

Bladder Management Following Spinal Cord Injury: What You Should Know

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

Consumer Guide Panel

Todd Linsenmeyer, MD

Kessler Institute for Rehabilitation
Department of Urology
West Orange, NJ

Sam Maddox

Christopher and Dana Reeve Foundation
Knowledge Manager
Westlake Village, CA

Consumer Focus Group

Linda Chambers, RN, BS, CCM

Travelers Property Casualty
Hartford, CT

Fred Cowell

Senior Health Policy Analyst and
Acting Director, Research and Education
Paralyzed Veterans of America
Washington, DC

James DuBose

Owner
J&R Medical
Houston, TX

Trevor A. Dyson-Hudson, MD

Kessler Foundation Research Center
West Orange, NJ

Kathleen Tevnan, MEd

Department of Defense, ret.
Silver Spring, MD

Tammy Wilber

Ms. Wheelchair Washington State Coordinator
Seattle, WA

Consortium for Spinal Cord Medicine Member Organizations

Academy of Spinal Cord Injury Professionals

- Spinal Cord Injury Nurses
- Spinal Cord Injury Psychologists and Social Workers
- Paraplegia Society

American Academy of Orthopaedic Surgeons

American Academy of Physical Medicine and Rehabilitation

American Association of Neurological Surgeons

American College of Emergency Physicians

American Congress of Rehabilitation Medicine

American Occupational Therapy Association

American Physical Therapy Association

American Psychological Association

American Spinal Injury Association

Association of Academic Physiatrists

Association of Rehabilitation Nurses

Christopher and Dana Reeve Foundation

Congress of Neurological Surgeons

Insurance Rehabilitation Study Group

International Spinal Cord Society

Paralyzed Veterans of America

Society of Critical Care Medicine

U.S. Department of Veterans Affairs

United Spinal Association

Copyright © 2010 Paralyzed Veterans of America

This guide has been prepared based on scientific and professional information found in *Bladder Management for Adults with Spinal Cord Injury: A Clinical Practice Guideline (CPG) for Health-Care Providers*, published in 2006. Users of this guide should periodically review this material to ensure that the advice herein is consistent with current reasonable clinical practice.

Bladder Management Following Spinal Cord Injury: What You Should Know

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

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

Copyright © 2010 Paralyzed Veterans of America

All rights reserved. This book may not be reproduced in whole or in part, by any means,
without written permission from Paralyzed Veterans of America.

ISBN 978-0-929819-23-5

Table of Contents

Introduction	1
Overview of the Urinary Tract System	3
First-Hand Account: One Man's Point of View	4
Some Common Issues and Concerns	6
Urologic Evaluation: Bladder and Kidney Tests	7
Catheterization	7
Intermittent Catheterization	
Credé and Valsalva	
Indwelling Catheterization	
Reflex Voiding	10
Stent	
Botulinum Toxin (Botox) Injection	12
Alpha Blockers	12
Anticholinergic Drugs	13
Surgical Procedures	14
Spincterotomy	
Bladder Augmentation	
Continent Urinary Diversion	
Urinary Diversion	
Cutaneous Ileovesicostomy	
Electrical Stimulation and Posterior Sacral Rhizotomy	
Mitrofanoff Appendicovesicostomy	
First-Hand Account: One Woman's Point of View	18
Advice for People with SCI Who Are On or Are Considering a Bladder Management Program	21
Useful Terms	23
Resources	27

Introduction

This consumer guide explains bladder management options for people with spinal cord injury (SCI). It is based on *Bladder Management for Adults with Spinal Cord Injury: A Clinical Practice Guideline (CPG) for Health-Care Providers* (Consortium for Spinal Cord Medicine, 2006). The CPG is written for health-care professionals and contains extensive clinical detail. It can be a useful resource for you and your medical team, along with this consumer guide. Both the CPG and this consumer guide are available by free download from the Paralyzed Veterans of America website at www.pva.org/cpgs.

No one management program can work for everyone. Injury levels vary, as do the effects of nerve trauma on bladder function. There are many factors involved in establishing your bladder management program, and males and females often have to consider different options. Lifestyle issues also factor in: an individual who is out of the house most of the day might not choose the same techniques or supplies as someone who stays home most of the time.

