastic air pumps on the legs to push the blood out of the legs and back up toward the heart. These treatments reduce the risk, but some people will still get blood clots.

Deep vein thrombosis

The following are common signs and symptoms of DVT:

- One calf or thigh feels warmer than the other, and it might be red.
- One calf or thigh is more swollen than the other. A simple way to check for swelling is to measure the size of both calves or thighs. A clot can develop and cause the leg to swell quickly. This is why the nursing staff might measure the size of your calves and thighs.
- One leg may be painful, tender, or feel heavy. However, if you don't have normal feeling in your legs, you may not feel anything.

Often, you and your doctors can't tell if you have a blood clot without doing special tests.

If one calf or thigh becomes larger than the other:

- > **Do not** increase your activity level.
- > **Do not** do range-of-motion exercises.
- > **Do not** move the leg. Increasing your activity might cause the clot to break loose.

Get in bed and call your health-care provider for instructions. If you do have a clot in your leg, you will be treated to dissolve it and prevent it from breaking free and moving to your lungs. Most people with a blood clot must take anticoagulants for three to six months after the clot is discovered.

Pulmonary Embolus

A pulmonary embolus [a clot in your lung] can be life-threatening. Most PEs are caused by clots in the legs, so the way to prevent them is to prevent blood clots from forming in your legs.

The following are common signs and symptoms of a PE:

- > Sudden shortness of breath and possibly a feeling of tightness in your chest.
- > Pain in your side, chest, or back. The pain is usually worse when you breathe in and lets up when you breathe out.
- > Sudden development of a new cough. This cough might produce sputum or phlegm that is slightly pink or red.

If you think you might have a PE:

- **Call 911.** A pulmonary embolus is an emergency.
- Contact your health-care provider.
- If you feel short of breath, sit up in a chair; this sometimes helps.

This problem requires further tests and treatment in a hospital.

Treatment of blood clots

If you get a blood clot in your leg, or if it goes into your lung, you'll probably receive blood thinners to help your body dissolve the clot. The most common blood thinners are heparin and warfarin [Coumadin]. The main side effect of these drugs is bleeding. Bleeding can be minor, like a nosebleed, or serious, like a bleeding stomach ulcer. Because of these risks, people on blood thinners need close medical follow-up. Frequent blood tests might be needed to make sure you're getting the right dose of the blood thinner. Also, some of these medications can interact with other drugs, or even with food. If you need to take blood thinners after you leave the hospital, be sure to ask the doctor or pharmacist for information about interactions.

Orthostatic Hypotension

Blood pressure is a measure of the force with which your blood goes through your blood vessels. It is determined by two things:

1. How well your heart can pump blood out.
2. How much tension is in your arteries.

Your blood pressure might be lower after SCI, because your blood vessels can't constrict to help keep it at a higher level. Most people get used to a lower blood pressure and don't have problems with it.

However, when you sit with your legs down or when you stand up, your blood pressure may drop even lower. This happens because blood tends to collect [pool] in the veins of your legs and feet instead of being pushed back up to the heart. If your blood pressure drops like this, it's called "orthostatic hypotension." Orthostatic means "changing positions," and hypotension means low blood pressure. If your blood pressure is too low, not enough blood will go to your brain. This will make you feel lightheaded or dizzy when you change positions, and you might pass out. This can be a problem soon after your SCI, when you first get out of bed. Fortunately, the problem usually fades away with time in most people.

If you faint or feel dizzy:

- Lie down and elevate your legs to above the level of your heart.
- If you're in a manual wheelchair, have someone tilt the wheelchair back about 45 degrees for a few minutes. [Be sure to lock your brakes first.]

To prevent lightheadedness and dizziness:

- When you get up from lying down, do it in steps:

- > Sit up slowly.
- > Rest for a few minutes.
- > Move your legs to a lower position.
- > Continue your activities.
- Don't change positions quickly. Take your time.
- Wear your compression stockings and abdominal binder [if prescribed]. They help move blood back up to your heart and prevent it from pooling in your legs.
- If you have a continuing problem with dizziness, make sure you're drinking enough fluids.

If you continue to feel dizzy or lightheaded despite following all these tips, call your health-care provider. You may need to take a medication to increase your blood pressure.

Decreased Heart Rate

After an SCI, your heart rate will tend to be slower. The same parts of the nervous system that control your blood pressure also control your heart rate. Most people don't feel any different with a decreased heart rate, but some people feel dizzy or lightheaded if their heart rate drops below 50 beats per minute. Your brain might have trouble increasing your heart rate if your injury is above the mid-thoracic level. If you can't raise your heart rate when you need to [like when you're exercising], you may feel dizzy or lightheaded.

If you do feel dizzy, call your health-care provider for instructions. It's a good idea to memorize your usual blood pressure and heart rate. That way, if you're treated by different doctors who don't have your medical records, you can tell them what's normal for you. Otherwise, they may think you have a new medical problem.

Control of Body Temperature

When people get sick, they often have a higher body temperature or a fever. “Normal” temperature is considered to be 98.6 degrees Fahrenheit [F] or 37 degrees centigrade [C], although many people have temperatures that are slightly higher or lower. Temperatures also tend to run higher in the afternoon and evening than in the morning. There is no absolute normal. Learn what’s normal for you. A fever is generally considered to be a body temperature that goes up more than 1.5–2.0 degrees F or more than 0.8 degrees C.

Your SCI may have affected your body’s ability to regulate your temperature. Your body can’t adjust how much blood goes to the skin because the control of the blood vessels is altered, so you might be very sensitive to the temperature of the air around you. If you sit in the hot sun for several hours, your body temperature might go up even though you’re not sick. Some people with SCI can’t sweat normally, so their bodies have even more difficulty staying cool. If you’re in a cold place, you might lose too much heat through your skin and become cold. Because of muscle paralysis, it’s difficult for you to shiver and create heat inside your body. Many people with SCI wear extra layers of clothing when it’s only a little bit cold.

The following are some suggestions to control your body temperature:

- Carry a spray bottle of water to mist yourself if you’ll be out in hot weather.
- Wear a broad-brimmed hat if you’ll be in the sun on a warm day.

- Drink more than your usual liquids to make up for the loss of fluid from fever or heat.
- Wear extra layers of clothing if you’ll be in a cold place.

If you have a fever and you think you’re sick, call your health-care provider. If you have a fever after you’ve been in the heat, take a cool bath or sponge yourself with a cool cloth, especially your head, neck, feet, hands, under your arms, and around your groin. If a fever lasts for more than a day, or if you have other new symptoms, call your health-care provider.

RESOURCES

Publication

Prevention of Thromboembolism in Spinal Cord Injury

www.pva.org/CPGs

1.i | Autonomic Dysreflexia

Autonomic dysreflexia [AD] is high blood pressure brought on by pain or discomfort. It is a complication that almost anyone with a spinal cord injury [SCI] above the seventh thoracic level [T7] can experience. It usually doesn't happen until at least two months after the injury, and it's most common in people with complete injuries. AD is an emergency situation—uncontrolled blood pressure can get high enough to cause a stroke or death. It's very important to recognize the symptoms and know what to do if this happens to you.

Causes

Figure 1 shows what happens in your body during an attack of autonomic dysreflexia. Autonomic dysreflexia is generally brought on by something that would have caused discomfort or pain before your injury. The parts of your body below your injury level can sometimes react to problems or symptoms that you can't feel. [Table 1.i.A] lists symptoms of AD.

The following are possible triggers for AD, with the most common ones listed first:

- Overfull bladder [frequently caused by a plugged or twisted catheter].
- Overfull bowel [severe constipation].
- Infections [of the bladder, kidney, etc.].
- Tests and procedures [cystoscopy, gynecological exam].
- Pressure ulcers or ingrown toenails.
- Pain from injury [severe cuts, burns, or broken bones].
- Hot or cold temperatures.
- Blisters or sunburn.

[Table 1.i.A] Symptoms of Autonomic Dysreflexia

- Severe pounding headache
- Seeing spots in front of your eyes
- Blurred vision
- Slow heart rate
- Goosebumps above level of SCI
- Sweating above level of SCI
- Flushing of skin above level of SCI
- Nasal stuffiness

- Tight clothes.
- Pressure on the testicles or penis.
- Severe menstrual cramps or labor [uterine contractions].
- Stomach ulcers, gallstones, appendicitis, or other problems in the abdomen.
- Sexual intercourse or ejaculation.

What to Do

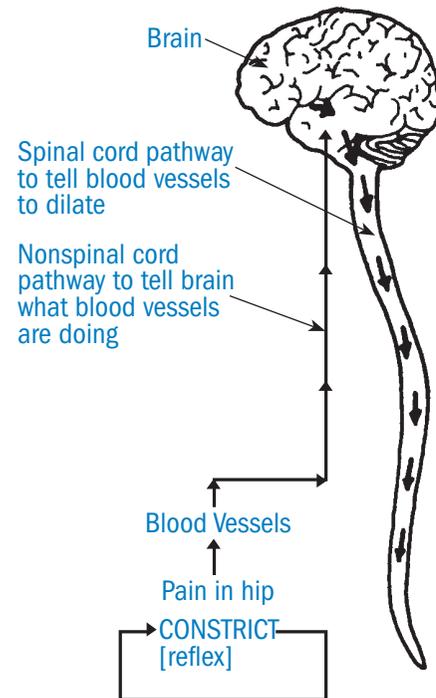
1. If you're lying down, sit up. This will reduce your blood pressure.
2. Loosen your clothing, including your abdominal binder if you wear one.
3. Find and remove the cause. AD usually will not go away until the problem has been corrected.
 - *Check for bladder problems first.* If you don't have a catheter in place, catheterize yourself. Empty your bladder slowly by raising the draining end of your catheter. If you empty your bladder too fast, you may cause it to go into spasm, which can cause your blood pressure to go up again.

[Figure 1.i.1] How Autonomic Dysreflexia Happens

THE BODY'S RESPONSE TO PAIN

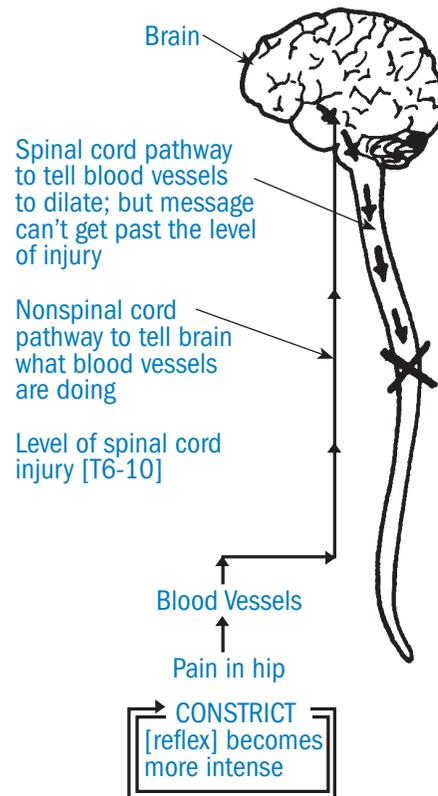
BEFORE SCI

1. Blood vessels constrict by reflex action in response to pain and raise your blood pressure.
2. Nerves send messages up to your brain through your spinal cord, and you feel the pain.
3. Your brain senses that the blood vessels are constricting and your blood pressure is too high.
4. Your brain sends a message down through the spinal cord to dilate [open up] your blood vessels, which lowers your blood pressure.



AFTER SCI

1. Blood vessels constrict by reflex action in response to pain and raise your blood pressure [same as before SCI].
2. You will most likely not feel the pain because the messages can't pass through the injured spinal cord and up to your brain.
3. Your brain senses that the blood vessels are constricting and blood pressure is too high [same as before SCI].
4. The area from T7 to T10 of the spinal cord sends messages to many of the blood vessels in your body. If your injury is at or above T6 level, your brain can't get the dilation message back down to the blood vessels below your injury. Your blood pressure stays high because the shut-off valve to lower it doesn't get the signal.



- *Next, check for bowel problems.* Check for stool. If there is stool in your rectum, remove it manually. Before removing the stool, you can apply a numbing medicine, such as lidocaine, to the anus and then wait a few minutes for it to work. This will prevent irritation to the area, which could cause your blood pressure to go up even more.
 - *Check for skin problems.* If neither your bladder nor your bowel seems to be the cause, strip and look for cuts, bruises, or pressure ulcers on your body.
4. If the symptoms don't go away or your blood pressure continues to be high [top number higher than 150], consider using a medication to temporarily lower it. Many health-care providers prescribe blood pressure medications you can keep on hand to treat AD, along with instructions on how to use them. The medicine will lower your blood pressure while you're trying to find out what is causing the AD. If you've been given nitroglycerin ointment, apply it to the skin above the level of your injury.
5. If you can't find the cause, *get help*. Notify your health-care provider immediately because *this is a medical emergency*. Call or go to the nearest hospital. Autonomic dysreflexia is an unusual problem, and not all health providers know how to treat it. Present your medical alert card for AD [SEE FIGURE 1.i.2] or ask the medical personnel to look up the treatment guidelines for AD published by the Consortium for Spinal Cord Medicine. These guidelines are available on the PVA website at www.pva.org/CPGs.

[Figure 1.i.2] Wallet Size Card for Autonomic Dysreflexia

CUT ON SOLID LINES		FOLD ON DOTTED LINES	
<p>Medical Alert Card for Autonomic Dysreflexia</p> <p>The bearer of this card,</p> <hr style="width: 80%; margin-left: 0;"/> <p>is at risk for autonomic dysreflexia, a life-threatening complication of spinal cord injuries above the T7 level. It is caused by an exaggerated sympathetic nervous system response to a noxious stimulus below the level of injury. The usual etiologies of AD are inadequate emptying of the bladder, a full bowel, tight clothing, ingrown toenail, etc.</p>	<p>Autonomic Dysreflexia Treatment</p> <ol style="list-style-type: none"> 1. Raise the head of the bed up to 90 degrees or sit the person upright. 2. Check for the source of the AD: full bladder or bowel, tight clothing, ingrown toenail, pressure ulcer, or any other noxious stimulus. Removing the cause will usually eliminate or decrease the symptoms. 3. Monitor the blood pressure and pulse every 5 minutes. 4. Drain or irrigate the bladder, using a topical anesthetic jelly for catheterization. 5. Check the rectum for stool, after first applying an anesthetic ointment to the rectal wall. If stool is present, begin digital stimulation to promote reflex defecation. 	Fold	Fold
<p>The symptoms can include elevated blood pressure, headache, nasal congestion, bradycardia, and flushing [above the level of injury]. Please note the normal blood pressure for an SCI patient is 90/60. If the AD is unresolved, it may result in myocardial infarction, stroke, retinal hemorrhage, or death. It is essential that the source be identified and the elevated BP be resolved immediately. Please see reverse of card for details of treatment.</p>	<ol style="list-style-type: none"> 6. If systolic blood pressure (SBP) is above 160, apply one inch of nitro paste to hairless skin, and cover with clear occlusive wrap. 7. If elevated SBP continues, apply one additional inch of nitro paste to equal two inches. 8. Wipe off nitro paste when SBP decreases to 130. 9. If SBP remains elevated despite two inches of nitro paste, give 10 mg of hydralazine. If SBP remains elevated after 10 minutes, give an additional 10 mg of hydralazine. 10. If SBP remains refractory to the above treatments, give 10 mg of bite-and-swallow nifedipine. If nifedipine is given, the patient is at risk for hypotension once the AD is controlled and must be monitored closely for several hours after administration of nifedipine. 	Fold	Fold

Prevention

In many cases, you can prevent AD. The most common cause is an overfull bladder or impacted bowel, so make sure that your bladder is emptied routinely, your catheter is draining well, and you have regular bowel movements.

You might be one of the people who has this problem more often than others. If so, your health-care provider might put you on medication to prevent it. If you have problems with AD, you should have a blood pressure cuff at home and know how to use it.

Educate yourself about AD. Read a copy of the PVA publication listed under Resources.

Carry a Card

Figure 2 shows an example of a card you can cut out and carry in your wallet. Put your name on the card in the space after “The bearer of this card.” Let people know you have the card and use it with health-care providers to help them give you the right emergency care. It may save your life!

RESOURCES

Publications

Autonomic Dysreflexia: What You Should Know
www.pva.org/consumerguides

Also available in Spanish.

*Acute Management of Autonomic Dysreflexia:
Adults with Spinal Cord Injuries Presenting to
Health-Care Facilities*

www.pva.org/CPGs

Maximizing Your Function

Before 1940, people with spinal cord injury [SCI] usually died within the first month after their injury. Since then, we've learned how SCI causes medical problems and what to do to avoid those problems. Now, people with a new SCI can focus on making themselves as independent as possible or learning to direct others to provide assistance. In this section you'll learn about equipment, home modifications, driving, and managing attendants who provide assistance for you. You'll also learn how to protect your limbs and posture.

2.a | Expected Outcomes

People with a new spinal cord injury [SCI] have questions about their recovery. Usually, one of the first questions is whether they'll be able to walk. With time, most people start wondering about other activities, such as feeding themselves, getting dressed, and driving a car. The term "functional outcomes" means the ability to perform these activities. Can they be done independently? Do they require assistance from someone else? Is some type of equipment needed to perform the activities?

Doctors, nurses, and therapists who take care of people with SCI often can predict a person's expected functional outcome. The expected outcome is not the same for everyone. For example, some people will need power wheelchairs or manual wheelchairs to get around, while others will walk with leg braces or canes. Some people will need assistance for almost all daily activities, while others will need no assistance. Your expected outcomes depend mainly on your injury level and injury completeness. People with more muscle strength can do more things independently. Other factors that affect functional outcome are age, fitness before the injury, injuries to other parts of the body [including the brain], and other medical conditions, like breathing problems.

How do you find out what your expected functional outcome is? Talk to the doctors, nurses, and therapists who are providing your care. When someone has a complete SCI [ASIA A] or an incomplete SCI that only spares sensation [ASIA B, or sensory-incomplete], it's easier to predict the function that person should achieve. The Consortium for Spinal Cord Medicine has pamphlets that describe the expected outcomes for all levels of SCI. Keep in mind that if you have an incomplete SCI with movement preserved below your injury level [ASIA C or ASIA D], your expected functional outcome will usually be different from what is described in the pamphlets.

RESOURCES

Publications

Expected Outcomes: What You Should Know
www.pva.org/consumerguides

Outcomes Following Traumatic Spinal Cord Injury: Clinical Practice Guidelines for Health-Care Professionals
www.pva.org/CPGs

2.b | Equipment

Equipment commonly provided to people with spinal cord injury [SCI] includes wheelchairs, cushions, and devices for self-care.

Each person will require different types of equipment. Keep the following things in mind when you're considering equipment needs.

Equipment can—

- increase your independence;
- protect you against injury;
- protect your skin;
- provide postural support and prevent deformity;
- help prevent injury to a caregiver;
- improve your comfort; and
- require a lot of maintenance.

There are a few things that equipment should **not** do. It should not—

- make life more difficult or complicated;
- be harmful to you or your caregiver;
- increase the clutter in your home; or
- break the bank.

Selecting the correct equipment can be confusing. A tremendous amount of medical equipment is advertised. Often, people see equipment and think it would be perfect for them. Purchasing the wrong equipment can be costly not only financially but to your health. Your rehabilitation team can evaluate and recommend the equipment that will best fit your specific needs. Ask if the particular item is useful for people with your injury. Whenever possible, try out the equipment first. Your therapist may be able to help set this up.

To ensure safety, avoid costly repairs, and extend the life of your equipment, it is important to

perform routine maintenance. Refer to instruction manuals for the proper care and functioning of all equipment. You are responsible for maintaining your equipment. You can either do it yourself, have a caregiver help you, or use a local medical equipment supplier. Before your equipment needs repairs or maintenance, identify someone in your community who can help you. To speed up maintenance and repairs, try to find a supplier who's familiar with your specific equipment.

Funding for equipment varies. Depending on your health insurance, the cost of the equipment might be covered completely or not at all. Most funding sources require equipment to be “medically necessary.” Your health-care provider can help write a medical justification for equipment you need. Funding for replacement equipment also varies.

The process for ordering equipment varies from one rehabilitation center to another. Find one that will evaluate and order the equipment you'll need after your discharge. Plan ahead—delivery can take several weeks.

Wheelchairs

There are many types of wheelchairs; for example, a wheelchair can be for everyday use or for recreational use. It's important to match the kind of wheelchair you get with all of the following:

- Your type of injury.
- Your skill level.
- Your home environment and community needs.
- Your postural needs.
- Your means of transportation.
- Your skin protection needs.

Get the right size wheelchair for your body. A poorly fitting wheelchair can lead to deformities and contribute to back, shoulder, neck, and arm pain. [See section 2.c, *Limb Preservation and Posture.*] Your wheelchair should provide comfort, mobility, and skin protection, and should ensure good posture. Work with your therapist to determine the best wheelchair for you. Whenever possible, try out the chair before you order it. Be sure the one you're trying is set up just like the one you'll order, so your test ride will be accurate.

There are three categories of wheelchairs: manual, power-assist, and power.

Manual Wheelchair

Manual wheelchairs can serve many functions. They can be your main way of getting around, or they can act as a backup to another chair or to walking. They can be designed especially for sports. There are many different kinds of wheelchairs, each with its own setup and options to provide you with the best fit. Wheelchairs can have rigid or folding frames. You should be involved in choosing your manual wheelchair, but your therapist will help you decide what you need and what will work best for you. They can anticipate what you'll need according to your level of injury and what you'll be able to do. Some of the things to consider in selecting a manual wheelchair are your home environment, lifestyle, transportation, postural needs, and function.

Anyone with SCI who uses a manual wheelchair full time should have a high-strength, fully customizable wheelchair made of the lightest possible material. A light chair requires less effort to propel. A customizable chair can be adjusted for the correct fit, so there will be less wear and tear on your body, and your seated posture will be better. Also, a high-strength chair is made of components that are not likely to break. Over the long run, this kind of chair will last much longer and be cheaper to operate.

Power-Assist Wheelchair

Power-assist wheelchairs combine the frame of a manual chair with powered rear wheels. The wheels have a built-in motor that makes pushing the wheelchair easier. In most cases, these wheels can be put on your manual wheelchair. Because of their weight, they are not as easy to put on, take off, and stow as regular manual wheelchair wheels. Power-assist wheels can help you push farther and longer than you would otherwise be able to.

Power Wheelchair

A power wheelchair is motorized. People who are unable to push a manual wheelchair in their environment should receive power wheelchairs for mobility. Power wheelchairs have three main parts: the base, the seating system, and the drive control. Bases come in rear-wheel drive, front-wheel drive, or mid-wheel drive. You and your therapist should determine the right base for you to match your home, recreational environments, and transportation needs. Some bases are meant for level indoor surfaces, while others are designed to drive outside on rough terrain. You and your therapist will also choose the seating system—it will depend on your postural and skin protection needs. Some seating systems are similar to those in manual wheelchairs, while others may tilt, recline, and elevate. Finally, power wheelchairs can be driven with a joystick, head control, breath control, or by someone else. You and your therapist should select your drive control based on your level of function and safety.

Your wheelchair is your mobility. If you don't take care of it, you might be stranded somewhere if it breaks down. A few things to remember:

- Keep your wheelchair clean.
- Keep the bearings clean.
- Make sure the wheel locks are adjusted correctly.

- Make sure the tires have the recommended air pressure.
- Keep all nuts and bolts tight.
- If you use a power wheelchair, be sure to maintain the batteries.

Cushions and Positioning Equipment

People with SCI often do not have working back and stomach muscles to help them maintain good posture. Positioning equipment helps you maintain posture. It can be used in bed or in a wheelchair. Positioning equipment is anything that's used to keep your body in a certain position, including a cushion, a backrest, and other supportive devices. The backrest helps keep you in an upright position. All positioning equipment should—

- protect your skin;
- help maintain correct alignment; and
- be comfortable.

Positioning devices can be as basic as foam, or they can be custom made. Some cushions use air, gel, foam, or a combination of materials. If you have complicated postural or skin protection needs, the positioning device can be custom molded to fit your body exactly. Sometimes pressure mapping [using a device that measures where you put most of your weight] can help you decide whether a cushion will give good pressure relief. Some other things to consider when you're choosing a cushion are—

- how much postural support you need;
- your wheelchair skill level;
- your skin protection needs; and
- your ability to care for the cushion [some are more complicated than others].

Hospital Beds and Mattresses

Hospital beds can increase your independence. They can also make it easier and safer for caregivers to help you. Hospital beds are available in fully electric or semi-electric styles. You can take off the wheels to make the bed the same height as your wheelchair. A wide variety of mattresses are available—choose one that matches your needs for skin protection, comfort, and ease of mobility for changing position in bed. If you change your mattress, be sure to check your skin thoroughly the first few days for any pressure problems. Your medical team can help you choose the best bed and mattress for your needs. Bed rails and trapezes are available, but remember that trapezes can cause shoulder injuries if they're used incorrectly.

Bathroom Safety Equipment

Choose your bathroom equipment on the basis of your ability, skin protection needs, and body size. The size and layout of your bathroom will also factor into the choice. One example of equipment is a bathtub transfer bench—it extends over the side of the tub to make transfers easier and safer. Other examples are raised toilet seats, grab bars, and hand-held showers.

Check your equipment regularly for cracks in the surface and framework, and make sure grab bars are installed securely, following the manufacturer's recommendations. Damaged or unsafe bathroom equipment can cause falls and injuries to the skin.

Transfer Equipment

Mechanical Lifts

If you can't transfer independently, a lift can increase your safety and the safety of your caregivers. Lifts work well for transferring to and from the bed, wheelchair, and shower/commode chairs. Some lifts allow transfers off the floor.

They can be electric or hydraulic. They're relatively easy to use but can be dangerous if they're used incorrectly, used with the wrong sling, or broken.

Different kinds of slings are available. It's best to use one that's easily removed. Don't sit or lie on the sling for any length of time, as it might cause skin breakdown. It's very important to get training to use lifts and slings safely.

Transfer Boards

Transfer boards bridge the distance between one surface and another to increase safety and improve independence. The type of transfer board you might use depends on your size and ability. Many shapes, sizes, and lengths are available.

Check equipment regularly. If your transfer board is cracked, replace it to reduce the risk of a fall or injury. And remember—always lift your bottom when you're using a transfer board. Sliding across the board can cause skin breakdown.

Equipment for Self-Care

Adaptive equipment is available to increase independence and improve safety while you're performing self-care. There are devices for feeding, food preparation, dressing, bathing, grooming, toileting, and communication. For example, you can use reachers [which come in many varieties and lengths] as an extension of your arm to reach items from your wheelchair. A *dressing stick* can make it easier to put on or remove clothing.

You may only need an adaptive device during early rehabilitation. Once your muscle strength improves or you learn special techniques, the device may not be necessary. For example, at first you may need to use an *adapted spoon* to feed yourself. If you learn to weave a regular spoon handle between your fingers, you might no longer need to use the adapted version. Or an adaptive

device might allow you to do things with little or no assistance. People have different opinions about the use of adaptive equipment. Some people don't like to use it. Others don't mind. It's your choice. Your therapist can help you decide what equipment will be most useful.

Splints and Braces

Splints and *braces* for upper and lower limbs are prescribed to prevent or correct deformity, prevent joint stiffness, decrease pain, or immobilize a body part while it's healing. Splints and braces can substitute for weak or no muscle strength, and they increase function and safety. They may be made of metal or molded plastic. Some are simple and others are complex, with many moving parts. Splints and braces must fit correctly to be useful. Learn how yours should fit so it functions correctly and doesn't harm your skin.

Your therapist will give you a schedule for wearing the splint or brace and will discuss precautions to protect your skin and joints. Be sure to look at your skin at least twice a day for pressure areas. If you see a red spot that doesn't fade within 20 minutes, or you have swelling or pain, stop wearing the splint or brace and notify your therapist.

Ambulation Devices

There are many different devices to help people walk more easily, including canes, crutches, and walkers. Specialized shoes and shoe inserts can also be used. Using special shoes or a cane can correct your walking pattern, and a good walking pattern can—

- increase your safety;
- increase the distance you're able to walk;
- increase your walking speed;
- decrease pain; and
- prevent future muscle and joint problems.

Walking patterns are very subtle, so it's important to have a trained professional help you decide what's best. Even if you've gained new strength in your legs and can walk without crutches, check with your health care provider before throwing them away. There may be another reason for you to use them. For example, they may be helping to protect your back and hips from problems years down the road.

Use your ambulation devices as directed to avoid falls and protect your joints. And check devices and specialized shoes for uneven wear or cracks, which can lead to falls.

Exercise Equipment

People with SCI may have special exercise needs. Talk with your therapist about setting up a home exercise program that's right for you. Be aware of any medical or physical restrictions or limitations that are a result of your injury. Exercise equipment can enhance your home exercise program and help you maintain or increase function.

It's not necessary to turn your home into a gym. Many people purchase a lot of expensive equipment and end up not using it. Your therapist can recommend a few small pieces of equipment that will allow you to have a successful home exercise program without taking up a lot of space or costing a lot of money. Adaptive equipment is available for persons with limited arm or leg function. *[See section 4.c, Exercise.]*

Driver Training and Adaptive Equipment

Technology has made it possible for people with very little muscle strength to be safe and independent drivers. There are many factors to consider in selecting a wheelchair and vehicle combination. Work with an expert in this field to ensure that the vehicle and the wheelchair are

compatible with the modifications you require. *[See section 2.e, Driver Rehabilitation and Training.]*

Computer Access

Adapted access to computers has greatly increased over the past several years. A computer can change the life of its user. It can provide access to communication, education, work, and recreation. Before you buy a computer, make sure you have a thorough understanding of your abilities and goals. Adaptive devices can range from a pointer stick to a modified mouse to voice-activated software or software controlled by the movement of your eyes. An assessment by a trained provider can help you determine things like how mobile the computer must be, what input devices are needed, and how the output will be received.

Environmental Control Units

An environmental control device is anything that helps you manipulate aspects of your environment, such as the heating and cooling system, lights, and appliances. It can be as simple as a garage door opener or as complex as a multitasking voice-activated environmental control unit [ECU].

People with SCI, especially those with high-level tetraplegia, may be unable to activate environmental control functions in the usual way. They may be unable to open and close doors, turn lights on and off, operate the thermostat, or answer the phone.

You may be able to perform all but a few activities. If this is the case, just some devices can be modified. For example, if you have the mobility but not the arm strength or hand control to pick up the phone receiver, you can use a speakerphone. One-item controllers, such as X-10 modules [small electronic boxes that plug

into electrical outlets and receive signals through the home wiring], are readily available and inexpensive. They allow you to operate a device, such as a light, from a remote switch the way you use the remote on a television.

An ECU is a system that allows people with extensive disabilities to independently perform tasks they would otherwise be unable to perform. The ECU enables the user to manage several electronic functions [such as lights, television, radio, or door opener] with a single device. An ECU can also provide peace of mind by giving the user the ability to call for help.

An ECU can be set up for use in bed, in the wheelchair, or both. One-room units are available, as well as multiroom units. They can be activated using any kind of switch, breath control, voice control, or a combination of switch and voice control.

All options have advantages and disadvantages. To select an ECU that will meet your needs, first have a thorough evaluation of your abilities and your goals for using the unit. Training and technical support are also necessary for successful use of the unit.

Funding for ECU is often a challenge. Not all insurance companies or health-care providers pay for them. Your rehab team can help you brainstorm potential resources.

Respiratory Equipment

Some persons with SCI use a ventilator or continuous positive airway pressure [CPAP] or other device to help them breathe while sleeping. They may also use a suction machine or insufflator-exsufflator [for example, CoughAssist] to help with secretion removal and respiratory care. If you require frequent suctioning, you should have a portable suction machine to take with you when you leave your home. Your health-care provider, respiratory therapist, home health nurse, or medical equipment supplier will be able to answer questions about this equipment. A backup generator is essential for ventilator users.

Evaluation, Purchase and Upkeep

A tremendous amount of medical equipment is available, and new equipment becomes available all the time as technology advances. Your insurance or health-care provider may help you pay for equipment. It's important to consult with your rehabilitation team when you're evaluating and purchasing equipment, to ensure that it fits your specific needs. And remember, it will be your responsibility to make sure the equipment is maintained so it stays in safe operating and mechanical condition.

2.c | Limb Preservation and Posture

Daily activities—such as sitting, transferring, or pushing a wheelchair—put people with SCI at risk for injuries to their limbs and postural changes to their spine. This section describes some of these conditions and what you can do to prevent them.

Limb Preservation

Both the upper limbs [arms] and the lower limbs [legs] are at risk for injury after SCI. Active use of your nonparalyzed limbs requires strong muscles and a working nervous system. Paralyzed limbs need special care to avoid injury and other conditions. Limb injury can have serious effects on your health and well-being. It can lead to postural deformity, skin ulcers, and chronic pain. It can cause you to lose functions, such as the ability to feed yourself, to transfer, or to propel a wheelchair.

Limb preservation means keeping your arms and legs in the best possible health by protecting the joints, nerves, muscles, and bones. Limb protection is important for both paralyzed and nonparalyzed limbs.

Range of Motion

The flexibility of a joint—how far it will move in any direction—is also known as “range of motion.” All the joints in your body are surrounded by muscles, tendons, ligaments, and a joint capsule that provides stability. The muscles that cross a joint create movement of the bones on either side. How tight or loose the structures surrounding your joints are will determine the available range of motion in each joint.

For limbs with normal strength and mobility, everyday movements are enough to keep your

joints and the muscles that cross them loose and flexible. However, the weakness caused by your spinal cord injury [SCI] may restrict the range of motion of your joints. Because of this loss of movement, you have to learn other ways to stretch your muscles and maintain flexibility in your joints and surrounding structures.

If you don’t move a joint through its full range often enough, the tendons and joint capsule will begin to tighten. Over time, tightness of the structures around a joint can lead to a permanently shortened range of motion. This is called a “contracture.” Contractures can cause problems such as pressure ulcers, postural changes, and loss of ability to perform some physical activities. For example, contractures can significantly interfere with hygiene. Limited range of motion in your joints can make it difficult for you or your caregiver to reach certain areas of your body during bathing. The treatment for contractures includes static stretching [prolonged positioning and stretching of the muscles and joints] and heat treatments. Severe contractures sometimes require surgery. The best plan is to work to prevent contractures.

Loss of motion often shows up in predictable patterns after a spinal cord injury. Sitting in a wheelchair shortens the muscles that cross the front of the hips and the back of the knees. If you’re not sitting in a fully erect posture—if you’re slouching—you may develop tightness in the front of the shoulders and neck. Blankets can cause your feet to point downward while you’re lying in bed, which can shorten the muscle at the back of your ankle. It’s important to stretch these muscles to prevent shortening, or the tightness can become permanent [a contracture] and can limit your ability to move. Tightness of your joints—

whether it's in your hips, knees, or shoulders—can limit the positions into which you can move your body. This, in turn, can limit the activities you can do for yourself.

In some cases your therapists may allow a certain amount of tightening in some of the tendons of your hands and wrists. This selective shortening can increase the function of your hands through an action called “tenodesis.” In tenodesis, when you raise your wrist, the fingertips draw together, which allows you to use your hands even though there is no strength in the muscles that bend the fingers.

Maintaining range of motion is very important, but it can be time-consuming and take away time from other activities. Ask your therapist which exercises are the most critical for you and how you can incorporate them into dressing or bathing activities. You may be able to design a program with exercises that rotate from one day to the next, so you're spending only about 30 minutes a day on range of motion. If you have a high cervical spinal cord injury, you may need assistance with many daily tasks, so it is helpful to combine range of motion with other daily activities.

If your SCI is at a low lumbar level, you'll have a different challenge—your muscles will probably have no spasticity or resting tone, and your joints may get too loose. Ask your therapist to show you how far you should be moving for all motions of your legs. Your physical and occupational therapists can show you how to perform appropriate range-of-motion exercises in an exercise program designed specifically for you. If you can't do the exercises by yourself, learn how to instruct others to do them for you. Remember, even if you're unable to do the exercises yourself, you're responsible for what is done to your body. *[See Appendix A for specifics on performing range-of-motion exercises.]*

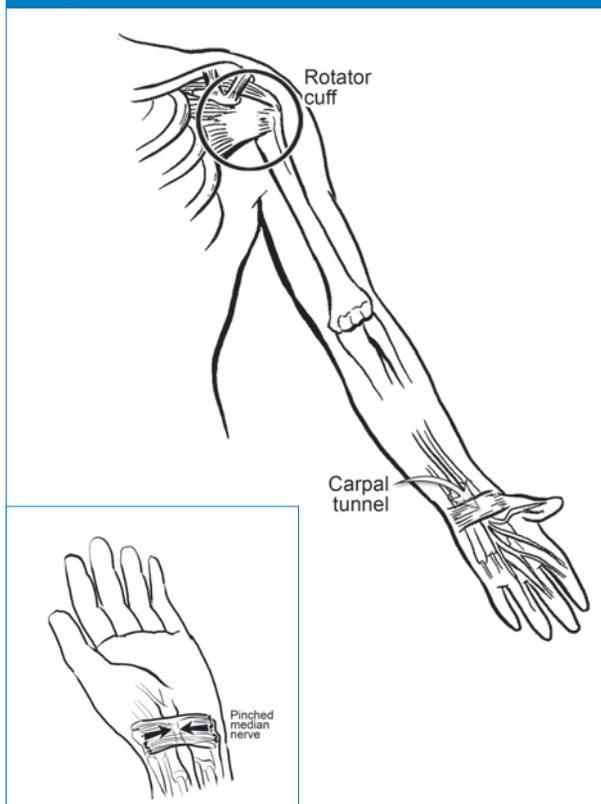
Common Upper Limb Conditions

Most people with SCI rely on their upper limbs quite a lot for mobility. Using a wheelchair, especially a manual wheelchair, requires much more effort from your arms than if you were walking. Many people with SCI who are able to walk rely on a walker or crutches. This, too, increases the weight carried by your arms and hands, and it stresses the shoulder, elbow, wrist, and all the joints of the hand.

Overuse injuries are less likely if you follow some simple advice:

- *Cuts, blisters, and abrasions on your hands:* You can get push gloves to protect your hands on your wheelchair. They're not essential if you have paraplegia, but if you can't feel all or part of your hands, protective gloves are a good idea.
- *Carpal tunnel syndrome* [SEE FIGURE 2.c.1]: The nerves that enter your hand are surrounded by a bundle of tendons. If these tendons get swollen or inflamed, they can squeeze the nerves, which causes hand tingling, numbness, or weakness. This is an overuse syndrome that can interfere with using your hands. Avoid extreme and repetitive wrist motions, especially flexion [bending your wrist down] and extension [bending your wrist up].
- *Ulnar nerve compression:* The ulnar nerve travels very close to the surface at the elbow. This is your “funny bone”—but it's not so funny when you bang it. Avoid leaning on your wheelchair armrests or a desktop, because the weight on your elbows puts pressure on the nerve, which can cause problems with feeling and movement in your wrists and hands. If you lean on your arms or hands for balance, talk to your therapist about a better wheelchair setup that gives you more trunk support and upper limb protection.

[Figure 2.c.1] Carpal Tunnel



- **Shoulders:** The main problems that affect the shoulders are biceps tendonitis, impingement syndrome, and rotator cuff tears. Biceps tendonitis is caused by overuse of the muscle, often from reaching overhead. Impingement syndrome occurs when tendons get squeezed between bones near the shoulder joint. This happens if your arm and elbow are at or above your shoulders and your palm is facing down; for example, reaching to a high shelf that is in front of you. Both problems relate to muscle imbalance, poor posture, and poor habits in transfers. A rotator cuff tear [SEE FIGURES 2.c.1] is more serious. With a major injury like a fall, or many minor injuries due to poor shoulder movement, the “cuff” of tendons that holds the ball in the socket of the shoulder joint can tear. Two other common conditions that cause pain in the shoulder region are arthritis and myofascial

pain [tight, painful muscles with tender points]. Your shoulder protection program should include stretching the anterior [front] shoulder muscles, strengthening the posterior [back] shoulder muscles and rotator cuff muscles, and avoiding motions that squeeze or compress tendons or nerves.

Shoulder subluxation [when the ball part of the shoulder joint comes partially out of its socket] is primarily an issue for people with high-level SCI who do not have normal shoulder strength or those with incomplete spinal cord injury whose shoulder muscles are only partially active. The problem is gravity—the weight of the arm pulls the upper arm away from the shoulder. The result can be very painful. The best prevention is to support the arm well. Don’t let your arms dangle, and don’t let anyone pull on them.

- **Edema:** Swelling of the hands can be a problem, especially for people with high tetraplegia, and swelling makes your hands more vulnerable to skin breakdown. Elevation and compression are the best way to manage this, combined with daily range-of-motion exercises. Consult your occupational therapist for more advice on dealing with edema. Chronic edema can be a symptom of other problems. If elevation and compression don’t reduce the swelling, contact your health-care provider.

Common Lower Limb Conditions

The problems that affect the legs are different from those that affect the arms. They are also less common, but when they occur they can be just as troublesome.

- **Hip dislocation [subluxation]** occurs when the leg bone [femur] becomes too loose in the hip socket [joint] and slips out of place. The hip is generally held together by the strong muscles around the hip and the

ligaments that surround the joint. When muscles are paralyzed, the ligaments can become overstretched and allow the hip to dislocate. The most common direction of dislocation is backward [the ball from the hip joint moves toward the buttock], as a result of overstretching the rear hip muscles [hamstrings and gluteal muscles]. To keep this from happening, avoid overstretching your hamstrings. Your therapist can give you some guidelines—the goal is to maintain a normal amount of tightness in the hamstrings, not to stretch your foot all the way to your head. In addition to muscle looseness, some leg positions may cause increased stress on the ligaments over time. *[See Leg Management for positions that avoid putting stress on the rear hip region.]* Dislocation generally does not occur if most of the muscles in your leg are working.

- *Fractures* are very common among people with SCI. *[For a detailed discussion, see section 1.g, Muscles and Bones.]* Be aware of the risk of falling during transfers and while propelling a manual wheelchair or driving a power wheelchair. Avoid quick, aggressive stretches. If you're standing or walking, even a small fall can cause a fracture. The risk of fracture increases with age.
- *Joint degeneration [arthritis]* is common among people with SCI who have leg weakness but are able to walk. This is because walking with only part of your muscles working causes you to have a different walking pattern than if all your muscles were working. Cartilage on joint surfaces provides a cushion to protect against stress in the joint. When the direction or location of the stress on the cartilage changes, it wears down more easily. Even a slightly different walking pattern can cause cartilage to wear down more quickly in all joints in the legs and lower back. The most common places

to see this are in the lower back, hips, and knees, including the kneecap [patella]. It may take 5–10 years of poor walking before the effects are felt. Sometimes joints gradually become too loose because the ligaments get stretched by the walking pattern or the limbs are overstretched during range-of-motion exercises. Most commonly, it's the back or sides of the knee that get overstretched. What you do today can influence the health of your joints and your pain level for years to come. *[See Ambulation for ways to minimize these effects.]* Sometimes using a wheelchair for longer distances can decrease the effects of poor walking on your legs.

- *Wounds* are a common problem in the legs and feet, which can get snagged during daily activities, get too close to a heat source, or get burned by spills. Even nonparalyzed legs and feet can get hurt by falls or ill-fitting braces. Protect yourself from scrapes and cuts in any activity, especially if you're out of your wheelchair. Severe leg wounds can lead to amputation if the blood flow to the legs is inadequate.

Prevention

Ergonomics means coordinating the design of devices you use, the systems and physical conditions in which you function, and your own capabilities and requirements. The following ergonomic principles can help you prevent injuries:

- Avoid repetitive arm motions.
- Avoid heavy weight bearing through your arms.
- Avoid lifting heavy loads.
- Avoid tasks where your hand is higher than your shoulder. If your hand is above your shoulder, be sure your thumb is pointed up. Don't use an overhead trapeze, grab bar, or car roof to lift your body.

- Avoid extreme positioning or overstretching your joints.
- To reduce the weight on all your joints, maintain an ideal body weight and avoid gaining weight.
- Whenever possible, push—don't pull—objects, including your own body.
- Have an SCI specialist help you set up all your equipment [manual wheelchair, power wheelchair, leg braces, crutches, bathroom equipment] to reduce stress on your joints.
- Discuss with your therapist safe ways to exercise without increasing stress on your limbs.
- Be sure all your wheelchairs are set up properly, including those you use for sports and recreation.
- Pain is an early indicator of joint problems. If you have pain in one of your joints or part of your shoulder or arm, and you didn't do something obvious to cause it, contact a therapist who understands SCI to help you troubleshoot and solve the problem. Early intervention is best.

Functional Activities

Range of Motion

Never use force when you're stretching. You or your caregiver should go slowly and gently with range-of-motion exercises. Do the exercises with the idea of eventually attaining the full movement possible at each joint. If full movement is not possible initially, try *gentle* stretching, using only enough force to allow the muscle to stretch. Hold the position still instead of bouncing, especially if you have spasms. This allows your muscle to relax and stretch. A good time to do your stretching program is in the morning with your self-care routine or in the evening, when you inspect your skin.

Sleep Positioning

Think about waking up with your hand “asleep.” This probably happened because your arms were positioned overhead or your elbow or wrist was bent to an extreme. Try to sleep with your arm and wrist extended [straight] to encourage good circulation and avoid nerve compression [SEE FIGURE 2.c.2]. Sleeping on your stomach is a very good way to stretch muscles that are otherwise difficult to stretch, like the front of your hip [SEE FIGURE 2.c.3]. If your arms are paralyzed, don't allow caregivers to move your upper body by pulling on them. Instead, have them change your position by reaching under or behind you, and making contact in the area of your shoulder blades. Place a pillow under your lower legs to suspend your feet in the air—“floating” your heels will protect your skin. Be aware of the position and placement of all of your limbs, and avoid catching them in bed rails, call light cords, or other obstacles.

