Health Considerations in Spinal Cord Injury:

A Handbook for People with SCI

Introduction

It was fall of 2013, and we were stuck. We wanted to ensure that all people with spinal cord injuries (SCI) living in our home state of Kentucky were receiving the most current and appropriate health care, but were taken with the size of that challenge. What if an individual with SCI lived in a very small town, and saw a doctor who hadn't cared for many people with SCI? What if that individual didn't have access to doctors who specialize in caring for people with SCI? We thought about trying to educate our state's primary care doctors about the specific medical concerns faced by people living with SCI, but soon realized the better option would be to target a smaller and more invested audience—the SCI community, itself.

Previously published handbooks have educated doctors about SCI, and have covered the anatomy of the spinal cord, considerations in treating individuals with recent injuries, and how best to care for people living with long-term injuries. In this book, however—*written for an audience with little or no medical training*—we sought to review core aspects of the medical care of people with SCI. Topics which affect both their quality of life and their ability to remain healthy. We developed our list of "chapters" by speaking with colleagues who specialize in caring for individuals with SCI, then asked doctors from our home institutions to help us write them.

The chapters in this handbook are short but cover the latest thinking in the medical care of people with SCI and offer references for readers (patients or doctors) who want more detailed information. Our intent is to distribute this handbook to people living with SCI so that they can read about and help direct their own medical care, but it may also serve as a basic resource for health care providers attempting to deliver better and more thorough care to their patients with SCI.

In planning this handbook, we were struck by the many barriers to health care faced by people living with SCI. A great number of health care facilities remain inaccessible to wheelchair users and individuals living with disabilities, very few health care providers have been formally trained in medical concerns specific to people with SCI, and research on chronic disease in SCI is still very much incomplete. Readers will note that many important questions—particularly about heart disease in SCI—have yet to be asked or answered. We hope, however, that people living with SCI will find this resource useful, and that it will empower them to help manage their own care, educate their health care teams, and advocate for themselves in a challenging health care system.

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Autonomic Dysreflexia

Autonomic dysreflexia (AD) is a condition in which the nervous system of individuals with SCI "overreacts" to a painful or uncomfortable stimulus, causing a sudden—and sometimes dangerous—increase in blood pressure. AD is usually triggered by an irritation below the level of injury and most commonly affects people with injuries above the level of T6 (1). AD is more likely to start in the first six months after the initial injury (2), but may present even years later.

The most common causes of AD are bladder distention and constipation (3), but it may also be due to pressure ulcers, a urinary tract infection, ingrown toenails, or even sexual activity (2). While increased blood pressure is the lead concern in AD, an individual with SCI may not know when his or her blood pressure is high. More noticeable signs and symptoms of AD include headaches, sweating, flushing, blurry vision, stuffy nose, nausea, chest tightness, and/or anxiety (4).

The following steps are important in treating an episode of AD:

> First, the person with AD should be placed in an upright position with tight clothing removed (5). This may help lower blood pressure.
>
> The next step is to identify the trigger for the episode. As bladder irritation is the most common cause of AD, a catheter should be placed. If a catheter is already in place, it should be examined for blockage and signs of urinary tract infection, such as cloudy urine (6).
>
> If there are no signs of problems with the bladder, then a rectal exam should be done to check for stool impaction.
>
> If there is still no obvious trigger, then a complete physical examination should be done to look for any other sources of irritation.
>
> Blood pressure should be checked every 2-5 minutes during an episode of AD, and if high pressures don't resolve on their own, medications may be given (7).

Autonomic dysreflexia can result in serious consequences, such as seizures or bleeding in the brain (stroke). Since it can be a life-threatening medical emergency that is not always diagnosed and treated correctly, it is important to know how to recognize its early signs and symptoms and to be able educate others about this condition. It is a good idea for people with SCI to carry wallet cards that list the symptoms of AD and the ways to treat it. These cards are available at various spinal cord injury support websites.

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Orthostatic Hypotension

Orthostatic hypotension, or "orthostasis," is a drop in the upper number of your blood pressure (BP) by 20 points and the lower number by 10 points (1). This drop in BP may occur up to 3 minutes after sitting or standing; may cause lightheadedness, dizziness, racing of the heart, nausea, or blurry vision; and may occur in up to 74% of people with new spinal cord injuries (2). It is more common in people with injuries at or above T6, but may occur in all individuals with SCI.

Upright posture causes pooling of blood in the legs, and this may drop your BP. In healthy individuals, this fall in BP is sensed by special sensors located in our blood vessels called "baroreceptors." Our brains respond to this information by sending signals through the spinal cord to activate certain nerves ("the sympathetic nervous system") that can help increase BP; however, after SCI these signals cannot pass beyond the level of injury, and this may lead to orthostatic hypotension (3). Additionally, leg muscles help pump pooled blood back to the heart, so people with weakness after an injury may also develop orthostasis (4).

Orthostatic hypotension is often more severe after initial injury. Over time, however, the body develops different mechanisms such as increases in levels of certain hormones (renin-angiotensin, aldosterone, and vasopressin) to prevent excessive falls in BP (5). Interestingly, developing tightness or "spasticity" in leg muscles—often viewed as an uncomfortable and treatable complication of SCI--can help improve return of blood to the heart and, hence, help maintain blood pressure (5).

The diagnosis of orthostasis is made clinically and is based both on symptoms and on measurements of BP in the laying, sitting, and standing positions, if possible (6). Your doctor may order laboratory tests such as a complete blood count and a basic metabolic panel to rule out potential causes of orthostasis such as infections, low blood sugar, anemia or low blood counts, and dehydration. If untreated, orthostatic hypotension can affect your ability to participate in therapy, exercise programs, and activities of daily living.

There are certain things you can do, short of taking medications, to improve orthostasis. These include (3,7):

- Keeping active and avoiding staying in bed for long periods.
- Avoiding quick changes in posture. Raise the head of your bed before sitting up. Sit up for few minutes before transferring to the wheel chair or standing.
- Wearing elastic stockings and an abdominal support binder. Placing these before sitting or standing can help prevent pooling of blood in your legs.
- Drinking enough fluids to prevent dehydration and associated low BP.
- Avoiding drinks that are diuretics, such as alcohol and caffeine. These can cause your body to lose water.
- Eating smaller meals, which may help prevent drops in BP sometimes associated with eating large meals.