Your options will depend on whether you have enough hand dexterity to deal with a catheter. If your hand function is impaired, is someone available to assist you? Do you have access to health-care providers who can give you expert care and immediate attention?

This guide will help you work with your health-care team to develop a program that best suits your living situation; one that you feel comfortable with; and, most important, one that protects your health, independence, and quality of life.

Your first line of information and medical support may come from your primary care physician, nurses, occupational therapists, and physical therapists. These are all qualified professionals with whom you can talk about your bladder management questions and concerns. It is also extremely helpful to talk with other people who have experienced SCI to find out about the bladder management techniques that have worked for them (and those that haven't)—and to discuss what they have learned about dealing with bladder management. Before making long-lasting decisions about bladder management, it is a good idea to talk to a urologist,

a doctor who specializes in urinary and bladder systems. Try to find one who has specific experience with bladder problems related to SCI.

This guide covers the more common methods of bladder management for individuals with SCI. Remember: if the method you're using doesn't seem to be working well, you should talk to someone on your health-care team about other options. It is not uncommon for individuals with SCI to try more than one method or to change methods over time.

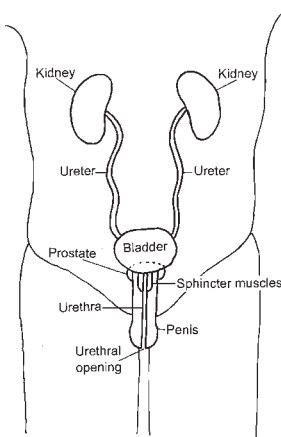
Generally, it is best to try nonsurgical methods first before attempting a procedure that may be risky or permanent. If you are considering an invasive or irreversible surgical procedure, get a second opinion from another health-care expert familiar with spinal cord injury and the neurogenic bladder.

IMPORTANT

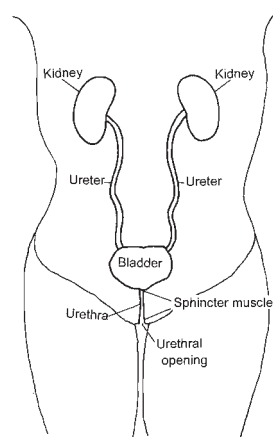
As you read this consumer guide, please keep in mind that the information provided about bladder management and urinary health should be discussed with your personal doctor and your health-care team before trying any new procedures or making decisions about your bladder management routine. Please keep your health-care team well informed of anything you read about in this document that you would like to try or that you have questions about.

Overview of the Urinary Tract System

When considering the various programs for bladder management, it is helpful to understand the anatomy of the urinary tract and how it works. The bladder is basically an elastic storage bag made of smooth muscle (called detrusor). Its function is to hold liquid waste (urine) that has been filtered from the bloodstream by the kidneys, which are located on either side of the spine at about the level of your lowest rib. The kidneys are connected to the bladder by a pair of thin tubes, about 12 inches in length, called ureters (*see illustrations*).



Front-facing cross-sectional view of the **male** urinary tract



Front-facing cross-sectional view of the **female** urinary tract

In an uninjured system, the bladder is relaxed and at rest until it becomes filled with urine and starts to stretch. When it has filled beyond about 10 ounces, most people will begin to feel an urge to urinate. When our brain receives the message that the bladder is full, we empty our bladder. The bladder contracts and forces urine from the bladder and out of the body through a tube called the urethra. In males, the urethra travels through the end of the penis. In females, the urethra emerges just above the vaginal opening. This difference in anatomy affects bladder management choices.

Spinal cord injury can disrupt the urinary process. Nervous system messages coming to or from the bladder are often lost; individuals with SCI frequently cannot tell when their bladders

are full, nor can they open their sphincters on command. Depending on the type of injury, some people's bladders cannot stretch to store urine. Other individuals experience high pressure as a result of bladder spasms—tight unpredictable squeezing of the bladder—that can cause spontaneous or accidental urination. An overly pressurized bladder, along with an overly tight sphincter, can force urine back up into the ureters (this is called reflux). This backflow must be addressed with medications, surgery, or modification of the bladder program because it can seriously damage the kidneys. Another type of bladder problem is a weak sphincter, leading to constant leaking (incontinence).