[Figure 2.c.2] Sleep Position 1



[Figure 2.c.3] Sleep Position 2



Bed Mobility

Surprisingly, arms and legs can be injured just by moving around in bed. Here are some simple tips to avoid injuries:

- If you need help to roll over, have your helper use your shoulder blade and hip to roll you. Don't ever let anyone pull on your arms.
- Whenever possible, avoid pulling on bed rails to turn. Pulling on bed rails can damage your upper arm muscle [biceps tendonitis].
- Sit up to scoot on your bed [up or down, or side to side] and lift your bottom to avoid shear on your skin. Scoot using your hands on the mattress surface. Don't use a trapeze, as it places the shoulder at risk for impingement.
- Follow the leg management guidelines below for getting your legs on or off the bed. Whenever possible, use your body weight to counterbalance the weight of your legs and feet.
- Avoid ladders, ropes, and rails. It's better to use your hands on the bed surface and to push your body rather than pull it. Pulling devices can stress your shoulder joints.
- Always watch where your legs are to avoid stress or fractures from catching them under the bed rails or falling off the bed.

Leg Management

Leg management means lifting or moving a paralyzed or partially paralyzed leg with your arms. When you do this, remember that your legs are heavy—protect your arms by using your body weight instead of your biceps to lift your leg. For example, reach down to your leg, place your hand under your thigh, tighten your arm muscles, and then rock your body back to lift your leg. When you're lifting your leg over an edge [edge of a bathtub, car door jamb, into a bed, into a boat],

remember the rule that *your first leg goes knee first and your second leg goes foot first*. This means you may have to reach down to your ankle and lift from there to bring your second leg over. It's very important to follow this rule so that you don't place your paralyzed leg in a position that will stress the hip or cause it to dislocate. Practice this until it becomes second nature. And remember to avoid hitting your ankle on the way over.

Dressing

Whether at the bed or chair level, position yourself so you can safely take rest breaks while you're getting dressed. Pull sleeves and pant legs onto the more impaired limb [arm or leg] first. Then dress the limb that is stronger or has better range of motion. Avoid bracing or balancing yourself on your elbows on a bed rail or armrest. If you use assistive devices to reach, make sure they're nearby. Your occupational therapist can work with you to improve your body mechanics and energy conservation, which will increase your independence with dressing.

Transfers

Manual wheelchairs get a lot of blame for shoulder and wrist problems, but independent transfers can cause major problems, too. Poor technique, hand placement, and wrist position all affect the stress on your joints. Your arms have to lift your body many times a day. It's important to do it right.

- Transfers between surfaces of equal height [level transfers] are much less stressful for your arms than transfers to a higher surface [over-height transfers]. Try to avoid over-height transfers whenever possible.
- All transfers should be done with your hands down—as low as possible—and with a trunk-forward position, so your head and upper body create a counterbalance that reduces the weight you're putting on your shoulders.

Your head should be down and away from where your bottom is going. This is the best joint position for your shoulders and provides the best skin protection, too.

- Learn balance skills so you're very steady during transfers. This will help you develop a good transfer technique.
- Avoid placing a flat hand on surfaces if possible. Instead, grasp wheelchair tubing or the edge of the surface [including your wheelchair cushion] to reduce stress on your wrists [SEE FIGURE 2.c.4]. Positioning your hand in a fist rather than flat on a surface will keep you from overstretching the muscles and tendons in your wrist. This may protect against carpal tunnel syndrome and preserve your hand function down the road.
- Keep your body weight down. The heavier you are, the more stress to your joints. [See section 4.b, *Nutrition and Weight*, for guidance on weight management.]
- If possible, reduce the number of transfers you must do each day. Talk to your therapist about how to reduce the number of transfers.
- Avoid placing your hands on backrests, armrests, trapeze bars, overhead grab bars, and car door jambs during transfers.

Remember, keep your hands, head, and weight down.

[Figure 2.c.4] Hand Gripping Surface



Power Wheelchair Setup and Protection

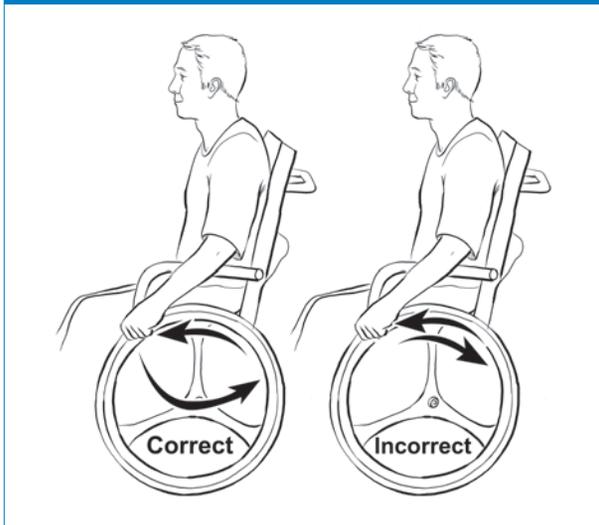
Wheelchair setup is critical. It is very important to avoid positioning your shoulders too high [where they are susceptible to impingement] or too low [where they are susceptible to subluxation, in which your upper arm becomes loose and pulls out of the shoulder joint]. Also, the upward or downward angle of your forearms can contribute to whether or not your hands swell. Ask yourself, "Is my joystick installed where I can use it without straining or losing my balance?" The same principle applies if you need to use a tilt switch. Can you reach it when you're tilted all the way back in your chair? Typically, your headrest is meant to be used only when you're tilting back. When you're sitting upright, your head shouldn't be touching the headrest. Your chair should be set up to allow you to sit "at rest." This means that you don't have to push down on your armrests to avoid falling forward. Make sure that your legs and feet are well protected and not pressing against any part of the wheelchair. Be very sure that your arms, hands, legs, and feet are secured when you're driving your power wheelchair.

Manual Wheelchair Setup and Propulsion

You want to prevent as much arm stress as you can when you're using a manual wheelchair. Poorly setup wheelchairs can cause shoulder, wrist, and hand problems, as well as increase the risk of leg injuries. Your manual wheelchair should be set up with the following goals in mind:

- Adjust the setup so you'll have well-balanced posture and won't need to scoot your bottom forward or use your arms for balance. Poor posture puts your shoulders and wrists in a bad mechanical position during pushing. [See section 2.c, *Limb Preservation and Posture*.]
- Push technique is important. Using a circular pattern may reduce repetitive stress on your shoulders [SEE FIGURE 2.c.5]. Don't lift your

[Figure 2.c.5] Push vs. Pull



hands above the wheels when you return them to the hand rim during a push stroke.

- The wheelchair should be set up for maximum efficiency to minimize the stress on your arms. Keep the weight of your wheelchair as low as possible. Fully adjustable [or customized] ultralight manual wheelchairs are the most appropriate type for people with SCI who rely on them for all mobility. Avoid items that add weight to the chair unless they're needed for safety or access to your environment. Avoid items that decrease push efficiency [like rear shocks] unless you need them for other medical conditions or environmental access.
- Set up your wheelchair with the rear wheels as far forward as possible without causing the chair to become too tippy.
- Check the rear wheel height in relation to your arm length—your elbow should be bent at about 100–120 degrees when your hand is at the top of your push rim. You may have to adjust where the axle attaches on the frame of your wheelchair.
- Work with your therapist on advanced wheelchair skills and adjustment of your rear axle position. Moving the axle forward

makes it easier to push your wheelchair and reduces stress on your upper limb, but it also makes the chair more likely to tip backward. Simple falls from a wheelchair can cause leg fractures, arm injuries, wounds, and worse.

- Make sure the leg rests fit well to help prevent pressure ulcers on your legs and to help keep your legs from falling off the rests and getting caught.
- Consider newer ergonomic hand rims to decrease stress on your wrists and hands.
- Avoid a tight grip on hand rims. The main point of contact between your hand rim and your hand should be the meaty part of your palm, just above your thumb.
- Avoid carrying large objects in your lap that block your view of the ground. Instead, carry things in a luggage carrier on your chair, or find some other way to transport them.

In addition to a well-set-up chair for posture and good push mechanics for arm protection, it's important to stretch the front of your shoulder muscles [which get overused and tightened in a wheelchair] and to strengthen the muscles in your back. Your physical therapist can show you some simple exercises that should be part of your daily routine.

Ambulation [Walking]

Many people strive to return to walking, but it can have some serious consequences for joint preservation. To compensate for weak leg muscles, many people with SCI bear more weight on their arms when they walk. This can cause problems for the shoulders and wrists. Weak muscles can also cause unusual movement patterns, looseness and instability in joints and, eventually, degeneration [arthritis] in the joints of your legs or low back.

You can minimize these risks by working with your therapist to normalize your walking pattern

[your gait] through exercise, stretching, and gait training. You may need to use leg braces, as well as crutches or a walker, to help make your walking more smooth and safe. Instead of looking at these devices as “disabling,” consider them enablers of your walking for the long term. Be sure the device is properly fitted and has good hand grips to reduce stress on your hands, wrists, and shoulders.

If you have a poor walking pattern, carefully consider your exercise activities—walking or running may increase joint stress. You might want to do more joint-protective activities like biking, swimming, or rowing for exercise and use walking only for getting from point A to point B. Also consider more protective options [like a wheelchair] for long-distance mobility.

Pressure Releases

Pressure releases are extremely important to protect your skin, but remember to protect your arms while you do them. The best way to do this is to vary the techniques you use and avoid using the same arm motions over and over. Your therapist can show you different ways to do pressure releases. The main one to avoid doing repeatedly is the straight arm press-up, especially pushing up on the armrest or tires of your chair. This press-up starts with your arm in an elbow-up, hand-down position, which puts your shoulder into an impingement position. It’s better to do a press-up from the front of your wheelchair frame, leaning forward and using the weight of your head to balance while you lift. Even better than a full lift is to simply lean forward into your lap, which means little or no arm stress. Your therapist can use a pressure map to show you that you don’t have to lean very far to relieve the pressure. In addition to a front lean, you can do side-to-side leans. To reduce stress on your shoulders, hold one wheel or the backrest post and lean over toward the opposite side. You can also lean onto an object,

if your chair is parked near a stable surface. It’s best to avoid hooking your arm around your push handles, but if this is the only way you can safely lean side to side, it’s acceptable. The most important thing to remember is to vary your technique throughout the day to avoid repeating the same motion.

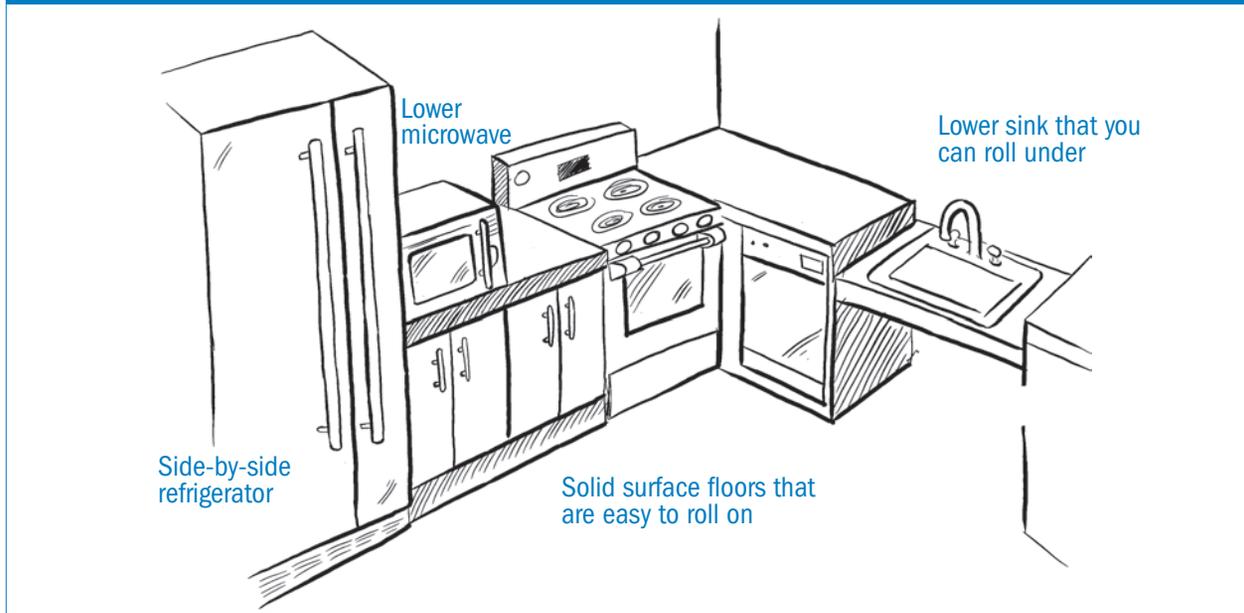
Equipment

Your equipment plays a large role in injury prevention, for both you and your caregiver. Work with your therapists to select the equipment that will best suit your needs and your environment. Assistive devices like a reacher or other long-handled pieces of equipment can help you reach items without stretching overhead. Manual and power wheelchairs can help you get around while also meeting your balance, stability, positioning, and functional needs. Adaptive equipment, such as patient lifts and padded bathroom equipment, can also help you prevent injury. Using a padded tub bench rather than transferring down into and back out of your bathtub will mean more safety and independence and will preserve the joints of your arms and legs.

Home Management

Your occupational and physical therapists will help you with safety and accessibility in your home. They may recommend modifications and additional equipment. *[See section 2.b, Equipment, and section 2.d, Home Modifications.]* For preserving your upper limbs, keep the following in mind. Whenever possible, choose furniture [beds, chairs, couches, etc.] that will allow level transfers. Consider the setup of work or office stations and appliances [laundry, sink, and shop environments] that will give you plenty of access and promote relaxed and supported positions for your shoulders, arms, and hands as you perform your daily routine, home management, and leisure tasks [SEE FIGURE 2.c.6].

[Figure 2.c.6] Kitchen



Maintaining Your Limbs

To protect and maintain your mobility and functional performance, it's essential to have an exercise program that includes flexibility and range of motion. It's also important to incorporate strength training into your program to increase your strength and endurance. To maintain upper and lower limb joint integrity and function and protect yourself against injury, you must make a commitment to overall health and consider using different techniques in your self-care routine, mobility, and daily activities. Vary your techniques. Practice energy conservation. Take rest breaks when you need them. As always, you are in charge of you. Remember: Protect yourself!

Posture

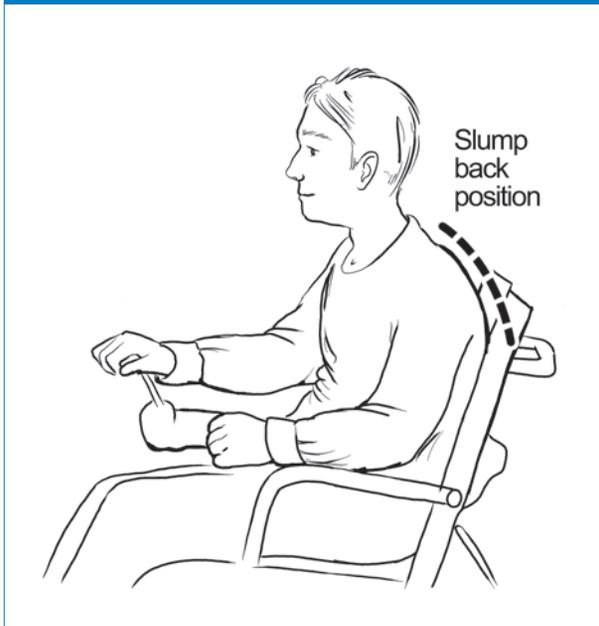
You probably heard it as a child: "sit up straight" or "stand up; stop slouching." Well, your parents were right—good posture is important. Posture is a form of communication. It expresses your confidence or authority, readiness or pride. After SCI you may not have the same control over your posture, but it is even more important. If you use a wheelchair full time, your seated posture will have a lot to do with your health and function.

Poor Posture

Poor posture can interfere with breathing, making it harder to exercise or even carry on a conversation. Poor posture can interfere with skin health, especially if you're sitting crookedly, with uneven pressure distribution. Poor posture can interfere with your ability to push a manual wheelchair or safely drive a power wheelchair. Poor posture can cause headaches, neck and back pain, and upper limb pain.

If you use a wheelchair full time, you will require postural support from the wheelchair. You should expect to sit upright without having to hold yourself up with your arms or a strap. You should be able to sit with your bottom at the back of the seat and not have to slide forward on the seat to feel stable. You should also be able to look forward without feeling as though you have to work to hold your head up [SEE FIGURE 2.c.7]. Unless you have a condition that limits your range of motion, you should look centered and even when you look at yourself in a mirror. You should sit straight up, without a "fold" at the bottom of your ribs on either side.

[Figure 2.c.7] Slump



Seating Evaluation

If you don't feel comfortable in your wheelchair, or you don't feel as though you're sitting as erectly as you could, request a seating evaluation from a therapist. You should also request this evaluation if you've had a change in your range of motion. A seating evaluation involves assessing your posture in your wheelchair, sitting on a firm surface, and lying on a mat. The therapist will gather information to match your postural support requirements to your body.

In the wheelchair: The therapists will assess how you sit in your wheelchair. They may take photographs and feel for bony "landmarks" of your body position. Then they'll measure the size and angles of your wheelchair and inspect your cushion.

Sitting on a firm surface: How you sit on a firm surface tells your therapists how your body responds to gravity and how much support your wheelchair should provide for you.

Lying on a mat: Your therapists will measure the range of motion in each hip, knee, and ankle while you're lying on a mat. They'll move your hips to

determine how much flexibility you have in your pelvis and spine.

Range of motion: Range-of-motion limitations can affect your ability to sit with good posture in your wheelchair. For example, if you don't have full hip flexion, you won't be able to sit fully upright in your wheelchair without some modifications to the chair or the cushion.

Standing and Walking

Posture also matters when you're standing or walking. If you're not standing straight, you're fighting gravity and working harder to stay upright. With SCI, you may be missing some of the muscle power people usually use to stand and walk. Braces and assistive devices [crutches or a walker] can make up for some of this missing strength, but if you're leaning heavily on the devices, you might be creating new problems for your hands, wrists, or shoulders. Also, you might create lower back pain.

Another way to compensate for missing strength is to hyperextend ["lock out"] a joint. This may seem like a good solution, because it makes the limb stable. But be very careful about using this technique—if you do it too often, it can cause joint instability and pain. Even if you don't have sensation in the joint, damage can occur. Locking out can also cause increased spasticity or autonomic dysreflexia in persons who are prone to either of these conditions.

Because all the parts of the body are connected, there will be "upstream" and "downstream" consequences of any odd positioning in a joint. For example, if you hyperextend your knee, you'll bend forward at the hip, placing stress on the lower back as you try to keep your head upright and look forward.

If you use braces or assistive devices to stand and walk, keep them in good working order. If

you think something has changed about your equipment or it's not working as well as it did in the past, ask a therapist to evaluate it. If you know you've lost range of motion for any reason, contact your therapist to see if your equipment needs to be modified. Work with your therapist to stand and walk as tall and straight as possible.

RESOURCES

Publications

Preservation of Upper Limb Function Following Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals

www.pva.org/CPGs

Preservation of Upper Limb Function: What You Should Know

www.pva.org/consumerguides

2.d | Home Modifications

Making your home accessible can mean many things. Your home may need only a few changes, such as a ramp to the entrance or grab bars in the bathroom. Or it may need more involved modifications, such as wider doorways and hallways, a new bathroom, or an elevator or lift.

As part of your rehabilitation program, your therapists may make a home visit. They will take measurements and discuss accessibility issues with you, so you can plan for any modifications you'll need. If you live far from your SCI rehabilitation center, you or a friend or family member may be asked to take the measurements, and the therapists will use them to suggest modifications.

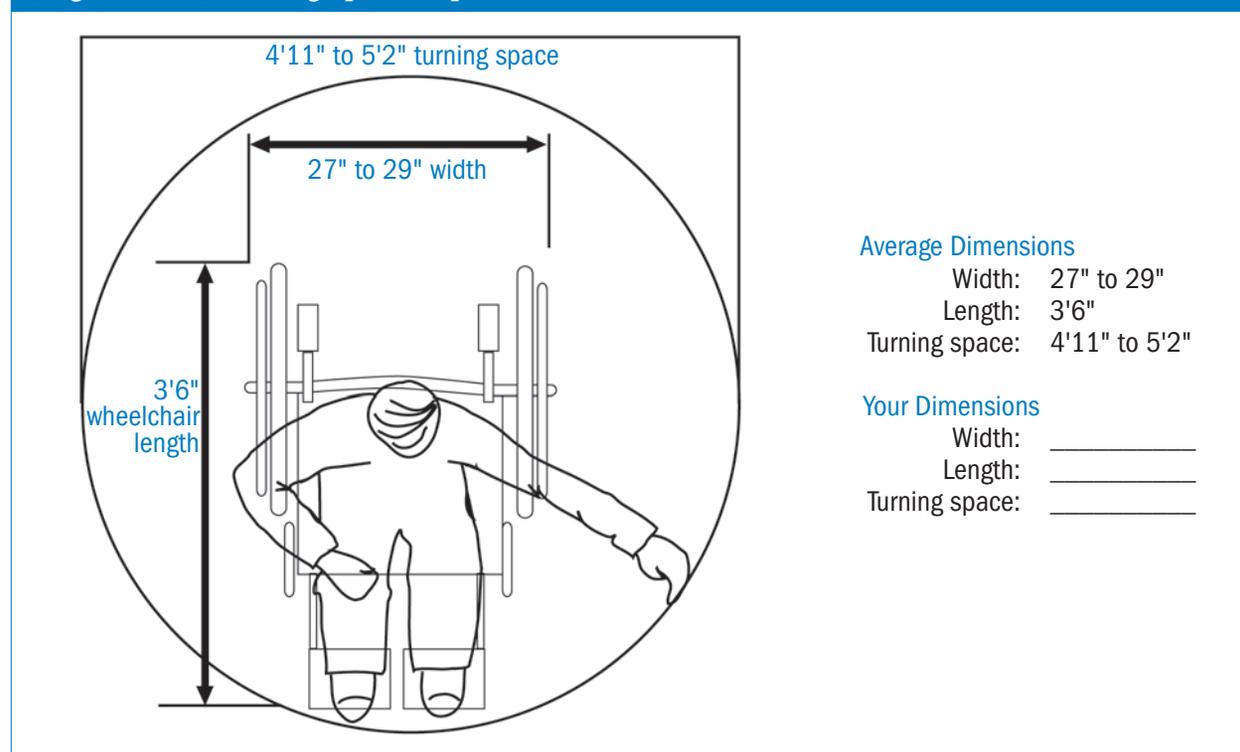
In making your home accessible, many guidelines exist so you can make sure the changes are safe and meet your needs. Your occupational and

physical therapists are good resources for this kind of information. Also, your therapists can help you set up your wheelchair to maximize accessibility in your home. Your social worker can help you identify financial resources for home modifications.

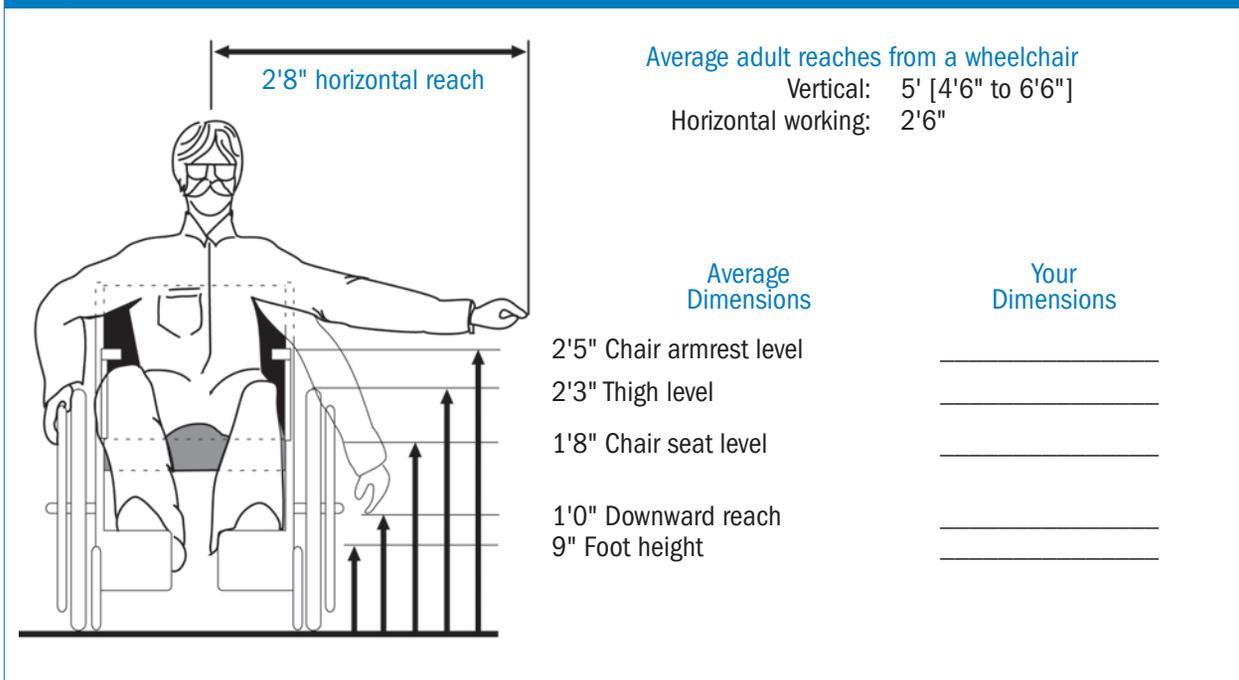
This section makes recommendations for heights, widths, distances, and other specifications for home modifications. Before you jump into anything, let us help you figure out exactly what you need. The drawings have blank spaces where you can fill in the requirements for your own modifications. [Note: Throughout this section, we use " for inches and ' for feet.]

The diagrams of wheelchair dimensions and levels can get you started in making sure work counters, tables, doors, and so on are accessible to you and

[Figure 2.d.1] Turning Space Required



[Figure 2.d.2] Wheelchair Dimensions



your wheelchair [SEE FIGURES 2.d.1 AND 2.d.2]. Your therapist can help you measure your chair and figure out turn spaces and your reach from the chair.

Planning for Accessibility

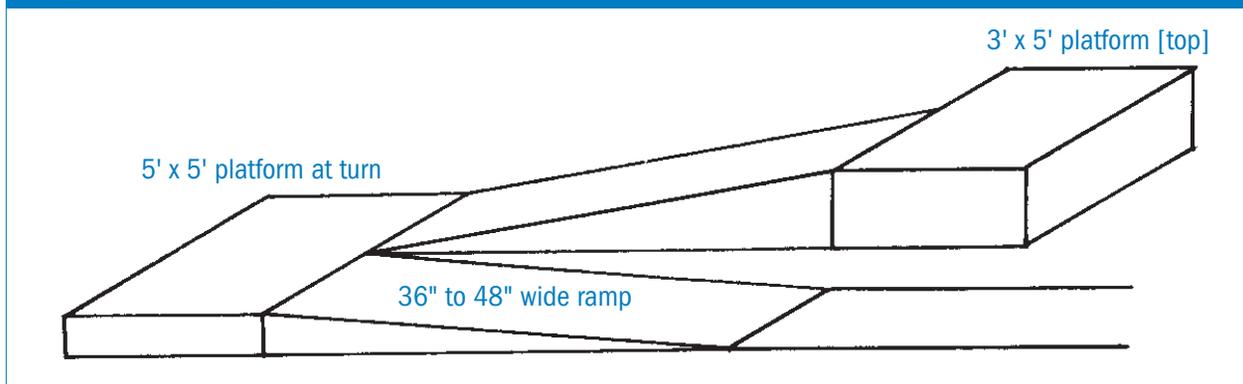
Ramps

Sometimes it seems that all the world is a staircase. Many places are wheelchair accessible because they have ramps, but many others are not. Your own home should definitely have ramps, which are a safe replacement for stairs. The following are some hints for building ramps.

- **Length:** Safe ramp lengths are one foot for each inch of rise [height]. This means a slope of 1:12, or an 8.33 percent incline. For example, if you have two 7" steps [a total 14" rise], you'll need a 14' long ramp.
- **Width:** The recommended width for ramps is 36"–48". A 48" width is convenient if you use plywood [exterior or marine-grade], which comes in 4' x 8' sheets.

- **Landings:** Landings are necessary at the top and bottom of a ramp, and at any intermediate level where the ramp changes direction. All landings should be at least 5' x 5' [SEE FIGURE 2.d.3]. Ramps longer than 30' should have a small landing every 30' to provide a resting spot. The top landing should extend 1'6" on the latch side of the door. This means that if you want to center the platform on a 3' opening, you need a 6' platform. If the door opens in, the platform can be 3' deep x 5' wide [SEE FIGURE 2.d.3].
- **Railings and edges:** Railings should be built on both sides of the ramp, approximately 32" high and securely fastened to the ramp. They can be made of 2" x 2" or 2" x 4" lumber, or 1.5" diameter pipe. The edges of the ramp should be at least 2" high to prevent wheelchair casters from going over the edge.
- **Surfaces of ramps:** Uncovered outdoor ramps can become extremely slippery and dangerous unless you use a nonslip surface like adhesive nonskid strips, ribbed rubber

[Figure 2.d.3] Ramps



matting, or a rough roofing material. A broom-swept finish works well on a concrete ramp. A painted surface is not recommended because it can be very slippery when wet. However, paint mixed with sand [one pound of silica sand mixed thoroughly with one gallon of paint] and nonskid deck paint are OK. The surface should not be so rough that it makes wheelchair travel difficult or unpleasant.

- *Materials for ramps:* To build a long-lasting ramp, treated lumber [such as exterior or marine-grade plywood], concrete, or 2" x 4" slats placed crosswise are recommended.

Walkways and Entrances

Walkways around your house are important to provide a solid, constant surface through rough terrain in your yard. Use concrete, lightly stamped concrete, or large pavers positioned close together. Select the surface texture that's easiest to roll on. That way, you won't have to worry about getting stuck, especially when the ground is soft after rain or snow.

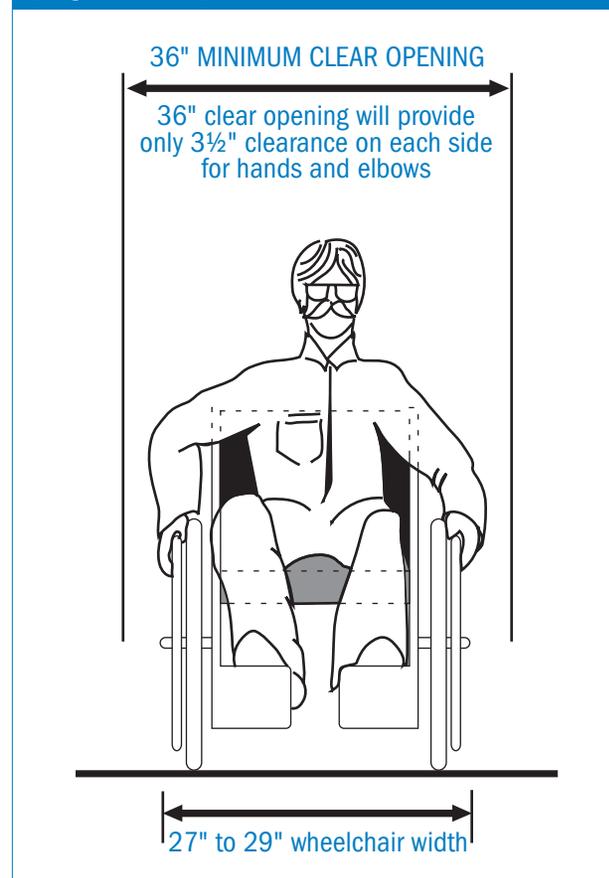
Walkways should be a minimum of 42" wide to lower the risk of a wheel slipping off the edge. They should be 5' wide on corners or switchbacks to allow for wheelchair turns. Doors and open entrances should have a clear, unobstructed opening of at least 32" [36" is better] with a level

or beveled threshold no more than $\frac{1}{4}$ " higher than the floor.

Doorways and Hallways

Ask your therapists to help you determine your wheelchair width [SEE FIGURE 2.d.4]. The minimum

[Figure 2.d.4] Door Width



width of doors should be 36". This will provide at least a 32" opening, even if the open door partially narrows the opening. Special attachments on your wheelchair may require even wider doors. Remember to take both door and door frame widths into consideration when you're measuring clearance. Measure the narrowest point of the doorway opening. Usually this is the distance from a rectangular strip of wood or metal on the doorframe near the latch across to the same strip on the hinge side of the doorframe. In many cases, the fully opened door blocks part of the doorway, so measure from the strip near the latch to the closest edge of the fully opened door. Sometimes standard hinges can be replaced with swing-away hinges so the opened door doesn't block the opening at all.

Doorways into bathrooms or other confined spaces should swing out. If you have a large bathroom with plenty of maneuvering space, you could have an in-swinging door, although it could be a hazard if you should fall and block the door. Sliding doors and pocket doors are great space-saver alternatives to a hinge door.

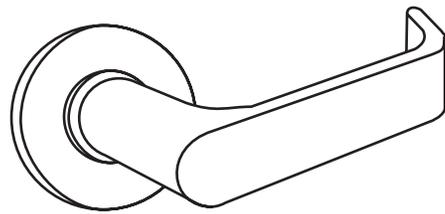
Doors can be one of the biggest obstacles in your daily life. There are a number of things about them that you should be aware of:

- Any door must be capable of being opened in a single motion.
- Lever-style handles are easier to grasp than round ones. Your therapist can recommend various ways to adapt door handles, cabinet door handles, and so on [SEE FIGURE 2.d.5].
- The best height for door handles is about 3'. Your therapist can help you evaluate your reach and determine what height works best for you [SEE FIGURE 2.d.6].
- No matter how careful you are, the footrests on your wheelchair will scratch the doors from time to time. Kick plates on both sides

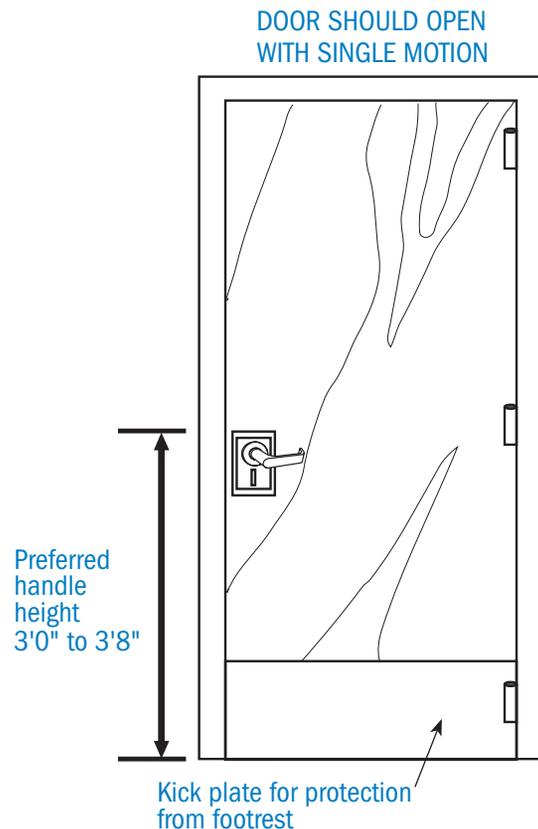
of your doors will protect them from this kind of damage.

- Hallways should be a minimum of 36" wide to allow wheelchair access to rooms; however, 48" is better. If a doorway is too narrow, turning may be difficult. Figure 2.d.7 shows the best hallway-doorway configurations for accessibility.

[Figure 2.d.5] Lever Style



[Figure 2.d.6] Door Dimensions



- To help you close an exterior door, screw a small robe hook into the center of the door within arm's reach. Another solution is to use a long pole with a hook at the end; use the hook to grab the handle and pull the door shut.

Convenient Heights

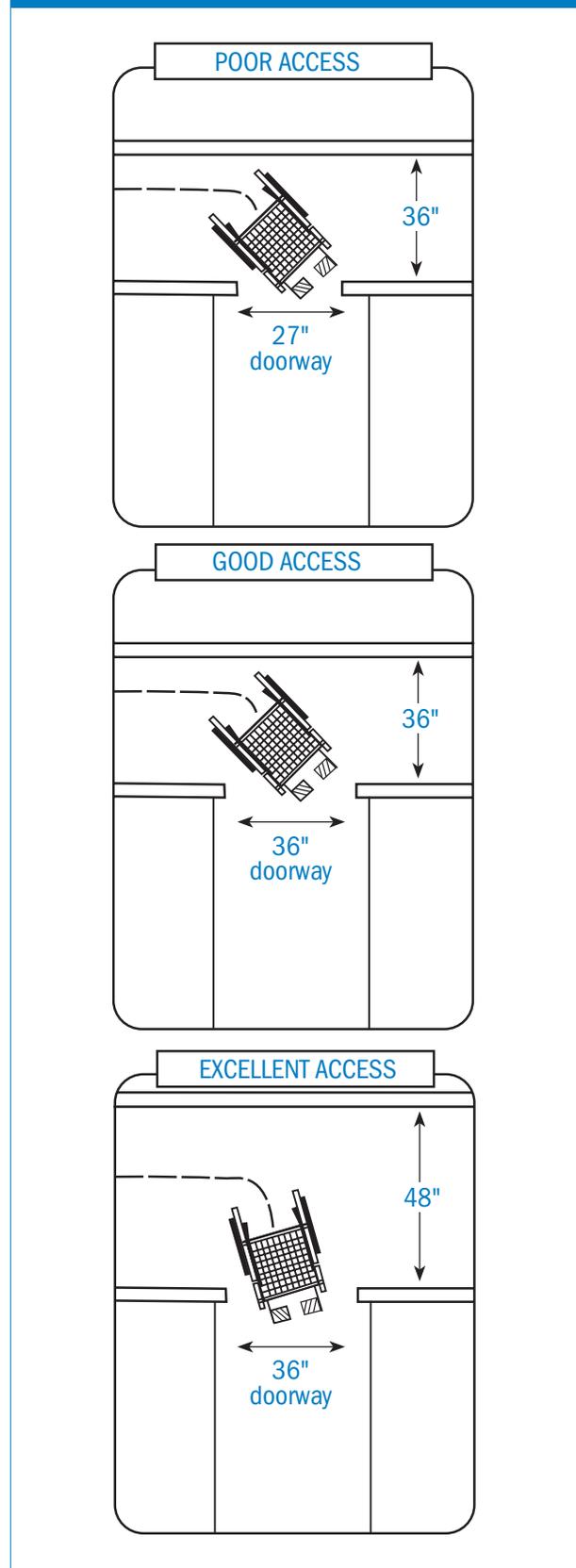
Small details are important. Make sure to check the following measurements. The heights given are optimal for wheelchairs:

- Counters, tables, and sinks: 27"–34"
[standard counters are 36" high]
- Electrical outlets: 18"–48"
- Light switch/thermostat: 36"–42" from floor
- Wall-mounted telephones: 32"–40" recommended; maximum, 48"
- Closets:
 - > Clothes hanger rod: maximum 48"
 - > Shelves: maximum 54"
- Windows: For viewing, a low sill height is recommended [no higher than 30"]
 - > Toilet: use a low residential model. When personal bathroom equipment is added [a raised, padded seat], the height should be level with your wheelchair seat. This will allow side access for bowel care and easier transfers. If a rolling shower commode chair is needed, the low residential model will allow clearance over the toilet.

Bathrooms

You and your therapist should thoroughly evaluate all bathroom fixtures and equipment. The height of toilet seats and the placement of grab bars will depend on you and the kind of bathroom you have. It's important to securely attach the grab bars into the studs in your wall. In new construction, reinforce walls where grab bars will be installed, the like the shower surround and walls next to toilets.

[Figure 2.d.7] Hallways



As your rehabilitation proceeds, your needs may change. Your therapist can evaluate your bathroom facilities and make recommendations for changes or adaptations.

Safety Considerations

- Exposed hot water or drain pipes [like those under a sink], motors, and other sources of burns or abrasions should be covered or insulated.
- Preset hot water heaters to less than 120 degrees and install anti-scald devices.
- Doors to any confined space with only one exit should swing out. In-swinging doors pose a potential danger if the wheelchair user falls and blocks the door.
- You may want to have two separate accessible emergency exits in the rear or side of the home in case of emergency.
- Consider an emergency warning signal—a system to alert neighbors, fire department, or police in case of an emergency. You may choose to notify your local fire department that a person in a wheelchair lives at your address.
- Install smoke detectors throughout your home [hallways, kitchen, upstairs, basement, and bedrooms]. If you have difficulty hearing, use a system that alerts you with lights or other means.
- Install carbon monoxide detectors if any appliances [including furnaces and stoves] use natural gas, propane, oil, wood, or any other fuel that is burned. If you have just one detector, it should be in your sleeping area.
- Fuse boxes or circuit breakers should be accessible.
- Provide adequate, even lighting throughout the house.
- Have an accessible telephone near the bed and a phone jack in the bathroom; consider carrying a cordless or cellular phone with you as you move about your home.
- Have a fire extinguisher in the kitchen, readily available and within reach.
- If you walk, be aware of obstacles like area rugs and cords.
- Have some battery-operated lights on hand for emergencies.

RESOURCES

Publication

Accessible Home Design

www.pva.org/publications

Organizations

Center for Universal Design
North Carolina State University

Box 8613

Raleigh, NC 27695-8613

[800] 647-6777

www.design.ncsu.edu/cud

The Ramp Project

Metropolitan Center for Independent Living

1600 University Avenue West, Suite 16

St. Paul, MN 55104

[651] 646-8342

www.mcil-mn.org

Trace Research and Development Center

1550 Engineering Drive

Madison, WI 53706

[608] 262-6966

[608] 263-5408 TTY

email: info@trace.wisc.edu

www.trace.wisc.edu

Websites

www.UDLL.com

The mission of the Universal Design Living Laboratory is to bring about awareness of the quality of indoor and outdoor lifestyles through universal design, green building, safety, and healthy home construction practices to the public and the building industry. The website provides information about this national demonstration home, which incorporates unobtrusive universal design, resource- and energy-efficient green building methods, advanced automation technology, a healthy home construction approach, and the design principles of feng shui.

www.ap.buffalo.edu/idea

The Center for Inclusive Design and Environmental Access offers resources on designing environments and projects incorporating principles of universal design.

www.hometime.com

Hometime is an online source for home improvement, remodeling, and repair information. It includes information on accessibility and universal design.

2.e | Driver Rehabilitation and Training

Driving is an important aspect of our lives. It allows us greater independence for activities of daily living. Many people with spinal cord injury [SCI] can relearn this skill with the assistance of a therapist who has specific education in driver rehabilitation, a certified driver rehabilitation specialist [CDRS], or a qualified driver trainer. These people can evaluate your need for adaptive equipment and provide behind-the-wheel training. Hand controls and steering devices can enable people with SCI to operate a vehicle.

Legal Considerations

To get a license, first contact your local department of motor vehicles [DMV]. Your state may require a physician to complete a form stating that you're medically able to drive. The form has sections that include information about your current medication, history of seizures, and need for adaptive equipment. Even if your current license won't expire for years, you are responsible for updating your status with the DMV to reflect the change in your medical condition.

The next step is to complete an evaluation with a CDRS or qualified driver trainer. This person will help you determine the specific equipment you'll need and provide the behind-the-wheel training in using it.

Finally, if you're driving with adapted equipment, you'll probably be required to take the driving test in your state. Your license will be updated with the equipment restrictions. In most states, it's illegal to drive with adapted equipment that is not reflected on your license.

Insurance

Inform your insurance company of the change in your medical status and your equipment needs. The company may require proof that your license has been updated with adapted equipment restrictions and that your physician believes you are a medically safe driver. Your insurance company cannot cancel your policy because of a spinal cord injury. It's important to list the adapted equipment you've installed on your vehicle. This will ensure that it's covered in your policy.

Driver Assessment and Training

You'll want to have an assessment with a certified driver rehabilitation specialist or qualified driver training instructor. Many rehabilitation medical centers and VA hospitals have driving programs for people with disabilities. The instructors are usually experienced therapists who have pursued additional training to become certified as driver trainers. If you can't find a qualified driver trainer in your area, contact the DMV, the American Automobile Association [AAA], or the Association for Driver Rehabilitation Specialists [ADED]. *[See Resources at the end of this section.]*

Many driving schools have hand controls installed in their vehicles and may be able to offer training with this equipment, but they may not know about your disability and the seating requirements for maintaining your balance when you're driving. To resume safe driving, you'll need behind-the-wheel training from a qualified instructor.

When Should You Start?

Your health-care provider and therapist should guide your decision on when to start training to drive. Some orthopedic or neurological

restrictions and medications may affect your readiness. In the first months after your injury, you should focus on the medical and therapeutic aspects of your rehabilitation, so you can achieve your maximum level of independence and strength. Driver training usually happens closer to discharge, or six months to a year after the injury. Before that, you can work on the endurance and skills you'll need to prepare for driving.

Especially if you have tetraplegia, be sure to take all the time you need to maximize your functional skills before you consider driving. One reason to take it slowly is a practical one: if you invest in costly equipment and changes occur in your skills, the equipment may no longer be useful or appropriate in a few months. If your injury included loss of consciousness, seizures, head injury, or stroke, there may be a six-month mandatory waiting period before you may resume driving. Contact the local DMV for details.