- Avoiding excessive exercise in hot environments. This may cause dehydration.
- Laying flat if and when you experience orthostasis. This can increase BP and may help with symptom relief.
- Functional electrical stimulation (FES), which is a method of contracting muscles by placing electrodes on the skin. FES may help in the pumping of blood from your legs to your heart (8), although there are limited data to support this treatment.

If the above strategies fail to improve orthostasis, your doctor may prescribe one of these commonly used medications (7).

- **Sodium chloride:** It elevates your BP by moving fluid into your blood vessels.
  Dose: up to 1 gm four times a day.
- **Midodrine hydrochloride** (9)**:** It constricts your blood vessels to increase your blood pressure.
  Dose: 2.5 mg to 10 mg three times a day.
- **Fludrocortisone** (10)**:** It helps you retain salt, and this helps keep your blood vessels "plump" with fluid.
  Dose: 0.05 to 0.1 mg daily

The aim of the treatment is not to normalize your blood pressure, which may remain low in SCI, but rather to relieve your symptoms.

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Syringomyelia

Syringomyelia, otherwise known as a "syrinx," is a fluid filled cyst or sack that can occur within the spinal cord, most commonly after a trauma (1). As many as 59% of people with spinal cord injuries will develop a syrinx (2-5)—almost always at the level of injury—but many never grow or cause problems, and are often found on review of an MRI of the spine.

Around 20% of syrinxes will grow, (2,6-9) and no one is certain why this happens. One idea is that blood vessels can leak into the cord and expand cysts (4,10,11), another is that the damaged cord becomes scarred, and blocks normal flow of the fluid which bathes the cord and the brain (12). This may cause pressure to build within the cord and syrinxes to expand, and when they do, they may cause symptoms.

Syrinxes can grow almost immediately after initial damage to the cord or many years later (13). The most common initial symptom is pain (8), which generally (though not always) starts on one side of the body and can be "burning," "stabbing," or "tingling." People generally say this pain is new and different from the pain they usually experience. People with expanding syrinxes may also lose sensation they used to have or develop new muscle weakness (1). Finally, syrinxes may cause more general symptoms, including an increase in spasticity, a change in bowel or bladder function, sweating, a drop in blood pressure with changing position, or autonomic dysreflexia (1,6,14). People who notice these symptoms, particularly if the pain or weakness is moving upward in the body, may be evaluated for an expanding syrinx.

Treatment of a syrinx is not "cook book." Some people with new or worsening symptoms may be seen by their doctor every 3-6 months and have frequent MRIs. As long as there are no significant changes in pain, symptoms, or function, no treatments may be needed. Surgery has been shown to be help people with significant loss of strength or worsening pain (1), and two options are generally considered. One is to create a "shunt," which is a tube that drains fluid from the syrinx (15-17). Another is to cut scar tissue around the cord, which allows fluid to again flow normally (17-19). Surgeons sometimes may use a combination of these two methods, and the goal of surgery is to stop the symptoms from getting worse and to hopefully reverse some of the symptoms (1).

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Spasticity

Spasticity refers to an increase in muscle tone and activity that is caused by injury to the body's central nervous system (1). Affecting 65-78% of people with chronic SCI (2), spasticity can interfere with activities of daily living and significantly affect quality of life, with symptoms ranging from slight muscle stiffness to difficult-to-control pain (3).

Many conditions may trigger new onset spasticity or an increase in baseline spasticity, including pregnancy, stress, anxiety, tight clothing, pain, fever, infections, bladder or bowel dysfunction, pressure ulcers, changes in posture/transfers, and cold temperatures (4,5,6). Interestingly, many people with SCI—particularly those with cervical-level injuries (7)—report more spasticity early in the morning than in the afternoon, leading some researchers to think that spasticity might be related to the body's internal clock, which is known as "circadian rhythm" (4).

Some people with SCI have identified their own spasticity triggers and can try to avoid them, but other treatments may be necessary. Most physiatrists (doctors of physical medicine and rehabilitation) recommend stretching as the first treatment for spasticity. Though there are no guidelines for the "best" types of exercises or stretches to treat spasticity or how often to do them, the goals of therapy are to minimize muscle contractures and to gain control of the affected muscles.

If spasticity is painful or if it interferes with sleep, function, or hygiene, medications may be added to help. The most commonly prescribed one is called Baclofen (8), and it may be taken as a pill or delivered at higher doses through an intrathecal pump, which sends it directly into the fluid surrounding the spinal cord (9,10). Tizanidine, also known as Zanaflex, is a muscle relaxant that has also been shown to help with spasticity (8). Another commonly used therapy is botulinum toxin injection ("Botox"), which should be given by a doctor who has experience in deciding when and if this is an appropriate treatment (11). Several other medications are used less often for spasticity, but may also have some positive effect. These include Gabapentin, Pregabalin, Diazepam, Clonidine, and Dantrolene (8,12,13).

Some people with SCI have very little spasticity, but others with this condition can suffer pain, contractures (14)—which are deformities caused by shortened muscles—and pressure ulcers. Working with a medical team to avoid these symptoms and complications is very important, and it may also lead to an improvement in quality of life.

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Pressure Ulcers

A pressure ulcer is an area of skin breakdown caused by prolonged sitting or lying over a bony part of the body. Ulcers most often develop on the buttocks or the heels (1). About 20-30% of people living with SCI develop an ulcer each year, and up to 85% will have one during his or her lifetime (2,3,4,5).

There are many risk factors for developing a pressure ulcer, including decreased activity and mobility, older age, being wet from loss of urine, malnutrition, significant weight loss, smoking, heart disease, diabetes, muscle spasticity and contractures, and a previous history of having a pressure ulcer (2,4,6). Level and completeness of SCI also contribute to risk of developing a pressure ulcer. People with tetraplegia develop more ulcers than those with paraplegia (5), and people without any muscle function and sensation below their level of injury develop more than those with some movement and partial or full sensation (2,4).