Eliminating urine from the body hygienically and conveniently is what a bladder management program is about. The main bladder goals for people with SCI are to keep the bladder capable of holding a large volume, to keep bladder pressure low, to avoid infection, and to keep skin dry.

There are many ways for people with SCI to stay dry and healthy. This guide will discuss some of the most common options.

FIRST-HAND ACCOUNT: One Man's Point of View

The struggle for regained individual independence following a spinal cord injury begins the day following initial injury. The battle to survive during initial recovery is followed by weeks of intense rehabilitation that is designed to maximize functional ability.

Perhaps one of the most fundamental steps toward regained independence following initial injury is the ability to successfully manage your bladder. Achieving a successful bladder management program enables people with spinal cord injuries to begin to believe they are back in control of their bodies again. Obviously, a successful bladder management program is fundamental to good health for individuals with spinal cord injuries. A sound program can help prevent frequent urinary tract infections and protect the vital functioning of the kidneys.

Additionally, the ability to control incontinence associated with our injuries enables us to improve our self-confidence so that our worries about embarrassing situations begin to fade. Once a

level of bladder self-confidence is achieved, it is possible to comfortably reenter social settings and do the things in life we most enjoy.

I am now almost 34 years post injury, and my bladder management program has changed three times since I was first injured. Each change required me to adapt to a new method and to establish a new comfort level before everyday self-confidence was regained. Each bladder management method I have used over the years worked well for me, but as I grew older, my body changed and new methods were necessary.

I will openly admit that bladder accidents happen in real life; I have experienced these embarrassing situations with each bladder program I have used. Over the years I have had catheter leaks, leg bag failures, catheter blockage, tape failure, and other frustrating events. However, with each method I have learned to cope with these situations and minimize them. I do know that it is vitally important to correct the situation as soon as possible when an accident occurs. Correcting the problem and getting clean and dry again is one of the first-line defenses to prevent pressure ulcers and get on with your day.

Through years of trial and error, I have learned to be observant. I inspect my “plumbing” situation throughout every day to make sure things are working properly. This can be done easily and without others around you knowing. By paying attention to your body, you can be on top of things early. For example, I have learned to tap my leg bag to see if my bladder is emptying as usual. Also, I frequently look to see if there are any signs of leaks. Sometimes I just need to adjust the position of my catheter to get things flowing freely again. To prevent unwanted odors, I clean leg bags daily.

I use a vinegar and water solution (in a spray bottle) to wash out my leg bag when not in use. I always keep several ready to go whenever I may need one. If traveling, I always keep spare parts with me. Something as simple as a broken bag strap can lead to situations I want to avoid. By using basic prevention steps, we can often prevent embarrassing things from happening.

REMEMBER...

...knowing your body and having a successful bladder management program is key to staying healthy and being in charge of your life. If things are going wrong more than you like, consult your spinal cord physician; together you can find solutions to the problems.

SOME COMMON ISSUES AND CONCERNS

Residual urine: Many people with impaired bladder function are unable to empty their bladder completely. Urine left behind (residual) increases the likelihood of a urinary tract infection (UTI).

Urinary tract infection (UTI): Typically, bacteria enter the urinary tract at the urethra. Bacteria can then migrate to the bladder and multiply. It is important to note that the presence of bacteria in the bladder does not necessarily mean treatment is needed. If you use a catheter, it is highly likely that you have bacteria in the urine, or bacteriuria. Unless you have symptoms of an infection, there is no need to attack the bacteria with antibiotics.

Early signs of an infection include cloudy, foul-smelling urine and/or sediment (gritty particles) or mucus in the urine. More serious symptoms may include fever, chills, nausea, headache, changes in the pattern of muscle spasms, and autonomic dysreflexia in people with T6 or higher SCI. These complications mean that you have a urinary tract infection that must be treated with antibiotics. In all cases, you should consult your doctor when you experience any of these symptoms.