Training

The training process starts with a complete assessment. Therapists will check your vision and spatial orientation and evaluate your strength, active range of motion, sensation, balance, coordination, and reaction time. They will ask about your previous driving record and experience, and about what type of driving environment and weather conditions you will encounter in your community. This information will allow you and your therapist to develop a training program that meets your specific needs.

After the in-clinic assessment, the therapist will educate you on the types of adaptive equipment available and what will meet your needs. This equipment can be set up on a driving simulator to help determine your abilities. After the appropriate equipment is chosen, you'll have a behind-the-wheel assessment and will be trained to use the equipment. The therapist will begin

teaching you to drive in a parking lot or other safe practice area. Most training vehicles have a dual-control brake for safety. As you become more skillful, you'll drive in more complex environments and will learn defensive driving techniques.

At the end of the training, you should be knowledgeable, safe, and prepared to take the DMV road test. If you haven't had the time or money to have your own vehicle modified, you can probably arrange to use the training vehicle for your test.

Equipment Options

A large selection of adaptive driving equipment is available—you'll have to figure out what is appropriate for you. Most adaptive equipment will not prevent other people from driving your vehicle using the standard controls [OEM, or original equipment manufacturer, controls].

Mechanical Hand Controls

Hand controls are mechanical levers attached to the foot pedals of the vehicle and mounted under the steering column. The standard method of operation is to push forward for braking and at a right angle/downward to accelerate. Hand controls eliminate the need to use foot pedals and can be mounted for right- or left-hand use. Low-effort braking is available if you don't have the hand strength to brake.

Steering Devices

When you're using hand controls, one hand must operate the gas and brake while the other hand does all the steering. To make this easier, a knob, yoke, or vertical steering device can be installed to help with the full rotation of the wheel, making turns faster and easier. The device must be removable so other drivers can use hand-over-hand turning.

Steering Force Reduction

If the standard OEM steering wheel requires too much force or range of motion to turn, the vehicle's steering box can be removed and rebuilt. The steering force can be reduced by altering the gear ratio. This modification is permanent and must include an emergency pump and backup system in addition to the standard power steering. A smaller steering wheel may be installed, but installation alters the air bag, so this is only done if there are no other options.

Left-Foot Accelerator

If you've lost the use of only the right side of your body, a left-sided gas pedal can be installed to enable your left foot to operate the gas and brakes. An accelerator guard is installed over the standard gas pedal to prevent you from accidentally hitting it.

Electronic Dash Switches

If you have limited reach or hand function, it can be hard to operate the gearshift, ignition, turn signals, headlights, wipers, heater/air conditioning, and cruise control. Electronic switches to control these functions can be installed in the dash—they require only light pressure and can be operated with an elbow or by voice control.

Electronic Hand Controls

For people with high-level tetraplegia, standard hand controls may require too much physical strength, range of motion, or endurance. Your sitting balance might limit how you use your arms to control the vehicle. Computer-interfaced steering and hand controls can enable a person to drive with a small-diameter wheel close to the lap and hand controls that operate with a push/pull motion, only a few ounces of force, and less than six inches of movement. This equipment is customized for the user—it is placed in the driver

compartment to specifically match your functional abilities. Electronic hand controls are typically used by persons who cannot transfer into an adapted driver's seat and cannot use mechanical equipment.

Transfer Seat Base

In a modified van, the transfer from wheelchair to driver's seat usually requires that the seat pivot away from the steering wheel and move forward and back with height adjustments. The power six-way transfer seat base allows a transfer inside the vehicle. The seat can be adjusted to a height close to that of the wheelchair seat and then it will swivel toward the steering wheel. You'll have to be able to lift and position your legs and feet.

Selecting a Vehicle

Your choice of vehicle will depend on whether you can transfer into and drive a car or if you need to use a van with an entry lift or ramp modifications. If you use a power wheelchair, you'll need a van with entry equipment. Although portable power wheelchairs are available, they usually require assistance to take them apart and lift them into the trunk for storage. Your choice of a vehicle will also depend on who else will be driving it and where you will park.

If you use a manual wheelchair, you'll need to choose a vehicle that matches your ability to transfer and to store the wheelchair. If you use a rigid frame wheelchair, you'll have to disassemble the parts and load them separately.

The seats on some cars are at the right height for the transfer to and from a wheelchair. On a truck, you might have to transfer up 10 or more inches, which may be difficult. Over the long term, transferring and loading a wheelchair can cause repetitive trauma to the arms and shoulders. The method you use to load the wheelchair should be efficient, provide personal security, and not expose you too much to bad weather.

What to Look For in a Car

Certain vehicles are better suited for transfers, wheelchair storage, and installation of hand controls. Your therapist can give you specific information on equipment and vehicle selection criteria. Some models need more customization than others, and manufacturers make changes every year. The following are general guidelines for buying an accessible car.

- A two-door vehicle is easier to access because longer doors open wider. This means you can position the wheelchair closer and have more space for your transfer.
- A medium-size or large car is generally recommended because the seat is probably higher and there's more legroom under the column where the hand controls are installed. Before you buy a vehicle, call the vendor who installs hand controls to make sure the vehicle can be modified. Adjustable steering columns, air bags, and under-dash vents make hand control installation more challenging and costly.
- Bucket seats may give you better balance and stability by providing support. On the other hand, a bench-type front seat will allow you to enter from either side of the vehicle and slide over to the driver's seat.
- Power seat options make the transfer easier and allow better positioning for trunk balance while you're driving.
- A center armrest/console may be desirable for long-distance driving and for stability and balance during turning maneuvers. It can also provide hand support for pressure relief.
- If you use a folding wheelchair, there should be enough room for storage between the front and back seats. Also check that seat belt anchors don't interfere with access.
- Seat belts must be worn in all vehicles. Seat belts and shoulder harnesses can help maintain stability and balance on stops, during turns, and on banked road surfaces. Operation of the seat belt may require some minor customization for hand function.
- A four-wheel-drive vehicle is recommended if you will be driving on snow and ice. Four-wheel drive is available on many different makes and models.
- Automatic transmission is required to operate hand controls. Some newer devices will allow an experienced hand control driver to use a hand clutch, but this makes steering and trunk balance difficult.
- Power steering is recommended for improved turning and to avoid overtiring your arms. Most people who use hand controls use their stronger arm and hand to steer—they use a one-handed technique and a spinner knob.
- The steering column must be designed so the bracket for the hand controls can be attached. Check with your equipment vendor before you purchase the car.
- A tilt steering column allows more legroom for entering and exiting, and allows you to adjust the wheel height. In some cases, a tilt or telescoping steering column must be locked in place before hand controls can be installed. Discuss this with your vendor to make sure that you won't lose the positioning flexibility you want.
- An antilock braking system and power brakes require less force—you may need these for safety and to control the vehicle.
- Cruise control allows you to maintain a steady speed without having to constantly press on the accelerator. This helps prevent arm fatigue during long-distance driving with hand controls.

- Power windows are recommended for drivers with limited hand function and for hand control users.
- Power door locks are recommended for drivers with limited hand function or limited mobility. You may want to carry the remote entry device on a strap or secured to your wheelchair to prevent it from falling on the ground.
- Air conditioning is recommended for people with respiratory problems. In some climates, it's a medical necessity for temperature regulation.
- Remote adjustable outside mirrors give the driver optimum rear vision. Backup sensors can be a valuable addition—they alert drivers with limited neck or turning range of motion to obstacles behind the vehicle. Wide-angle rearview mirrors are also useful for seeing traffic in the blind spot.
- A rear window defroster and wiper will improve overall vision and safety.

What to Look For in a Van

Buying and modifying a van with a wheelchair entry can be very expensive. The general guidelines for a van are similar to those for a car, but the type of van and equipment you need will be a personal matter. In selecting a van, work closely with your driver training professional. Not all vans can be modified, and your van will have to meet the national standards for conversion with crash-tested equipment.

You'll have to decide whether a full-size van or a minivan meets your lifestyle needs and the space requirements for transporting your equipment when you travel. A full-size van may require a lowered floor or raised roof so you can get through the door on a wheelchair lift. The minivan conversions have a ramp entry with a lowered

floor and lower suspension system to reduce the ramp angle, which is often too steep for manual wheelchair users.

You'll need your measurements in the wheelchair to plan the height of the entry, headroom, and turnaround space inside the van. A critical factor will be whether you plan to transfer into the driver's seat or use the wheelchair as the seat. Using the wheelchair as the driver's seat can increase your independence if you can't transfer. Your therapists will help you decide what special accommodations will be needed to your wheelchair for postural support and balance. A wheelchair is not designed to be used for seating in a van—only some makes and models can be locked down.

Choosing an Installation Vendor

Installation of the driving and entry equipment is critical for your safety, the warranty, and long-term repairs. The vendor should have the required training and certification to install specific equipment and should carry liability insurance to cover the equipment and the work performed. Ask your driver rehabilitation specialist to recommend a qualified local vendor or contact the National Mobility Equipment Dealers Association. *[See Resources at the end of this section.]*

Rebates

Some of the major vehicle manufacturing companies offer cash reimbursement for adapted driving equipment. These rebates range from \$500 to \$1,500. The following are general guidelines for all programs:

- Equipment must be installed on new/current model vehicles by a certified vendor.
- Customers must have a prescription for adapted equipment written by a qualified driver trainer professional.

- Customers who receive outside funding are eligible for reimbursement for their out-of-pocket expenses; the funding agency does not receive the rebate.
- Programs are offered in addition to any other applicable cash rebates in effect at the time of purchase.
- Reimbursement is intended for adapted driving aids or conversion equipment only.

For rebate applications and additional details, contact the manufacturer and the vendor. The following are three of these programs:

- Chrysler Motors Physically Challenged Resource Center [800] 255-9877
- Ford Mobility Motoring Program [800] 952-2248
- General Motors Mobility Program [800] 323-9935

Tiedown/Lockdown Systems

If you use a cabulance service, public transportation, or even ride in your van in your wheelchair, the wheelchair must be secured with a tiedown system—straps that secure it to the floor of the vehicle. You should also use a pelvic and chest belt to secure yourself to the wheelchair. The tiedown prevents your wheelchair from moving around. Your wheelchair brakes are not sufficient, especially in a crash. It's your responsibility to tell people the best way to attach the tiedowns to your specific wheelchair. Review this with your driver trainer or therapist.

The following are some general guidelines for tiedowns:

- Tiedown systems should be attached to the *frame* of the wheelchair. Never secure them to removable parts like footrests or armrests.

- A four-point tiedown system is required for safety. This system uses straps secured at four points on the wheelchair—two in the front and two in the back.
- In addition to securing your wheelchair, you want to have a separate wall-mounted shoulder/lap harness. This will keep you in the wheelchair in case of a sudden stop.
- Whenever possible, tiedowns should allow you to position the wheelchair so you're facing forward in the vehicle. You don't want your back lined up against a wall or window.
- If you use the wheelchair as the driver's seat in your van, you must have a power lockdown to secure it to the floor. This is a floor-mounted box with an electrical latch system that interfaces with pin-and-bracket hardware installed on the frame of the wheelchair. Some makes and models of power and manual wheelchairs are not suitable for use with power lockdowns. Check with the vendor to see if your wheelchair will work. A power wheelchair with mid-wheel drive requires an additional front lockdown to prevent it from tipping and the front wheels from coming up off the floor of the van.

Disabled Parking Permits and Assistance at Gas Stations

Contact your local DMV to get an application for a disabled person's parking permit. Most states require that your physician sign a form indicating your need for this type of parking. Most states will issue a removable placard that you can place on the dashboard or hang from the rearview mirror. Placards are more versatile than disabled license plates, because they allow you to use disabled parking when you're in someone else's car. If you travel, make sure that other states will honor your parking permit. The license plate permit is used by most independent drivers.

Find out about the state policy for getting help at a gas station. In many states, your disabled parking permit entitles you to purchase gas at self-service prices even though the attendant pumps it. This is meant to prevent price discrimination against persons who are physically unable to complete the task. You may want to develop a relationship with your local station and find out the best days and times for attendant assistance.

Funding Sources

Your state department of vocational rehabilitation [DVR] may provide funding for evaluations, training, and vehicle modifications. Technology services and devices may be considered as a provision of the 1992 reauthorization of the Rehabilitation Act of 1973. This legislation authorizes your state to handle assistive technology services under vocational rehabilitation. To establish your eligibility, you'll have to outline your vocational goals, how driving is critical for your plan, and what services you'll need. The DVR may help you with your individual written rehabilitation plan. The VA provides assistive technology equipment and related professional services to some veterans.

Looking to the Future

It's your responsibility to become a safe driver and to maintain your vehicle and adapted equipment. If your medical condition changes; if you have new neurological or orthopedic problems, increased spasticity, or new medications; or if you change your wheelchair [whether or not you use it as the driver's seat in your van], you should reevaluate your driving. Periodic professional reevaluations by your CDRS or qualified driver trainer can help you stay safe to drive.

Advances in technology have enabled people to drive a vehicle using a joystick for gas, braking, and steering. Voice control can operate the

windshield wipers and turn signals, making these operations completely hands-free. Although costs and risks are involved in using such technology, people with SCI have many resources and options to facilitate and prolong their ability to drive.

RESOURCES

Organizations

American Automobile Association Traffic Safety
1000 AAA Drive
Heathrow, FL 32746-5063
[407] 444-7000
www.aaa.com

The Disabled Driver Mobility Guide is particularly useful for drivers with a disability.

Association for Driver Rehabilitation Specialists [ADED]
711 Vienna Street
Ruston, LA 71270
[800] 290-2344; [318] 257-5055
www.driver-ed.org

ADED provides educational support for professionals in the field of driver education, transportation options, and equipment modifications for people with disabilities. ADED has a list of the certified driver rehabilitation specialists in your area.

National Mobility Equipment Dealers Association [NMEDA]
3327 West Bearss Avenue
Tampa, FL 33618
[800] 833-0427; [813] 264-2697
www.nmeda.org
NMEDA maintains the standards of practice for manufacturers and vendors of vehicles and adaptive equipment.

Websites

Association for Driver Rehabilitation Specialists [ADED]: www.driver-ed.org.

See “Model Practices for Driver Rehabilitation for Individuals with Disabilities.”

American Occupational Therapy Association [AOTA]: See “Driving Evaluations by Occupational Therapists” at www.aota.org/olderdriver.

Rehabilitation Engineering and Assistive Technology Society of North America [RESNA] is an interdisciplinary association of people with a common interest in technology and disability [www.resna.org].

AARP: www.aarp.org. See the AARP Driver Safety Online Course at www.aarp.org/drive.

AAA: www.aaa.com. See the AAA Driver Improvement Classes at www.aaa.com.

2.f | Attendant Management

As the employer of an aide or attendant, you will be running a small business and will need the same skills as a personnel manager. The purpose of this section is to help you succeed in this role.

Determining the Attendant Care You Need

The first step is to decide what activities you'll need help with. This is called a "needs assessment." The checklist in Table 2.f.A provides a general outline of the duties an attendant might perform. Go through the list and mark each activity that you'll need assistance with. Also note when and how often you'll need certain kinds of care. This will help you figure out how many hours a day and how many days a week you'll need an attendant. If you need assistance in areas that aren't on the list, write them in the "other" spaces.

You may find that you need more than one employee; for example, one in the morning and another at night if you don't need assistance during the day. Or you may need one for weekdays and another for weekends, so they both have time off. You may also want to find someone to work for you when one of your regular employees is on vacation, needs time off, or is sick. Sometimes previous attendants who are no longer working for you can do this, which is ideal, because they already know the job.

Checklist for Personal Care

Now that you've outlined your needs, the next step is to outline what each task requires. This will help avoid conflicts about duties and ensure that you get the care you need. Table 2.f.B is an example of a personalized care checklist—it gives step-by-step instructions for one element of your personal care.

It's impossible to include every detail of every step in your checklist, but if you leave out important information, the task might not be done right. Here are some general guidelines for developing your checklist:

- Be brief. Try to make the steps as short as possible.
- Put the steps in the order they will be performed.
- Include what, when, where. Make sure the attendant knows what materials are needed and when and where the job will be performed.
- Avoid how. A lot of the "how to" of many steps is too detailed to include in the checklist—you can teach attendants while they're performing the task. But make sure to include steps that are essential or likely to be neglected.

The items on your checklists should come from your needs assessment, and they should be listed in a workable order. For example, if bathing is the first task to be done each morning, the bathing checklist should be first. Some people also find it helpful to arrange the checklists in daily [e.g., dressing, eating]; weekly [e.g., shopping]; and monthly [e.g., wheelchair maintenance] order. Arranging the checklists in an orderly manner will simplify both your and your attendant's responsibilities. The checklists can be the basis for a very clear and complete job description for your attendant.

Preparing a Job Description

The job description needs to be very clear so an applicant can tell if he or she is interested. Don't try to make the job sound easier or less time-

[Table 2.f.A] Sample Needs Assessment Work Sheet

NEED	FREQUENCY	TIME NEEDED	AM	PM
ACTIVITIES OF DAILY LIVING				
Bathing				
Dressing				
Grooming [shaving, hair care, makeup]				
Meal preparation				
Eating				
Bowel care				
Bladder care				
Turning in bed				
Transferring				
Other:				
INSTRUMENTAL ACTIVITIES OF DAILY LIVING				
Washing dishes				
Grocery shopping				
Turning on computer				
Setting up equipment				
Making bed				
Charging wheelchair batteries				
Driving van				
Errands				
Mail and paying bills				
Answering phone				
Laundry				
Putting away items				
Housecleaning				
Child care				
Pet care				
Other:				
MEDICAL-RELATED CARE				
Pressure relief/positioning				
Medications				
Range-of-motion exercise				
Skin inspection				
Suctioning, respiratory care				
Other:				

[Table 2.f.B] Sample Checklist for Morning Routine

GETTING READY	
<input type="checkbox"/>	1. Get clothes ready.
<input type="checkbox"/>	2. Prepare bath water.
<input type="checkbox"/>	3. Check water temperature.
<input type="checkbox"/>	4. Make sure needed materials are available.
<input type="checkbox"/>	5. Ensure privacy.
ROUTINE	
<input type="checkbox"/>	1. Assist with bladder [e.g., catheterization].
<input type="checkbox"/>	2. Assist with bowel care [e.g., suppository insertion and digital stimulation].
<input type="checkbox"/>	3. Assist with clothing removal.
<input type="checkbox"/>	4. Move from bed to bath.
<input type="checkbox"/>	5. Wash and rinse body.
<input type="checkbox"/>	6. Assist with hair care.
<input type="checkbox"/>	7. Move from bath to dressing area.
<input type="checkbox"/>	8. Dry body thoroughly.
<input type="checkbox"/>	9. Conduct health check [e.g., for pressure ulcers].
<input type="checkbox"/>	10. Apply lotion or powder.
<input type="checkbox"/>	11. Apply deodorant, makeup, and/or shave.
<input type="checkbox"/>	12. Assist in dressing.
<input type="checkbox"/>	13. Assist with dental care.
<input type="checkbox"/>	14. Move to breakfast area.
CLEAN UP	
<input type="checkbox"/>	1. Put away all materials.
<input type="checkbox"/>	2. Clean bathroom.
<input type="checkbox"/>	3. Clean and disinfect bladder and bowel care materials.

consuming than it actually is just to persuade someone to take it. The job description must be based on your specific needs and should include the following information:

- Duties and responsibilities [as described in the checklists].
- Number of hours of work per week.
- Scheduled days and times.
- Holiday and vacation policy.
- Salary and benefits.

- Qualifications [e.g., ability to lift a certain weight, first aid and CPR training, driver’s license].

If the attendant is going to live with you, the job description should include specifics about the living arrangement:

- Work hours versus leisure hours.
- Days off.
- Sharing of common space, including kitchen and laundry.
- Roles and rights of other members of the household.
- Policy on visitors.
- Housekeeping.
- Attendant’s share of utility bills.
- Acceptable behaviors [e.g., smoking, drinking alcohol, partying, noise].

Ideas for Recruiting

To find an attendant, you can—

- advertise in the local newspaper;
- place flyers on bulletin boards;
- use word of mouth through family, friends, churches, and clubs; or
- use an agency, either for-profit or nonprofit, that will screen and refer applicants to you. Agencies can include the local employment security office [unemployment office].

Newspaper Ads

Your first objective is to attract the attention of prospective attendants. “Help Wanted” or “Handicapped Needs Help” will not do it. What is the attendant’s incentive to help? Weekly salary? Apartment near campus? Use this as the heading to spark curiosity. Then reinforce the incentive with more detail to further develop interest.

[Figure 2.f.1] Sample Newspaper Ad

ROOM NEAR CAMPUS IN EXCHANGE FOR WORK

Available to a quiet, reliable person able to assist a disabled woman with personal care and light housekeeping.

TWO POSITIONS AVAILABLE:

1. Monday through Friday.
2. Saturday and Sunday.

Two hours per day [evenings].

Nonsmoker preferred, no drugs or alcohol.
References required.

**For details, write to:
P.O. BOX 123
ANY CITY, USA 00000**

The ad should then give a brief but accurate idea of the obligation. If you don't sugarcoat this part, you'll get more serious, mature applicants. Finally, provide a way of contacting you [first name, phone, email address, or newspaper box number]. For your own safety and independence, do not include your last name or home address in the ad.

If space and expense allow, your ad could include days of the week, part-time or live-in, your gender, nonsmoker if required, and time to call. Because of discrimination laws, you may not advertise a preference for gender, age, or race. You also may not ask for a specific height or weight, but you can require the person to be able to lift what is needed, including you [SEE FIGURE 2.f.1].

Flyers and Bulletin Boards

Various college campus locations, personnel bulletin boards, hospital staff lounges, and public bulletin boards in supermarkets, libraries, DMV offices, and community centers are good places to put up a recruiting flyer.

The content and layout for a flyer or index card are much the same as for a newspaper ad. Use a splashy headline to attract interest; then include the details [see discussion of newspaper ads, p. 105]. You'll have more space on a flyer, so you can include more information. Copying costs are minimal, and you can be more creative with art. Be sure to include tear-tabs at the bottom of your flyer with your name and phone number [SEE FIGURES 2.f.2 AND 2.f.3].

Here are some considerations for posting your flyers:

- If you can do your posting independently, fine; if not, take a friend with you.
- To be sure your message is seen, pick a good place. Choose posting areas with a lot of pedestrian traffic of the type of people who might be interested in your offer. For example, if you post an ad on a college campus, you'll probably get responses from students who are goal-oriented, intelligent, and willing to learn; however, you should expect a high turnover rate because of school vacations, graduations, and transfers.
- Choose a place where people often check out notices [a job notice board or a favorite bulletin board], or where people will be waiting for something and may read from boredom [outside elevators or cafeterias]. When you find a good place, look for the best spot, where your message will be seen.
- Observe any rules for the posting area, and check your postings regularly to make sure they haven't been covered up or taken down.

Word of Mouth

Don't overlook the obvious: the people around you every day. Friends might turn out to be today's backups and tomorrow's attendants. The big advantage of recruiting this way is that you know the person. Ask family members and friends to identify reliable and dependable persons who might be interested in providing care for you—including themselves. You never know who might be interested in working for you.

Using an Organization or Agency

A number of not-for-profit organizations can be sources of attendants. Centers for independent living help people with disabilities live independently, and many maintain an information and referral service. So do many senior centers. Nursing schools may be able to help you locate nursing students who want to gain experience in the skills of their future profession.

State departments of developmental disabilities and vocational rehabilitation are another good resource. Sometimes a person with an intellectual disability can make a good attendant, and people with various physical disabilities may be interested in working. A refugee agency can be an excellent source of help. You can offer the person one-on-one exposure to advanced English, and the agency may provide you with additional services.

You can also use a home health-care agency as a resource. These people may have more training than attendants you find elsewhere, but you may not have the option of choosing your attendant. Agencies provide insurance and other benefits for their employees; this means a more stable workforce, but using an agency is usually more expensive than hiring an attendant on your own.

[Figure 2.f.2] Sample Bulletin Board or Poster Flyer with Tear-Tabs

LIVE-IN AIDE NEEDED

Community college area
only 1 block to bus stop

Modern 2-bedroom, 2-bath, big kitchen.
Share in return for live-in help to working
college-age man with wheelchair mobility.
[2-4 hours per day, on call at night.]

Mature person preferred.
No experience necessary.

For details, call George
555-5555
5:30 PM to 9:00 PM

To live with George,
Call 555-5555

[Figure 2.f.3] Sample Bulletin Board or Poster Flyer

NURSING STUDENTS: PRACTICE YOUR SKILLS AND EARN MONEY

Stable and dependable person wanted
to assist a disabled man with personal
care and light housekeeping.

Monday through Friday
Three hours in the evening
\$8 per hour

References required, prefer driver's license.

WRITE TO:
P.O. BOX 123
CITY, STATE ZIP

People Who Make Good Attendants

There is no specific profile of the perfect attendant, but here are a few tips that might make the task of finding one a little easier:

- Consider many options. Don't restrict yourself to someone of a specific ethnic background, culture, educational level, age, or social group.
- When you select an attendant, don't expect a long-term relationship but do expect dependable care. Select people you believe you can trust. You're choosing an employee to care for you on a regular basis.
- Family can be useful, but remember the employer/employee role. Hiring a family member can have its drawbacks!
- Use friends, the SCI team, and/or family members to help you check someone's references if you're really stuck or having trouble. But be careful not to overuse your privilege of friendship or family ties.
- Know your own likes and dislikes. Trust and dependable care depend on knowing yourself and letting others know what you prefer. What kind of people do you like to be around, and why?
- Learn how to assess personality [general style and behavior patterns] and emotions [how people express their feelings]. Pay attention to how people look, talk, and act. Notice whether they're well-groomed and confident. Does conversation flow smoothly? Trust your intuition: Does it feel right to be around this person? If you feel sad, angry, confused, or anxious around this person, you probably don't want to spend a lot of time with him or her. Attraction is another factor to be clear about: Remember, you're hiring an attendant, not a friend or a lover.

How to Handle Calls about the Job

When you get a call, give a brief description of what the job entails; for example, personal care, housekeeping, meal preparation, shopping, and driving. If the person is interested, ask some questions before you set up an appointment. Here are some topics you should cover before you meet an applicant:

- How do they feel about personal care? [You may have to be specific about what this entails, such as bathing and bowel or bladder care.] Can they handle the nudity that goes along with personal care? If they can't, there's no sense wasting their time and yours. If they don't mind, discuss basically what's involved.
- Describe basic household duties and other chores.
- Describe your living environment. Emphasize the positive.
- If you need a driver, find out whether they can drive the type of vehicle you own and whether they have a good driving record.
- Discuss your lifestyle and what you consider appropriate and allowable in your home.
- Ask what kind of work they've done and whether they have work references.
- Ask if there are any physical or emotional limitations that would make it difficult or prevent them from doing this job.
- Ask if they are available to work the hours you need assistance and what flexibility they have for additional hours or filling in on short notice.

If you get satisfactory answers, arrange a convenient time and place to meet for an interview. For your own safety and independence, you may want to meet somewhere other than your home. If people call, and you know you don't want

to hire them, tell them the position has been filled. Don't hire anyone you haven't met just because they sound nice on the phone.

Interviewing

Experience has shown that as many as half the people who make appointments for in-person interviews don't show up. Ask applicants to please call you if they change their minds about meeting.

Have a schedule and a job description the person can read. Have a notebook on hand to take down information like name, address, phone number, ability to lift or transfer, and at least two work references. Other acceptable references are counselors, teachers, and ministers. If the applicant is interested, you may need to obtain other identifying information in order to conduct a background check and to verify whether they have a valid driver's license. If you are severely disabled, have someone else there to write this information down. This person can also provide support during the interview.

Discuss the job in greater detail. Let the applicant know what social behavior you allow, what unexpected events might arise, what you like to do for recreation, and what areas of your life you want to be kept confidential.

Here's a short checklist you can use to help discuss background:

- How many years of education have they completed?
- What kinds of work have they done and liked the best?
- Have they had any experience being around a person with a disability?
- How long have they lived in the area?
- What are their attitudes toward disability?
- How do they deal with boredom and stress?

- Will the work hours fit into their schedule? How much flexibility do they have?
- Will they feel comfortable driving a large vehicle like a van?
- Would they mind getting up in the night to turn you or help you go to the bathroom?
- Do they understand that some lifting may be required?

Find out how long the person would be able to stay. The longer, the better—but that shouldn't keep you from hiring someone. Sometimes it's OK to hire a qualified person for a short time if you know you'll get good service. This can be helpful when you're about to be discharged from a hospital. You can look for a replacement after you are home.

Encourage the applicant to ask questions about your disability and lifestyle. When the interview ends, tell the applicant you'll call him or her with your decision. It's never a good idea to hire someone on the spot.

Checking References

Like any other employer, you shouldn't hire a person without checking references, even if it means writing or calling out of state. Noncitizens must have a work permit and a Social Security number. If they don't, you can't hire them because of Social Security, federal, and state unemployment tax requirements.

When you call the references, identify yourself and explain that you're disabled and are interested in hiring one of their past employees. Describe the nature of the work, stressing the need for someone dependable and honest. Consider asking the following questions:

- How long was the person employed?
- Was the person dependable?

- What about absenteeism?
- Did this person deal with money on the job?
- Do you consider this person to be honest?
- How well did the person take supervision and criticism?
- Can the person work independently?
- How was this person's rapport with other employees and supervisors?
- What was this person's reaction to stress?
- Why did this person leave the job?
- Would you rehire this person?

Making a Choice

When you're checking references, pay special attention to the answers regarding dependability, honesty, work ethic, and getting along with others, and to the circumstances under which the person left and whether the former employer would hire that person again.

Are your social lifestyles compatible? Don't hire someone thinking that the person will change for you or that you have the right to control that person's life. What the attendant does off duty should not concern you as long as it doesn't affect the quality of work. If you need a lot of driving, be sure the applicant has a good driving record, because that will affect both your safety and your insurance.

What can you tell about the person's physical and emotional health? Emotional problems can be very difficult to deal with. If you think the person might not be able to handle the job, hire them on a two-week trial basis.

Don't hire anyone out of desperation. If for any reason you don't feel comfortable with someone, do not hire that person.

Try to stay calm and clear-headed. If you publicize widely and have your schedule and job description

in good order, your chances for success will be good.

Using a Letter of Employment

To avoid misunderstandings, write a letter of employment to your personal assistants. The letter should cover hours of work, salary, vacation and sick leave, unacceptable social behaviors [such as smoking, alcohol use, profanity], what can lead to termination, who pays when the attendant accompanies you on social outings, and notice when the person decides to leave the job. It should also include a clear description of the arrangement for taxes and Social Security withholdings and for any noncash reimbursements, such as food. The job description should be attached to the letter.

For live-in attendants, you should also include information about utilities, newspaper, other shared costs, and use of your personal items such as shampoo, detergent, car, wheelchair, food, and so on. Keep a copy of the letter in your employment files.

Have a Backup Plan

Sooner or later, you won't have an attendant when you really need one. This could be due to an attendant's illness or to the attendant being fired or quitting without notice. Or you might just need more than one attendant, especially if you need care seven days a week.

When you first get into the business of employing attendants, figure out your backup plan. You can cut down on what you require from a backup attendant, like housecleaning or cooking. Do a second needs assessment, and be realistic about what care you can eliminate for a short period without sacrificing your health and safety.

Arrange with a family member or friend to know your personal care, so you can call on them to help you in an emergency. Make arrangements with a

neighbor who'd like to earn a little extra money occasionally to know your care, so that you can call on that person when you need to. You might have an agreement with another person who has an attendant to share the attendant in an emergency.

Some communities have organizations that can supply attendants on an emergency basis; for example, a visiting nurse service or an organization for persons with disabilities. These organizations often require an application and an assessment of needs and eligibility, so be sure to make arrangements in advance, before you actually need the service.

The same person doesn't have to meet all your needs. A visiting nurse will help with bowel and bladder care, but won't clean your house or run errands. You [or your family, friends, and neighbors] might know a responsible teenager who'd like to earn some money performing those tasks.

The most important part of handling the sudden loss of your attendant is having a backup plan for that situation. If you haven't overused your relatives and friends, they'll probably come through for you when you have no attendant.

Supervising Your Attendant

Being a supervisor may be a new role for you. To be effective, you need to understand the skills involved. Supervising doesn't mean being a boss. It means working with your attendant and guiding him or her to get the job done.

This section reviews the basic skills of effective supervision. It stresses the need to work with your attendant to solve problems and to be firm when necessary. Because of the close contact between you and your attendant, the employee/employer roles can get confused. It's important for you to use supervisory skills to stay in control, solve problems, and maintain a good relationship with your attendant.

Remember: Your attendant is only human.

Your attendant has formally agreed to be responsible for certain needs of yours. In return, he or she can expect your respect. Your attendant is not bound to you for more than the hours stated in the letter of employment. He or she has a life, and helping you is only one part of it. You have a right to expect that services will be satisfactorily performed, but you don't have an unlimited charge account on your attendant's time.

Don't be demanding. Use the same tact and warmth with your attendant as you would with a friend. If you find that you're often short-tempered with your attendant, try to step out of yourself and see what's causing it. Ask yourself before you snap at or argue with your attendant, "Is this a real problem that affects my needs or is it just a personal habit that gets on my nerves?" If you believe that your attendant is at fault, wait for a calm moment and say you'd like to discuss something. Describe the problem as you see it and get your attendant's point of view.

On the other hand, if you find that you are mostly at fault, stop yourself. Thinking before you speak will help you maintain control. [See section 3.b, *Psychosocial Adjustment, for suggestions on communication.*] Even an experienced attendant will sometimes forget parts of your daily routine. Try to be tactful with your reminders.

Finally, if you need help with a special project, give your attendant some advance notice. If it's time to change the bald tires on your wheelchair or to do a nonroutine spring cleaning of your apartment, let your attendant know about it well in advance, so he or she can schedule the project at a convenient time. This will help prevent friction and increase the likelihood of the job being done thoroughly.

In general, show the same gratitude and respect toward your attendant as you would to any friend. Everyone appreciates "please" and "thank you."

Confidentiality

Before you hire a person, make confidentiality issues clear. Respect each other's need for privacy when using the phone, having company, or handling financial, family, and social information. Have respect for each other's bedrooms and personal property.

If you discuss personal problems with your attendant and ask for an opinion, he or she may not be able to give the best feedback or advice. You're not hiring a counselor. Many people are uncomfortable listening to the problems of others, much less giving advice. Don't assume that your attendant is willing to do this. However, if he or she is willing to listen to you, you should be willing to do the same.

Performance Checks

As an employer and supervisor, you need to provide clear, helpful feedback about job performance directly to your employee. For many people, the idea of a performance check creates negative feelings such as fear, tension, or distrust. It's up to you to make this a positive, motivating experience, including praise for good performance.

Attendants should understand that performance checks benefit and protect them as well as you. They should be regularly scheduled. As a general rule, daily duties should be checked twice a month; weekly duties once a month; and monthly duties every two or three months. When you do them, use the same checklists you developed earlier for your routines. But there's no rigid rule about scheduling—you should give feedback any time a job is not performed to your satisfaction. With a new attendant, more feedback will mean that small problems can be solved faster.

Give plenty of positive feedback whenever duties are performed well. If your attendant is working hard and doing a good job, a little praise goes a long way.

Dealing with Conflict

Many problems arise because people make incorrect assumptions. Although the job description and letter of employment should clarify basic issues, conflicts can arise. If the conflict involves duties, pay, time off, social conduct, or use of property, remind the attendant about your agreement. If he or she refuses to comply, act promptly and firmly to find a replacement. When you depend on someone for survival, it's not easy to fire that person and find someone else. But allowing the situation to continue could jeopardize your health. Don't let things pile up. Deal with each issue as it arises. You may want to have an advocate help you and the attendant settle disagreements.

Communication

It's often not so much what you say as how you say it. When you're talking to a person face-to-face, make eye contact. If you look away, you convey the message that you don't want to listen to the person or deal with the issue, or you don't really mean what you're saying. If you think your attendant won't listen well, consider writing a letter about your concerns, or put them on tape if you can't write. Have an advocate—a friend who can help settle problems and check to see that you're OK. The advocate can also follow up on your progress. Don't put things off, especially if they relate to your care. Being assertive is very important. [See section 3.b, *Psychosocial Adjustment.*] Assertiveness is a skill that can be learned and practiced, and several good books have been written about how to ask for what you need without being rude, nasty, or obnoxious.

Assertiveness Examples

A man with a disability had planned far in advance to attend a concert. The day before the concert, his attendant asked him to find another driver, because the attendant had just gotten a dinner invitation from a buddy. The disabled man told the attendant that he appreciated and understood the attendant's desire to go to dinner with his friend. But he reminded the attendant of the previous agreement to drive him to the concert and pointed out that it was too late for him to make other arrangements, so the attendant would have to fulfill the commitment.

A woman with a disability hired a man to be her attendant. At the time of the interview, she explicitly stated that she had no interest in combining work with romantic involvement. After a month of employment, the man started making suggestive remarks to her. She reminded him of their earlier conversation. She said she did not feel the same way about him, and that she would appreciate it if he did not bring up the issue again. If he did, she would have to let him go. The man said he was sorry for making her uncomfortable and he would respect her wishes. He gave his two-week notice of termination because he could not promise that his feelings would change if he stayed on.

Salaries and Fringe Benefits

As an employer, you will be paying a salary to your employee. This money may come from various sources. Your financial resources and the community's going rate of pay will determine the salary. You may also be providing room and board and benefits.

Paying Your Attendant

Many programs exist that may pay for attendant care. Each program has different eligibility criteria, application processes, and employer expectations.

Consider using one or more of these programs for cash wages for the attendant. You can also provide noncash wages, room and board, and other benefits as the sole payment or in combination with a cash wage.

Your social worker and other members of your health-care team can help you explore various options. Review the material below and then discuss your attendant plan with your social worker or others. Unless you're using an agency, you are the employer—you'll be responsible for recruiting, hiring, firing, paying wages, and reporting cash and noncash wages for tax purposes.

Possible Payment Sources for Attendant Care

All these programs generally require paperwork, like medical documentation of need and financial statements. Check with each funding source about IRS and Social Security reporting requirements.

State Medicaid programs

Contact your local program about in-home attendant care programs. Some states have special income-waived programs, including funding for employed people who need ongoing attendant care after they return to work.

Workers compensation

Each state and federal program has different requirements for funding attendant care. Ask your agency contact person for more information.

Private insurance

Check your policy. Some policies cover attendant care.

VA

The Department of Veterans Affairs does not directly pay for attendant care for veterans but may supply extra pension and service-connected income to help with these expenses. Many VA

medical centers provide some limited skilled nursing, and a few may also provide some unskilled help in your home. Funds may be available specifically for bowel and bladder care. Ask your hospital benefits counselor or SCI center social worker for more information.

State vocational rehabilitation agencies

In rare instances, a vocational program may include coverage for attendant care.

Home health services

Home health care is typically based on a need for skilled care as defined by state and federal regulations. A physician's order is required. Depending on the funding source, you may also be able to get some additional unskilled assistance. Home health care may be skilled nursing or related to your occupational or physical therapy. The Joint Commission on Accreditation of Healthcare Organizations [JCAHO] certifies home health agencies that meet its standards; ask about this certification when you're researching an agency.

Your Responsibilities When You Pay Cash Wages

If you're receiving funds to pay your attendant, the funding source will probably tell you:

- What payment records you must keep.
- In what way and how often you will receive this aid.
- What procedure they suggest you use in paying your attendant[s].

The funding source may want the names and Social Security numbers of each attendant so it can pay them directly. Try to persuade your funding source away from this plan. When a check comes automatically to an attendant, it takes away some of your leverage as an employer to bargain with the attendant. Also, if you change attendants,

the paperwork and delay in the payroll process can result in your former attendant getting an extra paycheck or a long delay in the new attendant's first paycheck.

Ask your funding source whether it requires your attendant to declare the income on federal, state, or city taxes. As a matter of courtesy, inform your attendants of any taxes they must pay at the time you employ them.

Your Responsibilities When You Pay Noncash Wages

If you reimburse the attendant with noncash wages, you can deduct them from your income taxes. As you can see from Table 2.f.C, both the paperwork and the taxes to employer and employee are considerably less with noncash wages. However, more homework is necessary—the IRS has specific rules for deducting meals and lodging as medical expenses.

One of the simplest forms of noncash wages is a room in your home in exchange for services. For example, you decide that you need to hire two attendants. You rent a two-bedroom apartment, take one bedroom for yourself, give the other to your two attendants, and have them split the duties. You pay them in some combination of room, board, utilities, and other benefits.

Before deciding what to offer, you may want to explore what is medically deductible. The cost of any commodity beyond what you and your family would need might be medically deductible. For example, if you would normally need a one-bedroom apartment, but you have to rent a two-bedroom apartment for the attendants, the cost difference between the one-bedroom and two-bedroom apartments might be deductible. Likewise, the cost of additional food, electric power, and so on may be deductible. You may want to limit your noncash wages to deductible items.

Choose noncash items that are easy to prove with receipts or other records. Divide these expenses by the number of people in the living situation. For example, rent and utilities are easier to prove and divide than food costs.

To decide how large to make the noncash package, figure the amount of cash salary that would normally be paid and offer an equal amount in noncash benefits. Make it clear that the attendant will have to pay for whatever is not included in the noncash wage package, like food and clothing [SEE TABLE 2.f.C]. You will be telling the IRS who has received what amount of noncash “income” from you, although no FICA [Social Security] payments are required. Get these forms from your nearest IRS office—they are self-explanatory.

To safeguard your own interests in case of an IRS audit, see the notes at the end of Table 2.f.C for suggestions on record keeping. Certain filing requirements may be different from the information supplied here because of your personal situation or changes in IRS policies and rulings. Use Table 2.f.C as a guideline, but check with the nearest IRS office for your particular situation and the latest policies.

Keeping Track

It’s smart to keep a file on attendants you’ve interviewed and the ones you hire. You’ll need to keep information for tax reporting and W-2 forms.

A file box is good for keeping verification forms, your copies of tax reports, and canceled checks. You can use a card file or a notebook for information on applicants. The data should include:

- name,
- address,
- phone number,
- date of birth,
- Social Security number,
- driver’s license number,
- date hired,
- date terminated, and
- reason for termination.

Gracefully Parting Ways with an Attendant

Even though you’re careful about screening and choosing an attendant, the one you hire might turn out to be unsatisfactory. In that case, you’ll have to make your dissatisfaction plain and be firm in expecting better service. If there’s no improvement, move quickly to find a satisfactory replacement. An unreliable attendant is not healthy for your mind or body. To meet your goal of independent living, you must control how your basic needs are met. If you terminate an attendant, try to do so on the best possible terms because you might want to call on them in an emergency. Also, consider developing a checklist for what should be completed before an attendant leaves. For example:

- Make sure they’ve filled out whatever paperwork is needed to authorize payment for their last days of employment.
- Make sure all basic duties are completed so the new attendant can enter a clean and orderly household.
- Get their key to the house.
- Get a forwarding address or permanent phone number, and keep this information in your files.

[Table 2.f.C] Summary Chart of Federal Tax Forms for Employers of Personal Assistance Services

IRS FORM	USED PRIMARILY TO REPORT	WHEN WAGES ARE DUE
WAGES		
W-4	Employee-desired amount of income tax to be withheld from cash wages [for “household employment” tax may be withheld only if both employer and employee agree]	At beginning of employment and each time employee wishes to change withholding status
SS-4	To obtain employer’s identification number [EIN]	One number for employer’s lifetime. For use when filing various IRS forms
942	<ul style="list-style-type: none"> • Cash wages of \$50 or more paid to each employee in any calendar quarter • Income tax withheld during the quarter • FICA [Social Security] taxes [about 6% of each employee gross pay amount] withheld from the cash wages of any employee meeting criterion—to be matched in amount from employer [attach check for combined tax amount to FICA-942 form] 	4 times a year; within 30 days of the end of each IRS-defined calendar quarter [3-month period]
940 Federal Unemployment Tax	FUTA [Federal Unemployment Tax Act] to be paid by employer; for household employees who were paid wages of \$1,000 or more during any calendar quarter	1/31 for wages paid in preceding year; file 940
W-2	<ul style="list-style-type: none"> • Cash income to employee • FICA taxes withheld from employee • Income taxes withheld [see note for W-4 form regarding household employment]. Worker is responsible for paying withholding. 	1/31 for wages paid in preceding year or within 30 days of employee termination if before the end of year
W-3	To be filed with Copy A of W-2 and sent to Social Security Administration	1/31, with W-2
Each state has different rates. Find out your own state regulations to determine how much and how often to pay these taxes. In some states, nothing is due if wages are less than \$1,000 per quarter.		
NONCASH WAGES		
SS-4	Same as cash wages section	
W-2	Value of noncash wages paid	1/31 for wages paid in preceding year or within 30 days of employee termination if before the end of year

Preparing for the Recurring Cycle

The termination of an attendant will mean either a smooth transition into the employment of someone else or a frantic scramble for a replacement. Even the most experienced employer with the best planning and preparation may feel insecure in the transition from one attendant to a new one. Anxiety is natural feeling for anyone moving from a familiar situation into a new one. For people with disabilities, the anxiety might be a little more intense because of the level of dependency involved. The best way to minimize anxiety is to analyze and prepare for as many aspects of the situation as possible. We hope the suggestions here will help you to do this.

RESOURCES

Publication

Managing Personal Assistants: A Consumer Guide
www.pva.org/publications

Websites

www.nfcacares.org

National Family Caregivers Association [NFCA] helps raise awareness and support for those who provide direct care to people who are ill or have a disability.

www.eldercare.com

For information on attendants, go to the section on Independent Living Centers under Living Alternatives.

www.ilru.org

List of centers for independent living, listed by state or province. Many centers have resources for locating and training privately hired personal care attendants.