To prevent ulcers, people with SCI should perform pressure relief movements—including forward bending, leaning side to side, and vertical lifts—for about 2 minutes every 15-30 minutes (7). If unable to do these movements on their own, people using power wheelchairs can use "recline" or "tilt-in-space" functions for pressure relief (7). Daily skin checks should be performed on the lower back and buttock as well as on areas with decreased sensation in the arms and legs. Selection of the appropriate wheelchair cushion, particularly for those with significant sensory loss, is very important and can be performed at a specialized wheelchair seating clinic (3,7). Proper skin care is also very important in minimizing the risk of developing pressure ulcers, and people with SCI need to ensure that their skin stays clean and dry with as little exposure to urine and stool as possible (5). Finally, eating a well-balanced diet can both prevent ulcers from forming and help heal existing ones.

There are many serious complications associated with pressure ulcers, including skin, bone, and blood infections, and they can have a significant negative effect on quality of life (8). Maintaining regular visits with a primary physician as well as a rehabilitation physician is an important part of keeping healthy and intact skin.

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Bladder Dysfunction

While bladder dysfunction remains one of the most common complications of SCI, significant advances have been made in its treatment. In the 1950s and 1960s, studies showed that over 90% of veterans with SCI had urinary problems (1) and that many of them had resulting kidney damage (1,2). In recent decades, though, physicians have become better at bladder management in SCI, and rates of kidney failure have sharply dropped.

SCI causes bladder dysfunction by disrupting the normal communication between the muscles of the bladder and the nerves that supply them (3,4). This is also called "neurogenic bladder." Depending on the level of injury, a person with SCI may have "overactive bladder" or "underactive bladder" symptoms. In the first, there is trouble storing urine in the bladder, and people pass frequent small volumes. In the second, the bladder fills past its usual capacity, and people may have trouble emptying it. Both types of bladder dysfunction may cause urinary leakage or incontinence. Urinary retention, which is more common in "underactive bladder," may trigger episodes of spasticity or autonomic dysreflexia.

There are several goals of proper bladder management: to prevent infections in the bladder and kidneys; to avoid muscle stretch injury from over-distension of the bladder; to avoid damage to the kidneys caused by backup of urine; and to keep incontinence from interfering with daily activities and social interactions (5,6). When deciding on a long-term bladder management strategy, there are many factors to take into account, including age, amount of hand function and mobility, motivation, cost, and convenience. People with neurogenic bladder should work closely with their physicians to develop their personal plan for bladder management (7). It is also wise to include a urologist (a doctor whose specialty is the urinary tract) in the care of people with SCI because they can perform "urodynamic" examinations to look at the pressures in the urinary tract. There are no guidelines to say how often these tests should be performed, but a recent study showed that there is benefit to doing them yearly to help identify problems early before they cause damage that cannot be reversed (8).

Most people with bladder dysfunction from SCI use catheters to drain urine from the bladder. The most common types are indwelling catheters that stay in at all times, intermittent catheters that are placed and then immediately removed each time urine is drained, or suprapubic catheters that go through the skin above the pubic bone directly into the bladder. While many people with neurogenic bladder and their doctors prefer intermittent catheterization—believing they are more convenient and less like to cause infection--there are no studies that show one type of catheter is best (9). Most doctors agree that it is best to keep less than 500 milliliters of urine in the bladder. To achieve this, it is best for people to cath 4 times each day, removing around 500 milliliters each time. To avoid interfering with work and other social activities, it is often helpful to schedule caths for 6 AM, noon, 6 PM, and immediately before bed.

Medications can be important in the treatment of neurogenic bladder. Anticholinergics, tricyclic antidepressants, and antispasmodics are the main classes of medications that may be used (6). Botulinum toxin ("Botox") injections have also been shown to assist with urinary incontinence (10), but repeated injections are necessary to achieve long-term management (11). Surgical options are also available, including placement of electrical stimulators, sphincterotomy where the sphincter muscles are cut to relieve obstruction, bladder reconstruction, or urinary diversion procedures (6,12). Research is underway looking at other ways to manage, or even reverse, neurogenic bladder. In the future, nerve regeneration or stem cell therapy may be available to provide better management of bladder dysfunction for people with SCI (13,14).

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Bowel Management

Bowel function in SCI is a major concern, as injured people often suffer changes in gut movement and sphincter control. Studies have shown that up to 95% of people with SCI need some type of assistance to have a bowel movement (1).

Depending on the level of injury, there are two different types of bowel dysfunction. The "upper motor neuron" (UMN) bowel is seen after injuries to any part of the spinal cord except for its lowest portion. It causes an overall increase in tone, so the anal sphincter becomes very tight, and there is resulting constipation and stool back up (2). The other type of dysfunction, known as the "lower motor neuron" (LMN) bowel, results from injuries to the very bottom of the cord. LMN bowel causes loss of muscle tone in the anal sphincter and surrounding muscles, so it more frequently leads to fecal incontinence or leakage (3).

Long-term management of bowel function in SCI is most effective when many different treatment strategies are used (4). People with SCI should have a padded, upright commode to help reduce pressure on their bottoms, drink two to three liters of fluid a day, eat high fiber diets, and avoid medications that can cause constipation. Abdominal massage has, in limited studies, been shown to help with constipation and abdominal distension (5), though most individuals with SCI also need to take medications to help with having a bowel movement (6). These may include over-the-counter products like Metamucil, Citrucel, Colace, or Miralax, but some people may require intermittent use of enemas, suppositories, or prescription medications.

Many people with SCI need further assistance in passing their stool, so they should work with their physicians to develop an individualized bowel program. Most often, this involves "digital stimulation," in which the individual with SCI or his or her caregiver actually sweeps stool out of the rectum with a finger (7,8). Since constipation is a major cause of autonomic dysreflexia, many people with SCI prefer a daily program, even if they do not suffer from significant constipation.

If not managed properly, neurogenic bowel can cause skin breakdown, infections, abdominal discomfort, and decreased quality of life. If "conservative" strategies like attention to diet, medications, and digital stimulation aren't effective, more advanced (surgical and non-surgical) treatments may be offered (9).

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Bone Health

Loss of bone density, resulting in weak and brittle bones below the level of injury, is a well-known consequence of SCI. After an SCI, being unable to walk, changes in hormone levels, poor nutrition, and poor eating habits can lead to an imbalance between the processes of making and losing bone (1). This often leads to rapid loss of bone density or "thickness," but this process frequently levels off after the first two years post-injury (2).

"Osteoporosis" is a condition in which bones lose density, become weak and spongy, and are more likely to break, whereas "osteopenia" is a state in which bones have lost some density but have not yet reached criteria for osteoporosis. Evaluating and treating bone loss is quite important, as studies suggest that at least half of all people with SCI will sustain a fracture or broken bone due to osteoporosis within 7-10 years of their injury (3), and these fractures may happen suddenly or with very little trauma.