Without treatment, bacteria can travel further up the ureters, multiply, and infect the kidneys. Kidney infection, called pyelonephritis, was once a leading cause of death after spinal cord injury and is still a danger.

Autonomic Dysreflexia: This is a very important concern for people with spinal cord lesions at or above the T6 level. Autonomic dysreflexia is a potentially dangerous spike in blood pressure that can be accompanied by pounding headache, sweating, “goose bumps,” and blurred vision.

Autonomic dysreflexia is often triggered by an overly full bladder (distended) or a bladder infection. For full details on this medical emergency, consult with your doctor and see the consumer guide *Autonomic Dysreflexia: What You Should Know*, available from Paralyzed Veterans of America (**free download at www.pva.org/cpgs**).

Urologic Evaluation: Bladder and Kidney Tests

Because everyone's urinary system is different, it is important to tailor a bladder management program that is right for you. You will most likely undergo one or more bladder and kidney tests (many doctors recommend having these tests done once a year) to help make sure you and your health-care providers have the information needed to make the best choices for you. Testing will help to detect any problems, which may be silent because you are not able to feel any discomfort. The tests also aid in determining whether changes to your bladder program or new medications are working as they should.

After SCI, your doctor may want to conduct tests to determine how well your urinary system is functioning. These tests can reveal how your bladder and sphincter are working, whether urine is going backward from the bladder into the kidneys (reflux), and the speed with which urine passes through the kidneys and down into the bladder. Certain tests can also detect the presence of inflammation, bladder stones, tumors, cysts, kidney stones, or structural changes in the urethra, bladder, or kidneys.

Catheterization

Catheterization (often referred to as "cathing") is a bladder-emptying technique in which a flexible tube (catheter) is inserted into the urethra to drain urine. A catheter can be used periodically throughout the day or left in the bladder on a long-term basis, being changed every 2 to 4 weeks as recommended by your health-care provider. In the latter case, the catheter will have a balloon at the end that helps to keep it in the proper position.

Intermittent Catheterization

Intermittent catheterization is a bladder management method in which you or a caregiver empties the bladder at specified time intervals (usually every 4 to 6 hours) by inserting a catheter into the bladder, draining the bladder, and then removing the catheter. Urine can be drained directly into the toilet or urinal or into a collection bag. The advantage of

intermittent catheterization is that you do not have to wear a catheter and urine bag all the time. It is done on an “as needed” basis. Intermittent catheterization can be more convenient and healthier, and urinary tract complications are less common with this bladder management method. However, people who use intermittent catheterization need to keep track of their fluid intake and make sure that the catheterization is done on time. Many people who use intermittent catheters limit fluids after dinner to avoid having to catheterize in the middle of the night.

It is important not to allow the bladder to become too full because that will increase the risk for pain, infection, autonomic dysreflexia, and harm to the kidneys from elevated bladder pressure.

CLEAN VS. STERILE

Most individuals use single-use, sterile catheters; however, reuse of catheters with proper cleaning can be an acceptable alternative. **It is important to talk to your health-care provider to determine which option is best for you.** Sterile, touchless catheters are available in self-contained packaging, are prelubricated, and include a collection device. Although there is some evidence that these can reduce infection rates among intermittent catheter users, they are not typically prescribed unless a person has recurrent infections.

Another option for long-term intermittent use is the single-use hydrophilic catheter, which features a special coating that creates a smooth and more slippery surface.

Credé and Valsalva

Credé is a method to empty the bladder by manually applying pressure to your lower abdomen just above your pubic bone using a closed fist, in order to manually push urine out through the urethra. Credé is usually used when the bladder cannot contract on its own or has a weak contraction and needs extra pressure to push out urine. The effectiveness of Credé is limited by the sphincter—it is difficult to push urine out when the sphincter is very tight without using excessive force. Credé is more effective for people who can transfer to a toilet.