Coping and Living with SCI

Now that you've learned about medical conditions and how to maximize your function, it's time to think about other challenges. Leaving the hospital or rehabilitation unit to live somewhere else and resume your life activities is a big step. Resources are available to help you with this transition. Some people must cope with mental health conditions, pain, or the consequences of brain injury on top of the functional consequences of spinal cord injury [SCI]. For some, returning to school or employment is a high priority. Almost everyone must pay attention to the financial impact of SCI. This section covers some of the issues you'll face after you complete your initial rehabilitation.

3.a | Transitions

Whether you've recently sustained a spinal cord injury [SCI] or have lived with one for many years, you'll probably be making decisions about where you want to live and the type of social life you'll have. If you can perform all your daily activities without help, you might choose to live totally on your own—this is sometimes called independent community living. If you need help, various options are available for living with supervised and structured assistance. Another choice is to live on your own with family or roommates who might or might not be involved in your care. Or you might decide that you want to live alone and have an attendant come into your home for part of the day. As persons with disabilities age, they may choose to move from their home to a different setting, such as with family or in a nursing home. There's no right or wrong answer—what you do depends on your personal desires and resources.

Planning Your Transition

Leaving a hospital or other structured living situation is a complicated process. The questions in the forms that follow will help you plan your transition. Try to answer these questions with your family, friends, and all the members of your rehabilitation team. You can use this chapter as a workbook to formulate your plan. [Additional home safety and other checklists are available on the websites listed at the end of this section.] Here are a few tips to guide you as you search for the environment best suited to you.

Living Situations Where Assistance Can Be Provided

Selecting a living situation is a highly personal process. It's always best to ask exactly what type of help is available, as the names vary in different parts of the country. You should decide what features are most important to you and find a way to check out the facility. Ask for references, take a tour, and use the checklists that follow and those from the websites. Here are some options:

- *Private home*—You can receive home care services in a private home. You can arrange this through an agency or set it up yourself and hire the caregivers. [See section 2.f, *Attendant Management*.] If you'll be in a private home, make sure to review a safety checklist.
- *Retirement residence*—an apartment or single home setting in which most residents are older adults, some with physical disabilities. Meals, laundry, and housekeeping services are often available. In some cases, physical assistance can be provided, but you may need to arrange this separately. These homes generally have better wheelchair accessibility than other housing in the community.
- *Assisted living*—an apartment setting that provides some physical assistance with daily activities, in addition to meals, laundry, and housekeeping.
- *Adult family care home*—similar to assisted living, but usually in a single-family home setting, with caregivers available at all times. Most states require inspection and certification of these homes.

- *Nursing home*—a nursing facility with 24-hour staffing by registered nurses [RNs], licensed practical nurses [LPNs], or licensed vocational nurses [LVNs]. These facilities are regulated by state [Medicaid] and federal [Medicare] agencies and can handle complex medical problems. Levels of care range from basic to skilled or subacute [regular care from an RN].
- *Continuing care community*—a setting that can provide various levels of assistance and care, from a retirement residence through nursing home care. When patients' care levels change, they just move to a different part of the facility instead of to an entirely new residence.

MEDICATIONS AND SUPPLIES

Your OT, PT, nurse, doctor, pharmacist, or prosthetics team member can answer these questions for you. For additional information, refer to the chapter "Medications."

1. What are your medication and supply needs?

- A. _____
- B. _____
- C. _____
- D. _____
- E. _____
- F. _____

Medication: _____

Side Effects: _____

Medication: _____

Side Effects: _____

Medication: _____

Side Effects: _____

2. What are the side effects of your medications?

Medication: _____

Side Effects: _____

Medication: _____

Side Effects: _____

Medication: _____

Side Effects: _____

3. How and where will you get your medications and supplies refilled? [There may be a two-week lag time.]

How: _____

Organization: _____

Address: _____

Phone: _____

DESTINATION TRANSITION

Your social worker and other team members can explore the answers to the following questions with you. For additional information, check out the chapters “Community Resources” and “Home Modifications.”

1. Where will you be living?

Street Address: _____

City: _____ State: _____ Zip: _____ Phone: [_____] _____

2. Is your residence accessible or does it need modification?

Accessible Needs Modification

3. What modifications are needed?

4. How are you going to make your environment barrier free?

5. How can you obtain the equipment you will need to make your destination?

Who can you contact for modifications?

Company or Organization: _____

Street Address: _____

City: _____ State: _____ Zip: _____ Phone: [_____] _____

Company or Organization: _____

Street Address: _____

City: _____ State: _____ Zip: _____ Phone: [_____] _____

6. Who will pay for the adaptations?

Individual [you personally] Organization or government agency

Organization: _____

Contact Person: _____ Phone: [_____] _____

7. How will you pay for your living expenses?

Individual [you personally] Organization or government agency

Organization: _____

Contact Person: _____ Phone: [_____] _____

FOLLOW-UP AFTER TRANSITION

Your social worker and the rehabilitation team will explore the answers to the these questions with you. For additional information, refer to the chapter “Community Resources.”

1. What contact will you have with the medical center or another hospital after discharge?

2. How will you get appointments and who will pay for them?

Individual [you personally] Organization or government agency

Organization: _____

Contact Person: _____ Phone: [_____] _____

3. Will outreach staff from local community agencies visit you in your new residence? Yes No

If so, who? _____

If you need help with your daily routine, who will be available?

Organization: _____

Contact Person: _____ Phone: [_____] _____

Organization: _____

Contact Person: _____ Phone: [_____] _____

4. What community agencies will provide services after discharge?

Organization: _____

Contact Person: _____ Phone: [_____] _____

Organization: _____

Contact Person: _____ Phone: [_____] _____

5. How will you travel home?

6. Who will pay for and arrange your travel to and from medical appointments?

Individual [you personally] Organization or government agency

Organization: _____

Contact Person: _____ Phone: [_____] _____

7. Do you know whom to call if you have a problem at home?

Name: _____ Phone: [_____] _____

FAMILY, ATTENDANT, AND CAREGIVER EDUCATION

Your occupational therapist, nurse, social worker, or other team member can help answer these questions. For additional information, refer to the chapters “Attendant Management,” “Bowel Management,” and “Skin Care and Pressure Ulcers.”

1. What is your care routine? _____

2. How much help will you need? _____

How long do these tasks take to perform? _____
When do these tasks have to be done? _____

3. Who will pay for attendant services?
 Individual [you personally] Organization or government agency
Organization: _____
Contact Person: _____ Phone: [_____] _____

4. If you need an attendant, how will you find that person?

5. How and when does the attendant training begin?

6. Can you train someone else in your care routine? Yes No
If so, how are you going to do it? _____
If not, who can do it for you?
Organization: _____
Contact Person: _____ Phone: [_____] _____

7. How will the spinal cord injury/rehabilitation staff be involved with the training?

8. Who can you contact if you have a crisis with your attendant?
Name: _____ Phone: [_____] _____
Name: _____ Phone: [_____] _____

THOUGHTS ABOUT THE TRANSITION TO A NEW LIVING ENVIRONMENT

Your rehabilitation team, peers on the SCI unit or in the community, and others can help answer these questions. For more information, refer to the chapters “Psychosocial Adjustment” and “Sexual Health and Reproduction.”

1. How can you be sure that you are ready for the transition?

2. Are your family members, friends, and/or attendant ready for your discharge?

3. Have you thought about the questions others may ask you about your injury or your wheelchair?
What will you say?

4. If you need emotional/peer support, where would you go to find it?

5. Will you talk with your family or friends? Do you want to meet other individuals who are disabled?

6. Support group?

Organization: _____

Contact Person: _____ Phone: [_____] _____

7. Peer Counseling?

Organization: _____

Contact Person: _____ Phone: [_____] _____

8. Individual Counseling?

Organization: _____

Contact Person: _____ Phone: [_____] _____

TRAVEL AND TRANSPORTATION SERVICES

Your physical therapist, occupational therapist, or social worker can be your resource. For more information, refer to the chapters “Community Resources,” “Driver Rehabilitation and Training,” and “Recreation.”

1. Do you have accessible public transportation in your area?

Yes [list organizations and phone numbers below for easy reference] No

Organization: _____ Phone: [_____] _____

If no, how will you get around? _____

Who can you call for assistance? _____

Name: _____ Phone: [_____] _____

Name: _____ Phone: [_____] _____

2. What do you need to know about accessible public transportation, paratransit services, and special parking permits?

3. What about driving? Will you be the driver or will you need someone to drive for you?

4. How do you get a valid driver's license?

5. How will you pay for transportation?

Individual [you personally] Organization or government agency

Organization: _____

Contact Person: _____ Phone: [_____] _____

EQUIPMENT

Your physical therapy, occupational therapy, and prosthetics team members will work out the answers to these questions with you. For more information, refer to the chapter “Equipment.”

1. If you need adaptive equipment, how and where will you get it?

Organization: _____

Contact Person: _____ Phone: [_____] _____

Organization: _____

Contact Person: _____ Phone: [_____] _____

2. Who pays for the equipment?

Individual [you personally] Organization or government agency

Organization: _____

Contact Person: _____ Phone: [_____] _____

How do you get the equipment repaired or replaced?

Organization: _____

Contact Person: _____ Phone: [_____] _____

Organization: _____

Contact Person: _____ Phone: [_____] _____

ADDITIONAL RESOURCES FOR VETERANS

For more information, see the “Community Resources” chapter.

PVA representative:

Name: _____ Phone: [_____] _____

SCI coordinator for the VA medical center closest to you:

Name: _____ Phone: [_____] _____

Veterans benefits counselor:

Name: _____ Phone: [_____] _____

PERSONAL GOALS AFTER TRANSITION

The entire team can be a resource in answering these questions. For more information, check out the chapters “Employment and Vocational Rehabilitation,” “Recreation,” “Attendant Management,” and “Psychosocial Adjustment.”

1. In addition to your personal care, what will you do all day?

2. What kind of vocational training, employment, or volunteer opportunities are you interested in?

Where can you find assistance to help you get started in those areas you listed?

Organization: _____

Contact Person: _____ Phone: [_____] _____

Organization: _____

Contact Person: _____ Phone: [_____] _____

3. What will you do for fun and relaxation?

Where can you find assistance to help you get started in those areas you listed?

Organization: _____

Contact Person: _____ Phone: [_____] _____

Organization: _____

Contact Person: _____ Phone: [_____] _____

4. What will you do if a crisis occurs [for example, if your wheelchair breaks down or your attendant quits]?

5. What is your financial situation?

RESOURCES

Websites

www.alternativesforseniors.com

Includes a retirement residence checklist and other resources.

www.agenet.com

Includes a retirement residence checklist, nursing home checklist, assisted living checklist, home safety checklist, and other resources.

www.eldercare.com

CareGuide@home provides general information and resources on housing, legal planning, assisted living, and home care by geographic area based on a client profile of needs that you provide. Includes checklists to evaluate assisted living and nursing home facilities.

www.medicare.gov/publications

Includes information on financing and choosing long-term care and tools for locating and comparing nursing homes. Search for Guide to Choosing A Nursing Home and Compare Care—Nursing Home Brochure.

3.b | Psychosocial Adjustment

Having a disability like a spinal cord injury [SCI] creates a lot of questions about who you are, who you want to be, and how other people, including your family, will interact with you. You need to figure out how you'll live your life as a person with a disability. This section offers some ideas for ways to think about these personal questions. You'll be faced with many new emotions and challenges. Unlike questions about your physical needs, personal and social questions have no exact answers. What you decide to do with your personal and social life is up to you.

You're Still the Same Person

If you were excitable, silly, quiet, physical, intense, relaxed, very social, or a loner, chances are you'll be the same after your injury. SCI results in some physical changes, but it doesn't change your personality. Difficult emotions like sadness and frustration are normal reactions to a physical loss, and they typically diminish over time. You can minimize the impact of these feelings by learning more about your condition, preparing for some difficult times, and using all your social and emotional resources.

Normal Feelings

As time passes, the personal and psychological issues you face will be less focused on your injury and more on everyday life. The following discussion of feelings applies to emotions of crisis [right after your injury] as well as emotions that may come and go throughout your life. It's normal for people to experience a wide range of feelings after a major crisis. Anger, sadness, frustration, irritation, confusion, and isolation are common. Your feelings will not be exactly like those of others in this situation, but there are probably

many similarities. In this section, we discuss what you can do to deal with your emotional reactions. Not all the emotions will be uncomfortable ones—the process of rehabilitation also involves humor, pride, hope, and a sense of accomplishment. You can grow into a stronger and happier person.

Anger

Anger is a normal reaction when things go wrong. If you find yourself snapping at others, yelling when things go wrong, or boiling over, you're not alone. But it may be difficult for you to work with others if your anger carries over into everything you do. A good test is to ask yourself, "Would I like to be treated the way I treat others?" If the answer is no, ask yourself, "Who or what is getting in my way? Why am I angry?" This kind of self-talk can help you step back from a problem, cool off, and develop a positive plan of action. Also, ask others to help you stay calm by talking about problems openly, rather than letting something build up, so you can avoid exploding in anger.

Sadness and Grief

It's common to feel sadness after a major loss or significant change in health. This is similar to the grief you might feel when someone close to you has died. People express this sadness in different ways; for example, tears, withdrawal, avoidance, or talking with a close friend. These are normal, common reactions. However, if the sadness seems overwhelming or becomes persistent, you may want to consider getting some help to deal with it.

The main differences between grief and significant depression are that depression is often accompanied by hopelessness, a sense of giving up, physical exhaustion, trouble sleeping, and a change in appetite. Try talking to someone close,

planning something positive in your future, or doing something enjoyable. If you feel as though it's not worth trying, talk with a member of your rehab team. You can get help. [See section 3.c, *Mental Health Conditions, for more information on depression.*]

Self-esteem

Some people suffer a loss of self-esteem because they can't do some of the things they used to do. If you feel this way, take a look at why your feelings about yourself have changed. Changes in self-esteem often result from errors in thinking about your worth as a person. People with high self-esteem can usually see their true worth, understand what's really important in life, and accept that everyone has limits. A book called *A New Guide to Rational Living* [see Resources at the end of this section] describes specific ways to maintain a positive sense of self-esteem and pride.

The Long Run

Your feelings will change over time. Some people start to feel pretty good by the end of their rehabilitation, having learned and accomplished all that they have. A few people suffer a letdown when they leave the rehabilitation unit and go through difficult feelings again for a while. It helps to be prepared for the big changes that come with leaving rehabilitation and to build up a strong support system that includes family, caregivers, friends, and the staff from your SCI program. If you're ready for the transition, the period of adjustment can be very short.

Positive Adjustment

Everyone's reaction to SCI is different, and you might have some unexpected feelings about it. One common experience people report is that they feel their life is *better* after their injury. How can that be? Some people feel a renewed commitment to themselves, their families, and

their life. They take better care of their health and strive to develop a positive lifestyle. Some see their injury as a wake-up call and an opportunity to build a more meaningful life. They become more involved with their family, their community, or an important activity, like a charity or church. Of course, it's unrealistic to think you might feel positive and lucky all the time, but you will have these feelings sometimes. If you take advantage of the times you feel this way, you might be able to increase how often they happen.

Natural Coping Strategies

Most people have typical ways they cope with life, and they use the same coping skills to deal with all kinds of challenges. Most likely, your experience with an SCI will be like that. You might not even be aware of your typical coping pattern. Ask yourself, "What was the hardest thing I ever went through before this?" How did you get through that? What worked? What kinds of things didn't work or weren't worth the cost? You've probably dealt with many obstacles in your life so far. Your job now is to identify the skills you used then and apply them to this new situation.

Is Depression Necessary?

SCI is one of the most devastating events that can happen in a person's life. Shock, sadness, anger, frustration, feelings of betrayal, and confusion can all be normal reactions to such a major loss. People don't necessarily go through certain "stages" after a loss like this. Instead, they experience all kinds of feelings at different times, or sometimes many feelings at once. Surprisingly, only about 33 percent of people with a new SCI have clinical depression. That means that almost 70 percent do not become depressed. Some medical providers and family members might be concerned if you're not "depressed enough" about your injury, but some research suggests that people who maintain some denial about their injury actually do better in the long run.

The Importance of Hope

People who have a positive attitude about the future cope and adjust better after a traumatic medical loss. Everyone has a different amount of hope about the future, and you have only so much control over this. You can build hope in yourself, but it takes a lot of attention and effort to maintain hope. The development of hope comes in many forms—some people look to religion; others find hope in their family or elsewhere. Everyone is different.

Recovering Well

Getting back to your life after spinal cord injury takes work. Learning the skills you'll need to stay healthy takes commitment and time. Several things can help you succeed in this challenging task:

- Take advantage of your social support network—the people in your life who are encouraging and positive.
- Use effective problem-solving approaches. Take time to evaluate your options when you run into a barrier, and ask for help from an expert if you need it.
- Think back to a time when you became an expert at something, like driving a car. This feeling is called “mastery,” and it helps people have a positive experience when they're learning a complex thing.
- Set small, frequent goals for yourself. Your therapists and nurses will help with this. Goals need to be hard enough to be challenging but easy enough to be reasonable. It will help you in the long run to pick up this habit of setting goals and reaching for them.
- Pay special attention to the good things about yourself. Note every success, each thing you accomplish, and every change in the right direction, no matter how small. Keep these thoughts like bank deposits of positive feelings when you need them later.

- It's fine to compare your situation with those around you. Most people have something they do better than others—give yourself credit where it's due.
- Use the stress management skills you've learned along the way. Better yet, learn some new ones during your rehabilitation. One simple thing you can do is to stay focused on your experience right now. If you spend less time thinking about the past or worrying about the future, you'll have more energy to succeed today. This takes practice—ask your rehab team for resources on “mindfulness.”

If, despite your efforts to stay positive, you find that you're having trouble coping with your injury, are becoming depressed, or are anxious or worried about the future, read *section 3.c, Mental Health Conditions*.

Social Adjustment

When you have an SCI, parts of your social life will have to be reevaluated and adjusted. As you gain experience living with your SCI, you'll have more confidence in social situations. There are nearly 300,000 people with SCI in the United States. They have wisdom to share from their life experience. Many organizations, local support groups, and Internet websites offer information and peer support for persons with SCI.

Social Decisions

Social decisions—like where to live or whether to go back to school—are crucial to your future. There are no right or wrong answers to these questions. The answers depend on personal goals, and these goals can change throughout your life. The decisions you make will be the foundation for your social and emotional survival.

There are two major approaches to handling the social challenges your disability might create. First, decide whether you have the basic social and

communication skills that everyone needs. Second, decide if you need some special skills to deal with reactions to your disability. Meeting new people after your SCI is really no different from before your injury. Be yourself and talk about sports, the weather, or whatever you used to talk about.

Think about yourself as a person first and then as a person who happens to have a disability. Many social challenges—like finding a sexual partner, meeting new people, or wanting to be more assertive—are common to all people. Some challenges—like having a waitress ask your companion, “What does he want to eat?”—are directly related to having a disability. Many of the challenges you’ll encounter can be resolved by learning general social skills, such as assertiveness and anger management. The special skills related to your disability can include how to deal with the nondisabled population.

Social Survival Tactics

Social survival tactics are the tools you use to get the services, emotional support, and physical help you need. Tools for survival and independent living include general communication skills and an understanding of the responses of nondisabled persons, family, and friends.

Why a person with SCI needs social survival tactics:

- You are a member of a minority group in our society.
- You will run into negative stereotypes that people have about wheelchair or crutch users.
- Everyone will notice your disability.
- You’ll have more dealings with agencies and bureaucracies than the average American does.
- You will have to explain your limitations to strangers.

Four Basic Steps for Social Problem Solving

1. *You are your own best resource.* Whenever possible, speak for yourself.
2. *Other people have valuable experience they can share with you.* When you encounter a new situation and need information, find peer support.
3. *People who work for agencies can be strong advocates.* Find people who are willing to help you get services and who understand how the agency can work for you.
4. *Legal remedies are often available.* If you believe you’ve experienced discrimination, use the agency or program’s grievance process. As a last resort, hire an attorney. [See section 3.g, *Your Rights.*]

How to Make Decisions

Independent living means being in charge of your life and taking responsibility for your actions. The concept of independent living began in the 1970s as a social movement led by persons with disabilities. The goal was to gain civil rights and the ability to make informed choices in their lives. How you live your life, not where you live, is the core principle. This is a great way to approach your day-to-day life in society.

Making decisions about your equipment needs is a good example of independent living. Some people prefer to use equipment for assistance with tasks [high gadget tolerance]. Others enjoy the physical and mental challenge of doing difficult tasks and prefer to limit their equipment [low gadget tolerance]—they use “people power” when they need some help.

Free choice means making a decision based on—

- your needs,
- what you would like to happen,
- the resources available to you, and
- your willingness to accept the consequences of your choices.

Basic Communication Skills

Three basic communication styles are assertion, aggression, and passivity. In the following discussion, we describe each style and specific behaviors that are typical of that style. Notice that these are behaviors, not words. *How* you say something [facial expression, tone of voice, etc.] can be more important than the words you use.

Assertion

Assertion is the ability to express your ideas and feelings directly and honestly, while still taking other people's feelings into account. In assertive behavior, your body actions are consistent with the verbal messages and add support, strength, and emphasis to what you're saying. Your voice is just loud enough; eye contact is firm; body gestures suggest strength; and speech is fluent [without awkward pauses], expressive, clear, and with emphasis on key words. The goal of assertion is clear communication to achieve a common understanding.

Aggression

Aggression is one way to express yourself, but it ignores the feelings of others. It is almost always an inappropriate way to communicate and may create strong negative feelings such as anger or disgust. In aggression, the nonverbal behaviors dominate or demean the other person. These include staring someone down, a voice that's too loud and forceful for the situation, a sarcastic or condescending tone, and body gestures such as finger pointing. The usual goal of aggression is to

humiliate, degrade, belittle, or overpower other people so they become weaker and less able to express and defend themselves.

Passivity

Passivity is failing to express honest feelings, thoughts, and beliefs. By expressing your thoughts and feelings in an apologetic, self-defeating style, you allow others to easily disregard you. Passivity is nonassertion. It's conveyed by a soft voice, hesitant speech pattern, and submissive body gestures, such as avoiding eye contact, wringing your hands, or hunching your shoulders. The goal of passivity is to appease others, avoid conflict or offense, and show how helpless you are. Passivity is not an effective way to communicate your true feelings and get your needs met.

Effective Communication with the General Public

People with disabilities need to understand how nondisabled people think and act. At times, their actions and reactions are frustrating and difficult to understand. All communication—including miscommunication—involves two parties.

Nondisabled people often don't know what to do or say when they encounter a person with a disability. Social encounters can be awkward for both parties, so you'll need to think about how to handle them. If your disability is obvious, you'll most likely deal with two types of people. The first responds to you by wanting to do things for you, even if you don't want the help; for example, push your wheelchair when you prefer to do it yourself. They're trying to be kind and supportive, but their behavior makes you feel like a "captive" of their need to show how much they care. The second type of person is unsure what to do or say, so they avoid eye contact, act as though you're not there, and generally convey a sense of discomfort.

If the problem is lack of information, you need to educate them. If they're poor communicators, that's their problem. People with disabilities often think that nondisabled people are cruel and degrading when, in fact, they're just ignorant. They mean well, but they need suggestions for more helpful ways to interact with people who have disabilities.

When you're doing your best and things are still not going well, you may need to develop some special skills and understanding. For example, you can learn to judge when and how to discuss your disability with new friends and potential employers. You can learn these skills by experiencing the situations firsthand, talking to other people with disabilities, and researching the stereotypes about your disability so you can find effective ways to overcome those stereotypes. It's not easy, but being a member of a social minority group often requires that you become a teacher of the general population. You didn't ask for that role, but it comes with your wheelchair, crutches, and other equipment. Learning these skills can increase your self-determination and self-esteem.

Family and Friends

When you experience an SCI, the people close to you also undergo emotional and social turmoil. Try to remember that this sudden change for you was also unexpected for them. Give yourself and them time to adjust to all the changes.

Loved ones usually concentrate on helping to coordinate your health and rehabilitation needs following SCI. You should be focused on your survival and health. As time goes by, you and your family will reestablish common goals based on planning for the future. The best way to communicate with your family and friends is to decide how you feel about your situation and communicate assertively. Here are some tips for dealing with family and close friends.

- Your close friends and family may be afraid to bring up certain subjects for fear of causing you or themselves more pain, so you might have to start the ball rolling. It will be hard, but it may be best in the long run. Timing is very important. Adjustment is a healing process, so trust your gut instinct in dealing with certain issues. There will come a time when you will both feel right about it.
- You don't have to be strong for your family and friends. This only makes it harder for them to talk with you.
- Remember that your family and friends are part of the nondisabled population and may have misconceptions and attitudes about people with disabilities. When you can, talk to them about things you've learned about living with a disability.
- Sometimes, family and friends go overboard trying to do everything for you. This can make you feel smothered. Figure out how much help you'd like to have. If your family and friends are doing too much, talk to them about it. Let them know how it makes you feel and why you'd prefer that they not do so much for you. Remember that they're expressing their love and caring, even though it doesn't feel good to you.
- Let your loved ones know when your feelings about your injury have changed from the feelings you had when you were first injured. You may be more comfortable with the changes in your body and what you need to do to keep it healthy. Let them know about your increased self-esteem and confidence.

Adapting to an SCI is a unique and lifelong experience. Each person does it in his or her own way. Whatever way you choose is OK, as long as it keeps you healthy in both mind and body. Your family and friends will also adapt to your SCI. Many will come to realize that you're still the same person they've always loved. Unfortunately, a few may not

be able to adjust to the new physical you, no matter how much they love you. Relationships change in everyone's life, whether they're disabled or not. Being a person with a disability is a challenging experience that offers potential for growth.

Intimacy and Sexuality

A physically and emotionally intimate relationship can be part of your life. This section contains information about ways to communicate with partners. [See section 1.f, *Sexual Health and Reproduction, for information on how SCI can affect sexual function and the treatment options available to improve function.*] Like other relationships, sexually intimate ones may sometimes require professional intervention and counseling. Below are some guidelines for seeking sexual counseling. This book can also be used as a tool to educate counselors who may be unfamiliar with the conditions that affect a person with SCI.

Sexual Counseling

Sexual counseling services are a response to the growing number of people, disabled or not, who want to know more about their sexuality. Sexual counseling is available for individuals or partners. Seeking professional advice or counseling is not always easy to do. You should focus your attention on obtaining as much information as you think you need. Different kinds of counseling are available for different problems. You can probably find services in your area through various SCI organizations and on the Internet.

Getting started

The hardest part of the process is bringing up the subject and saying what the problem is. Don't get discouraged! Is the problem related to genital function? This includes changes in your ability to have or keep an erection or your ability to lubricate. If so, consult your health-care provider. Is the concern related to a sexual relationship, lack of one, or a desire to feel better about your

sexuality? Your health-care provider or local mental health center will be able to counsel you or refer you to a counselor in your community. If you're concerned about your ability to become a biological parent, you'll need to speak to a fertility specialist.

Finding a good counselor

While you're on a rehabilitation unit, you may receive counseling on sexual issues from the SCI team. Counseling may also be available for you through an outpatient rehabilitation clinic, a specialty clinic in a hospital, or another agency in your community. You may be paying for these services. Smart consumers know what they're buying. The person you need to see—such as a therapist, urologist, or fertility counselor—will depend on your issues or concerns. Here are a few questions to ask:

- How much experience do you have in sexual counseling?
- What type of training or professional degree have you received?
- Have you worked much with clients who have disabilities?
- How long will I need to see you, and how much will it cost?

Some sexual counselors don't have experience with clients who have disabilities, but that doesn't mean they can't help you if they're willing to learn about SCI. If the counselor has little experience with disabilities, ask:

- Are you interested in working with clients who have disabilities?
- Would you be willing to consult with some SCI specialists for more information about SCI?

Not all sexual concerns are a result of your disability. Sexual and relationship problems can occur in anyone's life. One way to get practical

information about these issues is to talk with other people who have disabilities. Some communities have peer support groups or independent living centers, where you can probably talk to someone who has found a way of adapting sexually to a disability. Your SCI team can also be a source of information about resources in your community, and you can learn from books, magazines, pamphlets, and websites. Some sources are listed below, but this list is by no means comprehensive. Websites often contain references links to other helpful websites.

Parenthood

Persons with disabilities, including those with SCI, may choose to become parents. As discussed in *section 1.f, Sexual Health and Reproduction*, fertility in women is reduced for only a short time after SCI. Men with SCI who wish to become biological fathers can usually do so, although it may require complicated and expensive medical procedures. Adoption is another route to becoming a parent.

Deciding to Become a Parent

As a first step, you'll probably want to explore your physical ability to have children. Check with your health-care provider about fertility options and possible effects on your health. [See *section 1.f, Sexual Health and Reproduction*.] You also may want to consult with your social worker or psychologist. Parenthood is a major life decision and should be carefully explored with all the people who will be involved in your child's life. Parenting is an adventure that's full of joys and challenges; talking to parents with or without SCI is a good way to get some perspective on the emotional pros and cons of parenting.

If You Are a Parent

Some people are already parents before they have an SCI. If so, here are some questions to consider:

- When and how should children be included in your rehabilitation program?
- How much information do they need?
- Should they attend family meetings?
- How often should they visit while you are in the hospital or rehabilitation unit?
- Would your children or partner benefit from peer contact with other families who have a parent with SCI?
- What is the best way to educate your children about
 - > the disability?
 - > your psychological adjustment?
 - > how your disability will affect the child's life and the family?
- Should you seek family/couples or individual counseling services about parenting from a rehabilitation social worker or psychologist?
- Should you receive outpatient counseling about parenting in your local community?

It's common for parents to be concerned about providing financial, physical, and emotional support for their children. Your rehabilitation social worker and psychologist can help by—

- clarifying your concerns;
- educating you about alternatives;
- referring you to other rehabilitation team members who can assess your equipment and home needs related to parenting; and
- counseling you and your family as you all adjust to the financial, physical, and emotional changes.

RESOURCES

Publications

Depression: What You Should Know: A Guide for People with Spinal Cord Injury
www.pva.org/publications

Anatomy of an Illness as Perceived by the Patient.
N. Cousins. Bantam Doubleday Dell Publishers, 1991.

The Relaxation and Stress Reduction Workbook.
M. Davis, E. Eshelman, and M. McCay. New Harbinger Publications, 2000.

Social Relationships and Interpersonal Skills: A Guide for People with Sensory and Physical Limitations. M. Dunn. Institute for Information Studies, Fairfax, VA, 1981.

A New Guide to Rational Living.
A. Ellis and R. Harper. Wilshire Book Co., 1997.

Don't Say Yes When You Want to Say No.
H. Fensterheim and J. Gaer. Dell, 1975.

Direct Decision Therapy.
H. Greenwald. EDITS Pub, 1975.

When Bad Things Happen to Good People.
H. Kushner. Avon Books, 1994.

How to Get Control of Your Time and Your Life.
A. Lakein. Signet, 1973.

When I Say No I Feel Guilty.
J. Smith. Bantam, 1985.

Contact: The First Four Minutes.
L. Zunin and N. Zunin. Balantine, 1975.

3.c | Mental Health Conditions

Depression and anxiety are the most common mental health problems in the United States, and people with spinal cord injury [SCI] are at a somewhat greater risk for these problems. It's very important to be aware of common mental health problems so you can detect them early and prevent them from getting worse. As you'll see in this section, depression and anxiety can be very serious, but they can be treated with counseling, medications, or a combination of the two.

Depression

As noted in *section 3.b, Psychosocial Adjustment*, not everyone with an SCI develops depression or has difficulty coping after their injury. About a third of people [33 percent] with SCI have depression at some point, which compares with about 10 percent among the general population. Even if you're not having any trouble with depression now, it's important to know what it looks like in case you develop symptoms in the future. Table 3.c.A lists some symptoms of depression.

Some of the symptoms are fairly obvious: feeling blue, hopeless, down, or discouraged. Other symptoms are less obvious. For example, people who are depressed often have changes in their appetite—eating more or less, or changes in sleep—trouble sleeping or sleeping more than usual. Energy and motivation may be low, and the people might lose interest in things they used to enjoy. Sometimes people also notice changes in their thinking. For example, memory and concentration may not be as good, and it can be hard to make decisions when you're depressed. Mood changes, like becoming more irritable, can appear. Some people with depression develop most of these symptoms, while others have only a few.

A very serious symptom of depression is thinking about suicide. People with an SCI are at higher risk for suicide in the first five years following their injury; after that, the rate decreases to that of the general population. Suicide in people with SCI can take several forms besides actively taking one's life, including self-neglect, or refusing needed care.

[Table 3.c.A] Symptoms of Depression

- Feeling sad most of the time
- Having no interest in activities you usually like
- Crying for no reason
- Having trouble sleeping or sleeping too much
- Getting careless about your appearance or health
- Feeling tired all the time or not being able to sit still
- Having no appetite or eating too much
- Avoiding your friends or family
- Using alcohol or drugs when you feel sad or angry
- A declining sex drive
- Feeling irritable much of the time
- Thoughts about death or suicide

How Can SCI Increase the Risk of Depression?

Chronic pain and other symptoms of SCI

Chronic pain can make you feel discouraged at times. Sometimes people with chronic pain also develop symptoms of depression. Fatigue is also common after SCI.

Life events, losses, and personal circumstances

Soon after SCI, many people experience feelings of grief, loss of self-esteem, and changes in their body image. Often many aspects of their life changes, including independence, mobility, housing, employment, income, and recreation. Not everyone receives the support they hope for

from friends and family. Medical complications and hospitalizations can get in the way of adjusting to life with SCI.

Disrupted sleep

Studies have found that disrupted sleep can lead to depression. The body makes chemicals during sleep that help regulate your mood. If these chemicals aren't made in sufficient quantities, you can develop symptoms of depression. Having a spinal cord injury may make it harder to sleep well; for example, you might have to wake up several times a night to turn, catheterize yourself, or take medications. A breathing disorder called sleep apnea is also common after SCI. It can interrupt sleep and lead to excessive daytime sleepiness.

Alcohol and substance abuse

As discussed in *section 4.e, Alcohol and Substance Abuse*, using substances to excess can have a negative effect on your life, health, and relationships, which, in turn, can lead to depression. Alcohol is a central nervous system depressant, so it contributes to the development of depressive symptoms.

Medications

Narcotics and some other medications used in excess can have the same effect as alcohol, making you more likely to develop symptoms of depression.

Traumatic brain injury

One-quarter to one-half of all people with SCI also received at least a mild brain injury at the time of their accident. Brain injury causes changes in the brain that can make you more prone to depression.

Depression risk factors unrelated to SCI

If you've had depression in the past, you're more likely to develop depression after a stressful event, such as having a SCI.

How Can Depression Affect Your SCI Care?

Studies have found that persons with SCI who are depressed have the following difficulties:

- decreased ability to be independent and mobile;
- longer hospital stays;
- fewer improvements in their rehabilitation;
- increased rates of preventable complications, such as pressure ulcers;
- greater need to hire attendants for care; and
- increased medical expenses.

What to Do if You Develop Symptoms of Depression

It's important to know the symptoms of depression so that if you see them in yourself, you can do something about it. Depression is a treatable condition. Counseling, medications, or a combination of the two are very effective in treating depression. It's important not to let yourself suffer needlessly. One powerful symptom of depression is the belief that the bad feelings will never end. If you become depressed, remember that it's a temporary condition and you'll feel better down the road—especially if you get help.

Anxiety

Most people worry or experience mild stress on occasion. About one in four people with SCI has trouble with ongoing anxiety or nervousness. Just like depression, not everyone has the same symptoms [SEE TABLE 3.C.B]. Symptoms of anxiety may include worrying a lot, feeling tense or fearful, difficulty sleeping, loss of appetite, shakiness, or a racing heart. Anxiety can affect how you feel physically—it can cause nausea or tension headaches. Some people experience panic attacks, which are intense episodes of anxiety that can

involve feeling dizzy, sweating, having a pounding heart, feeling panicked, trembling, and having a fear of losing control or dying. Panic attacks can be very distressing, but they are treatable.

Another form of anxiety is post-traumatic stress disorder [PTSD]. PTSD can develop after experiencing a traumatic event, such as an accident, natural disaster, assault, combat, or any situation in which a person has feelings that their own life or another person's is in danger. PTSD has many symptoms, including nightmares about the event, avoiding things that remind them of the event, being prone to anger or irritability, and having difficulties in relationships. Like other forms of anxiety, PTSD is treatable with counseling, medications, or a combination of the two.

How Can Anxiety Affect Your SCI Care?

Anxiety can affect your care in several ways. For example, during your rehabilitation, anxiety can keep you from participating in your therapies, especially if you're afraid to try new things. After discharge, it can interfere with getting a good night's sleep or prevent you from going out into the community. If fear or anxiety is keeping you from living your life fully, it may be time to address these symptoms.

Managing Stress

Having an SCI, or being a caregiver for someone with SCI, can be stressful. Research has shown that people with SCI who report more stress in their lives also report greater life dissatisfaction and more symptoms of depression. It's important to learn how to manage stress so it doesn't negatively affect your life. Physical exercise, relaxation exercises, and learning to "let go" of tasks and issues that really aren't important are ways to reduce stress. A mental health provider can help you learn to manage stress if you find it difficult to do so on your own.

[Table 3.c.B] Symptoms of Anxiety

- Feeling like your heart is pounding
- Sweating for no reason
- Trembling or shaking
- Difficulty breathing
- Feeling like the walls are closing in on you
- Fear of dying or going crazy
- Fear of going outside or of social situations
- Nightmares or unwanted thoughts about an upsetting event
- Avoiding activities that remind you of the event
- Feeling numb or detached from life
- Worrying a lot

Where to Go for Help

Most SCI programs have psychologists who can either work directly with your or refer you to a qualified mental health counselor close to your home. You can also ask your primary health care provider for a referral for counseling or treatment with medication. Another option is to go to your community mental health clinic. Different types of counseling and medications are effective in treating anxiety and depression. Discuss treatment options with your mental health care provider and choose the one that feels right for you. There's nothing shameful about having trouble with anxiety or depression—these symptoms are quite common throughout the general population. And treating anxiety and other mental health issues can help prevent some medical complications.

Prevention of Depression and Anxiety

The best way to avoid depression is to stay active and involved in your life. Studies suggest that people who keep doing the activities they usually like, even if they feel down, are less likely to get depressed. Keep an eye on your mood and look for symptoms of anxiety. Talk with your loved ones about how you're doing and let them know what to watch out for—they can help you get help early, when it can be most effective.

RESOURCES

Publication

Depression: What You Should Know: A Guide for People with Spinal Cord Injury, Consortium for Spinal Cord Medicine

www.pva.org/consumerguides

Websites

www.craighospital.org/SCI/METS/stress.asp

Information from Craig Hospital on understanding and managing stress after SCI.

www.spinalcord.uab.edu/show.asp?durki=21405&site=1021&return=21719

More information on stress management from the SCI Information Network and the University of Alabama Birmingham Model SCI System.

www.anxieties.com

A free self-help site for people with anxiety.

3.d | Community Resources

Every community has resources [services and programs] that may be helpful for you and your family. Depending on where you live, these services may be provided by the state, county, city, or community. Your social worker can guide you if you need assistance.

Because of the many available resources, we've separated them into general areas, like housing, financial programs, and transportation. Each area has a brief summary and general contact information.

Here are some tips for contacting a community resource:

- Call at the beginning of the workday.
- Always write down the name, title, and phone number of the person who gives you information, as well as some notes on your conversation and the date. If you still have questions, call the agency again.
- Write all your personal information on a note card: Social Security number, insurance coverage, VA benefits, hospitalization dates, doctors' names, and family contact names and numbers. You might as well be organized, because you're going to have to give this information many times.
- Be persistent. If the line's busy, call again. If the person's out, leave a message. Keep calling until you get the information you need. Don't give up!
- You may be able to get information faster if you visit the agency. If you can't do this yourself, appoint a spokesperson or advocate to go on your behalf. Or, visit the agency with your spokesperson.

Information and Referral Services

An information and referral service provides general information over the telephone. This is done confidentially, so you can ask whatever you'd like without having to identify yourself. This kind of service offers general information about all the programs that are available in your area. Ask if the program you're interested in includes disabled persons. When you discuss your specific need, tell the person what your disability is. This will help them know exactly how they can accommodate you.

Housing

Accessible housing is very important for persons with physical disabilities. Such housing may include ramps, accessible doorways and bathrooms, and, if possible, modified kitchen areas. When you're choosing a living arrangement, look for specific features that will accommodate your wheelchair. *[See section 2.d, Home Modifications.]*

Housing Authorities

Many counties and towns have housing authorities for low-income families, low-income elderly, and low-income physically disabled people. The waiting lists for low-cost accessible housing are usually very long [months to a year]. Call your county or city housing authority to get an application and get on the waiting list as soon as possible. If you're not ready or you don't need the housing when your name reaches the top of the list, you can always decline. Financial eligibility is based on a national formula. Many low-paid working people qualify. If you qualify, the basic payment formula is usually about one-third of your income.

Section 8

Rental assistance program funds are available to help eligible persons and families lower their monthly rental costs. Eligibility is based on gross annual income. The program uses existing housing. Usually the applicant must find the housing and negotiate with the landlord.

Housing Assistance Organizations

Programs are available in certain areas to help people locate housing. Call an information and referral agency about accessible housing.

Specially Adapted Housing for Veterans

This VA program is designed to pay some of the costs of buying a house. Eligible veterans with a service-connected disability who meet other requirements may receive a VA housing grant, which can be used only once. Contact your local VA office to apply.

VA Home Improvement or Structural Alterations

This program is designed to pay for some of the costs of remodeling your own house or a rental. Any eligible veteran may receive funds for major structural alterations and home improvements that comply with specific guidelines. Contact your local VA office or medical center.

Independent Living Programs

Some independent living programs provide transitional housing as well as peer counseling, advocacy, transportation, recreational activities, and more. Check with your social worker and the website resources at the end of this section to locate independent living programs in your area.

Vocational Services

You may be eligible for vocational rehabilitation services through federal and state government programs. *[See section 3.e, Employment and Vocational Rehabilitation.]* Vocational rehabilitation services can have different names in different states, such as the department or division of vocational rehabilitation [DVR], rehabilitation services, or vocational rehabilitation. Your vocational rehabilitation counselor can explain all the services the DVR can provide. These services may include the following:

- Medical, psychological, and vocational evaluations to help with job planning. Appropriate treatment can be authorized as well as equipment to aid in DVR programs.
- Counseling and guidance to implement your rehabilitation plan and achieve your employment goal.
- Vocational education in college, trade school, or commercial school, and on-the-job training.
- Maintenance and transportation funds while you're pursuing vocational goals.
- Job placement assistance and follow-up to determine whether a job is suited to your highest capabilities.

VA Vocational Program

The VA administers programs for education and training for eligible veterans. Seek out the vocational counselor at the nearest VA SCI center to determine your eligibility for vocational rehabilitation programs and general education or training.

Home Health Nursing Services

Maintaining your health is up to you, but help may be available through county or city resources, the Department of Veterans Affairs, and nonprofit services [for example, visiting nurse services].

These agencies have health professionals who will come to your home and help with care needs on a limited basis if you meet the eligibility criteria.

Many hospitals have home care programs that send staff into homes, depending on geographic location and insurance coverage. The cost of the service and who pays for it vary by agency, and a physician's order is usually needed for these services. Ask your social worker or the local public health department for the names of agencies.

Financial Assistance

Loss of income after a crisis like a spinal cord injury can be a major worry. Specific programs are available for persons with a financial need and a medical disability. The following is a general outline of federal and state programs.

Federal Financial Programs

The Social Security Administration (SSA) operates many programs that can provide benefits to people with disabilities. These include Social Security Disability Insurance [SSDI], Supplemental Security Income [SSI], the Medicare Prescription Drug Plan, and Retirement and Survivors Benefits.

- SSDI may provide a partial income for persons who have been employed and are now disabled. There is up to a seven-month waiting period before benefits begin.
- SSI provides some income to people in financial need without regard to past work experience. Eligibility is determined based on income, age [over 65], resources, and disability. If you receive SSI, you will also be eligible for Medicaid health insurance through the state.

- Medicare, a federal government health insurance program operated by the Center for Medicare and Medicaid Services, is available to recipients of SSDI after two years of receiving benefits.

Applications for SSDI, SSI, Retirement and Survivors Benefits, and Medicare can be taken over the telephone. You don't need to apply in person; a family member or representative can apply for you. It may take months or even longer before you begin receiving these benefits. Learn the Social Security rules and guidelines, and keep up to date. Call the toll-free number [800-772-1213] or visit the SSA website [www.socialsecurity.gov] for more information.

State Assistance Programs

State assistance programs are run through offices known as departments of social services, health and social services, welfare, or human services, to name a few. The eligibility requirements for income and Medicaid benefits vary from state to state.

Many programs may be available to you and your family. Call your county department of social services if you need help with the following services.

Medicaid

Medicaid is a state-operated program for low-income people. It provides medical coverage for hospitalization and treatment; homemaker, home health aide, and visiting nurse services; transportation related to medical needs; and equipment. The services vary from state to state.

Food Stamps

The Food Stamp Program helps people with low incomes buy the food they need for good health. If you're eligible to participate, you'll usually receive an electronic benefits transfer card [similar to a debit card] that you can use to pay for groceries. Your eligibility and monthly benefits

are based on your income and the number of people in your household.

Aid to Families with Dependent Children

This program is designed to provide financial assistance and benefits to families with dependent children who are in need. Financial assistance provides money to help pay for food, fuel, clothing, utilities, personal needs, and shelter.