People with SCI are at greater risk of developing fractures in the lower thigh and upper leg bones, but osteoporotic individuals without SCI generally develop fractures in their lower spines, hips, and wrists (3). Fractures in the setting of SCI may severely decrease independence and mobility, as well as put people at risk for associated medical problems including bone infection (osteomyelitis), joint contractures, and pressure ulcers.

A dual-energy x-ray absorptiometry (DEXA) scan is the preferred technique for measuring bone mineral density (BMD), and a diagnosis of osteopenia or osteoporosis is given based on that scan's result or "T-score." While there are no specific guidelines regarding screening for osteoporosis in individuals with SCI, many physicians who care for them recommend obtaining a scan soon after injury and repeating one every year or two thereafter.

Pharmacologic or medical treatment of osteoporosis may include:

1. **A combination of agents:** Calcium pills alone have not been shown to prevent or treat osteoporosis, but the use of calcium plus Alendronate (also known as "Fosamax") in people with SCI has been shown to arrest bone loss (4).

2. **Vitamin D supplementation:** This is recommended because vitamin D is crucial to building bone and almost one-third of individuals with SCI have low levels (5). Your doctor may choose to check your vitamin D level, and if it is low, "boost" it with an 8 or 12 week course of high-dose pills.

3. **Bisphosphonates:** These medications have been used for years to slow bone breakdown. Examples include Alendronate, Zoledronate, Ibandronate (common names are "Fosamax," "Reclast," and "Boniva," respectively) (4,6). Long-term use of bisphosphonates appears to be safe, but medical teams frequently offer "holidays" from

these medications after four years of use if a patient's bone density has remained stable.

4. **Hormonal agents:** Teriparatide, also known as "Forteo," is a man-made version of parathyroid hormone and has been shown to improve bone health in people with non-SCI related osteoporosis (7). Its usefulness in individuals with SCI is not known yet.

Non-Pharmacological treatment of osteoporosis may include:

1. **Mechanical loading by standing in a standing frame**: Results of studies in individuals with SCI have been inconsistent. Some have shown that this treatment helps maintain bone density, while others have not shown benefit (8).

2. **Functional Electrical Stimulation (FES):** Electrodes are applied to an individual's skin to produce muscle contractions. This causes muscles to load or pull on the bones, and in this way, helps stimulate bone-building activity. Studies of FES haven't consistently shown prevention or slowing of osteoporosis (8).

3. **Low intensity vibration:** Low magnitude mechanical signals are delivered by a vibrating platform. This has shown to maintain bone mineral density in animal and in some human studies (9,10), but isn't yet widely used.

Protecting bone density after SCI is important. Eating a healthy diet, avoiding cigarettes, limiting alcohol and caffeine intake, and staying as physically active as possible can all help prevent bone loss.

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Sex After SCI

Our genitals receive sensory input from the Pudendal Nerve, which is formed from sacral nerve roots very low in the spinal cord. Hence, men and women who are injured above the S4 level—*or nearly everyone with an SCI*--will develop "neurogenic sexual dysfunction."

Non-injured men develop erections for two reasons. Visual stimulation or fantasy can cause a "psychogenic erection," while physical stimulation or touching the penis causes a "reflexogenic erection." Erections resulting from a combination of visual and physical stimulation tend to be quite hard and last long enough for sexual activity.

Men who are spinal cord injured often have difficulty obtaining psychogenic erections, but can still have reflexogenic erections. Reflexogenic erections alone are generally not hard or long-lasting enough for sexual activity, so many men with SCI use medications such as Sildenafil ("Viagra"), Vardenafil ("Levitra") or Tadalafil ("Cialis") to become fully erect and to maintain their erections for sexual activity. While these medications are generally considered "first-line" for erectile dysfunction in SCI, men with inadequate responses may ask their physicians about mechanical pumps or agents which can be injected directly into the penis.

Women with SCI often experience decreased vaginal lubrication during sex and may have to use store bought lubricant.

The ability to achieve an orgasm depends on the amount of sensation preserved in the genitalia following SCI. Men and women with incomplete injuries will often have some preserved genital sensation and be able to achieve orgasm, while people with more complete injuries may have greater difficulties. However, stimulation of other sexually sensitive or "erogenous" areas of the body such as the nipples, armpits, neck, and the skin at the level where sensation change occurs may result in orgasm.

Men with SCI often have difficulties ejaculating due to weakness of the pelvic floor muscles. After orgasm, the sperm will often slide back into the bladder, and men may find sperm floating in their urine with their next catheterization. For men with SCI who have troubles ejaculating, fertility can be challenging. However, there are ways of obtaining sperm such as vibratory or electrical stimulation that can then be used for insemination.

In the initial months following SCI, women often stop having periods. In general, though, normal cycles soon return. Most women remain fertile following SCI, and their ability to conceive and carry a child to full term and to have a normal vaginal delivery is not affected by their injury. Women with injuries above the T6 level are at risk of autonomic dysreflexia during labor, and should have epidural anesthesia to reduce the risk of this condition.

Depression

Depression can be quite common among individuals with SCI. Approximately 25-40% of injured people are at some point diagnosed with depression, and 10-40% of those who have suffered a traumatic injury have post-traumatic stress disorder (PTSD) (1,2). The true rates of depression in SCI are likely higher than those quoted, as this condition often goes undiagnosed.

It is very important to recognize and properly treat depression because it can lead to low quality of life, decreased ability to perform daily activities and self-care, increased pain, more time spent in bed, and more frequent hospitalizations for medical complications (3).

Most doctors will screen their patients for depression by asking a series of questions or having them fill out a questionnaire (4). Common symptoms include loss of interest or pleasure in activities that used to be enjoyable, sleep disturbances, decreased energy, feelings of guilt, lack of concentration, loss of appetite, or thoughts of suicide. While all people with SCI should be screened for depression, some individuals are more likely than others to be affected and deserve special consideration. These include women, children, and those who are overweight or obese (5,6).