Valsalva is a method in which you use abdominal muscles along your diaphragm (the muscles directly below your rib cage) to push down on the bladder in order to empty it. Valsalva is used when the bladder is flaccid (i.e., does not have the muscle strength to contract) or when the bladder is able to contract but does not empty completely. Valsalva provides bladder pressure but does not ensure complete emptying. The effectiveness of Valsalva is also limited by the strength or tightness of the sphincter.

Credé and Valsalva are generally not recommended as primary methods of bladder emptying. Potential complications with Credé and Valsalva include high bladder pressure (which could cause back pressure on the kidneys), abdominal bruising when using the Credé method, hernia, pelvic organ (such as the bladder) slipping out of position (prolapse), or hemorrhoids.

Indwelling Catheterization

An indwelling catheter is one that is inserted into the bladder and stays in place for extended periods. The catheter continuously empties the bladder into a collection device. Indwelling catheterization works without the need for bladder contractions or coordinated action of the sphincter mechanism.

There are two basic types of indwelling catheters: Urethral indwelling catheters are inserted into the bladder through the urethra. Suprapubic indwelling catheters are inserted into the bladder through a surgical opening in the lower abdomen, just above the pubic bone. The care of both types of catheters is similar. Your health-care provider can provide instructions on proper cleaning.

A suprapubic catheter has some advantages over an indwelling urethral catheter: A suprapubic catheter does not cause damage to the urethra because it bypasses the genital area. There is less risk of blockage since a wider catheter is used, and it is easier to change and clean. A suprapubic catheter is also less likely to interfere with sexual activity. Suprapubic catheterization is reversible. If the catheter is removed, the hole into the bladder usually closes within 1 to 2 days.

Indwelling catheterization may be a good option for people with poor hand function or who have limited assistance from a caregiver for other types of bladder management (such as intermittent catheterization). Suprapubic indwelling catheterization is recommended for individuals with bladder neck obstruction or urethral abnormalities.

Be aware that the risk of potential complications with indwelling catheterization is higher than it is with some other bladder management methods. Complications can include bladder or kidney stones (especially in females), deterioration of the upper urinary tract (including increased reflux), and increased risk for bladder cancer (especially for individuals using indwelling catheters for longer than 10 years). While the incidence of these complications is low, doctors recommend more frequent monitoring when using indwelling catheters. Indwelling catheters can also lead to more bacterial presence in the bladder and higher rates of urinary tract infection.

An indwelling catheter is held in place by inflating a small balloon on the inside of the bladder. Typically, an indwelling catheter is replaced every two to four weeks, either by the individual using it or by a knowledgeable caregiver. The longer the catheter stays in place, the greater the risk of a hard crust of mineral deposits forming on the surface of the catheter. A suprapubic tube should be replaced immediately upon removal to avoid closure of the bladder opening.

There are a variety of indwelling catheters available. Work with your health-care team to determine what works best for you. Options are available for people who are allergic to latex.

Reflex Voiding

Reflex voiding is a bladder management method used by males. An external condom catheter is placed on the penis. This is not used by females because external urine collection devices do not currently exist for them. Reflex voiding requires a leg bag or other collection device to continuously collect urine.

Reflex voiding is a bladder management option if you have an overactive bladder, meaning the bladder contracts involuntarily whenever it receives signals from nerves in the

spinal cord that it is full—even when it is not. These signals cause involuntary reflexes that trigger bladder contractions. After SCI, a contracted bladder muscle is not always coordinated with a relaxed sphincter muscle. Therefore, as the sphincter relaxes and tightens intermittently, the flow of urine stops and starts involuntarily, and thus unpredictably.

Reflex voiding using an external condom catheter has some advantages. Perhaps the most important is convenience. The system requires little attention during the day, except for emptying the leg bag. Also, there is no restriction on fluid intake as there can be with intermittent catheterization. A possible disadvantage of reflex voiding is irritation of skin on the penis from contact with the condom device.

Reflex voiding can be used in combination with intermittent catheterization. Because it is common for people to have urine left in their bladder, combining both a condom catheter and intermittent catheterization can help ensure that the bladder is completely drained. Some males simply disconnect the extension tube from the condom catheter and insert the straight catheter through that same opening into the urethra. Others remove the condom catheter entirely each time they catheterize.