Chore services/attendant care

This program helps persons living in their own homes by providing essential housekeeping or personal care. The monthly cash grant can be paid to you as an employer of an attendant or chore worker, or it can be paid to an agency under contract to provide services to you. Some states have different administrative structures for housekeeping [chore services] versus personal care [attendant care services]. Contact your local, county, or city department of social services. Each state has its own eligibility requirements, some of which are very restrictive.

Workers Compensation

This state-regulated program provides employees injured on the job with health care, weekly income payments, and rehabilitation services.

Financial support and coverage by workers compensation is tied to insurance company support and coverage. It is ordinarily much more substantial than other state-supported financial programs.

To be eligible, an employee must be injured while working for an organization that has workers comp coverage. Each company contracts with its own insurance company, so benefits will vary.

You can get more information from your state department of labor and industries, workers comp, or industrial commission. Workers compensation agencies go by various names—

contact your employer's human resources or personnel department.

VA Assistance Programs

Veterans with disabilities may be eligible for hospitalization, medical treatment, educational programs, pensions, and other federal programs. You may have a state veterans service office in your city or town [usually in city hall]. Under extreme circumstances, this office can provide emergency financial assistance. Look in the phone book or on the Internet [www.va.gov] for the VA offices closest to you. A veterans benefits counselor should be available to speak with you at any VA SCI center.

Employment

For many people with SCI, employment is a significant part of their lives, not only for financial freedom but also for self-satisfaction. The Americans with Disabilities Act [ADA] prohibits discrimination in employment on the basis of a person's disability. [See section 3.e, *Employment and Vocational Rehabilitation*, and section 3.g, *Your Rights*, for more information on these topics.]

Government agencies help promote equal hiring opportunities. The federal Office of Personnel Management [OPM] conducts a rigorous program to ensure that people who have disabilities are hired. Other sources of employment information and assistance are the state department of employment security, the Federal Job Information Center, and VA vocational counselors. Talk to your vocational counselor for more specific information.

Mental Health Counseling and Crisis Intervention

Community health centers, family service agencies, and centers for independent living can provide crisis intervention and counseling

when difficulties arise. Talk to your social worker, psychologist, or community mental health center, and remember these general guidelines:

- Consider the experience and training of the person who is providing counseling services. Pay special attention to his or her experience with people who have SCI or other physical disabilities.
- Discuss your expectations for counseling sessions, such as issues to be discussed, number of sessions, and cost.
- Ask if the counselor is willing to consult with your doctors and others on your rehabilitation team.

Attendant Services

If you need an attendant to help with your personal care and household maintenance, programs are available to pay for these services. A variety of funding sources and methods of attendant management have been set up by different funding sources. National Medicaid policy has increased the options for state attendant care programs. Consult your local Medicaid agency. *[See section 2.f, Attendant Management.]*

Legal Assistance

Local Legal Aid Services

Most communities throughout the United States offer sliding-scale legal aid services. This means that your cost is determined by your ability to pay. If you can't locate your community legal aid office, contact the state bar or law association, which will refer you to the office closest to your home. Many law schools offer free or low-cost legal services. Information and referral services can help you find a lawyer.

Protection and Advocacy Systems

The federal government has mandated a system in each state and territory to protect the legal rights of people with disabilities. These protection and advocacy systems [P&As] were established in response to abuse, neglect, and lack of programming in institutions for people with disabilities. Congress has created laws and programs to address the needs of different populations of people with disabilities.

What Can You Do?

You can become active in the disability rights movement, working with other people with disabilities who share your views. Changing the system requires strength in numbers. Keep in touch with consumer organizations around the country to learn what they're doing. Federal programs and policies can influence many issues that affect the disability community. Activists should bring these issues to the attention of nondisabled consumers and reform groups to add strength to their organization through the media. Become knowledgeable and get involved!

Transportation

Travel always requires planning—when you have a disability, it just takes more planning. Almost all modes of transportation are accessible to people who use wheelchairs, but it's worth double-checking to avoid surprises.

When you're making arrangements, ask the right questions. What services can you expect from transportation personnel? Is there a charge for an attendant/personal assistant? Don't assume that policies are consistent from one transportation provider to another, or that they'll stay the same. Ask these questions each time you make a reservation.

The key to success in traveling is good planning. Develop a travel plan that covers all aspects of your personal needs: comfortable clothing, time requirements, bowel and bladder scheduling, meals, transfer techniques and tools, who might need information from you [like airline or train personnel], and access to medication. Make your travel plan part of your trip.

Public Transportation

For getting around town, many public transit vehicles are now wheelchair accessible. The ADA requires new transit buses to be wheelchair accessible and have at least two spaces for wheelchairs. Call your transit system to see if it's fully accessible; if not, it may accommodate you by putting an accessible vehicle on your route. Paratransit services [accessible vans or small buses] are used when conventional public transit vehicles don't meet the needs of disabled persons. If you're eligible for paratransit in your hometown, other cities must honor that eligibility when you visit—but be sure to notify them of the dates of your travel, and check for any restrictions. Project ACTION maintains an updated website [<http://projectaction.easterseals.com>] about accessible public transportation in many locations around the United States. Taxis are not required to be accessible under the ADA, but accessible cabs are available in many cities. Check the Project ACTION website or your local chamber of commerce.

Air Travel

Discrimination on the basis of disability is prohibited under the Air Carrier Access Act. Carriers must have policies and training programs to ensure that airline personnel know what is required. For example, a passenger who preboards and has a foldable wheelchair may stow the wheelchair in an onboard closet if it doesn't

displace other passengers' luggage already in the closet. You may want to keep your wheelchair cushion with you—it can help protect your skin during the flight. Don't forget to do pressure releases during the flight.

Airlines are responsible for assisting you in boarding and deplaning, helping you make connecting flights, and returning your mobility equipment to you in the same condition that you released it to them. If you're unable to walk, you usually will board the plane using an aisle chair, a narrow wheeled chair that airline personnel can maneuver down an airplane aisle. Half the aisle seats on new planes must have movable armrests in order to make transfers to and from the seat easier; in older planes, you may have to transfer over an armrest. Be assertive in asking for assistance and telling airline personnel how to help you.

If you can't evacuate the plane in an emergency, you must bring [and pay for] an assistant. If the airline thinks you need such assistance but you disagree, the airline will pay for an assistant, but it may choose the person, perhaps an airline employee. That person is responsible for assisting only in the event of evacuation. If you do travel with an assistant, the airline must seat you next to each other on the plane.

Airline personnel will not provide personal assistance on the plane. They'll help with boarding, stowing luggage, and helping you get to and from the bathroom. They won't assist in the bathroom or with eating.

Trains

Amtrak has a special discount program for rail passengers with disabilities. Amtrak personnel will help with boarding, information, and at-seat services, such as delivering meals, stowing luggage, and helping you get to and from the bathroom.

They will not assist with eating, personal hygiene, or medical services en route. Amtrak’s website [www.amtrak.com] has a section on services for travelers with disabilities and special needs.

Bus Lines

Greyhound Bus Line provides assistance to passengers with disabilities. So far, very few Greyhound buses are equipped with wheelchair lifts. Call Greyhound ADA Assist Line at [800] 752-4841 at least 48 hours before your departure to arrange for a lift-equipped bus. You will be asked for information to help Greyhound personnel provide the assistance you need. If you can’t notify them in advance, Greyhound will make every reasonable effort to accommodate you without delaying bus departures. With some restrictions, personal care assistants may travel free on Greyhound. The ADA Personal Care Attendant ticket will be issued only to the personal care attendant, only at the time of travel, and only as a one-way ticket. Other major bus lines have similar policies, but it is best to check with them in advance.

Tour Buses

Tour bus services are covered by the ADA, but they’ve been allowed to phase in new lift-equipped vehicles. Call ahead to make arrangements, whether you’re taking a tour or a regularly scheduled bus trip.

Rental Cars

All rental car companies must provide cars with hand controls. Contact the rental company a week in advance.

Ship Travel

The ADA covers foreign-flagged ships operating in U.S. ports; however, standards for compliance haven’t been developed yet. Generally, the bigger the ship, the better the chance that it’s accessible. There are mixed reports on crew availability to help. Contact the shipping line for information. Ask if they have an ADA coordinator [a person in charge of ensuring compliance with the Americans with Disabilities Act]. *See Hotels and Motels section* for questions you might want to ask.

Hotels and Motels

Hotels and motels are covered by the ADA. While most hotels have accessible rooms, you still need to ask the right questions:

- > How wide is the opening in the bathroom doorway, both with the door and with the door removed? [*See the section on Doorways and Hallways in 2.d, Home Modifications.*]
- > Are there grab bars and a handheld shower?
- > Are shower chairs with backrests available?
- > How high off the floor is the top of the mattress?

Don’t just take at face value the statement that the room is accessible—if it doesn’t work for you, it isn’t accessible. If you get to the hotel or motel and find that the room doesn’t meet your needs, talk to the hotel staff immediately. They may have a different room or different equipment that will be safer and easier for you.

RESOURCES

Publications

New Horizons: Information for the Air Traveler with a Disability

Department of Transportation

Aviation Consumer Protection

Division, C-75

400 Seventh Street, SW, #4107

Washington, DC 20590

<http://airconsumer.ost.dot.gov/publications/horizons.htm>

The ADA: Your Personal Guide to the Law

www.pva.org/publications

Websites

www.access-able.com

Access-Able Travel Source is dedicated to helping travelers with disabilities and mature travelers with practical information they need to go across town or around the world.

www.amtrak.com

Under the heading Traveling with Amtrak, see the section on special needs and accessibility. The site contains tips from Amtrak about accessibility services and tips for making your travel as barrier-free as possible. The site also includes information on routes, schedules, meals, and accommodations.

www.ctaa.org

Community Transportation Association of America's members are rural, small urban, and community-based transportation providers. See the section on passengers with disabilities.

www.fhwa.dot.gov

This site provides links to Department of Transportation ADA regulations and enforcement, and features information on the Air Carrier Access Act.

www.frommers.com

Arthur Frommer's budget travel online disability section offers airfares, hotels, cruises, and hot spots of the month, along with tips and resources for all travelers.

www.greyhound.com

Visit this site for trip planning information and to learn about Greyhound's services for travelers with disabilities. Or call Greyhound's ADA Assist Line at [800] 752-4841.

www.hud.gov

The Department of Housing and Urban Development site offers information on home buying and renting, fair housing laws, and accessibility issues.

<http://projectaction.easterseals.com>

Project ACTION Accessible Traveler's Database is a comprehensive database of accessible paratransit services in the United States, supplemented with information on accessible tours, airports, private shuttles, and taxi services.

www.napas.org

National Disability Rights Network Protection and Advocacy Centers are part of a federally mandated system in each state and territory that protects the rights of people with disabilities through legal advocacy.

www.ssa.gov

The official website of the Social Security Administration posts recent news releases from the administrator's office about changes in Social Security benefits. The site also provides access to Social Security forms, laws, and regulations.

www.travelintalk.net

Travelin' Talk is a global network of people with disabilities who share knowledge about their hometowns.

Organizations

National Council on Independent Living
1710 Rhode Island Ave., NW
5th floor
Washington, DC 20036
[202] 207-0334
[877] 525-3400
www.ncil.org

Centers for independent living are organizations that provide four core services for people with disabilities: systems and individual advocacy, information and referral, peer support, and independent living skills training. The goal of these centers is to create opportunities for independence and to help persons with disabilities achieve their maximum level of independent functioning within their families and communities. They work to ensure physical and programmatic access to housing, employment, transportation, recreational facilities, and health and social services.

3.e | Employment and Vocational Rehabilitation

Productive, goal-oriented activities help people adjust to disabilities. Employment, education, and athletic activities can all contribute to successful adjustment. Of all the goal-oriented behaviors, employment seems to be one of the most productive activities. After all, most Americans work for a living. Working not only improves your financial situation but also gives you a chance to meet new people, develop lasting friendships, and experience satisfaction from your accomplishments.

Some people follow the same career path throughout most of their adult lives. Others switch career fields for a variety of reasons—because their vocational interests change, economic developments affect their career field, or life circumstances force them into a career change. Whatever the reason, the good news is that you can follow certain steps that will allow you to make a successful career change. There’s a lot of help available to help you reach your vocational goals.

Where to Start

Since your SCI, you may be wondering what, if any, jobs you can do. Your life circumstances have changed, and you might not be able to return to the job you had. You also might have to look at your work life in a different way. For example, you might need to consider the physical demands of a job, which you may not have paid much attention to in the past.

You might think that since you were injured you’ve “lost” important job skills. At what level is your injury? Has it caused you to lose some of your previous physical abilities? Don’t short-change yourself! You probably have many job skills that you take for granted. You can still communicate,

persuade, teach, negotiate, direct, and listen. And how about the personal traits you’ve developed over the years? Are you friendly, empathetic, curious, assertive, imaginative, practical? Don’t forget your ability to learn new job skills.

When you’re up to it, start thinking about developing vocational goals for yourself and returning to work. A good way to begin the process is to evaluate yourself. What do you like to do? What are your interests? What are your transferable skills—things you did in your previous jobs that you can take with you to a new job? What are you good at? Where are your abilities? You’ll also need to think about any limitations you have and whether or not they’ll keep you from pursuing certain jobs. Another important consideration is the job market. What is it like in the area where you want to live? What employers are in your area, and what kind of workers do they need? Do you want to consider self-employment? If so, do you have the self-discipline and motivation to be successful owning your own business?

How to Get a Job

Things to Consider

- Jobs in general: 90 percent of jobs are not listed in want ads or with employment agencies.
- Blue collar and white collar jobs: 63 percent of these jobs are obtained through the efforts of the job seeker, including contacts through friends and relatives.
- Professional, technical, and managerial jobs: 75 percent of these jobs are obtained through personal contacts.

With numbers like that, it's clear that you need to keep your eyes and ears open when you're searching for job possibilities. Don't keep your activities a secret—let everyone know you're in the market for a new job. Listen to advice and follow up on any job leads people give you.

Need Some Help?

You may be one of the lucky people who's always known what you wanted to do. An SCI hasn't changed that. You also may be the type who knows how to get what you want. If so, you're a rare breed. Most of us spend much of our work lives searching for the "right" job. Many of us like to change jobs often, so we can test our skills and interests in different workplaces. However, few of us enjoy all the work that goes into making a job change.

Finding the motivation to begin and continue a job search is hard. It can be even harder if you aren't sure where to begin. Not to worry—as we said earlier, there's a lot of help available to you.

To start, there's a lot of information on the Internet and in books about conducting a successful job search. These do-it-yourself resources can give you a step-by-step approach for matching your skills with a suitable job. Consider using your public library to get information on job search activities.

Vocational Rehabilitation Programs

Many of us do better in career planning if we get some help. Fortunately, there are many state-funded and federally funded vocational rehabilitation programs that will provide you with personal assistance. Vocational rehabilitation programs offer a wide variety of services to help people with disabilities join the workforce. Trained vocational rehabilitation counselors can help you to prepare for, obtain, and keep

employment. They can help you assess your job interests and skills, academic capabilities, personal traits, and physical capabilities. They can help you set career goals and define ways you can achieve those goals. If necessary, they can help you get on-the-job training, specific vocational skills training, or college-level training, depending on the requirements of the job you're interested in pursuing. If you're ready to go to work, they can help you plan your approach to the job market. Vocational rehabilitation counselors can offer you the following specific services:

- Vocational evaluation—an assessment of your vocational interests, aptitudes, and abilities.
- Career exploration and career counseling to help you select an appropriate vocational goal.
- An individual rehabilitation plan—a strategy to help you achieve your vocational goals.
- Training assistance—on-the-job, vocational, or educational [college classes] to help you meet the qualifications for a specific job.
- Ongoing guidance and counseling to help you adjust to your life circumstances.
- Training in job-seeking skills and assistance with resume writing, interview skills, and job search methods.
- Job placement assistance.
- Job modifications.
- Independent living skills to improve your ability to deal with activities of daily living.

Vocational rehabilitation services can be a very useful resource. Whether you just want to discuss some career concerns or you're ready to start some serious career planning, a vocational rehabilitation counselor can help you. There are many vocational rehabilitation programs. The following are some of the programs, with descriptions of the populations they serve.

State Vocational Rehabilitation Programs

State vocational rehabilitation agencies provide a wide array of services to help people with disabilities return to work. They are designed to provide consumers with the training or other services they need to return to work, enter a new line of work, or enter the workforce for the first time. Every state has a vocational rehabilitation program with offices throughout the state. To find out about the vocational rehabilitation agency in your state:

- Use the Internet to locate your state’s home page—search for the name of your state plus “vocational rehabilitation services.”
- Look in the state government pages in your phone book to find the listing for the vocational rehabilitation agency.
- Ask your rehabilitation team how to get more information about vocational rehabilitation programs in your state.

PVA Vocational Rehabilitation Program

The Paralyzed Veterans of America [PVA] established a Vocational Rehabilitation Services Program in July 2007. This PVA program offers vocationally oriented services to veterans with disabilities, especially veterans with spinal cord disabilities. Through this program, a vocational rehabilitation counselor in a VA medical center will:

- Meet with veterans to discuss and explore their career options as early as possible in the medical rehabilitation process.
- Serve as the hub or coordinator for the various federal, state, and private vocational rehabilitation resources.
- Inform veterans about benefits available to them and, when appropriate, help them apply for Social Security benefits, state vocational rehabilitation programs, and community-based programs.

- Develop a network of employers who are willing to train/provide jobs for veterans.

For more information about PVA’s Vocational Rehabilitation Counseling Program, visit the PVA website at www.pva.org or call [202] 872-1300.

VA Vocational Rehabilitation and Employment Program

If you’re a veteran with a service-connected disability, you can apply for services with the VA’s Vocational Rehabilitation and Employment Program [VR&E], sometimes referred to as the Chapter 31 program. This program is designed to provide all the necessary services and assistance to help veterans with service-connected disabilities obtain and sustain suitable employment. The program provides up to 48 months of benefits, including training [on-the-job, vocational, and college-level] when appropriate. If you’re not yet able to return to work but need help to become more independent in completing activities of daily living, this program can provide you with independent living services. The program has more than 120 offices throughout the country. For more information about the program, including how to apply and where the closest office is, visit the VR&E home page at www.vba.va.gov/bln/vre; go to the VA main page at www.va.gov and look for the tab on vocational rehabilitation and employment services; or call VA at [800] 827-1000.

Other Vocational Programs for Veterans

Many programs are available to help veterans make the transition from the military to the civilian workforce. The following Websites have information on these programs:

- VA: vetsuccess.gov
- Department of Labor
 - > hirevetsfirst.gov
 - > www.dol.gov/vets

- > <http://realifelines.gov>
- > www.dol.gov/vets/aboutvets/contacts/main.htm
- > www.dol.gov/elaws/evets.htm

Americans with Disabilities Act

The American with Disabilities Act [ADA] is a civil rights law established in 1990 to protect people from discrimination based on disability. It's a wide-ranging law that prohibits discrimination against a qualified person with a disability with regard to job application procedures, hiring, advancement and discharge, job training, and other conditions of employment. It's important to be aware of your rights when you start your vocational planning activities. To learn more about ADA, *see section 3.g, Your Rights*, or go to the ADA website [www.ada.gov].

RESOURCES

Websites

disabilityinfo.gov

This is the federal government's main website for information for people with disabilities. The website has an employment tab that leads you to a wealth of information on job seeking.

www.bls.gov/oco

This Department of Labor website allows you to use the Occupational Outlook Handbook, an excellent source of career information for people who are making decisions about their future work lives. It's revised every two years and includes information about—

- specific job requirements, including required training and education;
- salaries;
- job prospects;
- what workers do on the job; and
- working conditions.

www.jan.wvu.edu

This is another Department of Labor website, the Job Accommodation Network, which offers free consultation on workplace solutions for people with disabilities.

www.earnworks.com

This website has information on the Employer Assistance and Recruiting Network [EARN], a free service that connects employers looking for quality employees with skilled job candidates.

3.f | Financial Planning

You're doing all the right things: studying this book, taking care of yourself, and staying connected with friends and family members. But when was your last financial checkup? Everyone should periodically look at their financial plan. Your injury has probably changed your circumstances, so it's especially important now to have a financial plan. Financial planning can ensure an adequate standard of living for you and your loved ones.

The financial planning process is similar for everyone, although it's a little more challenging for a person who has recently become disabled. You'll probably have new expenses, as well as new resources and income sources. Unique planning techniques and strategies are available for this situation, so it makes sense to find a professional adviser who's familiar with planning for persons with disabilities. This person will know what can affect your government or other benefits and will understand that different disabilities require a different focus in planning. He or she will also understand the emotional and psychological aspects of disability.

The Financial Planning Process

Successful financial plans are developed through a series of small, measured steps toward the desired result, and you may have to address each of these steps more than once. Successful planning requires cooperation with advisers, who may include a financial adviser, an accountant or tax adviser, an elder law attorney, and perhaps a geriatric care specialist. It also requires self-discipline. You might need to correct bad habits, like impulsive spending, that can derail your plans.

The six basic steps of intelligent financial planning are:

1. Clarify your goals and objectives.
2. Gather information.
3. Analyze information.
4. Create your plan.
5. Implement your plan.
6. Monitor your plan regularly and adjust it as necessary.

In the beginning, you might prefer to work alone. For example, you might feel quite comfortable doing the mental exercises to clarify your goals. So let's see how a successful plan is created.

Step 1. Clarify Goals and Objectives

There are as many styles of living as you can imagine, and they change throughout our lives. Don't be surprised if your ideas about what you want out of life have changed since your injury. Whether you see yourself headed in a slightly altered or entirely new direction, now is the time to identify your goals and objectives.

Goals are your general personal aspirations. For example, you may feel very strongly about not being a financial burden to relatives or living independently as long as possible. Goals are generally pretty easy to identify. Objectives are your detailed, specific aspirations. Your objective may be to arrange your financial affairs to provide a monthly income of \$3,000. You may find that you need some guidance on how to do this in your new situation.

Step 2. Gather Information

This is the most time-consuming step. You've decided what you want out of life. Now it's time to gather as much information as you can, so you'll have everything you and your advisers need to make sure your financial plan is based on a sound foundation. At a minimum, you'll need to know the following:

Current assets: For each asset, you'll need the purchase cost [basis], the current fair market value [FMV], and how long you've owned it [holding period]. The assets may include your home; collectibles or antiques; retirement accounts, such as individual retirement accounts [IRAs], 401[k], and pension accounts; investment assets, such as certificates of deposit [CDs] and stocks and bonds; annuities; and real estate holdings.

Cash outflows: Try to be as accurate as possible to avoid unpleasant surprises later. List the following current expenses, paying attention to any changes in the recent past, near future, or on the horizon: mortgage/housing expense, utilities, transportation expense/car payment, medical services/prescription medications and devices, credit card expenses, student loans, other debts, home health care and attendant expenses, and personal care supplies.

Track your spending habits for at least one month, preferably two or three. Make notes about any one-time or unusual expenses. Don't forget to identify expenses that you know are looming on the horizon. Estimate your future cash flow needs. These numbers can have a significant impact on your future standard of living, so try to project your needs as thoroughly as possible [this might require assistance from your attending physician, a geriatric care specialist, or other consultant].

Income sources: Your current income sources will generally include earnings [yours and your spouse's, if any], insurance benefits payable, rental income, income from investments, and

distributions from IRAs and other retirement plans, such as a 401[k].

Potential sources of income might be more difficult to pin down, especially where government and community assistance are concerned. It's generally more efficient to consult with your advisers about the nature and availability of these potential income sources. You might receive Social Security benefits when your parents die. You might be eligible for Social Security Disability Insurance [SSDI] and/or Supplemental Security Income [SSI]. These are federal programs that provide income for people who become disabled. There is no age requirement, but SSI is a needs-based program. The Social Security Administration [SSA] will determine your eligibility for benefits. For eligibility purposes, SSA generally requires a physician's statement that your disability prevents you from performing gainful employment and is expected to last 12 months or longer. [See section 3.d, *Community Resources*, for more information on these programs.]

Tax returns: Gather your tax returns from the past two or three years, along with all attachments. Your adviser can use them to identify any possible deductions for medical expenses and dependent care.

Estate planning documents: State laws vary dramatically concerning the specific language required in these documents, so it's generally not a good idea to use forms you get on the Internet or from a bookstore. Especially for the following three documents, it's best to consult an attorney.

1. *Durable power of attorney [DPOA].* Use this document to name a trusted person to handle your financial affairs if you are incapacitated. The powers you give can be as broad or narrow as you wish. The power may be "springing" [it becomes effective if you are incapacitated]; it should always be "durable," so that it will not be revoked if you become incapacitated.

2. *Will.* Your will divides your assets among your survivors after your death, identifying who gets what, when, and how. It must coordinate seamlessly with any trusts you have.
3. *Trusts.* Trusts and their uses vary widely by state. Persons with a disability often use a version of the special needs trust, which can hold assets that may be made available to you but will not cause you to lose your government benefits.

[See section 3.g, Your Rights, for information on living wills, durable powers of attorney for health care, and physician orders for life-sustaining treatment.]

After your injury, it's especially important to have the proper estate-planning documents in place. These documents work together to ensure that your medical and financial affairs are handled the way you want during any periods of incapacity and in the event of your death. Because your situation has changed, it's wise to consult with an attorney to update your existing documents or create new ones. For example, if you become incapacitated and you don't have a DPOA, a judge may appoint someone to serve as your guardian and handle your financial matters. This may not be the person you would have preferred.

Insurance information: You and your advisers will need to review your insurance coverage, including policies for your home, car, health, life, disability, and long-term care, as well as an umbrella policy. You should gather benefit information for all employer-provided health, disability, life, and other insurances.

Step 3. Analyze Information

If you haven't chosen a financial adviser yet, do so now. Take the time to select someone with whom you feel comfortable, so the lines of communication will stay open. It's important to

have an adviser who is well versed in the benefits, special techniques, and strategies available to a person with a disability. For example, if you use a special needs trust and improper investments are made inside it, you can lose your government benefits. It may be difficult for you to obtain health insurance other than Medicare, so it's crucial to keep your government benefits intact.

Your financial adviser will prepare and analyze your financial ratios. You've imagined your ideal lifestyle. Now your adviser must make sure you make financial decisions that will support that lifestyle. Is your emergency reserve sufficient? Is your budget where it should be? Are your assets allocated according to your tolerance for risk? Determining your risk tolerance is key to choosing the right strategies and techniques. Your financial adviser should be able to determine how and to what extent this tolerance has changed since your injury.

The adviser will help you identify appropriate investments. At this stage, they'll probably be identified in general terms, as a percentage of your portfolio—for example, so much to stocks, so much to bonds, and so much to cash. The exact stocks and bonds, and the specific strategies and techniques, will be determined later in the process.

In this step, your adviser might also help you identify new expenses or income sources, project future cash flow needs, work with your tax adviser, and educate you about your financial situation and any changes you need to make in your spending or other financial habits. In this stage, the adviser will work with you and your other advisers to get an accurate picture of your current and future financial situations.

Step 4. Create Your Plan

Working with you and your other advisers, the financial adviser will pull all the pieces together to create your personal financial plan. This may involve going back to Step 1 to modify your goals

and objectives. It will certainly involve combining the strategies and techniques you're most comfortable with and those that are best suited to your particular situation.

At this stage, many people feel optimistic and enthusiastic about their plan, even if it means belt-tightening or changing some spending habits. This is generally when you realize that your family might not have to disinherit you to protect your government benefits.

You and your advisers will create a plan that covers all the necessary bases, including future caregiver services and possible changes, such as the death or incapacity of your spouse. As in Step 3, you'll probably be in regular communication with your financial adviser, tax adviser, attorney, and geriatric care specialist [if any] as they work together on your plan.

Step 5. Implement Your Plan

Implementation is pretty straightforward—this is when you put your strategies and techniques into action. The success of your implementation might require you to take certain actions in a specific order. For example, say you have no estate-planning documents in place. You and your advisers will probably agree that your first priority is to get these documents in place.

Step 6. Monitor and Adjust Your Plan

You'll need to monitor and adjust your plan on an ongoing basis. Things are constantly changing: economics [housing markets, food prices, etc.]; interest rates; the return on your investments; family situations [divorce, death of a caregiver, etc.]. These changes may alter your goals and objectives, or your risk tolerance, which may in turn affect your financial plan.

The process of monitoring and adjusting requires cooperation and communication between you and your financial adviser. Your adviser can keep track of your investments and suggest appropriate modifications. Only you can provide the vital information about changes in your personal or family situation.

For every situation, try to give your financial adviser enough lead time to do a good job for you. Getting married? Notify your financial adviser as soon as you can. Getting a divorce? Your financial adviser needs to know. It will take time to make the appropriate changes in your financial strategies and techniques.

Do a periodic comprehensive review of your plan—at least once a year—with your adviser. Some of the assumptions or facts on which the plan was built might have changed. More frequent updates may be required if there's an unexpected change in your situation.

Monitoring and adjusting is a key part of your plan. If you fail here, the plan will probably fail, too.

Obstacles Overcome

As Henry Ford [founder of the Ford Motor Company] once said, "Obstacles are those frightful things you see when you take your eyes off your goal."

You've probably realized by now that financial planning takes some work. But if you make the effort and work with knowledgeable advisers, you can do a lot to ensure your financial success: obstacles overcome.

3.g | Your Rights

This section covers your legal rights as a person with a disability. This information primarily applies to residents of the United States, but many countries have similar laws. You'll find more information on these topics in other sections throughout the book.

Social and Legal Rights

Exercising Your Legal Rights and Responsibilities

People with SCI have the same constitutional rights as all other U.S. citizens. In addition, many federal laws support the legal rights of citizens with disabilities in the areas of vocational rehabilitation, education, transportation, accessibility, social and medical services, tax exemptions, and social security benefits. Each state guarantees various legal rights. This section identifies some of the major federal laws and shows how you—the voter and a person with a disability—can exercise your rights. We'll start with some general guidelines on how you can assert your rights and get the best results.

Be an Assertive Citizen

1. Know your basic rights!
2. Vote.
3. Keep a record of your transactions with agencies and programs. Keeping a file folder for each agency or program is a good idea. Include the following information:
 - Name and title of the person you talked to.
 - Copies of letters, applications, and other paperwork.

4. If you think your rights have been violated, ask to talk to a supervisor, the administrator, or the person in charge of grievances relating to civil rights.
5. Learn the channels for complaints in the agency.

It's your responsibility to be assertive [not aggressive], learn the established steps for civil rights complaints, and listen carefully.

Major Laws and How They Affect You

A number of laws are in effect that can work for you [SEE TABLE 3.g.A].

Americans with Disabilities Act

The ADA, passed in 1990, was the most significant piece of civil rights legislation since the 1960s. The ADA is a comprehensive ban on public and private discrimination against people with disabilities. Almost everyone in America is affected in some way by the need to comply with this federal law. The five major sections [titles] of the ADA cover employment, state and local government, public accommodations, telecommunications, and miscellaneous provisions. The laws and the regulations that have been issued by federal agencies are very specific about requirements. The Department of Justice, Department of Transportation, Equal Employment Opportunity Commission, Federal Communications Commission, and Architectural and Transportation Barriers Compliance Board have all published regulations to implement the ADA and provide technical assistance to help people apply the law. The Internal Revenue Service offers two tax incentives for businesses: [1] a tax

[Table 3.g.A] U.S. Laws that Affect People with Disabilities

YEAR	PUBLIC LAW #	TITLE OF LAW	KEY PROVISIONS
1968	90-480	Architectural Barriers Act	Requires that buildings built with federal funds or leased by the federal government be made accessible.
1970	91-453	Urban Mass Transportation Act	Requires eligible local jurisdictions to plan and design accessible mass transportation facilities and services.
1973	93-87	Federal and Highway Act	Requires that transportation facilities receiving federal assistance under the act be made accessible; allows highway funds to be used to make pedestrian crosswalks accessible.
1973	93-112	Rehabilitation Act	Prohibits discrimination against qualified handicapped people in programs, services, and benefits that are federally funded; creates Architectural and Transportation Barriers Compliance Board.
1975	94-173	National Housing Act Amendments	Provides for the removal of barriers in federally supported housing; establishes Office of Independent Living in the U.S. Department of Housing and Urban Development to serve people with disabilities.
1978	95-602	Rehabilitation Comprehensive Services and Developmental Disability Amendments	Establishes independent living as a priority for state vocational rehabilitation programs; provides federal funding for independent living centers.
1980	96-265	Social Security Disability Amendments	Removes certain disincentives to work by allowing disabled people to deduct independent living expenses in computing income benefits.
1984	98-435	Voting Accessibility for Elderly and Handicapped Act	Provides for access to polling places and ballots and all activities related to voting.
1986	99-435	Air Carrier Access Act	Prohibits discrimination on the basis of disability in the provision of air transportation.
1988	100-430	Fair Housing Amendments Act	Prohibits policies that discriminate on the basis of disability in housing; requires newly constructed multifamily housing to provide accessible units.
1990	101-336	Americans with Disabilities Act [ADA]	Extends to people with disabilities civil rights similar to those available through the Civil Rights Act of 1964.
1999	106-170	Ticket to Work and Work Incentives Improvement Act	Provides vocational, employment, and health-care support to people on SSDI and SSI who want to work.
2008	[pending]	ADA Revisions	To include changes in Standards for Accessible Design.

deduction for any business to remove barriers and [2] a tax credit for small businesses to comply with the ADA.

The following are the activities affected by the ADA:

Title I [Employment]. No employer with more than 15 employees may discriminate against a qualified person with a disability in any area of employment. This includes hiring, promotion, fringe benefits, and sick leave. An employer must make reasonable accommodations to enable an individual with a disability to perform the essential functions of a job, unless the accommodation causes an undue hardship.

Title II [State and local governments]. State and local governments and all their departments and agencies must ensure that their programs are accessible. These requirements apply to all parts of state and local governments, regardless of whether they receive federal funds. The most important consequence of this section is the creation of ADA coordinators for most government agencies. When consumers encounter accessibility barriers, they can get information and advice from a person who is knowledgeable about disability issues.

Buses used in public transportation must be equipped with lifts, and paratransit [vans or small buses that operate on demand] must be provided to persons with disabilities who are unable to use the established fixed-route system.

Title III [Public accommodations]. The coverage in Title III affects almost all private businesses, services, and agencies. A place of public accommodation is a facility operated by a private entity that falls into one of the following categories:

- Place of lodging, such as a hotel.
- Establishment serving food or drink.

- Place of exhibition or entertainment, such as a theater or stadium.
- Place of public gathering, such as a convention center or auditorium.
- Sales or rental establishment.
- Service establishment, such as a bank, dry cleaner, or the office of a lawyer, doctor, or accountant.
- Station used for transportation.
- Place of public display or collection, such as a museum or library.
- Place of recreation, such as a park or zoo.
- Place of education, such as a private school.
- Social service establishment, such as a senior center, day care center, or homeless shelter.
- Place of exercise or recreation, such as a gym or golf course.

Places of public accommodation must remove architectural and communication barriers where it is readily feasible to do so. All new construction is to be accessible. Private entities that provide transportation services must, depending on the circumstances, acquire accessible vehicles or provide equivalent service to persons with disabilities. This means that if it's relatively easy and inexpensive to take out a barrier, it must be done. Barriers include steps, narrow spaces, lack of TDD [telephone device for the deaf] phone service, or a policy prohibiting a waiter from reading a menu to a visually impaired person. If barrier removal would cause undue hardship, each entity has an identified ADA appeal process.

Title IV [Telecommunications]. This title reformed the national telephone system to include people with hearing and speech impairments. Providers of telephone service must provide "relay" service. Relay operators allow persons using TDDs to talk to persons using regular phones.

Title V [Miscellaneous]. Title V says that the Architectural and Transportation Barriers Compliance Board [Access Board] will issue guidelines to ensure that facilities and vehicles are accessible to persons with disabilities.

Section 504

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination against any qualified person on the basis of his or her disability by an entity that receives federal funding. The regulations apply to every program of the federal government. Three very important areas covered by Section 504 are education, employment, and community services.

Ticket to Work and Work Incentives Improvement Act

The 1999 Ticket to Work program is a new approach to providing vocational services with an emphasis on customer choice in providers. It's designed to increase flexibility in delivering services.

The Work Incentives Improvement Act [1999] was developed to provide more services for working people with disabilities so more of them can enter the workforce. The act extended Medicare Part A [hospitalization] benefits without any premium payments to seven-and-a-half years [the previous limit was three years]. The law gave state Medicaid programs the option to provide coverage for people with disabilities who are working. It calls for expedited reinstatement of Social Security benefits if a person leaves work status, and does not allow medical review if a person using the Ticket to Work program returns to work.

Work and Education

Work is an important part of our society and our personal identity. Laws exist to protect you in the workplace and in educational environments.

Post-high school educational programs and institutions must provide reasonable access to admission exams, classrooms, testing, student housing, and support services. In some instances, the educational institution provides onsite assistive devices. If you're interested in continuing your education and/or getting a job, meet with a vocational rehabilitation specialist. *[See section 3.e, Employment and Vocational Rehabilitation.]*

Legal Options for Planning Your Future

Advance Care Directives

An advance care directive, directive to the physician, living will, durable power of attorney for health care, do not resuscitate order [DNR], and physician order for life-sustaining treatment are all documents that let you control the health care you receive. They specify the scope and type of health care you wish to receive in a life-threatening situation if you are unable to communicate your desires, or they allow another person to make those decisions for you. The formats for these documents may be different from state to state. Hospitals and other care facilities are required to inform you about the option of establishing an advance care directive.

A DNR order is a physician order that directs hospital or nursing home staff not to perform cardiopulmonary resuscitation [CPR] if your heart or breathing stops. [If you don't have this order, you'll receive full CPR, which may involve artificial respiration, chest compression, electrical shocks to the heart [defibrillation], and medications. Some states allow you to prepare a DNR order for emergency personnel in the community. The DNR is sometimes called a physician order for life-sustaining treatment [POLST]. Ask your health-care provider if this option is available in your state.

A living will lets you specify the health-care procedures you would or would not want done if you were unable to communicate. A durable power of attorney for health care allows you to designate a person who will make health care decisions on your behalf if you are unable to communicate. The person you choose does not have to be a family member. You need to show this person your advance care directives and discuss your health care wishes with him or her.

Legal Options for Another Person to Handle Your Money

A time may come when you need another person to help you manage your money. The terms used to describe this process can be confusing, and they may vary from state to state. If you aren't sure, consult an attorney.

Power of Attorney

This document gives someone else the authority to manage your money, and may include the power to sell property. Power of attorney means that you and the other person can both do your business—you're *sharing* the power, not giving it away.

VA Fiduciary

This is an internal VA process through which it is determined that you are unable to handle your own money. The VA appoints an official [fiduciary] to handle your VA money and possibly your other income from government sources. The fiduciary controls this money and pays your bills.

Court-Appointed Guardian of Estate [Money]

This is a court procedure through which it is determined that you are unable to handle your money. The court appoints someone to handle it for you. You don't control your money, but the guardian is required to make reports to the court.

Court-Appointed Guardian of Person [Social and Health Decisions]

This is a court procedure through which it is determined that you are unable to make decisions about your medical care or social well-being—that you are a danger to yourself or others. The court appoints someone to make these decisions for you. This guardianship has nothing to do with your money.

RESOURCES

Check out your local resources, including referral agencies, vocational rehabilitation agencies, and your state's independent living centers. [*Also see section 3.d, Community Resources.*]

Publication

The Americans with Disabilities Act: Your Personal Guide to the Law
www.pva.org/publications

Websites

www.ada.gov
U.S. Department of Justice - The ADA home page on the Justice Department website links to technical assistance materials, the Department of Justice information line, status reports, enforcement information, and more.

www.eeoc.gov
Equal Employment Opportunity Commission - This website provides information on laws, regulations, and policy guidance regarding employment.

www.adata.org
Disability and Business Technical Assistance Centers - These centers are located throughout the United States to provide technical help related to the ADA.

3.h | Pain

This section deals with a difficult issue: pain. If you've had significant pain in the past, you understand the impact it can have on your life. Chronic pain is common among people with SCI—as many as 40 percent report ongoing issues. But pain does not have to interfere with happiness. With the right diagnosis, treatment, and attitude, people with chronic pain can maintain a very high quality of life over the long run.

Kinds of Pain

A person with SCI might have no significant pain, one primary pain issue, or pain resulting from a variety of sources. The different kinds of pain can be described by location and duration.

Muscle, Bone, or Tendon Pain

This kind of pain often results from injury to muscles, bones, or tendons that might occur from overuse, overstretching, or falls. This pain can last for weeks or months if your body reacts to the injury with inflammation or muscle spasm. Common sites for this kind of pain are shoulder, low back, neck, and hands, but pain may occur in other sites as well. This pain might feel like aching, grinding, or gnawing; activity often makes it worse; and it is relieved by rest. It be caused or aggravated by heterotopic ossification [bone formation in soft tissues], arthritis, or shoulder impingement. *[See section 1.g, Muscles and Bones.]*

Nerve Pain

Nerve pain can come from pressure, irritation, or stretching. This can occur at the neck or back where the nerves leave the spine; for example, with a slipped disk. Nerves can also be compressed at the elbow or the wrist. One

type of wrist pain due to nerve compression is carpal tunnel syndrome—it can feel like aching, heaviness, tingling, or numbness in the fingers or hand.

Spinal Cord Pain

This is a mysterious kind of pain. Cutting the spinal cord does not cause immediate pain, but SCI can, over days to weeks, lead to pain. It originates in the spinal cord or brain and is often called central pain or neuropathic pain. It might be felt at the level of the spinal cord injury [SCI] as a band around the body that is hypersensitive to touch, or it may tingle or burn. Another type of central pain is a burning, tingling, or freezing sensation below the level of the injury—this may be felt in the feet or around the anus. Another type of central pain is a brief shock or jolt, or a series of quick shocks, often in the legs. Spinal cord pain can develop days to weeks after a spinal cord injury, or even years later if there is additional damage to the spinal cord—for example, if an expanding fluid-filled cyst [called a syringomyelia or syrinx] develops in the spinal cord. Persons with incomplete SCI or cauda equina injuries [low-level SCI at L1 or lower] often have the most severe spinal cord pain, although even those with complete SCI may experience this pain. Neuropathic pain is unpredictable, which makes it hard to tolerate and hard to treat.

Organ Pain

Your internal organs—like your stomach, intestines, or bladder—develop pain if they're overstretched. If you're constipated and your intestine overstretches or if your bladder overfills, you may feel internal abdominal pain. Internal organs can also develop pain if they lose their blood flow; for example, in a heart attack, chest

pain occurs when blood flow to the heart is interrupted. Organ pain [also called visceral pain] can be difficult to distinguish from spinal cord injury pain. If a pain suddenly worsens, it's important to identify it as internal organ pain, a worsening spinal cord problem, or a new muscle, bone, or tendon pain. Bladder overfilling, inflammation of the gallbladder, and heart attack are medical emergencies that require prompt treatment. After spinal cord injury in the neck [cervical] or upper back [thoracic at T6 or higher], sensation from the heart, stomach, intestines, and bladder may be dulled and difficult to pinpoint.

Headache from Autonomic Dysreflexia

People with SCI above the T6 level can develop autonomic dysreflexia [AD], in which blood pressure rises rapidly to high levels in response to bladder distension or some other pain stimulus below the spinal cord injury. Blood pressure can rise to dangerously high levels [higher than 180 mm Hg], which is a medical emergency. [See section 1.i, *Autonomic Dysreflexia*.] AD often causes a kind of headache pain that is unique to spinal cord injury.

Duration of Pain

Acute or short-duration pain

Sudden, severe pain might indicate a medical emergency [for example, AD, heart attack, bleeding ulcer, or appendicitis]. Get prompt medical advice or go to an emergency room. Mild to moderate pain that lasts for days to weeks is often muscle, bone, or tendon pain. It will usually resolve on its own and can benefit from treatment with rest and mild pain medications.

Chronic or long-duration pain

Severe pain that lasts for months or even years with a burning, tingling, shock-like, or shooting quality is often spinal cord pain. Long-lasting mild to moderate pain that has an aching quality and is

aggravated by activity is usually muscle, bone, or tendon pain. Occasionally, this muscle, bone, or tendon pain can be severe.

Diagnosis

It can be hard to identify the exact causes of pain. A health-care provider will listen to your symptoms and examine you, and may need to perform tests. If the cause of the pain can be identified, treatment can be targeted. If the specific cause can't be identified, treatments are on a trial-and-error basis. If you have a sudden onset of severe pain, get medical advice right away.

Treatment

Muscle, Bone, and Tendon Pain

Muscle, bone, and tendon pain can often be reduced or cured. Treatments include short-term rest [less than three days], cold or heat, stretching, massage, mild analgesics [e.g., acetaminophen], and/or anti-inflammatory medications [e.g., aspirin, ibuprofen]. Other treatments for persistent pain might include improving your posture, modifying your mobility techniques, injections into a muscle or joint, and electrical stimulation to the skin [transcutaneous electrical nerve stimulation, or TENS]. Many people can reduce this kind of pain if they improve their technique for activities like transfers and wheelchair propulsion.

Nerve Pain

Nerve pain can be reduced by avoiding pressure or stretching—for example, a wrist splint can relieve night pain due to carpal tunnel syndrome or an elbow pad may relieve pain due to pressure on the ulnar nerve. Splints, pads, alternative wheelchair armrests, positioning aids for computer use, a neck collar, and TENS may help. Occasionally, surgery can help relieve pressure on nerves.

Medications that are used for nerve pain include antiseizure medications, mild pain medications [e.g., acetaminophen, aspirin, ibuprofen], and strong pain medications [e.g., oxycodone, methadone]. Antidepressants can also help reduce pain by increasing neurochemicals in the brain that act as natural pain killers.