Treatment options for people with SCI and depression include individual counseling, group therapy, and antidepressant medications. Exercise, when possible, has been shown to be beneficial, and rehabilitation therapy can play an important role in treating depression (7). Cognitive behavioral therapy is a treatment that combines relaxation techniques, problem solving training, and other behavior modifications. Studies have shown that it is highly effective in treating depression in individuals with SCI (8). People with depression should work closely with their doctors to design the treatment plan that works best for them.

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Testosterone

Testosterone is a hormone that affects many areas of the body. Men with too little testosterone may notice a decline in their desire and ability to have sex, a reduction in muscle mass and strength, as well as a decrease in motivation, mood, and energy (1). They may also be at risk for bone fractures and are known to have higher rates of the "metabolic syndrome"—marked by belly fat, high blood pressure, high blood sugar, and unfavorable cholesterol levels. This condition increases their risk for heart disease (2,3).

A good number of studies have looked at testosterone levels in spinal cord injured men, and some have found mostly normal levels (4,5,6) while others have found low levels in at least forty percent of participants (7,8). No clear connection between testosterone levels and level or severity of SCI has been established. There is a good deal of interest in further studying testosterone in SCI, however, as most physicians believe that men with SCI are at real risk for low testosterone.

There has been only one study looking at the effect on function of giving men with SCI additional testosterone (9), but no benefit was noted. Other studies are planned that will look at whether giving testosterone to men with SCI can reduce their risk of bone fractures, depression, and heart disease—all of which are common in SCI—but their results are still years away.

There are no firm recommendations for checking testosterone levels in men with SCI, but because we suspect many men with injuries have low levels, it is likely a good idea. Any physician can order a "total" and "free" testosterone, tests which need to be drawn in the morning. If these levels are low, they need to be re-checked with several other labs, including "LH," "prolactin," and iron levels. If a man is found to have "primary" testosterone deficiency, he can easily have his levels boosted with injections or patches, and most physicians can begin and monitor this treatment without having to involve specialty-level colleagues.

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Obstructive Sleep Apnea

Obstructive Sleep Apnea (OSA) is a disease in which people stop breathing while they're asleep. OSA has long been known to cause memory loss, mood changes, and daytime fatigue, and for this reason has traditionally been considered a lifestyle concern. More recently, though, OSA has been linked with diabetes (1), unfavorable cholesterol levels (2), stroke (3), high blood pressure (4), and low testosterone levels in men (5), and due to these important health risks, OSA has received increasing attention from researchers and doctors.

A study from 2002 suggested that around 5% of American adults have OSA (6)—although most experts in the field believe the number is higher than that—yet no one is sure what percent of people with SCI have the condition. Women and people with paraplegia haven't been studied as often as men or those with tetraplegia, so we don't have an accurate understanding of how this disease affects all people with SCI. Some researchers believe that only 9% of people with SCI have OSA (7), but most believe the true estimate is between 30 and 50% (8,9).

One of the most concerning aspects of OSA is its link with heart disease. Recent studies have shown that people with untreated OSA have higher risk of heart failure, heart attack, and stroke than those without OSA (3,10,11). This being said, a 2005 study demonstrated that people with severe OSA who are properly treated for the condition—usually by wearing a breathing mask at night—have a dramatically lower risk of suffering or dying from a stroke or a heart attack than those who are untreated (12).

Not everyone with OSA has classic symptoms, so it is appropriate for all people with SCI to ask their doctors if they should be screened for it. Testing involves overnight monitoring, either in a dedicated facility or in one's own home, and it is relatively easy to arrange.

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Coronary Artery Disease

People with chronic SCI have high rates of heart disease. The best-known studies in this area have looked mostly at men (not women) with SCI, but they have taught us that at least 50% of people with paraplegia and 80% of people with tetraplegia have evidence of heart disease when they undergo stress testing (1,2), even if they never get the classic symptoms of chest pain or problems with breathing. Over 20% of people with SCI will die of heart disease (3), but that number may increase as people with SCI are living longer lives than they did even two or three decades ago.

No one knows for sure why people with SCI have high rates of heart disease. Between 70 and 80% of people with SCI have abnormal cholesterol levels (4), around 20% have diabetes, and 30% of people with paraplegia have high blood pressure (less common among people with tetraplegia) (5,6). Each of these conditions can increase the risk of developing heart disease, as does a lack of physical activity. There are other risk factors for heart disease in SCI which we are only beginning to understand. Low testosterone levels in men with SCI may contribute to unfavorable cholesterol levels, and sleep apnea—a problem with breathing at night, which as many as half of people with SCI may have (7,8)—may also increase overall risk.

There have only been two journal articles looking at treating people with SCI with cholesterol-lowering medications (9,10). Unfortunately, neither one questioned if doing so reduces the risk of having a heart attack or dying; they only examined whether these medications can be safely used by people with SCI, which they can.

There are no specific guidelines for screening people with SCI for heart disease, although national guidelines recommend checking cholesterol levels every five years. Given that people with SCI are at high risk, their physicians should check their EKGs (an office-based test of how your heart functions) and may consider asking them to take a cholesterol reducing medication (called a “statin”), even if their “bad” cholesterol levels appear normal. Other risk factors for heart disease should be discussed, including blood pressure, lack of exercise, and sleeping problems. Doctors evaluating individuals with SCI who have breathing complaints, nausea, chest pain, dysreflexia, or certain other symptoms should consider the possibility of heart disease.

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Respiratory Health

Lung disease—particularly pneumonia--is one of the leading causes of death in individuals with SCI (1,2). After SCI, muscles required for breathing may become weak or paralyzed, and this may lead to decreased air intake, decreased expansion of lungs, a weak cough, increased mucus secretion, and an inability to clear mucus from the lungs. These complications may eventually lead to "atelectasis," or collapsed air spaces in the lungs, and this may cause pneumonia and respiratory failure (3). Traditionally between 9 and 15% of individuals with SCI entering rehabilitation have developed pneumonia (4), but some centers have developed strategies that dramatically reduce that risk.

People with tetraplegia or high paraplegia have an underlying respiratory issue known as "restrictive lung disease" or "respiratory insufficiency." This means they can't expand their lungs as well as people without SCI, so they have difficulties effectively filling their lungs or coughing with enough strength to clear mucus and protect their airways. Helpful interventions include frequent mucus suctioning as well as chest clapping, percussion, or vibration to loosen secretions. A properly fitted abdominal binder can help increase lung capacity in people with recent high-level injuries (6), and using an incentive spirometer (widely available through clinics or from physicians) can help strengthen respiratory muscles. In individuals with little or no respiratory muscle strength, "glossopharyngeal breathing" may be used. In this technique, gulps of air are pushed down the windpipe using muscles in the mouth.