You should have a thorough urodynamic evaluation to determine if your bladder and sphincter are working well enough for you to use reflex voiding.

When sphincter-bladder coordination is lacking (dyssynergia), some males require other interventions, including medications or Botox injections to relax the sphincter (see p. 12). Other more permanent interventions include surgical placement of a metallic tubular device called a urethral stent (discussed below) or surgery to cut the muscles of the sphincter (sphincterotomy) (p. 14) to keep the flow of urine moving.

Stent

A urethral stent is a tubular device made of metallic mesh used to prop open the sphincter to facilitate reflex voiding in males. Stents can accidentally shift position above or below the sphincter; if this happens, they are not effective. Also, should

problems arise, a stent can be difficult to remove; it can eventually cause scar tissue and narrowing of the urethra (urethral stricture). Placing a stent requires minor surgery and anesthesia.

Botulinum Toxin (Botox) Injection

Coordinated bladder contraction with sphincter relaxation is often limited or lost after a spinal cord injury. Sometimes your health-care team will recommend injections of botulinum toxin (better known as Botox) to relax your urinary sphincter. If an individual who plans to reflex void has detrusor sphincter dyssynergia, he may want to consider the use of botulinum toxin injections into the sphincter to help improve voiding.

Botox is usually injected by passing a long needle directly through the skin, rendering muscles unable to contract. In bladder management, a Botox injection is typically made through the urethra into the sphincter. For males, the drug is sometimes injected by inserting a needle through the skin between the scrotum and rectum and into the sphincter.

The effects of botulinum toxin injections are not permanent, usually lasting about 3 to 6 months. It may take 2 weeks for Botox to begin working, and 4 weeks until maximum benefit. Reinjections are done when the effects of the initial injections wear off. There is no limit to the number of reinjections you can have.

Botulinum can also be used by individuals using intermittent catheterization to relax an overactive bladder. Botox is injected directly into the bladder muscle, effectively reducing contractions, increasing bladder volume and thus reducing leakage.

Alpha Blockers

Alpha blockers are a class of medications that can be used to help improve urination in males who have a lack of coordination between the bladder and sphincter by relaxing the sphincter and prostate. This allows urine to flow more freely and helps the bladder empty more completely. Alpha blockers can also help lower the pressure in the bladder during voiding.

Alpha blockers relax certain muscles and help small blood vessels remain open and relaxed. This improves blood flow and lowers blood pressure.

Alpha blockers are available in either short-acting or long-acting forms. Short-acting medications work quickly, but their effects last only a few hours. Long-acting medications do not start to work as fast, but their effects last longer. Your doctor can help you decide which one is best for you.

Consider the use of alpha blockers on their own or as a supplement to other forms of treatment, such as transurethral sphincterotomy (p. 14). Consider avoiding alpha blockers if you have symptomatic hypotension (low blood pressure) since they can lower your pressure even more.

When first given an alpha blocker, it is best to take it at night right before lying down. This is particularly important for males who have a high-level spinal cord injury, in which case the effect of the medication is more likely to cause low blood pressure, possibly making you dizzy or faint, especially if you sit up (orthostatic hypotension).

Males who take or are considering taking alpha blockers along with other medications, including Viagra, Cialis, or Levitra, should check with their doctor. The combination can make blood pressure drop dangerously low.

Anticholinergic Drugs

Anticholinergic are a class of drugs commonly prescribed for people who use intermittent catheterization. These drugs help relax the bladder, thus increasing its capacity and reducing contractions that might cause leakage. They work by blocking certain nerve signals that activate muscle activity. Side effects of anticholinergic drugs can include dry mouth, blurred vision, drowsiness, and constipation.

Surgical Procedures

There are a number of surgical procedures to help people with spinal cord injuries gain more control over poorly functioning bladders, especially if the bladder has become smaller or is prone to spasms. Descriptions of several types of procedures follow.