Spinal Cord Pain

Current treatments often can't fully relieve spinal cord pain, so the focus should be on improving your quality of life. Various treatments can lessen the pain. Stretching, active exercise, TENS, and relaxation exercises can help. Certain medications can lessen spinal cord pain: antidepressants [e.g., amitriptyline, desipramine] and antiseizure medications such as carbamazepine [Tegretol] and gabapentin [Neurontin]. Topical pain medications [such as capsaicin or analgesic balm] can also help. Sometimes narcotic medications, such as codeine and methadone, are used. The disadvantages of narcotics are that they cause constipation and that you can develop a tolerance to them over time. Whatever approach you negotiate with your health-care provider, make sure you give it enough of a trial. Sometimes it takes several weeks before you can tell if a treatment or medication is helping.

Various kinds of surgery have been tried to relieve spinal cord pain, but nothing has been 100 percent successful. These surgeries include cutting pain pathways in the spinal cord and implanting an electrical stimulator to interrupt the flow of pain signals to the brain.

Expanding vocational, social, and recreational activities may help by allowing you to focus away from your pain. Sometimes other factors—like depression, muscle/bone/joint pain, or visceral pain—can add to spinal cord pain. Treating these

other factors will help reduce the spinal cord pain. The effectiveness of herbal medicine and chiropractic manipulation on spinal cord pain has not been demonstrated. Some studies have found that acupuncture is helpful for reducing SCI pain, but more research is needed.

A Note about Chronic Pain

Most people have some pain at the time of their injury, but fortunately it goes away over time. Some people will have to cope with chronic pain on top of the injury itself. It's important to keep pain from becoming a disabling condition. Many of the treatments for chronic pain only take the edge off. What remains is sometimes called "residual pain." The challenge for people with SCI is to generate activities and live a productive life in spite of residual pain. After the frustration of not finding a complete solution wears off, most patients with chronic pain settle into the task of making meaning in their lives, and this allows them to cope effectively.

If you're dealing with chronic pain, watch for signs that you're getting overwhelmed by it. The following are warning signs that you need to get some help:

- Not participating in important activities.
- Prolonged negative mood or irritability.
- Withdrawal from important relationships.
- Using alcohol or drugs to cope with pain.
- Using pain medications more than the directions say to use them.

If you see these symptoms in yourself, contact a psychologist who's familiar with pain after SCI or meet with a local health care provider who specializes in the management of chronic pain.

Successful Management of Chronic Pain

Pain management is often most successful when people take a broad approach and examine many aspects of their life, relationships, and habits.

Focusing on the following areas can help you live better with chronic pain:

- *Stress management.* Studies have found that when people's stress level increases, their pain also increases. Learning to reduce stress can be beneficial for many reasons, including reducing pain.
- *Time/activity management.* Most people with chronic pain do more when they feel better and less when they feel worse. However, this pattern can lead to a cycle in which people do too much on good days, leading to a spike in pain. Then they need several days to rest. They get frustrated by doing nothing and feel like they are falling behind, so they do too much on their first good day. Studies have shown that people are more productive when they maintain a steady, moderate level of activity regardless of their pain level. It might be a very low level of activity at first, but you can increase slowly to see what works best for you. On days when you have less pain, rest anyway—think of rest as “money in the bank.” This can keep your pain level more even and help prevent disabling spikes.
- *Relaxation techniques.* Relaxation exercises help reduce muscle tension and stress, and they can improve your overall sense of well-being. This can also help with pain management. Use whatever relaxation technique you like, or ask a psychologist or social worker to help you learn a new approach.

- *Counseling.* If your relationships are strained, you're likely to feel more stress and be less satisfied with your life. When you have chronic pain, it's important to have positive things to focus on to distract from the pain. Improving your relationships and learning to do what makes you happy can be a focus of individual or family counseling.

Using the approaches described in this section, you and your health-care team can do a lot to prevent pain problems from developing. As you can see, dealing with pain involves a lot more than medications and trips to the hospital. Medical approaches to pain often make only a moderate difference, so the most important part of the job belongs to you. The critical factors to prevent pain from becoming a disabling condition are understanding the things in your life that make your pain worse, having realistic expectations about what health-care providers can do to reduce your pain, and making the quality of your life the focus of your care.

RESOURCES

Websites

www.spinalcord.uab.edu/show.asp?durki=4119
Pain following SCI: Information on types of pain and how it's treated, from the SCI Information Network.

http://sci.washington.edu/info/newsletters/articles/01sum_pain_sci.asp
Causes and treatments for pain: Information from the Northwest Regional SCI System.

www.spinalcord.uab.edu/show.asp?durki=21607&site=1021&return=21874
Pain management: The National SCI Association has links to articles on pain following SCI.

3.i | Brain Injury

One-quarter to one-half of all people with spinal cord injury [SCI] also have had a brain injury, either at the time of their SCI or earlier in their lives. A blow to the head can occur in a motor vehicle collision, a fall, or a blast; when the head is struck by an object; or in other ways. Often, there are no lasting symptoms from a mild injury to the head, but sometimes the force is severe and the brain is permanently injured. In a brain injury the brain may be shaken around and get bruised from hitting the inside of the skull. Like a black-and-blue mark on your arm or leg, this will heal over time. The brain has many thousands of long, thin nerve fibers. Some of these nerves can be damaged in an injury. Also, the brain has blood vessels that can tear and bleed into or around it. Finally, the injury might interrupt the flow of oxygen to your brain for a period of time.

How Serious Was the Injury?

One way to judge the seriousness of your brain injury is to determine how long you were unconscious. If you weren't knocked out at all or you were unconscious for less than an hour, the injury was probably minor or mild. Most people who have a brain injury fall into this category. Although you may have some symptoms, you'll probably recover completely. The longer you were unconscious, the longer your recovery will probably take. If you were knocked out for more than an hour but less than a day, your injuries were most likely moderate. Recovery will probably take a while, and a few symptoms may be permanent. Your rehabilitation program may need to address some of these symptoms to allow you to achieve your maximal independence.

People who are unconscious for more than a day have likely suffered a severe brain injury. Although some of these people make a good recovery even

[Table 3.i.A] Symptoms of Postconcussion Syndrome

SYMPTOMS	PERCENTAGE OF PATIENTS
Poor concentration	71
Irritability	66
Fatigue	64
Depression	63
Memory problems	59
Headaches	59
Anxiety	58
Trouble thinking	57
Dizziness	53
Blurry or double vision	45
Sensitivity to bright light	40

after a severe brain injury, symptoms can often last for some time, and many symptoms will be permanent. People with severe brain injuries will always need additional rehabilitation treatments beyond those they need for their SCI.

What Symptoms Can I Expect?

Bruises, brain swelling, damaged nerves, and broken blood vessels are the causes of symptoms after a brain injury. The most common symptoms after a mild brain injury are called the “postconcussion syndrome.” These symptoms are listed in Table 3.i.A, along with the percentage of brain-injured persons who experience each symptom at some point in their recovery.

How Long Will the Symptoms Last?

How long it takes to recover depends on the severity of the injury, your age at the time you

were injured, and whether or not you have suffered another brain injury in the past. The most rapid recovery usually occurs in the first six months after brain injury. If your injury was mild, you'll probably see most of your recovery in the first three months. If you suffered a severe injury, recovery can take as much as two years. During the second year, improvements will be more gradual, and some symptoms may never go away completely.

Not everyone recovers at the same rate. People younger than 40 recover faster and have fewer complications while they're recovering. Older people are more likely to suffer from anxiety, depression, and memory and thinking problems. People who are older should expect recovery to take 6–12 months, even after a mild brain injury.

[Table 3.i.B] Symptoms of Stress for People Without a Brain Injury

Poor concentration
Irritability
Fatigue
Depression
Memory problems
Headaches
Anxiety
Trouble thinking
Dizziness
Sensitivity to bright light

Neuropsychological Testing after Brain Injury

If you've had a brain injury, your health-care team may want you to have neuropsychological testing. This involves a visit with a psychologist, where you'll answer questions, solve problems,

and possibly do paper-and-pencil tests. These tests look at your ability to learn, remember information, pay attention, solve problems, and use language. The purpose is to see if you've developed any problems with these abilities as a result of your brain injury. Testing may be done again later to see if the problems have cleared up. Neuropsychological testing can sometimes be divided up over a few sessions so you don't get overly tired. The results of these tests can give important information to you and the rehabilitation team about how you can best learn, or about the best way for you to return to work and other activities.

What Can I Do about the Symptoms?

At first, postconcussion syndrome can make it hard to work, get along with others, or relax. The best way to deal with this is to resume activities and responsibilities a little at a time. Pace yourself and be sure to get all the rest you need. If your symptoms get worse or if you notice new postconcussion symptoms, you're probably pushing yourself too hard.

Ignoring your postconcussion symptoms and trying to tough it out can make the situation worse. Symptoms are your body's way of giving you information. A broken bone or a torn muscle hurts so you won't use it and it has time to heal. Postconcussion syndrome is your brain's way of telling you that you need to give it a rest. You'll recover faster if you get enough rest and resume your responsibilities gradually.

Some of the symptoms you notice after brain injury may actually be caused by stress. The symptoms of postconcussion syndrome are pretty much the same as the symptoms of ordinary, day-to-day stress. Table 3.i.B lists of the common symptoms of stress.

Having a brain injury adds more stress to your life, not just bumps and bruises to your brain. The

accident itself and being in the hospital add stress. Bills can pile up, time is lost, and other parts of your body were injured as well. It's important to talk to a health-care provider about your symptoms. You may want to consider counseling to help you cope with the symptoms of your brain injury and to help you learn how to manage everyday life to reduce your level of stress.

Specific Symptoms and What to Do

Poor concentration

The main cause of poor concentration is fatigue. When it's hard to concentrate on what you're doing, take a break—15 to 30 minutes should be enough. If you continue to have problems, temporarily shorten your schedule. Trying to do too much will only make things worse.

Reducing distractions can help. Turn off the TV or radio, or try to work where it's quiet. Don't do too many things at once. Writing while you talk on the phone or taking notes as you listen to someone talk are examples of doing two things at the same time. At first it might be hard for you to concentrate on more than one thing at a time. You'll be able to concentrate better when you've had enough rest.

Irritability

Irritability can be caused by injury to the frontal lobes, which are located at the front of the brain. As your brain heals, you'll become less irritable. Fatigue makes people irritable, too. People lose their tempers more easily when they're tired or overworked. Adjust your schedule and get more rest if you notice yourself becoming irritable.

Everyone gets angry from time to time, sometimes with good reason. Being irritable becomes a problem when it interferes with your ability to get along with other people. If you find yourself getting into arguments, try to change the way you think about things. Our thoughts often make us angrier than what actually happened.

If you find that you're more irritable since your injury, acknowledge it and plan accordingly. You may need to learn to [1] watch your interactions with others closely, [2] remain calm, [3] take a break from an interaction if it gets heated, and [4] say you'd like to "come back" to a subject later. Problems are more likely to be solved if you stay calm and explain your point of view. Others will respond more positively to you and will be more likely to listen. Try to remind yourself of this when you find yourself getting irritable.

Fatigue

It's normal to be more tired after a brain injury, and the only sensible treatment for being tired is to rest. Avoid wearing yourself out. Increase your activity level gradually. Most people with brain injury have more energy in the morning than later in the day. You may benefit from scheduled rest breaks or naps. If your symptoms get worse, you're pushing yourself too hard. Many of the medications taken by people with SCI can cause fatigue. Poor sleep is another common cause of fatigue soon after a spinal cord injury. This can be caused by many things, including nursing care during the night, noise from other patients, or nighttime breathing difficulty such as sleep apnea.

Depression

Some people become depressed after a brain injury. Depression after traumatic brain injury can be situational—meaning that you're depressed because you have a new problem. It can also be caused by physical changes—the injury may have affected some of the areas of your brain that control your feelings and emotions. Counseling and/or medications can help with depression after a brain injury.

Memory problems

Memory problems have several causes. The temporal lobe [a part of the brain involved in learning] is often damaged in a brain injury. These injuries heal with time, and memory

problems usually improve. If you can remember the accident, chances are your brain was not injured severely. Many of the memory problems people notice after a brain injury are not caused by bruising; instead, they come from poor concentration and being tired. To remember something, you have to pay attention to it in the first place. If you don't concentrate long enough, the information is never stored in your memory. Concentration problems are a normal part of recovering from a brain injury. You'll probably be able to concentrate and remember better when you get enough rest. Memory problems can be a sign that you're pushing yourself too hard. Writing things down or using a pocket tape recorder are excellent ways of coping with temporary memory problems. Doing these things will help recovery, not slow it down.

Of course, no one's memory is perfect anyway. People sometimes forget that they had trouble remembering things even before the accident. Some of the symptoms you notice may have nothing to do with your brain injury. Don't make too much out of forgetting things occasionally.

Headaches

Occasionally, headaches are caused by serious medical problems. Because a headache can indicate a serious complication after brain injury or a medical complication like autonomic dysreflexia, be sure to discuss it with your health care provider. On the other hand, headaches are very common during the recovery process after a brain injury and usually do not indicate a serious problem. Headaches are another cause of irritability and concentration problems after a brain injury.

One of the most common causes of headaches after a brain injury is stress or tension. This may be the cause if the headaches start several weeks after the injury. These headaches might mean that you're trying to do too much. They'll

probably disappear if you take breaks and relax. Stress and worry cause tension headaches—the muscles in your neck or forehead become tense and can stay tight without your realizing it. And once a headache starts, they can get even tighter, because muscles automatically tense in reaction to pain. This makes the headache worse. If you have tension headaches, you'll need to learn ways to relax and reduce your stress. It might be helpful for you to learn meditation, relaxation techniques, or better ways to manage stress.

Dizziness, visual problems, and light sensitivity

Have your health-care provider check these symptoms. They usually go away by themselves within three to six months—and sometimes sooner. If you find them troublesome, talk to your provider about appropriate treatment.

SCI Rehabilitation with a Brain Injury

If you've had a moderate or severe brain injury, you may need to take part in a brain rehabilitation program before you can fully participate in a rehabilitation program for your SCI. SCI rehabilitation can be challenging after brain injury, because you need to learn so much new information. Also, fatigue from your brain injury may keep you from getting the most out of therapy sessions.

When you start your SCI rehabilitation, let your therapists know if you're having any trouble remembering information or learning new skills. They can repeat information more often and write down important points for you to remember. You might also find that you get tired easily or are easily frustrated. If so, you might need to move through your rehabilitation at a slower pace. Let your therapists know if you need to take a break or schedule shorter appointments at first. Also, let people know when you're starting to feel frustrated, and try some of the suggestions above for dealing with irritability. It's important for you

to communicate your needs and symptoms so you can learn and participate in the ways that work best for you. Don't be shy or embarrassed. It's normal to have these symptoms after a brain injury.

What If the Symptoms Are Permanent?

If you're still having memory, thinking, or behavior symptoms that are not going away, you'll have to learn to adapt to and compensate for these symptoms. A psychologist can help you develop strategies for this. It might be helpful to involve your family in visits to the psychologist, because all of you are learning to adapt to the changes. You might also need to modify your work or other goals. The most important thing is to continue engaging in enjoyable recreation and work activities [paid or volunteer] and continue working toward creating meaningful social relationships, just as you did before you had a brain injury.

About This Chapter

The information presented in this chapter is based on (1) a guide from The Defense and Veterans Brain Injury Center at Wilford Hall Medical Center, Lackland AFB, Texas; (2) Mittenberg, W., Zielinski, R.E., & Fichera, S. (1993) "Recovery from mild head injury: A treatment manual for patients," *Psychotherapy in Private Practice*, 12, 37-52; and (3) other published scientific research.

RESOURCES

Websites

www.biausa.org

Brain Injury Association of America

<http://depts.washington.edu/rehab/tbi>

University of Washington TBI Models Systems;
click on TBI Newsletter

www.mayo.edu/model-system

Mayo Clinic TBI Models Systems; click on
Guide for Families

Staying Healthy After SCI

Not so long ago, staying healthy after a spinal cord injury wasn't an issue because most people died of medical complications within the first year after their injury. Now, life expectancy is not reduced much at all for many people with spinal cord injury [SCI]. The same things that keep people healthy if they don't have SCI—exercise, nutritious foods, and avoiding obesity and substance abuse—work for those with SCI. It's also important to receive regular medical follow-up and preventive services. This section covers some of the things you should consider to maintain your health.

4.a | Recreation

Recreation! What images or ideas come to mind when you hear that word? Camping? Watching movies or playing video games? Biking, skiing, or gardening? How about cooking or reading a book?

Recreation is simply the activities we pursue in our free time. We choose these leisure activities for a variety of reasons, and they might change throughout life or even by the season of the year. Think about all the activities you've enjoyed on a regular basis [like exercising or reading] or when the opportunity arises [like skiing, fishing, or traveling]. Each of us has a unique set of recreation or leisure interests—the ones you choose reflect who you are and what is important to you.

Leisure activities have many meanings in our life. They allow us to express ourselves, release tension, master skills, meet people, and improve our health. We need these activities to experience risks and challenges, to be exposed to new ideas, to accomplish things, and to build pride. Most important, through, we need them to help us relax and have fun. Your recreational activities are the options that make up your leisure lifestyle.

This section aims to motivate you to feel the freedom of expressing yourself through your leisure activities. It offers information, answers questions, and identifies resources to help you toward that goal.

Recreation in Rehabilitation

While you're in the hospital, you should have the opportunity to explore how leisure fits into your life. Recreation or leisure might be the last thing on your mind while you're busy learning critical skills to take home with you. But once you master those skills, you'll find yourself with some free

time. This is important time that you can use to pursue the things in life that bring you joy. We all do the things we need to so we can do the things we want to. As you progress in your rehabilitation, you may have opportunities to participate in recreation or recreation therapy programs in the hospital and in the community. Give them a try. Programs in the hospital will allow you to enjoy an activity that you have an interest in. These programs also are usually designed to support the skills or strengths that you're focusing on in your other therapies.

Playing a board game with other patients or family or developing a hobby can relieve stress and add some fun during a very difficult time. These activities also can help you build hand function, increase endurance, and provide other benefits that support your recovery. Community activities are also essential to your rehabilitation. The thought of going outside the hospital might seem scary at first. These feelings are very important, and there's no need to minimize them. But don't let them stop you. You might have the opportunity to go out to eat, to the movies or shopping, or to a sporting event. These experiences will help you discover your strengths, learn about accessibility, enhance your wheelchair skills, and have fun. The first outings may be difficult, but they'll get easier.

Remember that your recreational interests are a part of you. Don't cross important interests off your list because you think you can't do them anymore. Give yourself time to heal and get stronger. You'll discover that something that doesn't seem possible right now actually is. The first time you try an activity you formerly enjoyed—such as painting, swimming, shooting pool, or playing ball with your son or daughter—might be challenging. But keep at it. Eventually,

4.a

you'll look back and congratulate yourself on how far you've come.

Be patient with yourself, and don't give up!

Recreation and Adaptation

When you're thinking about participating in an activity, there are some things to consider. Has your injury affected your mobility, the way you get around? How much strength and coordination do you have in your arms and hands? Are people available to provide assistance if you need it to participate in the activity? How have your endurance and stamina been affected? Talk with your therapists and doctors and get a clear idea. It's important to understand the effect your injury has had on you. There may be some medical or safety precautions that you should consider when you're making decisions about specific activities. You need to know what these precautions are. Whether you use a community-based recreation service or try something for the first time with family or friends, it's up to you to consider the needs of your body. It's your job to make sure an activity is healthy for you, not harmful. Your rehab team is available to help you.

You may benefit from adaptation or assistance to do the things you enjoy. The purpose of assistance and adaptation is to help you do an activity as independently as possible. Assistance comes in many forms—it might be equipment or another person. Could you benefit from a power reel and fishing pole holder? Or maybe you just need someone to bait the hook for you. A minor adaptation to the rules or techniques might be all it takes to increase your independence with an activity. Not every person or every activity requires modification.

Many sports and games have modified rules that are a form of adaptation. These modified rules don't really change the game; they just make it

practical for the competitors or participants. An example is the two bounces allowed for wheelchair tennis. This double bounce allows the player using a wheelchair to keep the game challenging and competitive. Some games and sports are exclusively wheelchair sports, like power soccer and quad rugby. These two sports have unique rules of play that differ significantly from the rules for the original sport, but they retain their intense and competitive nature. Golf is a game where you can use adaptive equipment, but the rules remain the same. For safety reasons and practicality, some sports—like softball, hockey, and basketball—require that everyone use a sport chair to play. In fact, some community centers keep a stock of basketball chairs on hand so non-wheelchair-users can play with wheelchair-users. Most team sports have a classification system that evaluates a person's function and regulates the competition.

Not into team or organized sports? Fine. This is all about identifying an activity that's rewarding for you. Equipment is available to support nearly any interest you might have. Your functional level will determine your equipment needs. You can hunt using a sip-n-puff trigger mechanism. Some mounts allow chin control of a joystick to make fine target adjustments. Painting with a mouth-stick might require little more than the mouth-stick, an easel, and someone to set it up for you. For some pursuits, the equipment is customized; for others, standard gear is all you might need. Camping? Get a tent with a large enough opening for your wheelchair to pass through. If you use a power wheelchair, get a campsite with power hook-up so you can charge your chair at night. Every sporting goods store sells inflatable camping mattresses. The 18-plus inches of air makes for a good night's sleep and an easy time transferring in and out. However, the mattress surface might not meet your skin protection needs—consult with your health-care provider for recommendations; you may need only to turn more often during the

night. Swimming? You might be independent and not need any floatation equipment, or you might need someone to support you and help you move through the water.

Resources for Recreation

Some recreation resources are right around the corner. Look in the Yellow Pages and search the Internet. Contact your local YMCA or YWCA, community centers, and the parks and recreation department for information on events and organizations. Call local rehabilitation professionals and ask about recreation organizations, or ask them to refer you to other people with disabilities. Peers are a terrific resource to let you know what's happening and to provide support. Colleges and community centers offer many classes that are a great way to start increasing your activity. Take a cooking class or learn a language. Parks and recreation departments, churches, and veterans and community organizations also offer classes and programs. Try something different. For example, getting involved in local government is a good way to meet people.

A number of sports and outdoor recreation resources are listed under Resources at the end of this section. Many of these organizations have been very successful in developing equipment and resources to support greater independence and more opportunities. Look for ideas in bookstores under Outdoor Recreation and Sports. Don't feel as though you should stick to disabled sports resources—every sport has a magazine full of opportunities and ideas. Be creative!

Depending on your interests, recreational equipment can be very expensive. Handcycles, for example, can cost several thousand dollars. Buying this kind of equipment yourself might not be an option, but there are other ways to obtain it.

Talk with your health-care provider and explain your goals for getting the equipment [like exercise and healthier living]. Ask the provider to write a prescription for that equipment, just like they would for a wheelchair or other assistive device. With a prescription, your health insurance might pay for the equipment. You can also check out grants from organizations like the Challenged Athletes Foundation—there will probably be an application process to determine your goals, financial need, and so on. If you're a veteran, your VA hospital might be able to purchase sports equipment for you. Check with the local VA facility to determine your eligibility. Two other options are to search the Internet for used equipment or to network with others in your area to borrow equipment. Before you purchase or borrow equipment, make sure it's in good condition and it fits right. Sports equipment should be customized for you just as much as your everyday wheelchair.

If having recreational equipment is important to you, be persistent.

Local, State, and Federal Recreation Passes

Many local, state, and federal agencies offer free or discounted recreational programs for people with disabilities. Look on the Internet and call your city, county, and state parks and recreation departments and ask what programs they offer. When you're looking for programs, consider all the categories that might apply to you—person with a disability, senior citizen, veteran, and so on. Always ask if a recreational program or business offers a discount for you and possibly for your attendant as well. Some movie theaters, museums, and so on will give your companion a discount or free pass if he or she is also your "attendant." The following are just a few examples of the programs that exist.

Many cities have programs for people with disabilities, and some offer reduced or free admission for parks, zoos, aquariums, and so on. States may offer similar programs. For example, California offers a disabled discount pass that gives a 50 percent discount on the use of all basic facilities at any unit of the California state park system. California also has a disabled veteran/prisoner of war [POW] pass program that provides free access to all state park system facilities. Every state has its own set of permits and regulations for hunting, fishing, and outdoor recreation for people with disabilities. Some discounts and permits require a doctor's signature.

The National Park Service offers a Golden Access Passport to permanently disabled U.S. citizens. This program offers lifetime free entrance to all national park system areas and 50 percent off camping fees in federal campgrounds.

Recreation is a very important part of your life. Leisure activities are a significant source of self-confidence and satisfaction in life. Be patient and start by setting small goals. You may look back in a year and be amazed at how far you've come. Have fun—recreation is great medicine.

RESOURCES

Sports Organizations

Amputee Sports

Disabled Sports USA
451 Hungerford Drive, Suite 100
Rockville, MD 20850
[301] 217-0960
www.dsusa.org

Archery

Wheelchair Sports USA
1236 Jungermann Rd., Suite A
St. Peters, MO 63376
[636] 614-6784
www.wsusa.org

Physically Challenged Bowhunters of America
[PCBA]

2152 Route 981
New Alexandria, PA 15670
www.pcba-inc.org

Arts

VSA arts
818 Connecticut Ave., NW, Suite 600
Washington, DC 20006
[800] 933-8721
www.vsarts.org

Mouth and Foot Painting Artists [MFPA]
2070 Peachtree Industrial Court, Suite 101
Atlanta, GA 30341
[770] 986-7764
www.mfpausa.com

Basketball

National Wheelchair Basketball Association
6165 Lehman Drive, Suite 101
Colorado Springs, CO 80918
[719] 266-4082
www.nwba.org

International Wheelchair Basketball Federation
[IWBF]
189 Watson Street #109
Winnipeg, Manitoba, Canada R2P 2E1
[204] 632-6475
www.iwbf.org

Canadian Wheelchair Basketball Association
2211 Riverside Drive, Suite B2
Ottawa, Ontario, Canada K1H 7X5
[613] 260-1296
www.cwba.ca

Billiards

National Wheelchair Poolplayer Association, Inc.
9757 Mount Lompoc Ct.
Las Vegas, NV 89178
[702] 437-6792
www.nwpainc.org

Bowling

American Wheelchair Bowling Association
P.O. Box 69
Clover, VA 24534-0069
[434] 454-2269
www.awba.org

Flying

Able to Aviation
60 Benson Avenue
Sayville, NY 11782
[631] 374-3680
www.able-to-aviation.com

Freedom's Wings International
P.O. Box 7076
East Brunswick, NJ 08816
[800] 382-1197
www.freedomswings.org

International Wheelchair Aviators
P.O. Box 440
Big Bear City, CA 92314
[951] 529-2644
www.wheelchairaviators.org

Football

Universal Wheelchair Football Association
University of Cincinnati Raymond Walters College
Disability Services Office
9555 Plainfield Road
Cincinnati, OH 45236-1096
[513] 792-8625
www.rwc.uc.edu/kramer/page1.htm

Golf

United States Golf Association Foundation
Resource Center
1631 Mesa Avenue
Colorado Springs, CO 80906
[719] 471-4810, ext. 15
www.resourcecenter.usga.org

Handcycling

U. S. Handcycling
P.O. Box 3538
Evergreen, CO 80437
[303] 459-4159
<http://www.ushandcycling.org/>

Hockey

United States Sled Hockey Association
http://www.usahockey.com/disable_hockey/default.aspx

Horseback Riding

American Competition Opportunities for Riders
with Disabilities [ACORD], Inc.
[www.allbusiness.com/membership-organizations/
membership-organizations/4048603-1.html](http://www.allbusiness.com/membership-organizations/membership-organizations/4048603-1.html)

North American Riding for the Handicapped
Association
P.O. Box 33150
Denver, CO 80233
[800] 369-7433
www.narha.org

Motorcycling

National Handicap Motorcyclist Association
404 Maple Avenue
Upper Nyack, NY 10960
[914] 353-0747

Multisport

Wheelchair Sports USA
1236 Jungermann Rd., Suite A
St. Peters, MO 63376
[636] 614-6784
www.wsusa.org

Casa Colina Outdoor Adventures
255 E. Bonita Avenue
Pomona, CA 91769
[909] 596-7733
www.casacolina.org

Disabled Sports USA
451 Hungerford Drive, Suite 100
Rockville, MD 20850

BlazeSports America National Office
280 Interstate North Circle, Suite 450
Atlanta, GA 30339
[770] 850-8199
www.blazesports.org

Parks

National Park Service
www.nps.gov
Golden Access Passport and information on
national parks for people with disabilities.
www.nps.gov/fees_passes.htm

Power Soccer

Wheelchair Sports USA
1236 Jungermann Rd., Suite A
St. Peters, MO 63376
[636] 614-6784
www.wsusa.org

World TEAM Sports
P.O. Box 15632
Boston, MA 02215
[617] 512-7161
www.worldteamsports.org

Quad Sports

Bay Area Outreach and Recreation Program [BORP]
600 Bancroft Way
Berkeley, CA 94710
[510] 849-4663
www.borp.org

United States Quad Rugby Association
www.quadrugby.com

Racquet Sports

International Tennis Federation
[Wheelchair Tennis Department]
Bank Lane
Roehampton
London SW15 5XZ
United Kingdom
[011] +44 [0] 20 8878 6464
www.itftennis.com

United States Tennis Association
www.usta.com/playnow/wheelchair/default.sps

Road Racing

Wheelchair Track and Field-USA [WTFUSA]
www.wsusa.org

Shooting

NRA Disabled Shooting Services
11250 Waples Mill Road
Fairfax, VA 22030
[800] 672-3888
www.nrahq.org/compete/disabled.asp

Wheelchair Sports USA
1236 Jungermann Rd., Suite A
St. Peters, MO 63376
[636] 614-6784
www.wsusa.org

Skiing

Disabled Sports USA
451 Hungerford Drive, Suite 100
Rockville, MD 20850
[301] 217-0960
www.dsusa.org

Ski for Light, Inc.
1455 West Lake St.
Minneapolis, MI 55408
[612] 827-3232

U.S. Disabled Alpine Ski Team
www.usskiteam.com/public/home.php?dId=5
[970] 453-7532

Softball

National Wheelchair Softball Association
6000 West Floyd Avenue, #110
Denver, CO 80227
[303] 842-1229
www.wheelchairsoftball.org

Table Tennis

American Wheelchair Table Tennis Association
[AWTTA]
23 Parker Street
Port Chester, NY 10573
[914] 937-3932
<http://www.awtta.org/>

Water Sports/Recreation

Access to Sailing
423 Suite Shoreline Village Dr.
Long Beach, CA 90802
[562] 501-9999
www.accesstosailing.org

American Canoe Association
1340 Central Park Blvd., Suite 210
Fredericksburg, VA 22401
[540] 907-4460
www.acanet.org

Handicapped Scuba Association International
1104 El Prado
San Clemente, CA 92672-4637
[949] 498-4540
www.hsascuba.com

USRowing
2 Wall Street
Princeton, NJ 08540
[800] 314-4ROW
www.usrowing.org

U.S. Wheelchair Swimming, Inc.
Wheelchair Sports USA
5224 Harvest Loop
Eugene, OR 97402
www.wsusa.org

Water Skiers with Disabilities Association
USA Water Ski
1251 Holy Cow Road
Polk City, FL 33868
[863] 342-4341
www.usawaterski.org

Weightlifting

Contact Wheelchair Sports USA office
www.wsusa.org

Magazines

Sports 'n Spokes
2111 E. Highland Avenue, Suite 180
Phoenix, AZ 85016-4702
[888] 888-2201
www.pvamagazines.com/sns

Sports Equipment

Access to Recreation
8 Sandra Court
Newbury Park, CA 91320
[800] 634-4351
<http://www.accesstr.com/>

Note: Paralyzed Veterans of America sponsors numerous sporting and recreational events.
Go to www.pva.org/sports for more information.

4.b | Nutrition and Weight

What should you eat to stay healthy? Hardly a day goes by without someone trying to answer that question. Newspapers, magazines, books, radio, and television give us a lot of advice about what we should or should not eat. Much of this advice is confusing because we don't know enough about nutrition to identify the "ideal" diet for each person. People differ, and their food needs vary depending on their age, gender, body size, physical activity, and other conditions—such as a spinal cord injury [SCI].

But there are some basic guidelines for healthy eating:

- Eat a variety of foods.
- Maintain ideal weight.
- Avoid too much fat, saturated fat, trans fat, and cholesterol.
- Eat foods with adequate complex carbohydrates and fiber.

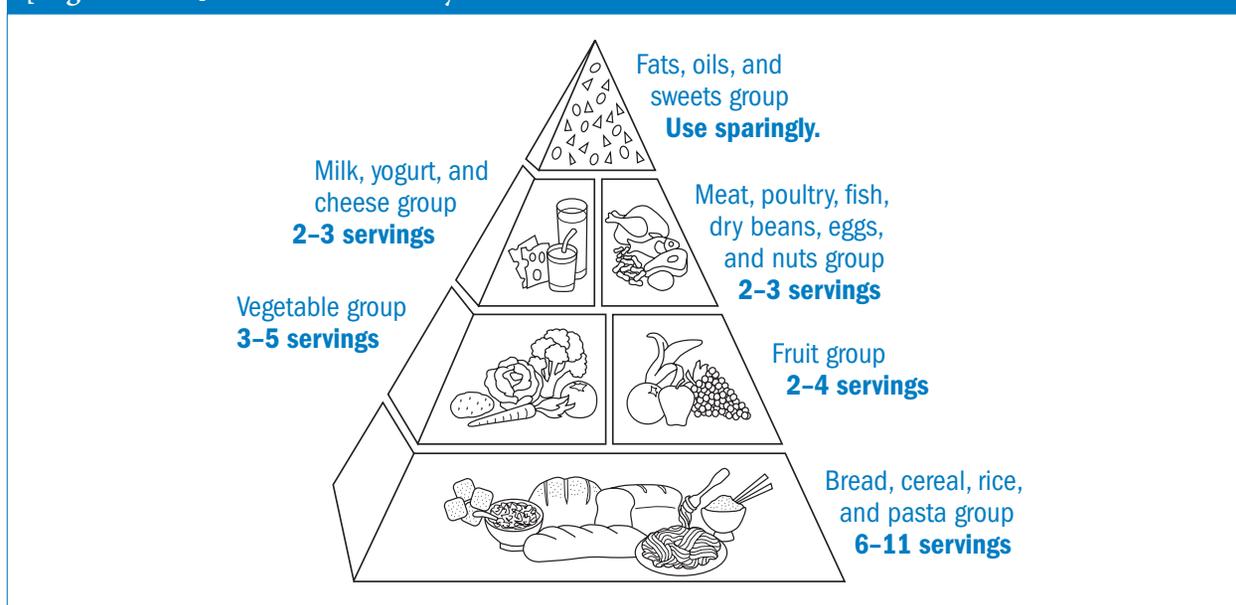
- Avoid too many sweets.
- Avoid too much sodium.
- If you drink alcoholic beverages, do so in moderation.

Eat a Variety of Foods

To stay healthy, you need about 40 different nutrients, including vitamins, minerals, protein, carbohydrates, fats, and water. No one food supplies all the nutrients your body needs, so you should eat a variety of foods. One way to ensure variety and a well-balanced diet is to use the Department of Agriculture's food guidance system, MyPyramid [SEE FIGURE 4.b.1 AND GO TO THE WEBSITE AT WWW.MYPYRAMID.GOV].

If you eat a wide variety of foods, you won't need to take vitamin or mineral supplements. But if you're not able to eat according to the MyPyramid guidelines, a multivitamin and mineral supplement might help you meet your nutritional needs. Check with your doctor or dietitian first.

[Figure 4.b.1] The Food Guide Pyramid



Maintain an Ideal Weight

If you're too heavy, you'll have a much greater chance of developing a chronic disorder. Obesity is associated with diabetes, high blood pressure, and high levels of fats in your blood, which can lead to heart disease and hardening of the arteries, and can increase your risk of having a heart attack or a stroke. Obesity can also increase your risk of developing pressure ulcers and can impair your

mobility. If you transfer independently, the extra weight can lead to shoulder problems. If you require assistance for transfers and bed mobility, the extra weight makes the job that much harder for your caregivers.

If you're underweight, you may be less able to fight infections and may tire more easily. If your bones stick out, you may be more likely to get pressure ulcers. Being underweight is also associated with a shortened lifespan.

[Table 4.b.A] Acceptable Weight Ranges

HEIGHT [feet/inches]	WEIGHT [pounds]
MEN	
5'1"	123-129
5'2"	125-131
5'3"	127-133
5'4"	129-135
5'5"	131-137
5'6"	133-140
5'7"	135-143
5'8"	137-146
5'9"	139-149
5'10"	141-152
5'11"	144-155
6'0"	147-159
6'1"	150-163
6'2"	153-167
6'3"	157-171
WOMEN	
4'9"	97-106
4'10"	98-108
4'11"	99-110
5'0"	101-113
5'1"	103-116
5'2"	106-119
5'3"	109-122
5'4"	112-125
5'5"	115-128
5'6"	118-131
5'7"	121-134
5'8"	124-137
5'9"	127-140
5'10"	130-143
5'11"	133-146

So the goal is to maintain your ideal weight. How do you determine what's ideal for you? There is no absolute answer for this. Paralyzed muscles often become much smaller, so body weight usually drops 10 pounds for people with paraplegia and 20 pounds for people with tetraplegia. Table 4.b.A gives acceptable weight ranges for most people with SCI. Ask your health-care provider or dietitian what your ideal weight should be.

Weight Loss

Do you need to lose weight? If so, you have to take in fewer calories than you burn. You either have to select foods that have fewer calories or increase your activity—or both. Here are some ways to lose weight:

- Limit the size of your portions.
- Don't have seconds.
- Eat slowly, allowing at least 20 minutes per meal.
- Enjoy every bite.
- Make eating a separate activity [for example, don't watch TV while you eat].
- Try not to skip breakfast or lunch, and avoid overeating at dinner.
- Don't use food as a way of dealing with boredom, anger, fatigue, or anxiety.
- Consciously choose food for its nutritive value.

- Avoid keeping high-calorie, low-nutrient snacks around the house.
- Eat less fat and fatty foods.
- Eat less sugar and sweets.
- Eat only when you're hungry.
- Be active.
- Know the danger periods during the day when you tend to overeat. Be prepared with other activities.
- Be forgiving. No one's perfect. If you fall off your diet for one meal or one day, eat less the next meal or the next day.

Lose weight gradually so your body can adjust to the change—one or two pounds a week is safe. If you lose weight gradually, you're less likely to gain it back again. Long-term success depends on finding new and better habits of eating and exercise. If you want to lose weight, your dietitian can help you plan a diet that meets your needs.

The EATRIGHT® Home-Based Weight Management Program for Persons with SCI

There are a million weight loss programs out there. Although many of them rely on reducing calories, the weight loss is often temporary, because people don't go beyond weight *loss* to weight *management*. Weight management requires you to learn some skills that will enable you to maintain your ideal weight through diet, physical activities, and behavioral changes. Learning these skills will promote your long-term health.

If you manage your weight, you can lower your risk for heart disease, high blood pressure, diabetes, respiratory illness, pressure ulcers, urinary tract infection, urinary stones, and some forms of cancer. Weight management can help decrease feelings of anxiety, loneliness, and stress

while improving muscle strength, endurance, self-image, and your ability to fall asleep and sleep well. Weight management can also help you manage muscle spasms and chronic pain, as well as your bowel program. All these benefits will make it easier to accomplish everyday tasks and will help you live a longer, healthier life.

However, most weight management programs aren't designed for persons with SCI. Your nutritional needs and physical abilities aren't the same as those of people in the general population. For example, if you follow a diet that's low in carbohydrates and high in protein, you're more likely to have kidney problems. If you exercise the wrong way, you can add stress and strain to your muscles and joints, which can cause chronic pain.

In 1976, a team of University of Alabama at Birmingham [UAB] physicians, dietitians, and psychologists developed the EATRIGHT Weight Management Program. In 2003, UAB completed a four-year study of a modified version of the program developed especially for persons with SCI. Study participants attended 12 weekly classes to learn the necessary skills for effective weight management. The modified EATRIGHT program was shown to be a safe and effective weight management program that can reduce medical risks and improve quality of life for persons with SCI.

To make this program available to the people who need it, the Paralyzed Veterans of America [PVA] made a grant to UAB to create the EATRIGHT Home-Based Weight Management Program for Individuals with Spinal Cord Impairments. This program uses videos and workbooks to guide people through the 12 elements of effective weight management [SEE TABLE 4.b.B].

[For information on how you can take advantage of this program, see Resources at the end of this section.]

[Table 4.b.B] 12 Elements of Effective Weight Management

1. Getting started
2. Making healthy food choices
3. Improving self-talk
4. Goals
5. Planning meals
6. Participating in physical activities
7. Shopping
8. Understanding nutrition
9. Cooking
10. Reducing stress
11. Dining out
12. Maintaining long-term success

[Source: EATRIGHT™ Program]

Weight Gain

If you need to gain weight, do it gradually. A steady gain of one to two pounds a week will allow your body to gain muscle mass and not just fat. The following are some ways to gain weight:

- Eat at least three balanced meals each day.
- If you have a small appetite, eat six small meals a day.
- Eat foods that have a higher fat content, like whole milk, milkshakes, eggnog, raw vegetables with dip, and cream soups.
- Use thick gravies and cream sauces.
- Eat high-calorie snacks between meals, like dried fruit, nuts, ice cream, and milkshakes. If you're busy during the day, carry your snacks with you.
- Make mealtime as pleasurable and relaxed as possible by planning your meals ahead of time and eating with a friend. Avoid arguments during mealtime.
- Prepare foods that look good and are tasty.
- Save foods that fill you up fast and eat them at the end of the meal [for example, liquids and high-fiber foods like salads, vegetables, and fruits].

- Add extra peanut butter, jelly, or jam to bread and crackers.

Avoid Cholesterol and Certain Fats

Saturated fat, trans fat, and cholesterol can increase your risk of developing heart disease. Saturated fats are mainly found in animal foods [like meat, butter, and whole milk dairy products] and in tropical vegetable oils [coconut, palm kernel, and palm oils]. Trans fats [short for trans fatty acids] are found in stick margarine, solid shortening, and many prepared foods, like crackers, cookies, doughnuts, snack foods, and commercially fried foods. Like saturated fats, they raise your blood levels of bad cholesterol and increase your risk of heart disease. Cholesterol is an essential component of every cell in your body, but you don't need to eat it because your liver makes all you need. It's found in food that comes from animal sources. Too much cholesterol in your diet will increase the cholesterol level in your blood.

To avoid too much fat and cholesterol:

- Choose lean meat, fish, poultry, dry beans, and peas as your protein sources.
- Limit eggs to three a week or less and limit organ meats such as liver.
- Limit your intake of butter, cream, stick margarine, shortenings, coconut oil, and foods made with these products.
- Trim excess fat and skin off meats.
- Broil, bake, or grill food rather than frying it.
- Read labels carefully to see how much and what kind of fat is in the food, especially baked goods.

Note: Don't avoid all fats if you're underweight, but focus on monounsaturated and polyunsaturated fats, such as olive oil and sunflower seeds.

Eat Foods with Complex Carbohydrates and Fiber

The main sources of energy in the average U.S. diet are carbohydrates and fats. If you limit your fat intake, you should increase your intake of complex carbohydrates to make sure your body gets enough energy. Carbohydrates are good if you're trying to lose weight, because they have less than half as many calories per ounce as fats do. Complex carbohydrates are better than simple carbohydrates. Simple carbohydrates—like sugar, syrup, and honey—provide calories but not many nutrients. Complex carbohydrates—like beans, peas, nuts, seeds, fruits, vegetables, whole grain breads, and cereals—contain fiber and many essential nutrients.

The average American diet is relatively low in fiber. Fiber [roughage, bulk] can't be digested by the human stomach because it resists digestive enzymes, so it helps with your bowel program and keeps you regular. Regularity can be a problem for people with a spinal cord injury. To make sure you get enough fiber and complex carbohydrates in your diet, eat fruits and vegetables, whole grain breads, and cereals. The following are some foods that are high in fiber:

Breads and cereals:

- All-bran cereals, some cereals with whole wheat or raisins, 100% whole wheat bread or whole rye bread, cracked wheat bread. Read the labels on cereal boxes—look for 3–5 grams of fiber per serving.
- Brown or unpolished rice.
- Potatoes, baked or boiled in their skin.
- Cracked wheat, barley, and millet.

Fruits:

- Fresh fruits, like oranges, apples, pears, all types of berries, grapes, peaches, and plums.
- Dried fruits, like raisins, prunes, peaches, apricots, dates, and figs.

Vegetables:

- Raw vegetables, like cabbage, celery, chicory, cucumbers, escarole, lettuce, tomatoes, and carrots.
- Cooked vegetables, like all kinds of beans and peas, greens [beet, mustard, collard], broccoli, kale, squash, brussels sprouts, corn, etc.

Nuts and seeds:

- Walnuts, peanuts, sunflower seeds, pumpkin seeds, etc.

Avoid Too Many Sweets

The major health hazard from eating too many sweets is tooth decay, but sweets are also high in calories and low in nutrients. Especially if you need to lose weight, limit the sweets in your diet. If you don't need to lose weight, you can add them to your diet, but only in addition to the nutritious foods recommended in the MyPyramid guidelines. To avoid sugars and sweets:

- Use less of all sugars, including white sugar, brown sugar, raw sugar, honey, and syrups.
- Eat fewer foods containing sugars, like candy, soft drinks, cakes, and cookies.
- Select fresh fruit or fruits canned without sugar or with light syrup rather than heavy syrup.
- Read food labels. If the words sucrose, glucose, maltose, dextrose, lactose, fructose, or syrups appear first on the list, that means there's a lot of sugar in the food.