Up to 62% of the individuals with SCI suffer from obstructive sleep apnea (5), which is discussed elsewhere in this handbook. This condition often goes undiagnosed, although it can easily be diagnosed with a sleep study then treated with one of several well-tolerated therapies.

The Centers for Disease Control and Prevention (CDC) recommends annual vaccination against influenza (the "Flu Vaccine") for individuals with SCI (7). The CDC also recommends vaccination against pneumonia (the "Pneumovax") in individuals younger than 65 if they have longstanding heart or lung disease or a condition that puts them at high risk for pneumonia (8). While not specifically covered by this strategy of early vaccination (average risk people receive the pneumonia shot only once at age 65), people with SCI are at high risk for developing pneumonia, so most physicians believe they should receive the pneumonia vaccine once before age 65 then again at age 65.

It is very important for people with SCI avoid or stop smoking, as inhaled tobacco products can decrease lung health and increase an individual's risk of developing bronchitis, pneumonia, emphysema, and lung cancer. There are many options available to people who wish to quit smoking, including nicotine replacement products, psychological counseling/support groups, and medications, and your medical team should be able to help with this process.

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Exercise and Nutrition

Many individuals with SCI do not get enough exercise, and lack of activity can lead to muscle weakness, high blood sugar, high blood pressure, and unfavorable cholesterol levels. To decrease the risk of these complications, structured exercise activities must *when possible* be added to each person's regular schedule (1). Experts agree that people with SCI should maintain active lifestyles and participate in daily exercise programs (2,3), as doing so can enhance endurance, quality of life, and overall health (1). Before starting a new activity-based program, anyone with SCI ought to consult with his or her doctor to make sure the exercise regimen is safe and appropriate (4).

It is not clear which type of exercise best improves fitness in people with SCI, but good evidence supports the use of upper extremity aerobic exercise and functional electrical stimulation (FES) training (5). Upper extremity exercises could include chest and shoulder presses, horizontal rowing, latissmus pulls, arm curls, and seated dips. The muscles strengthened during these activities are the same ones used to roll a manual wheelchair and transfer, so engaging them may decrease an individual's chance of developing shoulder pain or a rotator cuff injury (4). Depending on a person's level of injury, he or she may also be able to use an arm bike, which is known as an "arm ergometer." People with incomplete injuries may be able to perform leg exercises such as walking, biking, or swimming, but even those with little or no lower extremity function can participate in functional electrical stimulation.

Research studies have proven that exercise in SCI has various benefits. One showed that a 6 week course of 3 times a week moderate to vigorous activity improved exercise and cardiovascular (heart) fitness (5), while another demonstrated that 12 weeks of resistance training with neuromuscular electrical stimulator (NMES) improved certain cholesterol levels in individuals with SCI (6). Adults with SCI should *if possible* engage in twice weekly moderate to vigorous intensity aerobic activity and twice weekly strength training exercises (7), and should work with their doctors and physical therapists to develop an exercise program that is appropriate for them.

Eating a sensible and balanced diet can help individuals with SCI maintain their ideal body weight, and this is important in long-term preservation of mobility, function, and overall health. Many insurance plans will pay for patients to visit and consult with a nutritionist, and your physician can help arrange this for you, but even basic changes in diet can be crucial in preventing complications of SCI. Eating enough proteins (found in lean meats, fish, chicken, pork, beans, or nuts) may help heal pressure sores, adequate fluid intake can help prevent kidney stones, fiber (found in supplements, fruits, and vegetables) can help maintain bowel health, and reducing fat and salt intake can help prevent heart disease and high blood pressure (8). Balanced meals should include whole grains and lean proteins like baked chicken and fish, and a good rule of thumb is to fill half of your plate at each meal with fruits and vegetables.

Every individual with SCI should have a set of dietary goals and an exercise plan to avoid weight gain and to maintain healthy habits. This may help reduce the risk of other medical complications.

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Preventive Medicine

National organizations have published a great many screening and preventive care recommendations, but very few are SCI-specific. The following are recommendations of which all people with SCI and their medical teams ought to be aware.

Influenza Vaccine:

The Center for Disease Control and Prevention (CDC) recommends an annual flu shot for individuals with SCI (1).

Pneumococcal vaccine:

The CDC recommends immunization with Pneumococcal vaccine, otherwise known as the "pneumonia shot," for all adults 65 years of age and older. CDC also recommends a one-time vaccination for individuals younger than 65 if they have longstanding heart or lung disease or any other condition that put them at high risk for pneumonia and other infections. While there are no specific recommendations for individuals with spinal cord injury, SCI does put individuals at higher risk for pneumonia, so the pneumonia shot is recommended before age 65 (2). Of note, repeat vaccination at age 65 is recommended for people who already received the vaccine, but it should be given at least 5 years after their previous immunization.

Bone Loss:

Almost all people with SCI will suffer from weakening of the bones (3). "Osteopenia" means that the bones are "soft" with a bone density that is slightly lower than normal, while "osteoporosis" represents more severe weakening of the bones and places people at increased risk of a fracture. There are no established guidelines on when to screen people with SCI for osteoporosis; however, since the greatest amount of bone loss occurs in the first six months after injury, a baseline bone scan—also known as a "DEXA Scan"—is often obtained within a year of the initial injury (4). Low Vitamin D levels can also increase the risk of fractures, and a simple blood test can be performed to ensure that patients' levels are adequate (6). Several studies have shown that medications called bisphosphonates are the most effective treatment for osteoporosis in people with SCI (5,6).

Diet and weight monitoring:

Individuals with SCI are at risk of losing muscle mass and becoming overweight or obese. Even with exercise, it is more difficult for people with SCI to burn fat (7), and this increases the risk of obesity. Measuring body weight at every doctor's visit or at least yearly is recommended. The best ways to keep weight down are to eat a balanced diet and to keep a routine exercise/therapy program, if possible. The ideal meal composition would be 45% carbohydrates, 30% fat, and 25% protein, and people with SCI should eat 25 to 30 grams of

fiber each day (8). Recommended foods include lean meats (like chicken or fish) prepared by baking or broiling, nuts and beans, fresh or frozen fruits and vegetables, and whole wheat breads and pastas. In the event that diet and exercise are not able to control weight in a person with SCI, there are certain medications that can be tried. In severe cases, a patient and his or her physician could consider gastric bypass, which has been performed successfully in individuals with SCI (9).