A NOTE ABOUT SURGICAL PROCEDURES

The procedures described in this guide are highly technical procedures and should be performed only at centers with experienced surgeons and strong clinical support teams. Careful consideration is needed before proceeding with any surgery. Discuss any surgery thoroughly with your health-care team and your surgeon. With any surgical procedure, it is a good idea to get a second opinion before making a final decision. It can be very helpful to talk to other people with SCI who have had surgeries to find out about their experiences.

Sphincterotomy

Transurethral sphincterotomy (TURS) is a surgical procedure in which an incision is made in the urinary sphincter. This procedure is for males who use reflex voiding and have detrusor sphincter dyssynergia. The objective of this procedure is to lower the pressure in the bladder and allow better emptying when an individual has an overly tight sphincter that does not relax when the bladder contracts. Cutting the sphincter muscle allows better bladder drainage and can help to reduce the frequency of urinary tract infections and autonomic dysreflexia. TURS can also help maintain better renal function by reducing back pressure from the bladder to the kidney. Sphincterotomy is considered permanent and irreversible, although 30 percent to 60 percent of procedures will require reoperation as a result of the formation of scar tissue.

Following TURS, bladder drainage is provided with an external condom catheter connected to a leg bag, which requires daily care (i.e., changing and cleaning).

Be aware that potential complications of a sphincterotomy include erectile dysfunction (difficulty having erections) and ejaculatory dysfunction (difficulty having ejaculations).

Bladder Augmentation

After a spinal cord injury, your bladder may shrink or become overactive. Bladder augmentation (known medically as augmentation cystoplasty) is a surgical procedure to increase bladder capacity. The bladder is enlarged by surgically grafting (attaching by surgically stitching or stapling) segments of the small intestine, stomach or other tissue to the bladder. By expanding bladder capacity, bladder augmentation can reduce leaking and help protect the kidneys from damage.

Continent Urinary Diversion

Continent urinary diversion completely bypasses the bladder, using a section of the stomach or intestine to create an internal pouch or pseudobladder. The ureters are sewn into the newly created pouch to carry urine from the kidneys. This method may be used if your bladder cannot hold urine without problems (urine backup or overfilling of the bladder) and the bladder cannot be augmented. Depending on your anatomy, the internal pouch can be attached to your urethra or to a permanent outlet (stoma) in your lower abdomen. Urinary management is maintained by intermittent catheterization, either through a stoma or the urethra. The stoma can be placed where it is easy to access for catheterization without undressing. Because there is more mucus in the urine (as a result of the intestinal lining of the pouch), it is necessary to regularly flush (irrigate) the pouch with saline solution.

Urinary Diversion

Urinary diversion also redirects the flow of urine by bypassing the bladder. This surgery is used for urinary management when the bladder is no longer functional and less invasive methods have failed. The ureters are cut just above the bladder, connected to a segment of intestine, and attached to the skin of the lower abdominal wall where a stoma is created. A stoma (as mentioned above) is a permanent opening in the skin that provides an access point through which you can

attach drainage tubes and/or catheters. A tube is attached to the stoma to collect urine externally and can be connected to a leg bag during the day and a bed bag at night. The equipment used to support urinary diversion (e.g., the drainage tube, leg and bed bags) is designed to stay in place securely and often only has to be changed weekly.

Urinary diversion can be used as an alternative to bladder augmentation, bladder removal, or continent diversion when hand function does not permit self-catheterization. As with any form of bladder management, the primary goal is to preserve the upper urinary tract (the kidneys) and prevent incontinence.

Cutaneous Ileovesicostomy

Cutaneous ileovesicostomy is a kind of urinary diversion in which a segment of the small intestine is made into a tube, connected to the bladder, and then brought to the lower abdominal wall where a stoma is created in the skin. This creates an opening between the final section of the small intestine and the “pouch” (called the cecum) where the colon begins. This method has the advantage of leaving the ureters connected to the bladder. It provides for lower pressure, thus allowing urine to move through an external collector.

You may want to consider cutaneous ileovesicostomy if you have a damaged urethra that cannot be restored and want to preserve normal bladder anatomy.

Other surgical procedures may be needed to prevent urethral urinary incontinence. For example, the bladder neck may need to be surgically closed to prevent leaking.