Avoid Too Much Sodium

Table salt contains sodium and chloride. Both are essential elements, but too much sodium is a hazard for people who have high blood pressure or heart disease. It also can cause edema [swelling due to water retention]. Sodium is present in many beverages and foods, especially certain processed foods, condiments, sauces, pickled foods, salty snacks, and sandwich meats. Baking soda, baking powder, monosodium glutamate [MSG], soft drinks, and even many medications [antacids, for instance] contain sodium. So it's not surprising that adults in the United States consume much more sodium than they need. It's a good idea to reduce your sodium intake. Use less table salt. Don't eat foods that contain a lot

of sodium. Watch out for “hidden” sodium in preservatives or flavorings added to food. To avoid consuming too much sodium:

- Learn to enjoy the unsalted flavors of foods.
- Use only a little salt when you cook.
- Add little or no salt to food at the table.
- Limit salty foods, like potato chips, pretzels, salted nuts and popcorn, condiments [soy sauce, steak sauce, garlic salt], cheese, pickled foods, and cured meats.
- Read food labels carefully to determine which foods have sodium in them.
- Use herbs and spices to season your food. Season lightly—a little goes a long way.

[Table 4.b.C] Seasonings to Use Instead of Salt

SPICES	USES
Allspice	ground meats, stews, tomatoes, peaches
Basil	eggs, fish, lamb, ground meats, liver, stews, salads, soups, sauces, fish cocktails
Bay leaves	meats, stews, poultry, soups, tomatoes
Caraway seeds	meats, stews, soups, salads, breads, cabbage, asparagus, noodles
Chives	salads, eggs, sauces, soups, meat dishes, vegetables
Cider vinegar	salads, vegetables, sauces
Curry powder	meats, chicken, fish, tomatoes, tomato soup
Dill	fish sauces, soups, tomatoes, salads, macaroni
Garlic [not garlic salt]	meats, soups, salads, vegetables, tomatoes
Lemon juice	meats, fish, poultry, salads, vegetables
Marjoram [sweet]	soups, sauces, salads, lamb, pot roast, pork, veal, fish, vegetables
Mustard [dry]	ground meats, salads, sauces
Onion [not onion salt]	meats, vegetables, salads
Paprika	meats, fish, stews, sauces, soups, vegetables
Parsley	meats, fish, soups, salads, sauces, vegetables
Rosemary	chicken, veal, meatloaf, beef, pork, sauces, stuffings, potatoes, peas, lima beans
Sage	meats, stews, biscuits, tomatoes, green beans
Savory	salads, egg dishes, pork, ground meats, soups, squash, green beans, tomatoes, peas
Thyme	eggs, meats, sauces, soups, peas, onions, tomatoes, salads
Turmeric	meats, eggs, fish, sauces, rice
Wine	may be used in marinades

Start with a quarter teaspoon per four servings. Some common spices and their uses are listed in Table 4.b.C.

Drink Alcohol in Moderation

Alcoholic beverages tend to be high in calories and low in nutrients. Heavy drinkers often lose their appetite for foods that contain essential nutrients. They commonly have vitamin and mineral deficiencies, partly because they don't eat right but also because alcohol changes the way nutrients are absorbed and used in the body. Heavy drinking can cause a variety of serious conditions, such as cirrhosis of the liver and some nerve disorders. Cancer of the throat and neck are much more common in people who drink and smoke than in people who don't. If you drink, do it in moderation. And even moderate drinkers might need to cut back if they want to maintain their ideal weight. Moderate drinking can be defined as:

- One or two 6-ounce glasses of wine.
- One or two 12-ounce bottles of beer.
- One or two 1-ounce shots of 80-proof hard liquor.

RESOURCES

American Dietetic Association
120 S. Riverside Plaza, Suite 2000
Chicago, IL 60606-6995
[800] 877-1600
www.eatright.org

This website is maintained by the American Dietetic Association [ADA], the world's largest organization of food and nutrition professionals. The site includes food and nutrition news, a marketplace, nutrition resources, "Find a Dietitian," and other information. The ADA promotes nutrition, health, and well-being. It publishes a monthly journal on food and nutrition topics for professionals and consumers. Its programs include government

affairs, which monitors food and nutrition-related regulations and legislation; education and registration for nutrition professionals; information on insurance coverage for nutrition services; and a nutrition hotline. The hotline, at [800] 366-1655, has recorded messages on nutrition topics and referrals to dietitians.

EATRIGHT® Home-Based Weight Management Program for Individuals with SCI – The PVA Education Foundation funded the modification of the original EATRIGHT® program to meet the needs of persons with SCI. For information on this program, go to www.eatright.uab.edu.

Mayo Clinic
200 First Street, SW
Rochester, MN 55905
[507] 284-2511
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www.mayohealth.org

This is the Mayo Clinic's Health Oasis, maintained by the Mayo Foundation for Medical Education and Research. Health Oasis provides information about patient care, research, and education programs. The website's Nutrition button offers news, a reference library, recipes, a searchable cookbook, food quizzes, and more.

Figure 4.b.1
www.mypyramid.gov

4.c | Exercise

Nearly every day we hear or read something about the benefits of regular exercise. The physical and psychological benefits of a fit and healthy lifestyle are well documented and widely publicized. Now that you have a spinal cord injury [SCI] it's even more important for to you make exercise an integral part of your life. During rehabilitation right after your injury, you'll be exercising regularly under the guidance of skilled health professionals. After you're discharged from the hospital, it will be up to you to make exercise a part of your daily life, to maximize your abilities and overall health.

Why Is Exercise So Important?

Targeted exercise early in your rehabilitation helps you activate all the muscles that are still working and use them to their greatest potential. SCI causes muscle paralysis, so you have fewer muscles that you can control, and some of those that remain have limited function. Exercise builds strength and endurance in those muscles so you can do as much for yourself as possible. Lifelong exercise will help you keep your muscles strong and conditioned, maximize your function, reduce your risk of injury, and help you stay healthy.

Exercise can also prevent cardiovascular disease. Cardiovascular disease is common in people with SCI; in fact, it's the leading cause of death for persons who've had a spinal cord injury longer than 30 years and those over 60 years old. The risk of developing cardiovascular disease rises at a faster rate among people with SCI because of cholesterol levels [not enough high-density lipoprotein—HDL, the “good cholesterol”], obesity, inactivity, loss of muscle mass, diabetes, and a related problem called “metabolic syndrome” [obesity, high blood pressure, excess fat in the blood, and a condition similar to diabetes].

Exercise is also important to manage body weight. Many persons with SCI have too much body fat. Paralyzed muscles don't burn as many calories as contracting muscles, and people with SCI are typically less active than the general population, which results in a tendency to gain weight in the form of fat. Exercise and an active lifestyle are critical to prevent weight gain. Not only does exercise directly burn calories, it also increases your resting metabolism, which means that your body will burn more calories throughout the day. *Section 4-b, Nutrition and Weight*, has some great ideas for healthy eating habits that have a direct impact on weight management. In addition to reducing risks associated with cardiovascular disease, staying at your ideal weight allows you to move more efficiently and lessens the risk of injuries.

Exercise also plays an important role in posture. Whether you use a wheelchair full-time or you can stand and walk, specific exercises can help you maintain the correct body alignment. A neutral upright posture, either sitting or standing, allows the body to move and operate most efficiently. It also minimizes discomfort and the risk of injury. In addition to properly adjusted equipment [wheelchair configuration], specific stretching and strengthening exercises can help you fight the force of gravity, which is the main culprit in postural compromise. [See *section 2.c, Limb Preservation and Posture*.] Exercise can also help you keep your bones strong, participate in leisure and recreational activities you enjoy, sleep well, and feel good about yourself and your body.

Benefits of Specific Kinds of Exercise

A well-balanced program for improving fitness and function includes several different kinds of exercise.

Strengthening increases the force of contracting muscles, while endurance training increases a muscle's ability to contract repeatedly without becoming fatigued. Exercise to improve muscle strength and endurance is important for a number of reasons:

- To allow you to get where you need to go, whether you push a manual wheelchair, drive a power wheelchair with your hand or head, or walk.
- To enable you to move and take care of yourself as independently as possible.
- To protect you from injuries.
- To support good upright posture.

Cardiorespiratory [Aerobic] Conditioning

Aerobic conditioning improves the body's ability to use oxygen by training the heart, lungs, and muscles to work more efficiently during a sustained activity. Aerobic exercise is important for the following reasons:

- To improve your heart and lung function both at rest and during activity.
- To improve blood flow and oxygen delivery to muscles and skin.
- To decrease the risk of heart disease.
- To improve the body's ability to burn fat.
- To provide the body with more energy for daily activities.

Stretching

Flexibility exercises help maintain or increase the length and mobility of muscles and tendons to allow the body to move as normally as possible. *[For details on stretching, see section 2.c, Limb Preservation and Posture, and Appendix A, Range-of-Motion Exercises.]*

Muscle Strength and Endurance Training

Depending on your injury level and amount of paralysis, you'll have some muscles that you can control and some that you can't. *[See section 1.a, Anatomy, Physiology, and Research.]* The muscles above your level of injury should be unaffected, but they might be weak because of the bed rest and inactivity after your injury. If you have a complete paralysis below your injury level, some muscles no longer work at all, so they can't be strengthened with exercises. If you have a motor incomplete SCI, some of the muscles below your level of injury work, but they're probably weak. The goal of strengthening exercises is to encourage the muscles that you can control to work as well as possible.

During your rehabilitation, your physical and occupational therapists will design an exercise program to target all the muscle groups that you can strengthen. Your program is tailored specifically for you. For example, people who can't move anything but their heads and necks will have a program to target the neck and breathing muscles, while people who can move all their limbs will have extensive programs that target all muscle groups. Regardless of your level of injury, breathing exercises are important to keep your respiratory system strong and healthy. *[See section 1.c, Respiratory Care, for detailed information.]*

There are many equipment options for strength training, including weights, pulleys, and resistance bands. Whether you're just finishing your rehabilitation or have had your spinal cord injury for a while, the recommendations for muscle strength training are as follows:

- Intensity [resistance or weight]: 50%–80% of the most weight you can lift once.
- Duration: 2–3 sets of 10 repetitions.
- Frequency: at least twice a week.

Endurance training requires exercise at a lower intensity with more repetitions.

What Is Functional Exercise?

The best exercises are usually those that are “functional”—they mimic the activities you need to do in your everyday life. Your occupational and physical therapists encourage these exercises because they help you learn to coordinate your movements while you’re improving muscle strength and endurance. For example, you might use your finger to move small objects from one place to another—this improves the use of your hand muscles for self-care activities. Or you might practice your transfer technique over and over, so your shoulder muscles become trained to move your body weight. All the skills you practice in therapy sessions have a purpose; if you’re not sure why you’re doing an exercise or activity, ask your therapist to explain. Functional exercise also includes all the things you need to do each day to take care of yourself and move around. Managing the position of your legs for dressing and driving, pushing your wheelchair, and transferring, as well as personal grooming, writing, and typing are examples of everyday activities that help keep your muscles working well.

Aerobic Conditioning

When you hear “aerobic exercise,” you might think of jogging, cycling, aerobics classes, or other activities you did before your spinal cord injury. Now you’ll need to find other ways to improve your cardiorespiratory system through aerobic training. You’ll have different options depending on your level of injury:

- Pushing a manual wheelchair.
 - Seated aerobics videos.
 - Arm ergometry [exercising on a stationary bike that you pedal with your hands].
 - Handcycling [riding a bicycle that is propelled by pedals you turn by hand].
- Seated rowing.
 - Wheelchair road racing.
 - Swimming.
 - Seated cross-country skiing.
 - Other adaptive sports, such as basketball, quad rugby, and tennis.

[For more ideas, see section 4.a, Recreation.]

The goal of aerobic training is to get your heart and lungs working harder than they do during your everyday activities. The American College of Sports Medicine recommends the following for effective aerobic conditioning with SCI:

- Intensity: 50%–80% of predicted peak heart rate *[see below]*.
- Frequency: 3–5 days a week.
- Duration: 20–60 minutes per exercise session.

How to Measure Your Heart Rate

When you’re participating in an aerobic exercise program, it’s important to monitor your heart rate [pulse]. If you can’t take your pulse yourself, teach someone to do it for you. Here’s how to do it:

1. Use a watch or clock that counts seconds.
2. Find your pulse with your first two fingers [not your thumb] at one of two places:
 - [a] On the thumb side of your wrist with your palm up, just above the fold of your wrist
 - [b] At one side of the middle of your neck, right next to your windpipe
3. Count the number of beats in a 10-second period.
4. Multiply the number of beats by 6 to get your heart rate in beats per minute [bpm].

Example: 20 beats in 10 seconds

$$20 \times 6 = 120 \text{ bpm heart rate}$$

Peak Heart Rate and Training Zones

In the recommendations for aerobic conditioning [above], you see that you're supposed to work at 50%–80% of your predicted peak heart rate. What does that mean?

Peak heart rate is the maximum number of times your heart can beat in one minute [bpm]. The most accurate way to find your peak heart rate is with a laboratory stress test. But since stress tests aren't always available, there's a simple formula to figure it out: 220 minus your age. For a 40-year-old nondisabled person, the peak heart rate would be 180.

To calculate a heart rate training zone at 50%–80% of peak heart rate:

$$\begin{aligned} 220 - 40 &= 180 \text{ peak heart rate} \\ 50\% \text{ of } 180 &= 90 \text{ bpm } [0.5 \times 180 = 90] \\ 80\% \text{ of } 180 &= 144 \text{ bpm } [0.8 \times 180 = 144] \end{aligned}$$

So the training heart rate zone for a 40-year-old nondisabled person would be between 90 and 144 bpm.

Because some people with SCI don't fully control their heart rate [see section 1.h, *Circulatory System*], they can't reach the predicted maximal heart rate. For example, they might not be able to make their heart rate go above 120 bpm. If that's the case for you, measure your heart rate at rest and add 20–30 beats. For example, if your resting heart rate is 60, your training heart rate zone would be 80 to 90 bpm.

Rate of Perceived Exertion [RPE]

Another way to determine the intensity of exercise is to judge how hard it feels and compare it on a scale. Figure 4.c.1 shows an RPE scale. When you're working in an aerobic training zone to improve fitness, you should be exercising between level 4 “somewhat strong” and level 7 “very strong”

strong.” If the exercise feels “moderate,” you need to work harder; if it feels more than “very strong,” you need to slow down. Research has shown a good correlation between heart rate training zones and the RPE.

If your spinal cord injury is at or above T6, your body might not control your heart rate the way it used to. When you exercise, your pulse doesn't increase the way it should, so it's hard to get to the training zone using your heart rate. Use the RPE scale instead and base the intensity of your exercise on how hard you feel you're working. The RPE scale can also be used for injuries below T4. It's often a more convenient way to measure how hard you're working, especially if it's difficult to stop the exercise to take your pulse.

Importance of Warm-Up and Cool-Down

You shouldn't ask your body to abruptly start or stop an intense exercise. To allow the muscles, joints, and cardiovascular system to warm up before and cool down afterward, do at least five minutes

[Figure 4.c.1] Rate of Perceived Exertion

0	Nothing at all
0.5	Very, very weak
1	Very weak
2	Weak
3	Moderate
4	Somewhat strong
5	Strong
6	
7	Very strong
8	
9	
10	Very, very strong Maximal

Borg Scale [from Borg, A.A.: *Med. Sci. Sports Exerc.*, 14:377, 1982]

of low-intensity exercise before you move into your training zone and again when you finish your workout. Gentle stretching during the warm-up and cool-down periods will also help prevent injuries.

Basic Principles of Exercise Physiology

To make the most of your exercise program, you should know some general concepts. Basic principles developed for nondisabled people also apply to those with SCI. These principles are important whether you have a new SCI or have been injured for some time and are starting a new exercise program.

Overload Principle

To benefit from exercise, you have to do it at an intensity that's greater than your everyday activities. And you have to progressively increase the intensity over time so the exercise continues to be challenging. You can modify the frequency [how often], intensity [how much], and duration [how long] of any exercise to make it more challenging. A general rule is to increase the intensity of an exercise approximately every two weeks.

Specificity Principle

Your body reacts to an exercise on the basis of what that exercise is intended to do, with little carryover in other areas. For example, lifting weights will increase your strength but will have little effect on your cardiovascular fitness. Also, the best way to train for an activity is to actually do that activity. For example, if you want to improve your swimming, you should swim a lot.

Reversibility Principle

We've all heard the phrase "Use it or lose it." The positive effects of exercise will keep coming as long as you continue and progress in your exercise program. As soon as you stop exercising, your

body will start to get weaker and will lose all the hard work you've put into it. And, unfortunately, we lose fitness at a much faster rate than we gain it. It's important to stick with your exercise program so you don't have to start over from scratch.

Exercising with SCI

The following are some important considerations for exercising with SCI:

- *Skin protection:* Don't forget to do your pressure releases. Avoid staying in one position for a long time, as this can damage your skin. If you're using fitness or sports equipment, make sure you have an appropriate cushion to reduce the risk of skin breakdown.
- *Bone density:* People with SCI often develop osteoporosis, which weakens your bones. To minimize the risk of a broken bone, be careful not to drop heavy weights on yourself, and avoid falling during exercise activities.
- *Temperature regulation:* Your body's ability to regulate temperature may be impaired by your SCI. Be especially cautious when you're exercising in very warm or very cold environments. Dress appropriately in layers that can be added or removed, and use a spray bottle of water to cool yourself off if you get too hot.
- *Hydration:* Drink plenty of water before, during, and after exercise. Balance your water intake with bladder management.
- *Bladder and bowel:* Empty your bladder or leg bag right before you exercise. Maintain a consistent bowel maintenance program to avoid autonomic dysreflexia or accidents during exercise.
- *Body stabilization and hand supports:* If your trunk muscles are paralyzed, you may need to use special straps or belts to stabilize your body while you exercise. If your hand strength is impaired, you may need to use

special gloves, elastic wraps, or Velcro cuffs to secure your hands to the equipment.

- *Illness*: If you're sick, take a break from your exercise program until you're feeling better.
- *Low blood pressure [hypotension]*: If your upright resting blood pressure is less than 90/50, you should wear an abdominal binder and compression stockings while exercising. Blood pressure often drops in people with SCI when they're exercising, so know the symptoms of hypotension and monitor how you're feeling.
- *High blood pressure [hypertension]*: Some kinds of exercise can induce autonomic dysreflexia for some people with SCI at T6 level and above. Know the symptoms, stop exercising if they arise, and seek medical attention if necessary.
- *Pain*: Don't do exercises that cause or aggravate pain. Consult your doctor or therapist for recommendations about alternative exercises that don't cause discomfort.

A Few Final Suggestions

- *Choose activities you like*. You're more likely to continue a program that's fun. Consider exercising with a friend or family member to keep things enjoyable.
- *Don't overdo it*. "No pain, no gain" means you should work hard; it doesn't mean you should work to the point of hurting yourself. You might feel some minor muscle soreness when you start or progress in an exercise program. This should fade away in a day or two.
- *Smoking and exercise don't go together*. The many harmful effects of smoking negate the many benefits of exercise. There's plenty of information and support out there to help you quit smoking.

- *Medications can affect exercise tolerance*. It's not uncommon to take many medications to manage SCI issues and other medical conditions. Some medications directly affect the body's tolerance for and reaction to exercise. Check with your doctor about the medications you're taking—ask specifically about your medications in relation to exercise.
- *Fitness and function are more important than looks*. Your goal should not be to have bulging muscles like a body builder but rather to have a healthy and fit body that allows you to do what you need to do without fatigue and pain.
- *Eat well*. Good nutrition is a very important aspect of your exercise program. Read *section 4.b, Nutrition and Weight*, and contact your dietitian if you have specific questions.
- *Ask for help*. If you're unsure how to do a particular exercise or need guidance to start a new exercise program or ramp up an existing program, ask your SCI therapists to get you going in the right direction.
- *Get an evaluation before you start an exercise program*. It's usually safe to start an exercise program without undergoing any special testing, but people with certain medical problems—like heart disease or diabetes—may need some testing before they start doing aerobic exercises. It's a good idea to discuss your exercise plan with your health-care provider before you begin.

Regardless of your level of injury, exercise is important to keep your body as physically fit as possible. You need your muscles to be strong, your heart to be healthy, and your body to be flexible to maximize your independence. Make a commitment to keep exercise a part of your healthy lifestyle.

4.d | Medications

This section provides general information about medications. It does not give you specific information about your own medications, although it's important for you to learn about the medications you take. Here, we'll just talk about how medications work, how they're delivered to the body, and why they're prescribed for you. We'll also provide some guidance on how you can play an active role in your medication management and health maintenance.

How Medications Work

The body is made up of chemical substances that are continuously undergoing chemical reactions to create effects. These effects might be to digest food, heal an infection, or maintain blood pressure. Medications are chemicals, too. This means that when you take a medicine, it interacts with your body's own substances to cause a certain reaction. Some medication can be used by the body in the form it was delivered, and some has to be broken down into a substance the body can process. Most medicines are not things the body would normally use, so they're eventually removed from the body, usually in the urine or stool. Each medication takes a certain amount of time to be processed and used by the body before it's eliminated. Some are meant to pass through the body very quickly, while others build up in the body and have a longer-lasting effect. Many medicines are processed by the liver or filtered from the blood by the kidneys. If you have problems with your liver or kidneys, your health-care providers might adjust the amount of medicine you receive or choose a different one.

Names and Forms of Medicines

Medicines usually are known by at least two names: a generic [or common] name and a brand [or trade] name. This can be confusing. Learn both the generic and brand names of your medications, as well as the doses and how often you take them. Make a list of all the medicine you take and keep it with you at all times. This is important when you receive routine or emergency medical care.

The medications you take come in different forms, including tablets, capsules, syrups, drops, inhalations, injections, ointments/creams/lotions, skin patches, and suppositories. The form of the medicine affects how it works in the body. Your health-care provider or pharmacist will give you information on how to take your medication effectively.

Side Effects

Medicines are prescribed to have specific *intended effects* on the body, but almost all of them have additional effects that are called *side effects*. Your health-care provider and pharmacist will tell you about possible side effects from medications before you take them. It's important to report any new symptoms you experience after taking a new medicine. Side effects are classified in many ways, and they can be mild or serious.

Pharmacologic Side Effects

These are the effects of the medication that are predictable and controllable. Because a medication is absorbed by the entire body, it may affect more than one part of the body. Often, your body just needs some time to adjust to the medication and its effects. But if the dose is too high, the medicine might have too much of the intended effect, and this can cause problems, too.

Allergic Reaction

This is an abnormal reaction to a medication. It has nothing to do with the action or dose of the medicine and is often unpredictable. Allergic reactions come in many forms and may show up immediately or weeks after starting a medicine. Skin reactions—ranging from redness and itching to swelling and blisters—are the most common. Keep track of any allergic reactions you have, so your health-care providers can avoid prescribing similar medicines in the future. If you think you're having an allergic reaction, call your health-care provider immediately.

Anaphylaxis

This is an immediate, severe, abnormal response to a medication, and it can be life-threatening. You may experience difficulty breathing or a drop in your blood pressure. This is the same type of reaction as in people with severe allergies to bee stings. Stop using the medication and call 911 at once.

Medication Interaction

One medication can interact with another one, or with other substances like alcohol or food. Sometimes the combination will increase the effect of one or both medications. For example, alcohol will make a sedative even more sedating. On the other hand, an interaction might stop one medication from working correctly.

For examples of intended effects and side effects, consider the following about aspirin:

- The *intended effect* of aspirin is to reduce a fever or pain.
- The *pharmacologic side effects* include stopping platelets [small particles in the blood] from clumping together and forming blood clots. Aspirin is often prescribed when this side effect is desirable. However, this also increases the risk of bleeding stomach ulcers.

- Some people have an *allergic reaction* after receiving aspirin and will develop skin rashes or other symptoms.
- A few people have a more severe *anaphylactic reaction* when they receive aspirin. They will develop breathing problems or low blood pressure. Allergic reactions and anaphylaxis are especially common in people with asthma or allergies to other anti-inflammatory medications.
- Aspirin can have a *medication interaction* with some diabetes medications. It can make the diabetes medication more active and lower the blood sugar to a dangerous level.

Pregnancy and Breast Feeding

If you're pregnant or think you might be, contact your health care provider immediately. Many of the medications you take can have serious effects on the fetus, especially early in the pregnancy. Many medications leave the body in breast milk. If you plan to breast feed, review all your medications with your health care provider to make sure your child is safe.

Categories of Medications and Dietary Supplements

In the United States, the Food and Drug Administration [FDA] determines how medicines and supplements are regulated and sold. Some medications require a prescription from a health-care provider. Others—over-the-counter [OTC] medications—do not, or are not regulated at all. The difference between an OTC medication and a prescription medicine is that OTC medications are generally safer, have fewer and milder side effects, and have no potential for abuse or addiction. Prescription medications must be prescribed by a licensed health-care provider. They usually have more serious side effects or some potential for abuse and addiction, so their use is monitored.

Dietary supplements are products that contain dietary ingredients [including vitamins, minerals, amino acids, herbs, or other botanicals] that are taken by mouth and are intended to supplement your food. A botanical [herbal medicine or phytomedicine] is a plant or plant part. In the past, supplements were only found in health food stores, but now they're in most pharmacies and supermarkets, and are sold over the Internet. Some supplements are being added to food and drink products sold in grocery stores.

The FDA treats dietary supplements like foods, not medications. The manufacturers must follow the same safety standards that are applied to foods, but supplements don't have to be tested to see what ingredients they contain or how much of the active ingredient is in the product. The manufacturers don't have to prove that there's any health benefit from taking the supplement, so they're not allowed to make claims about treating specific diseases. That's why most of the health benefits claimed for these products are a little vague. Because more and more people are taking supplements, the U.S. government has established an Office of Dietary Supplements to collect information about the safety and effectiveness of supplements. Some supplements may be effective in treating certain conditions, but much more research and testing are needed before supplements can be classified as safe or effective.

Just because a substance is "natural" doesn't mean it's harmless. Used in excess or in combination with other medications, it might have a bad effect on your health. Herbs and supplements can enhance or block the action of other drugs. For example, ginkgo biloba [an herbal supplement] can interact with warfarin [a prescription blood-thinner] and increase the chance of internal bleeding. Supplements can also adversely affect bowel and bladder function. If you choose to take supplements, read the labels—some supplements contain trace amounts of toxic substances.

If you're also using an over-the-counter or prescription medicine, talk to your health care provider before you start taking a supplement. It might be helpful to bring in the substance in its labeled container so the health-care provider can determine if it's safe for you to use.

What Does Your Prescription Say?

Most prescriptions include the follow parts:

- Your name, birthdate, medical record number, and address.
- The prescription or Rx symbol, followed by the name and strength of the medication, how the medicine is to be taken [the doctor may abbreviate it, but it will be fully written out on the container], and the quantity.
- Refill information.
- The date.
- The health-care provider's name, address, and registration number.
- The provider's signature.

Most medications can be prescribed by a health-care provider to a pharmacist over the phone. But this may not be done with prescriptions for controlled substances, including some pain, anxiety, and stimulant medications. These medicines can only be obtained with a written prescription that's taken to a pharmacy. Also, some controlled medications can't be prescribed for longer than 30 days without a new written prescription. The original prescription for a medication will indicate how many refills are permitted. As long as you have refills left, you can get more medicine when you run out. If you've used your last refill or the medication doesn't allow refills, you'll have to contact your health-care provider for a new prescription. Ask your providers about the procedure for getting refills and new prescriptions. It's a good idea to contact them a couple of weeks in advance so you don't

run out of a medication. Most hospitals and pharmacies use a computerized system to order your medications and keep track of refills.

Advertisements about Medications

As a health-care consumer, you should know all about the medicine you take or might take, not just what an ad says about it. Read the package inserts to learn about possible side effects. Talk to your health-care provider about medications you've heard about. Find out what they can do and whether they'd be safe and appropriate for you.

At Home

In the hospital people tell you when and how to take your medications. At home you're responsible, so you need to know what you're taking and when and how much to take. You also need to know how to store your medications—

some need to be stored away from heat or direct sunlight or even kept in the refrigerator. Be aware of any changes in your prescriptions, and monitor your body for possible side effects. Read the labels on everything you take. Contact your pharmacist or health-care provider if you have any questions at all about your medications.

You're the Leader

You're the leader of your health-care team, so you're responsible for your medications—that means educating yourself about their purposes, uses, and effects. Your health-care team will be happy to provide you with this information. It's also important to be honest with your provider about all the medicines, supplements, alcohol, and illicit drugs you use. At any time, you may need to give your health-care provider a complete medical history and a list of current medications. If there's been a change in your health, let your provider know.

RESOURCES

Publications

The Pill Book: The Illustrated Guide to the Most-Prescribed Drugs in the U.S., 12th edition, Harold M. Silverman, Bantam Books, 1997.

Johns Hopkins Complete Home Guide to Pills & Medicines, Simeon Margolis, MD, PhD [ed.], Black Dog and Leventhal Publishers, 2005.

The Medical Advisor: The Complete Guide to Alternative and Conventional Treatment, 2nd edition, Time-Life Books, 2000.

Websites

www.mayoclinic.com

The Mayo Clinic's website has a Drugs and Supplements section with a searchable drug guide.

<http://dietary-supplements.info.nih.gov>

The National Institutes of Health Office of Dietary Supplements website provides information on the use and safety of dietary supplements, as well as nutrient recommendations and database resources.

www.altmedicine.com

Alternative Health News Online provides alternative, complementary, and preventive health news.

<http://nccam.nih.gov>

The National Center for Complementary and Alternative Medicine at the National Institutes of Health has information on complementary and alternative medicine for practitioners and the public.

4.e | Alcohol and Substance Abuse

Alcohol use is a complicated issue for people with SCI. On the one hand, it's a socially acceptable and legal activity under many circumstances. On the other hand, it can have many negative effects. Now that you have a spinal cord injury [SCI] you may want to consider whether it's safe for you to drink, and, if so, how much is a safe amount. This section addresses some health risks and other issues related to drinking for people with SCI. By the end of the section, you should be able to make informed choices about what's best for you. Prescription medications and illegal substances are also discussed.

What Is Alcohol Abuse?

To understand your own situation, you don't need formal definitions of alcohol use, abuse, and addiction. What you do need to consider is the fact that everyone is different in their physical reaction to alcohol, past experience with alcohol, and attitude about alcohol use. And these variables change over the course of a person's lifetime, so there's no single right answer about what to do. Your body is different now that you have an SCI. You can make healthy decisions only if you learn what you need to know about the possible consequences of your actions.

Nearly everyone agrees that alcohol use ranges from low-risk minimal drinking to high-risk unhealthy drinking—even in the same person. Because everyone has their own opinion about how much might be too much, let's focus on the consequences of drinking. A simple way to look at alcohol use is to identify the problems it causes in people's lives: legal, medical, and in personal relationships. In this section, when we refer to an "alcohol problem," we're referring to consequences in these areas.

How Common Is It?

Alcohol use problems are very common among the U.S. population—some estimates suggest that about 10 percent of Americans have significant problems with drinking. People with SCI are at an even greater risk. Nearly half have had problems with drinking at some time in their lives, and about 25 percent are currently dependent on alcohol. Now that you have an SCI, you need to make your decisions about alcohol in the context of this greater risk for developing a problem, especially if you've had drinking problems in the past.

Alcohol Use and Rehabilitation

We suggest that people avoid alcohol altogether during their initial rehabilitation, for several medical reasons that will be discussed later in this section. The emotional and physical challenges of rehabilitation often lead people to fall back on their past methods of coping. Drinking to relieve stress, fear, and pain can be a tempting option, especially if this is what you did in the past. But there are problems with this approach. First, some research suggests that alcohol use might interfere with neurological recovery. Second, drinking during rehabilitation can prevent you from learning the physical skills you need to stay healthy. Third, using alcohol as a coping device can keep you from developing other healthy ways of coping with problems that you'll encounter down the road. Fourth, during the first year after SCI, you are at the greatest risk for reinjury, and alcohol increases the risk of falls by impairing judgment and slowing your reaction time. Finally, alcohol use has been linked to many medical problems for people with SCI [*see next section*]. So even though alcohol is often used as a quick escape, this is one time when it's a bad idea. In an effort to make things better, you might make them worse.

Alcohol Use after Rehabilitation

Decisions about alcohol are more complicated once you've settled into your postrehabilitation life. Some people feel additional sadness when they're discharged from rehabilitation and are confronting the challenges of life with an SCI. Generally, you'll have the same social pressures as before, because most people will expect you to behave pretty much the same as you did before your injury. But some people might not understand that although you're the same person, your body is different. Plan ahead for dealing with typical social drinking situations. Ask yourself what you might say in response to an invitation to drink or what limits you might have for your own behavior. This kind of planning might seem a little awkward, but remember that you're at a much higher risk for developing drinking problems now that you have an SCI. Here are some things to consider when you're thinking about alcohol and your health:

Alcohol and injury

- After SCI, you're at higher risk for being injured again. Drinking puts you at even greater risk for falls out of your wheelchair, while transferring, or while walking.
- A fall or other injury could cause more damage to your spinal cord.
- It's harder to remember to check your skin, relieve pressure, and transfer carefully when you're drinking. Your risk for pressure ulcers might be increased if you drink.

Alcohol and bladder function

- Alcohol causes your body to lose water and become dehydrated.
- If you're not extra careful when you drink, you might overfill and overstretch your bladder. This can happen if you don't have a Foley catheter or suprapubic tube.

- Stretching your bladder can damage your kidneys, which filter waste from your blood.
- Overfilling the bladder can also cause autonomic dysreflexia, which is a dangerous medical condition.
- Dehydration can put you at increased risk for developing pressure ulcers.

Alcohol and sex

- Alcohol reduces the production of the male sex hormone [testosterone] in men.
- Alcohol reduces sexual desire in men and women.
- Alcohol reduces sexual performance [erection and ejaculation] in men.
- Alcohol reduces sexual satisfaction in men and women.
- Abstinence from alcohol improves sexual ability and sexual activity in men and women.

Alcohol and immune functioning

- Alcohol lowers your body's ability to fight off infection.
- Even one drink temporarily lowers your immune function.
- Regular drinking lowers immune function, and the lowered immunity can last up to two months after you stop drinking.
- Abstaining from alcohol for two months allows your immune system to return to normal.
- After your SCI, you're at increased risk for urinary tract infections. Drinking alcohol may further increase your risk of these infections.

[Figure 4.e.1] Balance Sheet: Using Alcohol after SCI

Drinking is part of life for many Americans—it’s part of many social events and public activities. Even if you choose not to drink, you’ll encounter alcohol use after rehabilitation. One way to think about drinking is to consider the benefits and the risks. You might think, “Alcohol has been nothing but trouble for me” or “I haven’t had any problems from drinking.” For most people, alcohol has mixed results—sometimes it causes pleasure and other times it leads to problems. This is the difficult part of understanding alcohol in your life.

We’ve described some of the unique risks of drinking after SCI [health problems, drug interactions, etc.], so you probably understand that your relationship with alcohol needs to change now that you have an SCI. But how do you make a complex decision like this? One way is to compare the good things about it with the not-so-good things. Think of a scale on which you balance the benefits and the risks. Use the columns below to list some of your thoughts.

	GOOD THINGS	NOT-SO-GOOD THINGS
Example:	Helps me relax socially.	Bad interaction with my medications.

Alcohol and medications

- Alcohol can cause bad reactions if it’s combined with medications, especially those used for pain, spasticity, and infection.
- Alcohol can increase or decrease the effect of medications, even over-the-counter drugs.
- The main medications to worry about in connection with alcohol are baclofen, diazepam [Valium], warfarin [Coumadin], aspirin, anti-inflammatories, antidepressants, certain antibiotics, and narcotics.
- Stopping your other medications so you can drink is not a good solution, because many medications stay in your system for

several days. And, of course, you’ll probably have adverse effects from stopping the medications.

Alcohol and mental health

- Alcohol use is associated with depression, self-neglect, and suicide in persons with SCI. That doesn’t mean that alcohol will necessarily cause problems for you, just that drinking might be a warning sign that you need some help.
- Excessive alcohol use can cause you to neglect your family and friends, resulting in problems in your relationships with important people in your life.

Reducing the Risk of Drinking

There are several things you can do to reduce your risk of alcohol problems. Of course, not drinking at all is the best bet—you run no risk. This is the most effective option, especially if you’ve had problems with alcohol in the past. If you do decide to drink, here are some ways to increase your safety:

- Ask your health-care provider about any specific alcohol-related concerns in your condition and with your medications.
- Avoid stretching your bladder by drinking a lot at one sitting.
- Watch out for autonomic dysreflexia.
- If you do drink, keep a record of the time and number of drinks.
- Leave at least an hour between alcoholic drinks.
- Alternate between alcoholic and nonalcoholic drinks.
- Avoid driving and situations where you might fall.
- If you find yourself using alcohol to treat sleep problems, pain, or spasticity, talk to your health-care provider to find alternatives.
- Associate more with people who don’t drink or who drink moderately.

Other Substances

Prescription Medication Abuse

Most people with SCI need to take some kind of medication to stay healthy—often several each day. Some medications that are prescribed for pain, anxiety, and spasticity can pose a risk—people can develop unhealthy use patterns over time. Some examples of these are narcotics [short-acting morphine, oxycodone, etc.] and benzodiazepines [Valium, Ativan, etc.]. Your medical team will try to keep your medications

at a minimum, and you certainly shouldn’t feel guilty about needing medications to handle pain. But you should understand the risks and benefits associated with each drug you take. Health-care providers pay special attention to medications that show increasing use over time and that require frequent increases in dose. Also, they watch for “lost” medications and unexpected early refills. They know these are signs of a prescription abuse problem, and they can help you with strategies to prevent a worse problem from developing.

Use of Illegal Substances

Drug problems are fairly common among people with SCI. Substance use increases the chances for ongoing medical problems—mostly because these people don’t take good care of themselves. It’s important to remember that your body is very different than it was before your injury, and drugs can have unpredictable and unhealthy effects. Just like alcohol, many illegal substances have unwanted interactions with prescription medications, which could cause serious problems. The safest choice is not to use illegal drugs at all. If you do, please let your provider know.

What If You Have a Problem?

There are many different ways to find and get help with an alcohol or other drug problem. Ask your health care provider to refer you to professionals for an evaluation to determine how they can help you. Most people cannot change a drinking habit overnight, so don’t get discouraged if you have a setback. Health-care providers understand that many people experience a “relapse” after trying to quit. The important thing is to develop a plan that involves you, your family, and your health-care team to help you succeed. But it all begins with you. Only you can take an honest look at yourself and your behavior and decide to change the way you drink or use other substances.

RESOURCES

Your health-care provider or any member of your SCI care team can refer you to a local resource.

Contact the addictions treatment program at your local hospital or use the Substance Abuse and Mental Health Services Administration [SAMHSA] Treatment Facility Finder—a searchable directory of alcohol and drug treatment facilities throughout the country. <http://findtreatment.samhsa.gov/>

Organizations

Alcoholics Anonymous—offices and meetings all over the world; check the phone book, or www.aa.org

Moderation Management, 22 W. 27th Street, New York, NY 10001, [212] 871-0974, www.moderation.org

Rational Recovery, Box 800, Lotus, CA 95651, [530] 621-2667, www.rational.org

AlcoholScreening.org—an online resource that includes an alcohol screening self-test, information, and resources

4.f | Health Care

Before you leave the hospital, make plans for how you'll receive health care. The person who provided your medical care before your injury might still be able to take care of you. However, many people with SCI didn't go to a doctor regularly before their injury. Who should be involved in your health care? What should you consider when you're choosing health-care providers?

Only about 1 in 1,000 people in the United States has an SCI. Because it's so rare, you might be your doctor's only patient with SCI. Many doctors don't know about the medical problems it can cause. What would be a relatively minor symptom or problem for a person without SCI could be a grave and even life-threatening problem for someone with SCI. On the other hand, some patients end up having unnecessary testing or treatment because their doctors aren't familiar with conditions that are common with SCI, such as these:

- *Autonomic dysreflexia [AD]*. An extremely rare kind of tumor can cause similar blood pressure elevation. All doctors have heard of the tumor, but very few have heard of AD.
- *Heterotopic ossification*. Some doctors mistake it for a rare bone tumor when they see it on an x-ray.
- *Bladder colonization with bacteria*. This may be confused with a bladder infection, leading to unnecessary treatment with antibiotics.

If your health-care providers aren't familiar with SCI, share this book with them. If you've already studied the book, you may know more than your doctor!

Primary Care and Health Maintenance

You'll probably need someone to act as your primary care provider [PCP]. This person is responsible for health maintenance, medical care for common conditions, and referrals to specialists for more complicated problems. It could be a physician, a physician assistant [PA], or a nurse practitioner [NP]. Some insurance companies require you to choose a PCP, who is the only person who can refer you to specialists.

The VA has policies for health-care services for veterans with SCI. If you live close to a VA SCI center, you'll usually receive primary care through that center. If you live closer to a VA hospital that doesn't have an SCI center or SCI support clinic, you should be assigned to a PCP who has received extra training in SCI. Your PCP will work with a team of providers who treat patients with SCI and will coordinate services with SCI centers.

Some people [including many who are treated by the VA] receive their primary care from specialists who've had training in SCI. Many of these physicians have trained in the specialty called physical medicine and rehabilitation [PM&R], but many other kinds of doctors can provide both primary and specialty care to people with SCI. You may also be treated by doctors from other specialties like urology, orthopedics, or neurosurgery, depending on what kinds of problems you have.

You should plan to see a physician or other health-care provider at least once a year. Some kinds of tests are recommended annually to detect medical complications of SCI. For example, your doctor should check on the status of your kidneys to make sure your bladder management program is preserving the health of your kidneys.

Someone should also check your strength and sensation—some conditions can cause you to lose some of your function. If you receive health care through the VA, you can be evaluated by physical or occupational therapists to check on your functional status and see whether you need new equipment. You'll also have access to psychologists and social workers. If you're not a veteran, check with your health-care providers and discuss what services are available to you. In addition to special services, you should be receiving all the preventive services that are appropriate for any person. If you develop a new problem, don't wait—make an appointment to get it checked out.

Returning to the Hospital

In the first year after SCI, almost half of all patients will become sick enough to be admitted to a hospital. Even persons who were injured a long time ago have a good chance of being hospitalized. The most common reasons for hospitalization are urinary tract infections [UTIs], pressure ulcers, and breathing problems like pneumonia.

Don't assume that every doctor and nurse knows how to take care of someone with your type of SCI. Spinal cord injury is a rare condition. Unless you're in a hospital ward that takes care of many patients with SCI, you're at great risk for having problems. The nurses might not know how frequently you need to be turned to prevent pressure ulcers. They may not know how to assist with a quad cough or other techniques to get secretions out of your lungs. Discuss your needs with them. Show them this book. Ask them to look up the guidelines published by the Consortium for Spinal Cord Medicine [*available at www.pva.org/CPGs*]. If you usually use a special mattress, request that the hospital provide something similar or see if you can bring your own mattress from home. Let the nurses know if you need help repositioning yourself in bed.

Make sure you can activate the call light for assistance. If you're too sick to manage your care, your family or other care providers should step in and make sure you get what you need.

The following are the most common [and preventable!] problems that develop when people with SCI are hospitalized:

- Pressure ulcers.
- Contractures.
- Low blood pressure [orthostatic hypotension] when you first start to sit or stand again after bed rest.
- Pneumonia.

If you know you'll be hospitalized for surgery, ask about the kinds of patients the hospital treats. Do they perform surgery on many patients with SCI? Will the nurses know how to take care of you after the surgery? If you're not satisfied with the care you're receiving, discuss it with your nurses, physicians, social workers, and other care providers. If you're still not satisfied, ask to speak to the hospital's patient advocate.

What kinds of hospitals usually do a good job taking care of people with SCI? The same hospitals that take care of people with a new spinal cord injury are well suited to care for those who need to be rehospitalized. The Commission for Accreditation of Rehabilitation Facilities [CARF] can provide you with a list of hospitals that have certified rehabilitation programs for people with SCI. Regional trauma centers and hospitals that are part of medical schools often take care of people with SCI. Your rehab doctor or your primary care provider can help you choose a hospital.

RESOURCES

Websites

<http://www.pva.org/CPGs>

Clinical Practice Guidelines published by The Consortium for Spinal Cord Medicine. These guidelines help health care providers manage some of the most common and important complications in people with SCI. Development of the guidelines has been funded by Paralyzed Veterans of America.

www.carf.org

The Commission on Accreditation of Rehabilitation Facilities [CARF] evaluates and certifies spinal cord injury rehabilitation programs.

4.g | Aging

The aging process affects everyone, but aging with a spinal cord injury [SCI] presents its own challenges. This section reviews some possible complications of aging with SCI.

Before the 1940s, most people with SCI died within a year as a result of medical complications from their injury, so little was known about how aging would affect people with SCI. The introduction of antibiotics and other specialized treatments gradually increased the life expectancy of persons with SCI. Recently, survival and life expectancy have also improved for people who need ventilators to help with their breathing. Now that people with SCI live much longer, we can see what problems might develop as they age.

Level of Injury

The level of injury to your spinal cord will probably stay the same as you age. Some people with SCI develop a condition known as posttraumatic syringomyelia [syrinx] that can increase the injury level. A syrinx is a cyst-like, fluid-filled area inside the spinal cord near your original injury. It sometimes causes a loss of strength or sensation by injuring a part of the spinal cord that's still working. Whenever you experience a change in sensation or function from your baseline, report it to your health-care provider right away.