Equipment monitoring:

Individuals with SCI ought to have their wheelchair and cushion evaluated for any wear and tear at each doctor's visit. Physical and occupational therapists should also be involved in assuring that a patient has proper equipment.

Skin inspection:

People with spinal cord injury or their caregivers should check their skin at least once a day. The Agency for Health Care Policy and Research (AHCPR) recommends that individuals with SCI turn every 2 hours while lying bed (10), and that weight shifting or pressure relief maneuvers be done at least every 15-30 minutes for 2 minutes each session. People who cannot use their arms to change position should activate the tilt-in-space option on their power chair (11, 12).

Joint protection:

Due to the risk of overuse syndrome in the shoulders, elbows, and wrists, routine evaluation of arm function in individuals with SCI is recommended. Current recommendations are to limit the number of times people with injuries use their arms for repetitive tasks (like transfers or reaching overhead), to minimize the exertion that is required for them to perform tasks with their arms, and to avoid potentially damaging positions of the wrist, elbow, and shoulders (13). Physical therapy for strengthening and proper wheel chair propulsion is essential to help limit injuries.

General health evaluation:

These sessions involve thorough questioning about any potentially worrisome problems or symptoms and a complete physical examination. There is no general agreement about how often these evaluations should be performed (14).

Dermatological or skin evaluation:

Skin cancer screening is recommended for high risk people such as those with a family history of skin cancer, abnormal moles, or a history of significant sun exposure and severe sunburns. The frequency of skin examinations should be discussed with your dermatologist and depends mostly on your individual risk (15).

Cardiovascular or heart evaluation:

There are no specific recommendations for screening people with SCI for high cholesterol, but as people with chronic injuries may have greater risk of cardiovascular disease, aggressive cholesterol management can be considered (16), and everyone with SCI ought to have their levels checked starting at age 20 and at least every 5 years thereafter (17). As people with SCI are likely at higher risk for "silent" heart attacks, it may also be reasonable for their medical teams to perform yearly EKGs (17).

New guidelines for management of high blood pressure were recently released, and they advise that pressures of 140/90 or less in people younger than 60 are acceptable, as are pressures of 150/90 or less in people over 60 (18).

Diabetes or high blood sugar screening:

People with SCI seem to be at high risk for developing diabetes (19), but it is not clear which tests are best for diagnosing diabetes in SCI. While there are no specific recommendations for testing people with SCI for diabetes, it may be reasonable to have your fasting blood sugar or glucose levels checked at least every 3 years. Feel free to discuss this matter with your medical team.

Genitourinary or bladder and kidney evaluation:

People with spinal SCI who user catheter have an increased risk of bladder cancer (20,21), yet no firm guidelines tell us when and how to screen for this disease. Your doctor may send you for a yearly evaluation with a urologist, who may choose to look inside your bladder with a scope. Further, people with neurogenic bladder (discussed elsewhere in this handbook) are often sent for yearly testing to check bladder function and pressures, and these evaluations can help your doctors tailor your cathing and medication schedules.

Colorectal cancer screening:

This screening is recommended for people over 50 using either a) high sensitivity fecal occult blood testing (FOBT), b) sigmoidoscopy with FOBT, or c) colonoscopy (22). Recommended intervals include annual screening with FOBT, sigmoidoscopy every 5 years with FOBT every 3 years, or screening colonoscopy every 10 years (15), though these may change if a person is found to have polyps or other high-risk abnormalities.

Even though the colonoscopy preparation and procedure may be challenging for a person with SCI, studies have shown that it is still a safe and beneficial procedure (22), and that it detects potential cancers earlier than FOBT or sigmoidoscopy. People with SCI often need additional assistance when preparing themselves to undergo colonoscopy. Your doctor may need to admit you to the hospital to have you safely complete that process.

Men's Health:

Prostate cancer screening is performed with a "digital rectal exam" (sliding a gloved finger into your bottom) and a blood test called "PSA" (23,24). Prostate cancer screening in SCI is quite controversial. First, PSA levels are often elevated in men who cath (25,26), so may be a less reliable test for cancer. Second, our nation's major health care task force recommends against routine screening for prostate cancer, as the benefits may not outweigh the risks (27). Given the complexity of this issue, we recommend talking to your family physician or urologist about prostate cancer screening.

Women's Health:

CDC recommends that average risk women undergo breast cancer screening with a mammogram every two years between ages 50 and 74 (28). Mammograms may be offered to women younger than 50 if there are abnormal findings on breast examination or a family history of breast cancer. It is important to talk to your health care provider before you go for a mammogram to make sure that the testing center and equipment are handicap and wheelchair accessible.

The American College of Obstetricians and Gynecologists (ACOG) recommends an annual pelvic or genital examination in women older than 21 (29), and a PAP smear to screen for cervical cancer every three years between the ages of 21 and 65. Between ages 30 and 65, the PAP test may be done every 5 years if it is combined with screening for Human Papilloma Virus (HPV), and women over 65 receive PAP smears only if they have abnormal examinations or concerning symptoms (30).

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Health Care Accessibility

The Americans with Disabilities Act of 1990 (ADA) requires health care providers to ensure their services are fully available to people with disabilities, even if reasonable accommodations must be made. Below is a list of specific ADA requirements for medical facilities which people with SCI may use while searching for physicians to help care for them.

Accessibility requirements:

People use many type of devices for mobility in the community, including canes, crutches, walkers, wheelchairs or scooters. In order to accommodate the majority of people who use mobility devices, the ADA requires that hospitals, clinics and doctors' offices be able to accommodate a "common wheelchair" that measures 30-inches in width and 48-inches in length. The thought is that if a wheelchair meeting these dimension can access the patient areas of the office or clinic, then someone using crutches, a cane, a walker, or another device can access the clinic as well.

All patient areas should be accessible and easily navigated by a person seated in a wheelchair. If an area isn't accessible, a reasonable accommodation should be made, such as having the nurse or assistant complete a blood draw in the exam room, rather than in a small lab space.

Common patient areas or items that should be accessible include:

Building entrance
Clinic or office doorway(s)
Sign-in/reception counter
Hallways/pathways to restroom, exam room or other patient service areas
Weight scale
Restroom
Exam room
Checkout counter

Feel free to ask about accessibility of these areas in advance of your visit to a medical office or facility.

Accessible doorways and hallways:

Doorways are required to be at least 32-inches wide when the door is opened to 90 degrees. There should also be room to maneuver a wheelchair or walker on either side of the door – there shouldn't be boxes, chairs, or equipment near the door that can interfere with navigating through the doorway.

All hallways that lead to patient areas (exam room, blood draw area, weight scale) are required to be at least 36-inches wide. If a hallway includes turns, then a walker or wheelchair must be able to make the turn without getting stuck.

Accessible weight scale:

Body weight is considered essential medical information. Doctors rely on body weight for certain diagnostic tests, treatments, or for prescribing accurate dosages of some drugs. If patients without mobility disabilities are routinely weighed at the clinic or office, then a person using a wheelchair, walker or other device should be weighed as well.

An accessible weight scale should be available in the clinic or office, or in a nearby accessible location. An accessible weight scale should have a platform large enough to fit a common wheelchair, and a weight capacity to accommodate weighing a person while seated in his/her wheelchair. It should also have handrails to provide support. Wheelchair users should be weighed while seated in their wheelchair then the wheelchair should be weighed while unoccupied. The weight of the unoccupied wheelchair will be subtracted from the weight obtained while the individual was sitting it to get individual's body weight.

Helpful hint: Wheelchair users should know the weight of their wheelchair or mobility device. This should be included in the owner's manual, or can be obtained by calling the manufacturer's customer service department. This information should be kept with all medical information.

Accessible restrooms:

There should be enough room in front of the toilet to maneuver a wheelchair and to allow for transferring. The restroom or stall should also have enough space to allow a wheelchair user to turn around and exit the stall/room facing forward. Two grab bars should be provided for transfer assistance – these should be located between 33 and 36-inches from the floor and be 42-inches in length.

The sink should have enough underneath clearance space to allow a wheelchair user to approach and use the sink. The rim of the sink shouldn't be more than 34-inches above the floor to ensure accessibility for washing hands.

Accessible exam room:

Exam rooms need to be accessible. A wheelchair or walker user must be able to enter the exam room and maneuver his/her device next to the exam table. At minimum, there must be an area measuring at 30-inches in width and 48-inches in depth next to one side of the exam table.

It is generally not acceptable to examine a patient while seated in his/her wheelchair simply because they cannot get onto the exam table independently. The ADA requires that all patients

receive equal medical services. However, if the exam doesn't require that a person lie down (such as an exam limited to the face or neck), then the person may remain seated in a chair.

To provide equal medical care, offices should have at least one exam room with a height adjustable exam table that can be lowered to between 17 and 19-inches from the floor. Transfer aids (ex. sliding board, hoyer lift) should be provided. If no transfer aids are available, then clinical staff who are trained and willing to provide assistance should help with transferring. It is not acceptable to tell a patient that he/she must bring someone to an appointment to help him/her undress and dress, or get on and off the exam table or other equipment. Once on the exam table, if a patient needs help maintaining balance or position, a staff member should stay with him/her, or positioning supports should be provided (wedges or similar aids).

For more information about patient rights under the ADA, please refer to these documents. Each can be downloaded for free from the internet:

U.S. Department of Justice (2010). "Access to medical care for individuals with mobility disabilities." from http://www.ada.gov/medcare_ta.htm.

U.S. Architectural and Transportation Barriers Compliance Board (Access Board) (September 2002). "Americans with Disabilities Act (ADA) Accessibility Guidelines for Buildings and Facilities ". from http://www.access-board.gov/adaag/html/adaag.htm.

Available Resources

Social Security Disability (SSD)
Website: www.SSA.gov
Phone: 1-800-772-1213

Medicare
Health insurance for individuals over 65 and those on social security disability
Website: www.medicare.gov
Phone: 1-800-633-4227

Medicaid
State specific health insurance for children and adults, long term care resources as well as waiver services
Website: www.medicaid.gov

Ticket to Work Program
Social Security program that helps people who receive disability payments return to work
Website: www.choosework.net
Phone: 1-855-835-0010

National Adult Day Services Association
Information available on a state level for adult day services
Website: www.nadsa.org
Phone: 1-800-677-1116

National Family Caregivers Association (NFCA)
Information available on a state level for caregiver resources and support
Website: www.thefamilycaregiver.org
Phone: 1- 877-980-7500

Paralyzed Veterans of America
An organization to change lives and build brighter futures for our seriously injured heroes
Website: www.pva.org
Phone: 1- 800-424-8200

Christopher and Dana Reed Paralysis Resource Center
An organization that is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy
Website: www.christopherreeve.org
Phone: 1-800-539-7309

National Spinal Cord Injury Association
A national organization with chapters available at each individual state level to improve the quality of life of all people living with a spinal cord injury or disease
Website: www.spinalcord.org
Phone: 1- 718-803-3782

Needymeds.org
A prescription drug program for those with annual income of $42,000 or less.
Website: www.needymeds.org
Phone: 1-877-726-0815

Partnership for Prescription Assistance
A prescription drug program that helps qualifying patients without prescription drug coverage get the medicines they need through the program that is right for them. Many will get their medications free or nearly free
Website: www.pparx.org
Phone: 1-888-477-2669

RX Hope
A helping hand to people in need in obtaining critical medications that they would normally have trouble affording
Website: www.rxhope.com
Phone: 1-877-267-0517

National Domestic Violence Hotline
A hotline available to men, women or children that are suffering from domestic violence
Phone: 1-800-779-SAFE (7233)

Alcoholics Anonymous
A hotline available to men, women or children that are struggling with the use of alcohol for local meetings and resources
Phone: 1-800-467-8091

Alcohol/Drug Hotline
A hotline that provides local resources to any person or family with issues of drug or alcohol abuse
Phone: 1-800-729-6686

Narcotics Anonymous
A hotline that provides local resources to any person or family with issues of drug abuse
Phone: 1-800-662-HELP (4357)

The list above does not include all resources that might be available to you at a local, state or national level and would recommend that you ask to speak to your SCI physician, primary care provider or social worker if one is available to you for further information.