Skin

SCI increases your risk for skin injury because of reduced sensation and decreased movement. Prolonged pressure can lead to pressure ulcers. As you age, you lose the layer of fatty tissue under the skin that provides padding and protection from injury. Some people also have less blood flow to their skin, which causes slower and more difficult healing when skin breakdown does occur. As

you age, it's more and more important to do your pressure releases and use bed and seating surfaces that reduce pressure on your skin.

Musculoskeletal System

After SCI, many people use wheelchairs or crutches for mobility. Activities like pushing a manual wheelchair, holding yourself up during transfers, and using crutches put increased demands on your arms. Repetitive stress on the arms can increase your risk for problems in your shoulders and wrists. Some of the most common injuries to the arms are rotator cuff tears [a tear in one or more of the muscles surrounding the shoulder], tendonitis [inflammation of the muscle's connective tissue], and carpal tunnel injury [injury to the nerves in the wrists]. The risk of overuse or repetitive stress injuries increases over time. Many of these problems can be prevented with early intervention with regard to equipment, proper transfer training, and education [see sections 1.g, *Muscles and Bones*, and 2.c, *Limbs Preservation and Posture*]. To prevent loss of function, it is important to be aware of movements and activities that can cause repeated stress to joints, and find ways to avoid this stress.

Circulatory System

Heart disease is common among people with SCI and is one of the leading causes of death. SCI can lead to decreased physical activity and weight gain, which are two of the main causes of heart disease. Many people with SCI, especially those with tetraplegia, have too much low-density lipoprotein [LDL, the "bad cholesterol"] in their blood and not enough high-density lipoprotein [HDL, the "good cholesterol"]. Your doctor should check your cholesterol levels; medications are available to change these levels and reduce your risk for

heart disease. For your part, it's crucial to establish and maintain healthy eating and exercise habits.

Respiratory Care

The number one thing you can do to avoid breathing problems after SCI is not to smoke. People with SCI who smoke are much more likely to develop serious breathing problems than those who don't smoke, and breathing problems get worse as people age. Vaccinations against respiratory infections [pneumovax and flu vaccines] are recommended for everyone with SCI, especially for older people.

Bowel

Section 1.e, Bowel Management, describes the changes in bowel function after SCI. Further changes in bowel patterns occur as you age with SCI. You may experience more constipation or hardness and difficulty passing stool, or more frequent involuntary bowel movements. It can take longer to complete bowel care. You should perform your bowel program at least every other day to avoid overstretching your colon. Problems like shoulder pain or weight gain can make it more difficult to perform bowel care, and some people lose the ability to do it independently. If you notice changes in your bowel pattern, review your program with a health-care provider.

Bladder

Kidney failure was once a very common complication of SCI. With current bladder management programs, very few people with SCI will develop kidney failure. To preserve kidney function, you need to adequately drain your bladder, avoid urinary tract infections, and get prompt treatment for any complications, like kidney stones. Decreasing kidney function might not be obvious to you, so you should have kidney function tests every year.

Muscles and Nerves

As people age, they lose muscle mass; you'll probably lose some strength in muscles that aren't paralyzed. Some nerve cells are lost over time as well. This is part of the normal aging process, but it can make it harder to propel a manual wheelchair and increase the amount of assistance you need to transfer out of a wheelchair. For people who can stand and walk, the loss of strength with aging may make it necessary to use leg braces or crutches to walk safely and avoid falls. Some people will use a wheelchair more often. Older people with SCI typically aren't as active as younger ones, which can cause further loss of strength and weight gain. To minimize the loss of strength that comes with aging, it's important to maintain your weight, eat well, and stay active [without causing overuse injuries to your joints]. Your therapist can help you evaluate your strength and make specific recommendations for you and your mobility needs.

Bones

People with SCI have reduced bone strength below the level of injury. This is called osteoporosis or osteopenia. It's due to lack of weight bearing through the bones, lack of forceful muscle contractions, and other factors. It's commonly found in the pelvis, hips, and legs. The bones lose calcium most rapidly right after the injury, but bone density loss continues with age. Older adults with SCI are considered to be at an increased risk of broken bones. Because of this risk, it's very important to prevent falls. Your therapist can evaluate your mobility, transfers, and walking, and make suggestions for preventing falls.

Range of Motion

With aging, joint capsules tighten and muscles lose elasticity. This can reduce the range of motion in your joints, especially if you experience spasticity. Even a minor loss of motion can prevent you from performing simple tasks independently, like standing, walking, dressing, and transferring. It's important to have a regular program for stretching your arms and legs to prevent loss of motion and maintain your independence. Your therapist can evaluate the motion of your upper and lower limbs, and give you some exercises to improve your range of motion. Even if you need assistance with stretching, it's very important to make it part of your daily routine. For efficiency, you can combine stretching with bathing or dressing.

Equipment

As people with SCI age, they may need more assistance with mobility and caring for themselves because of loss of strength, pain, injury from repetitive stress, or weight gain. Your therapist can evaluate your mobility, strength, and function, and suggest possible adaptive equipment to help you with your tasks. In some cases, older people with SCI might need to start using an attendant to help with their care.

People with SCI who have a repetitive stress injury—like carpal tunnel or a rotator cuff tear—may have difficulty with independent transfers because of pain in one or both arms. If you develop joint pain in your arms years after your SCI, a therapist can evaluate your transfers to make sure you're using the right technique to avoid injury and pain. The therapist might suggest that you reduce the number of transfers to avoid stress on your arms. Some people start

to use a mechanical lift. Older people can also develop difficulty with transfers into vehicles. A transfer board can be helpful and improve safety during vehicle transfers and uneven [overheight] transfers. You might also think about modifying your wheelchair or vehicle. Many older people with SCI switch to a van with a wheelchair lift to eliminate difficult transfers.

Older people with SCI who develop pain or weakness in their upper limbs might not be able to push their manual wheelchair long distances, which can reduce their ability to participate in community life. If this happens to you, get an evaluation of your wheelchair setup and accessories and your posture to make sure your equipment is still appropriate. If you're having a hard time using your manual wheelchair in the community, consider switching to a power chair.

Finally, persons with SCI who are able to walk may lose strength and need to consider assistive devices. A walker, cane, crutches, or leg braces can improve your stability and prevent falls. Some people might need to consider using a manual wheelchair instead of walking.

Aging Gracefully

Whether your injury occurred in your older adult years or it occurred a long time ago and you are aging, the goal is to maximize your potential in all areas. If you start off by working hard in rehabilitation, you'll have the tools you'll need to live a full life. As you age, appropriate equipment and training can help you maintain your independence and participate in community life despite increased pain or weakness.

4.h | Disasters

Disasters happen! Some are predictable and can be prepared for in advance, like blizzards, windstorms, and hurricanes. Others are sudden and unexpected, like flash floods, earthquakes, and tsunamis. Most people can easily survive weather events like blizzards or windstorms by having adequate food and water supplies and a backup heating system in case the power goes out. A person with SCI needs some additional preparation to be ready for disaster possibilities.

Kinds of Disasters

You should know what kinds of disasters are most likely to occur where you live. For example, if you live in Minnesota, you'll probably have a few blizzards every winter, so you should be prepared to "shelter in place" for one to three days at a time. Shelter in place means stay where you are [which might be at work] and survive there until the authorities or your own common sense tells you it's okay to go out. There are three major kinds of disasters: natural disasters [such as earthquakes, hurricanes, or winter storms], human-related disasters [such as terrorism or civil disturbances], and technological disasters [such as failure of utilities].

Think about the likelihood that a certain kind of disaster could happen in your community and make a plan to deal with it.

Know Your Resources

Know where the closest health-care facilities are, even if you don't usually receive your care there. Be prepared to provide for your own health needs if you're not injured. If staff at hospitals and medical facilities are busy taking care of seriously injured people, your routine care needs won't be a priority for them.

Know where the nearest wheelchair-accessible emergency shelters are. You can get this information from your local emergency management department. Be sure to ask if the bathrooms are also accessible at these shelters. Contact the local fire department to see if they keep a list of people who might be at increased risk in an emergency. Contact the customer service department of your local power company to see if there's a priority list for reconnection after a disaster and whether you qualify. Post emergency phone numbers [police, fire, poison control center, oxygen vendor] in your home and at work. Get a home phone with a cord—most cordless phones won't work if the power goes out, even if the telephone lines are still working. Consider getting a cell phone, too, so you won't have to depend on electricity from a wall plug or wall jack.

Have a Plan and Keep Yourself Alive

Being ready for a disaster is part of maintaining your independence. If you're prepared in advance, you'll be able to cope with it when it happens and recover from it faster. But remember that many people with disabilities who are self-sufficient under normal circumstances will need some assistance in a disaster.

Have a family disaster plan and include your caregivers in it. Have a network of caregivers, friends, and relatives you can ask for assistance. Ask them to check on you if you live alone. Consider giving one or two neighbors a key to your house so they can assist you without delay. When you're establishing your networks, consider organizing your neighborhood into a mutual aid society. If you live in a multilevel building,

how would you get to the ground floor if the power went out? Elevators and escalators won't be operating unless the building has an emergency power supply. Learn, and be able to instruct others in, the proper way to transfer or move you. Be able to tell someone who's assisting you which exit routes from your building are best.

Public transportation might not be working, or routes and schedules might be changed. Caregivers might not be able to reach you.

Put together a portable disaster kit. Use a drawstring bag, a pouch with lots of pockets, a fanny pack, or a small backpack. Keep it within reach. It should include a copy of your emergency information list and medication list; a small flashlight; a whistle or noisemaker; water; extra medication and copies of prescriptions; an extra pair of glasses; a hearing aid if you wear one; sanitary supplies; a pad and pencil or other writing device; and a pair of heavy work gloves for wheeling over glass and debris. Keep a small version of your emergency kit in your car/van and at work. Keep a basic first aid kit.

You should plan on at least one gallon of water per person per day, and plan on using stored water for at least three days. Change your water supply every six months. If water supplies fail, boil any water you drink or use for food preparation. Have a two-week supply of nonperishable foods on hand. Choose foods that require no refrigeration, no cooking, and little or no added water. Keep refrigerator and freezer doors closed—foods will keep up to four or five days if the seal is tight.

Sheltering in Place or Evacuating

If you're told to shelter in place, stay where you are. Tune in to a local radio station for information and specific instructions. Use your disaster supplies to meet your needs. Consider asking your caregiver and his or her family to live with you while you're sheltering.

If you're told to evacuate, leave immediately. Gather all your medications and take your pets and service animals with you.

Each person should have at least one change of clothing and footwear. Include shoes, rain gear, blankets or sleeping bags, egg crate or air mattress, hat, gloves [leather is best if there's broken glass in the area], thermal underwear, and sunglasses. Include disposable incontinence pads as needed, and any supplies that you need for bladder and bowel care. Don't forget glasses and contact lenses, supplies for any babies [diapers, bottles, formula], and supplies for any pets. If you use a power wheelchair, consider bringing a backup manual wheelchair in case you are unable to recharge your battery.

RESOURCES

Organizations

American Red Cross: www.redcross.org

World Health Organization: www.who.int/en

Federal Emergency Management Agency:
www.fema.gov

National Center on Emergency Preparedness
for People with Disabilities [part of the Inclusion
Research Institute]:
www.disabilitypreparedness.org

Appendices

Glossary

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Appendix A | Range-of-Motion Exercises

The following are some examples of range-of-motion [ROM] exercises. The best idea is to have your therapist design a program for you that's based on your specific needs, but these stretches are a good starting point for maintaining your flexibility.

If you can move on a bed by yourself, you can do the exercises in section 1 [Self-Stretching]. If you need assistance, you can have an attendant help you do the exercises in section 2 [Assisted Stretching]. For all these stretches, use a slow movement and a long hold.

Important Points to Remember

1. Never use excessive force when you're stretching. All you need is enough force to allow the muscle fibers to lengthen [stretch]. Too much force can result in fractures, torn or pulled muscles, or dislocated joints.
2. Hold the position still rather than bouncing, especially if you have spasticity. This allows your muscle fibers to relax and stretch. Bouncing increases tension in muscles.
3. Good times for stretching are in the morning or in the evening when you do your skin inspections.

Self-Stretching

A passive range-of-motion [PROM] technique should be an efficient package. The following is one example of a quick stretching program; your therapist can recommend specific stretches if you need them for other areas.

1. Lie on your stomach [prone] with your feet off the end of the bed. [This will help keep your hips down on the bed.] Move up onto your elbows but keep your belly button on the bed surface. Stay here for about 5 minutes—longer if you have a lot of spasticity. This is a good way to get some reading done. If you can't lie on your stomach or your hip muscles are tight, an alternative stretch is to sit at the corner of

the bed. Hold one leg and roll onto your back. Keep the leg tight up against your chest [this keeps your back flat on the bed] and let the other leg dangle off the edge of the bed. Hold this for 1–2 minutes. Sit up and switch legs.

2. Sit up against a wall with your feet out in front of you ["long sitting"]. Bring one knee up toward your chest, then cross that leg over the other one, with your foot just above your other knee. In this position, you can do a number of stretches.

First reach to the foot of the top leg and stretch the foot toward the knee with your toes pointing upward. This works best if you place the bottom of your foot against your forearm so you can push up while you're pushing down on your knee with your other hand. This "hug" position also stabilizes you for the stretch.

For the second stretch, reach for your foot on the straight leg with the arm on that same side. To reach your foot, rotate your body in. Hold the bottom of your foot and stretch/pull it toward your body. This will give you both a hamstring stretch and an ankle stretch, and will also stretch your hip and knee joints. Be sure to keep your foot in line with your leg—don't let the foot roll in or out.

Switch legs and repeat the two exercises.

As you do your ROM exercises, allow time for your muscles and other structures to loosen and

stretch. When you're moving your body, do it slowly and smoothly. As you hold the position, maintain a firm but gentle pressure for 30 seconds or a slow count of 10. Don't bounce your body—this tends to encourage spastic muscles to tighten.

Assisted Stretching

These instructions outline the correct motions and body positioning required to perform range-of-motion exercises safely. Remind your attendants to use careful movements so they don't hurt their own backs.

[SAM]

S: Your **STANDING** position

A: Your **ATTENDANT'S** position

M: The actual **MOVEMENT**

Trunk Rotation

S: Lying on your back with your knees bent to your chest.

A: Kneeling at your feet with both hands placed on your knees.

M: Rotate your knees and hips to one side; bring them as close to the bed as they will go; keep your shoulders flat on the bed. Your attendant may need to put one hand on your opposite shoulder to hold it down.



Trunk Bending

S: Lying on your back with your legs together and your knees bent toward your chest.

A: Kneeling at your feet with both hands placed on your knees.

M: Bend your knees to your chest, stretching your back muscles.



Hip Abduction with Knees Bent

S: Lying on your back with your legs bent.

A: Kneeling with your feet between attendant's knees to hold them in place, each hand placed on your knee.

M: Spread your knees apart, and down towards the bed, applying a firm (but not heavy) pressure.

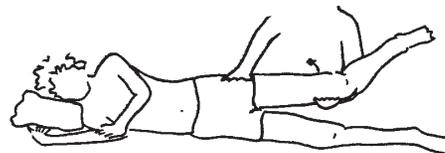


Hip Extension

S: Lying on your side, not leaning forward or back, with your upper leg slightly bent.

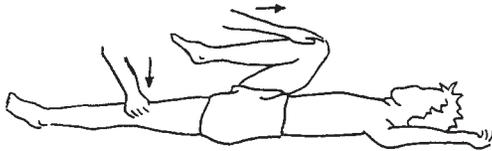
A: Kneeling behind you, one arm cupping under your knee with your calf resting on his or her forearm, and the other hand holding your pelvis in place.

M: Pull your leg straight backward toward your attendant.



Stretches (Hip Flexion & Extension)

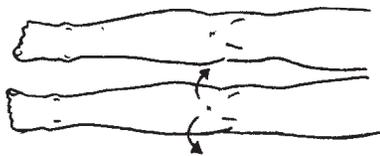
S: Lying on your back with your toes pointing toward the ceiling, one knee bent toward your chest.



A: One hand placed on your bent knee, the other hand placed just above the knee of your straight leg.

M: Bend your bent leg further toward your chest, keeping your other leg straight on the bed.

Leg Rotation



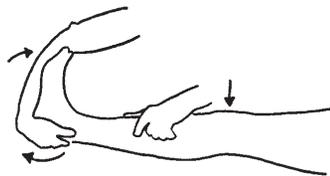
S: Lying in bed, your legs straight and relaxed.

A: Hands placed on top of your thigh, or one hand on top of your thigh, the other underneath your thigh.

M: Roll your knee in and out. Do not have your attendant's hands placed below your knee or there will be excessive stress to your knee.

Heel Cord (Gastroc/Soleus)

S: Lying on your back with your knees straight.

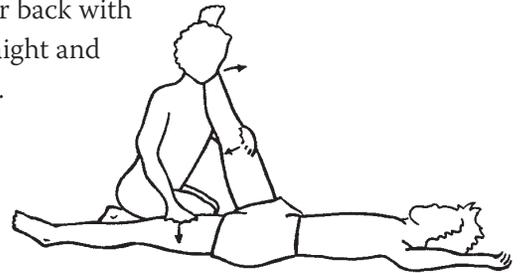


A: One hand cups the inside of your heel, with the forearm pressed up against the ball of your foot.

M: Keeping your knee straight, pull down at your heel and press up with the forearm, bending your foot toward your knee.

Straight Leg Raise (SLR)

S: Lying on your back with your legs straight and slightly apart.



A: Two positions possible:

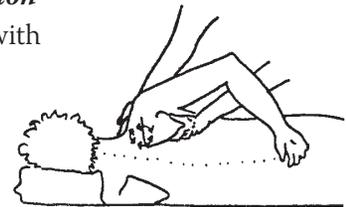
1. Kneeling between your legs, with one hand cupping your heel while the other hand is holding the knee of the same leg. The attendant's knee may be resting lightly on your other thigh to stabilize your leg on the bed.

2. Kneeling between your legs, with your heel cord resting on the attendant's shoulder. One of the attendant's hands should be placed on that knee to keep it straight, the other hand should be on your other thigh to stabilize that leg on the bed.

M: Slowly raise your leg up, keeping your knee straight. Do not allow your leg to roll out. When your raised knee begins to bend slightly from the tension, have your attendant lower your leg slightly and hold. Do not move beyond the leg pointing straight up to the ceiling.

Scapular Circumduction

S: Lying on your side with your arm resting on your hip or behind your back.

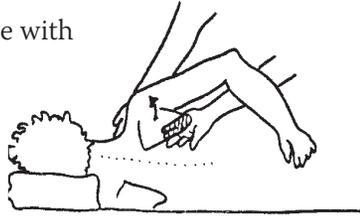


A: One hand cupping the front of your shoulder, the other placed so the web of the thumb meets with the angle of your shoulder blade.

M: Moving both hands circularly in the same direction, roll the shoulder blade slowly in a large circle.

Scapular Protraction

S: Lying on your side with your arm resting on your hip or behind your back.



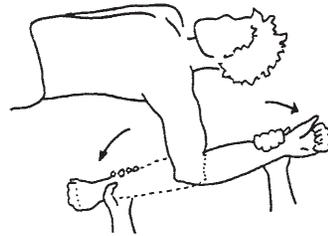
A: One hand cupping the front of your shoulder, the other placed so that the pinkie side of the attendant's hand is next to your shoulder blade.

M: Applying a firm pressure backward on your shoulder, slide the other hand under your shoulder blade, lifting away from your back.

Shoulder Rotation

S: Your arm out from your side at about 45 degrees, your elbow bent 90°.

A: One hand cupping your elbow, the other supporting your wrist and hand.

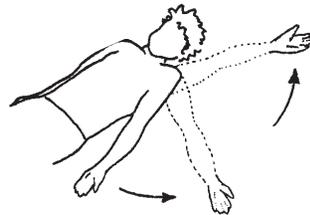


M: Rotate your hand toward the bed by your pillow, and then toward your hip. Keep your elbow bent at 90°.

Abduction

S: Lying on your back with your arm at your side and your palm up.

A: One hand supporting your hand and wrist, the other cupping your elbow.



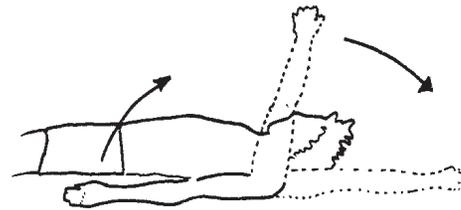
M: Bring your arm out to your side up to your head (similar to the movement in jumping jacks).

Forward Flexion

S: Your arm at your side, palm up.

A: One hand supporting your wrist/hand, the other supporting the back of your elbow.

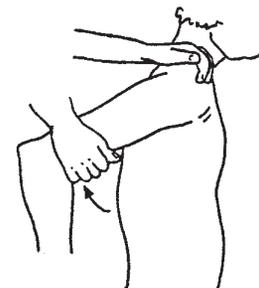
M: Raise your arm up over your head, with your thumb leading, pointing first at the ceiling and finally the wall. Keep the elbow relatively straight.



Shoulder Extension

S: Sitting in your chair or lying on your side in bed.

A: One hand stabilizing your shoulder, the other cupping your arm near your elbow.

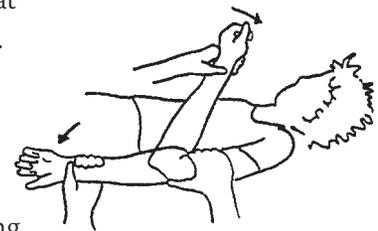


M: Bring your arm back behind you as if you were going to reach into your rear pocket.

Elbow Flexion/Extension

S: Your arm straight at your side, palm up.

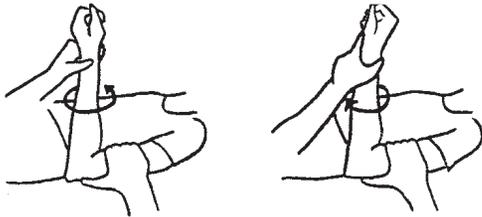
A: One hand supporting your wrist and hand, the other stabilizing your upper arm.



M: Straighten your arm to its fullest, then bend your elbow, bringing your hand to your shoulder.

Supination/Pronation

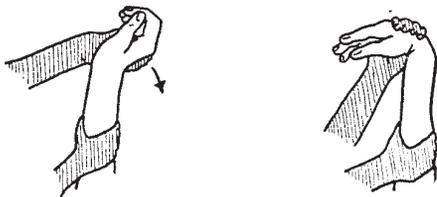
- S:** Your arm at your side with your elbow bent 90 degrees.
- A:** Supporting your wrist/hand and stabilizing your arm just above your elbow.
- M:** Turn your palm up; then turn your palm down.



Repeat the above with your elbow straight. You can combine this exercise with the one above (Elbow Flexion/Extension)

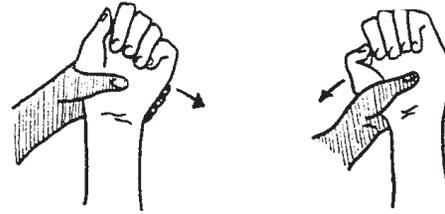
Wrist Flexion/Extension

- S:** Wrist and fingers relaxed.



- A:** One hand supporting your forearm, the other hand clasping your palm—be certain that your fingers are free to move.
- M:** Bend your wrist down, allowing your fingers to straighten at will. Bend your wrist up, being certain that your attendant's hand and fingers do not interfere with your fingers' bending.

Wrist Deviation



- S:** Your wrist in line with your arm, not bent up or down.
- A:** Supporting your hand, the other stabilizing your forearm.
- M:** Move your hand side to side, not allowing your wrist to bend up or down.

Finger Flexion

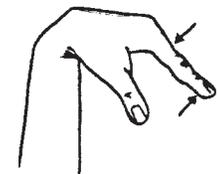
- S:** Your fingers relaxed, your wrist bent up.



- A:** Supporting your hand and wrist.
- M:** Gently bend your fingers toward your palm, being certain to keep your wrist cocked (bent) up.

Finger Extension

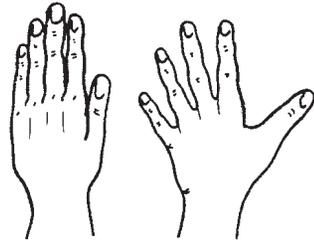
- S:** Wrist and fingers relaxed.



- A:** One hand supporting your forearm and keeping your wrist bent down, the other hand cupping your fingertips.
- M:** Keeping your wrist bent down, straighten your fingers. The movement should come from your knuckles and the joints of your fingers, not your wrist.

Finger Abduction

S: Wrist straight, fingers and thumb relaxed.

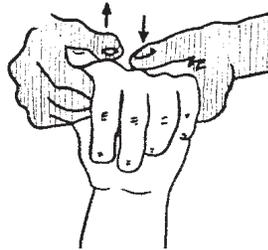


A: Holding adjacent fingers straight.

M: Spread fingers apart.

Hand Mobilization

S: Your palm down with your thumb and fingers relaxed.



A: Cupping your hand in both hands, the attendant's right thumb and index finger hold one knuckle while the left thumb and index finger hold the next knuckle over.

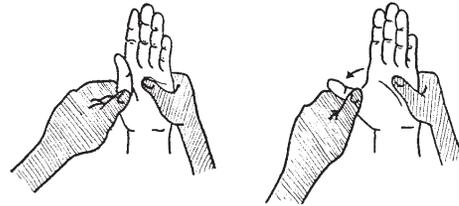
M: One hand gently pushes down on the knuckle it is holding while the other hand pushes up. Reverse directions. Move across your hand.

Thumb Abduction/Extension

S: Palm up with your fingers and thumb relaxed.

A: One hand stabilizing your palm, the other grasping your thumb with your attendant's thumb at the base of your thumb.

M: Move your thumb out and away from your palm as if you were hitchhiking.

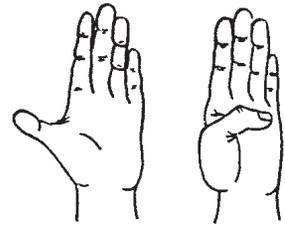


Thumb Opposition

S: Palm up with your fingers and thumb relaxed.

A: Holding your thumb over your nail.

M: Touch the tip of your thumb to the base of your little finger.



Appendix B | Resource Organizations

The following organizations have a wide range of goals, objectives, programs, services, and interests related to spinal cord injury [SCI].

Association of Programs for Rural Independent Living

2001 Pershing Cir., Suite 200
North Little Rock, AR 72114
[330] 678-7648
www.april-rural.org

Canadian Paraplegic Association [CPA]

1101 Prince of Wales Dr., Suite 230
Ottawa, Ontario, Canada K2C 3W7
[613] 723-1033
email: info@canparaplegic.org
www.canparaplegic.org
[The CPA is concerned with every phase of SCI rehabilitation, from initial trauma to lifelong adjustment.]

Canine Companions for Independence [CCI]

P.O. Box 446
Santa Rosa, CA 95402-0446
[800] 572-2275
www.caninecompanions.org
[CCI is a nonprofit organization that provides highly trained assistance dogs to people with disabilities and to professional caregivers.]

Christopher Reeve Paralysis Foundation

636 Morris Turnpike Suite 3A
Short Hills, NJ 07078
[800] 225-0292
www.christopherreeve.org
[The Christopher Reeve Foundation supports research to develop effective treatments and a cure for paralysis, and to improve the quality of life for persons living with disabilities.]

Christopher and Dana Reeve Paralysis Resource Center

636 Morris Turnpike Suite 3A
Short Hills, NJ 07078
[800] 225-0292
www.paralysis.org
[This center promotes the health and well-being of people who are living with spinal cord injury, paralysis, and mobility impairment by providing comprehensive information, resources, and referral services. It publishes a comprehensive Paralysis Resource Guide.]

Disabled American Veterans [DAV]

P.O. Box 14301
Cincinnati, OH 45250-0301
[859] 441-7300
www.dav.org
[This veterans service organization provides assistance to all veterans and members of their families. Membership is open to all military service-disabled veterans.]

Easter Seals

230 W. Monroe St., Suite 1800
Chicago, IL 60606
[800] 221-6827; [312] 726-6200
[312] 726-4258 TTY
www.easter-seals.org
[A national organization with local chapters. Serves all people with disabilities. Comprehensive and individualized to meet each client's needs.]

Helping Hands

541 Cambridge Street

Boston, MA 02134

[617] 787-4419

www.monkeyhelpers.org

[Helping Hands is a nonprofit organization dedicated to improving life for quadriplegic individuals by training capuchin monkeys to assist them with daily activities.]

International Campaign for Cures of Spinal Cord Paralysis [ICCP]

www.campaignforcure.org

International Collaboration on Repair Discoveries [ICORD]

www.icord.org

[These two organizations promote interdisciplinary research for the development of strategies for functional recovery after SCI.]

Job Accommodation Network [JAN]

West Virginia University

P.O. Box 6080

Morgantown, WV 26506-6080

[800] 526-7234

www.jan.wvu.edu

[JAN is not a job placement service, but an international toll-free consulting service that provides information about job accommodations and the employment of people with disabilities.]

National Council on Independent Living [NCIL]

1710 Rhode Island Ave., NW

Washington, DC 20036

[202] 207-0334

[202] 207-0340 TTY

www.ncil.org

[NCIL is a membership organization that advances the independent living philosophy and advocates for the human rights of and services for people with disabilities.]

National Institute on Disability and Rehabilitation Research [NIDRR]

400 Maryland Ave., SW

Washington, DC 20202-2572

[202] 245-7640, voice and TTY

www.ed.gov/about/offices/list/osers/nidrr/index.html

[This federal agency supports the regional model SCI care system and related research efforts. It administers grant programs, including the Rehabilitation Research and Training Centers.]

National Institute of Neurological Disorders and Stroke [NINDS]

NIH Neurological Institute

P.O. Box 5801

Bethesda, MD 20824

[800] 352-9424

[301] 496-5751

[301] 468-5981 TTY

www.ninds.nih.gov

[Part of the National Institutes of Health, NINDS conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke.]

National Organization on Disability

910 Sixteenth Street, NW, Suite 600

Washington, DC 20006

[202] 293-5960

[202] 293-5968 TTY

www.nod.org

[The National Organization on Disability promotes full and equal participation of America's 54 million men, women, and children with disabilities in all aspects of life.]

National Spinal Cord Injury Association [NSCIA]

1 Church St., #600
Rockville, MD 20850
[800] 962-9629
www.spinalcord.org

[This organization provides advocacy, peer support, and other services to persons with SCI, their families, and their health-care providers. It supports research aimed at improving care for people with SCI and developing a cure. NSCIA has chapters in many states that can provide information about local resources, social activities, and advocacy.]

Paralyzed Veterans of America [PVA]

801 Eighteenth Street, NW
Washington, DC 20006
[800] 424-8200; [202] 872-1300
[800] 795-4327 TTY
www.pva.org

[PVA is a congressionally chartered veterans service organization that works to improve the quality of life for persons with spinal cord injuries and disorders through research, education, and advocacy for health care, civil rights, and opportunities for its members and all Americans with spinal cord injury or disease.]

Office of Disability Employment Policy [ODEP]**U.S. Department of Labor**

200 Constitution Avenue, NW, Room S-1303
Washington, DC 20210
[866] 633-7365
[877] 889-5627 TTY
www.dol.gov/odep

[This office communicates, coordinates, and promotes public and private efforts to enhance the employment of people with disabilities.]

Spinal Cord Injury Information Network**University of Alabama at Birmingham [UAB]****Department of Physical Medicine and Rehabilitation**

619 19th Street South, SRC529
Birmingham, AL 35249-7330
[205] 934-3283
www.spinalcord.uab.edu

[UAB hosts a model spinal cord injury center that supports research and patient education projects. The Rehabilitation Research and Training Center conducts research and training in the prevention and treatment of secondary conditions of spinal cord injury. Under a grant from NIDRR, it maintains a website that provides links to educational and research information.]

United Spinal Association

75-20 Astoria Blvd.
Jackson-Heights, NY 11370
[718] 803-3782
www.unitedspinal.org

[Dedicated to enhancing the lives of people with spinal cord injury and disease.]

University of Washington

Box 356490
Seattle, WA 98195-6490
[206] 543-3600
www.sci.washington.edu

[The website of the Northwest Regional SCI System at the University of Washington in Seattle offers extensive resources for researchers, health-care providers, and consumers.]

Glossary

A

Abdominal binder

A cloth and elastic support worn wrapped around the abdomen to provide support for the abdominal wall muscles or sometimes to improve breathing.

Acute stage

The time directly after injury when one is in the hospital and may have many kinds of medical problems.

Adaptive equipment

Equipment that is used to help adapt your environment to your personal needs. Examples include ramps, splints to hold pens or forks, and hand controls to drive vehicles.

ADL—activities of daily living

Self-care activities, such as bathing, dressing, toileting, eating, grooming, etc.

Advocate

Someone who supports and represents your best interests in a given situation.

Anemia

A lack of red blood cells carrying oxygen to the tissues of the body.

Appliance

A device used to perform or help you perform a certain activity.

ASIA classification of spinal cord injury

The International Standards for Neurological Classification of Spinal Cord Injury (usually called the ASIA classification system, as it was first developed by the American Spinal Injury Association) uses standardized muscle testing and sensory examination to classify the level and completeness of SCI. Completeness of SCI is recorded using the ASIA Impairment Scale.

Atherosclerosis

Thickening of artery walls; hardening of the arteries.

Atrophy

A condition in which muscles diminish in size as a result of lack of stimulation from nerves.

Attendant

An individual (family, friend, paid staff, etc.) hired to assist with household tasks or personal care on a routine basis.

Automobile adaptive equipment

Items and/or devices necessary to permit the safe operation of or the ability to get in and out of an automobile or other types of vehicles.

Autonomic dysreflexia

Episodes of high-blood pressure, often accompanied by headache or flushing, that can occur in people with SCI level T7 or above. It is triggered by painful conditions or things that would be perceived as painful by someone with normal sensation.

B

Bladder dysfunction

General term used to describe changes in the bladder's ability to store and empty urine.

Bowel care

The procedure for starting and completing a bowel movement.

Bowel program

The total, individualized management plan to regularly empty the colon of stool. It includes diet, exercise, medication, and regularly scheduled bowel care.

Braces

Splints used to support, align, or hold parts of your body in correct position.

C

Capillary

A fine vessel that carries blood to tissues

Carbohydrates

Sugar and starches, a primary source of energy in the average U.S. diet. Complex carbohydrates (beans, peas, nuts, seeds, fruits, vegetables, whole grain breads, and cereals) supply fiber and many essential nutrients as well as calories.

Caregiver

General term used to describe any person who provides physical, emotional, psychological, or social care.

Cath

Slang for catheterization.

Catheterization

Inserting a thin tube into your bladder to empty urine.

Cervical

Refers to conditions or things associated with the spine at the level of the neck; also refers to the cervix, the necklike end of the uterus.

Cholesterol

A waxy-like, nonfat substance found in blood that is made by your liver or taken in from food sources of animal origin.

Chronic pain

Pain that is present most of the time for more than three to six months. If the pain began with an injury, the pain lasts longer than the expected time for the body to heal from that injury.

Chux

Absorbent pads used to protect a mattress, also known as "blue" pads.

Cirrhosis

A disease of the liver aggravated by excessive alcohol consumption.

Clothing allowance

An annual sum of money specified by Congress to be paid to each veteran who, because of his or her service-connected disability, wears or uses a prosthetic or orthotic appliance (including a wheelchair) that tends to wear out or tear the clothing.

Contractures

Permanent limitation of joint movement usually due to neglecting severe spasms, poor positioning, or neglect of range-of-motion exercises.

Contraindicated, contraindication

Bad for health; a symptom, condition, or medication whose presence indicates that some other treatment or medication should not be used.

Credé

A method of emptying the bladder by applying firm pressure on the abdomen with the hands to push the urine out.

D

Decubitus ulcer: see *pressure ulcer*

Deep vein thrombosis (DVT)

Formation of a blood clot in a deep vein of the lower limbs or, less commonly, the upper limbs. If the clot breaks free from the wall of the vein, it becomes an embolus.

Digital stimulation

Gentle movement of a gloved finger in a circular pattern in the rectum to relax the sphincter muscle so that stool may pass during bowel care.

D.O.: doctor of osteopathy

One of two medical degrees that permits licensure as a medical physician in the United States. *Also see M.D.*

Dosage

The amount of medication you should take and when to take it.

Drugs

Substances that affect the body or mind. This includes both medications taken to get better and substances that are abused.

E**Edema**

Fluid collecting in a given area of the body, causing swelling.

Eligibility

The determination of whether one qualifies for certain entitlement programs. VA benefit payments are based on certain facts, including your period of service; whether one has had an honorable or other discharge from the service; income guidelines; and a documented physical disability.

Electrodiagnostic testing or electromyography (EMG)

Tests to find out how your nerves and muscles are working, using electronic equipment.

Extension

Unbending of a joint, for example, straightening your arm.

Extremity

A medical term referring to your arm or leg. Upper extremity includes your arm, forearm, and hand; lower extremity includes your thigh, lower leg, and foot.

F**Fabricate**

To construct, assemble, or manufacture.

Flaccid

Lacking muscle tone.

Flexion

Bending of a joint, such as when bending your leg at the knee.

Foley

Short for a Foley catheter, a tube used to continuously drain urine from your bladder.

G**Gait**

Description of an individual's style of walking.

H**Halo**

A metal ring attached to your head, used to treat broken necks. When used with a plastic vest, this keeps your neck and body straight.

HBHC—hospital-based home care

The service offered by a hospital that provides care for people in their own homes.

Health promotion

Activities and attitudes that help you live a healthy life.

Health risks

The things, such as living conditions, heredity, attitudes, or activities, that increase your chances for poor health.

Hygiene

Condition or practices leading to health; usually used in reference to personal cleanliness.

Hypersensitive

Excessively sensitive, a condition in which there is exaggerated response by the body to stimulation, such as touching, stretching, or movement.

I

ICP: see *intermittent catheterization program*

Impaction

Something that gets lodged in and clogs a space, such as an impaction of the bowel.

Incentive spirometer

A device used to build lung volume and breathing strength.

Incontinence

Inability to exercise voluntary control over your bowel or bladder, leading to leaking or other accidents.

Independent living unit

A full apartment on the rehabilitation unit where patients can test new skills and be evaluated on what they have learned in therapy sessions.

Intermittent catheterization program

ICP or cath—a routine program by which the bladder is emptied at regular intervals by catheterization to prevent urinary accidents and infections.

Involuntary

Independent of the will; not under voluntary control.

L**Ligament**

A band or sheet of fibrous tissue connecting two or more bones, cartilages, or other structures.

LPN—licensed practical nurse

A person trained and licensed to provide routine nursing care.

Lumbar

Refers to a condition or thing in the area of the lower back.

M**M.D.: doctor of medicine**

One of two medical degrees that permits licensure as a medical physician in the United States. The degree is received on completion of medical school. *Also see D.O.*

Medical history

The important information about your (and your family's) past and present health.

Medication—medicine

A therapeutic substance you take that is prescribed by your doctor or purchased “over the counter.”

N**NA—nursing assistant**

Someone who assists nurses by performing routine, nonclinical tasks, such as serving meals and making beds.

Neurogenic

Refers to a condition or thing that is controlled by nerves or in which the control by the nerves has been damaged.

Neuropathic pain

Pain that is caused by injury or dysfunction in the nervous system (spinal cord, nerves, or brain).

Nutrition

The food you eat and how your body uses it to live, grow, keep healthy, and get the energy it needs for work and recreation.

O**Occupational therapy or therapist—OT**

The profession or professional that focuses on the range of motion, strength, and coordination of fine, or small, movement of muscles and joints, with or without adaptive devices. The end result is to enable you to perform ADL tasks or various vocational skills.

Oral

Pertaining to or taken through your mouth.

Orthosis, orthotics

A device applied to the exterior of the body to support, aid, and align the body and limbs or to influence motion by assisting, resisting, blocking, or unloading part of the body weight. These devices may include, but are not limited to, braces, binders, corsets, belts, and trusses.

Orthostatic hypotension

A form of low blood pressure that occurs in a standing posture.

Osteomyelitis

Bone infection. This can occur when a deep pressure ulcer extends to the bone.

P**Pandemic**

An epidemic that affects an unusually large area and population.

Para—paraplegia

Paralysis of the legs and lower body.

Paralysis

The inability to control movement of a part of your body.

Paraparesis

Incomplete paralysis or weakness of the legs only.

Personality

Thoughts, feelings, and behaviors that are specific to an individual, often representing a particular pattern or style of life.

Physical therapy, physiotherapy, physical therapist, PT

The profession or professional that deals with the strength, coordination, and range of motion of gross movements of your muscles and joints.

Pneumonia

Inflammation of the lung tissue and filling of the airspace with fluid. Most cases are due to infection by bacteria or viruses.

Pressure reliefs

Changes in position in the wheelchair or bed to let your skin rest and increase circulation of blood flow in the buttocks or areas of pressure; used to prevent pressure ulcers.

Pressure ulcer (bed sore, pressure sore, decubitus ulcer)

A reddened area or open sore usually found on the skin over bony areas, such as your hipbone or tailbone. Too much pressure on those areas for too long a time usually causes them.

Primary care

The medical care of routine illnesses, such as colds, flu, etc.

Prone

Lying flat, especially face down.

Prosthesis

An artificial substitute for a missing body part.

Prosthetic appliances

All aids, appliances, parts, or accessories that are required to replace, support, or substitute for a deformed, weakened, or missing anatomical portion of the body. Artificial limbs, terminal devices, stump socks, braces, hearing aids and batteries, cosmetic facial or body restorations, eyeglasses, mechanical or motorized wheelchairs, orthopedic shoes, and similar items are included under this broad term.

Psychological

Related to mental and emotional factors that influence behavior (motivation, awareness, personality, etc.).

PT—physical therapy, physical therapist: *see physical therapy*

Pulmonary

Having to do with your lungs and breathing.

Pulmonary embolism

A thrombus, or blood clot, that has broken loose from the wall of a vein and become stuck in an artery to the lungs.

Q**Quad—quadriplegia, tetraplegia**

Paralysis of all four limbs.

Quadripareisis

Weakness or incomplete paralysis involving the arms and legs.

R**Range of motion—ROM**

An arc of movement of a joint of your body, also used to refer to the exercises done to maintain and increase the arc of movement.

registered nurse—RN

A professional, trained and authorized by a state board of nursing examiners, who plans and provides nursing care. Your primary care planner is usually an RN.

Rehab—rehabilitation

The process of doing away with, adapting to, or compensating for disabilities.

Residual

In the case of bladder voiding, urine left in the bladder after voiding has taken place.

Respiratory

Having to do with breathing.

Respiratory therapy, respiratory therapist—RT

The profession or professional that centers on therapy of the lungs and breathing.

S**Sacral**

Relating to the area at the lowest part of your spine around your tailbone.

Sensation

Physical feelings of vibration, touch, pain, hot and cold, or awareness of where a body part is in space.

Side effects

The effects of something, usually medication, that are different from and additional to the outcome for which it was originally planned.

Sleep apnea

Pauses in breathing during sleep.

Spasm

A sudden, often uncontrolled, contraction of a muscle; a muscle jerk.

Spasticity

Movement in your arms and legs due to muscle spasms that may occur as a result of spinal cord injury. It may be somewhat controllable. Spasticity may also be useful in maintaining muscle size, bone strength, and circulation.

Spine immobilizers

Braces or devices that keep you from moving your back or neck.

Spine stabilization

Use of spinal surgery or external bracing to hold the bones of the spine in correct alignment and treat an injury to spinal bones or ligaments.

Splint

A rigid or flexible appliance used for the fixation (holding in place) or support of a displaced or movable part of the body.

Stones

Solid, hard masses that form and can become stuck in the urinary tract. This can block normal urine drainage from the kidney or bladder, or it can cause urinary infections to recur.

Suctioning

Removal of mucous from the throat and lungs by a small tube attached to suction.

Support system

The people who are important to you because they strengthen your emotional, physical, and social well-being. They include your family, friends, coworkers, neighbors, and members of your church or veterans group.

T**Tenodesis**

The action of fingers and thumb pinching together when the wrist is bent backward. Most commonly this refers to passive finger and thumb movement when the muscles to those digits are paralyzed.

Tetraplegia: *see Quadriplegia*

Therapy

Treatment of diseases, disorders, or disabilities.

Thoracic

Refers to a condition or thing in the region of the spine at the chest or mid-back level.

TRS—therapeutic recreation specialist

The person responsible for your recreational therapy.

U**Urinalysis**

A sampling test of urine to evaluate the contents of the urine and check for problems.

Urinary system

The body parts that turn wastes into urine, store it, and eliminate it. Kidneys filter blood to wash it clean and make the urine. Ureters are tubes to bring the urine from the kidneys to the bladder. The bladder is a dynamic storage tank for the urine. The urethra is a tube to bring the urine from the bladder to the outside.

V**VA—U.S. Department of Veterans Affairs**

The branch of the federal government responsible for providing health care and other benefits to eligible veterans of the armed forces.

VBA—Veterans Benefits Administration

Branch of the U.S. Department of Veterans Affairs responsible for administering compensation and pension benefits to eligible veterans.

Ventilator

A piece of equipment that helps you to breathe when you cannot do it yourself.

Vital capacity

The largest full breath that can be breathed in or out. People with weak breathing muscles have a smaller vital capacity.

Vocational

Work or job-related activities.

Voc rehab—vocational rehabilitation

Developing skills to improve work habits or to increase employment potential.

Void

To empty the bladder.

VRS—vocational rehabilitation specialist

The person who assists you in developing skills and determining changes or improvements in your job or vocational status.

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