Electrical Stimulation and Posterior Sacral Rhizotomy

Electrical stimulation of the nerves that control bladder contractions (the sacral center parasympathetic nerves) is sometimes used to stimulate the bladder and therefore initiate urination on command. The procedure has been available for many years and is approved by the United States Food and Drug Administration. It is not, however, currently on the market in the United States. It is available in Europe as the Finetech-Brindley device.

Research has shown that electrical bladder stimulation can reduce incontinence and related complications; residual urine volumes are low after application, which promotes better

bladder health and limits urinary tract infection. Electrical stimulation can also lower the costs of bladder management, reducing the need for indwelling or intermittent catheters and limiting the need for anticholinergic medications.

Electrical stimulation is accomplished by surgically implanting electrodes under the skin on the specific nerves or nerve roots that control urination. These electrodes are attached to a stimulator placed under the skin of the abdomen or chest. The stimulator is powered and controlled by radio transmission from a battery-powered remote control that you can operate when you want to urinate.

Usually, the electrode implant is combined with a rhizotomy, a permanent surgical procedure that cuts certain sacral nerve roots that are related to bladder spasms. A rhizotomy can reduce incontinence by increasing bladder capacity and reducing bladder contractions. However, cutting sacral nerves also eliminates the ability for males to experience reflex erections, reflex ejaculation, and related sacral sensations.

Mitrofanoff Appendicovesicostomy
(see "One Woman's Point of View" p. 18)

The Mitrofanoff appendicovesicostomy procedure is a surgical procedure where the appendix (or a short section of your small intestine) is used to create a connection between an opening, called a stoma, in your skin (usually through your belly button) and your bladder (sometimes the stoma is placed elsewhere in a convenient place in your abdominal region). This procedure makes it easier to catheterize yourself because you do not have to insert a catheter into your urethra, which can be difficult to do, especially for females. Placing a catheter through the urethra also requires more space, often requires a transfer out of your wheelchair, and requires removal of your clothes and underwear. With the Mitrofanoff procedure you may simply lift your shirt or dress, insert the catheter directly into the stoma and drain the urine into a toilet or other collection device. This procedure often eliminates the need for assistance from another person.

Some people who choose this form of bladder management may also need a bladder augmentation.

FIRST-HAND ACCOUNT: One Woman's Point of View

In 1993, at the age of 17, I was injured in a car accident, and because I was not wearing a seatbelt, I was ejected from the car when it rolled over three times. The result was a complete T5–6 spinal cord injury from mid-chest down. I also had internal injuries and had to have my right kidney removed. During that first week I was on so many pain killers that my memories were a blur. I don't believe I understood the full extent of my injuries until one day I looked at the nurse and said, "I think I need to use the restroom." What I remember going through my head at that moment was that I had been lying in a hospital bed for almost a week, but I didn't remember getting up to go to the bathroom. Then it all started sinking in: (1) I couldn't walk anymore to get up to go use the bathroom; (2) I wasn't getting up to go use the restroom because I was told I had a catheter in my bladder; and (3) I was told I no longer could feel or control my bladder and bowels. That is a lot to take in when I was still thinking I was just healing from a major back injury.

Before I was discharged to go to a rehabilitation hospital, the nurses started coming into my room every 4 to 6 hours to catheterize me. I was told when I got to the rehabilitation hospital that they were going to teach me to do it myself. So rehab started and the nurses still catheterized me, and in between I used Depends® for when I had incontinence issues. The Depends® were so embarrassing; I was horrified that I was wearing adult diapers at age 17.

I worked with my nurse on how to catheterize myself. I practiced with a mirror—trying different locations like my wheelchair or transferring onto a towel, commode, or bed. While trying all these different positions, the goal was not only to keep the environment sterile, but to find the correct opening, my urethra.

The nurse even gave me a practice vagina to learn on, and when my friends came to visit me in the hospital that was an interesting conversation piece.

Every time I "cathed" on my own successfully, my nurse played the song "Whomp! (There It Is)" and we would dance. In fact, just days before being discharged from the hospital, my grandmother came to visit and the nurse came in to do a cathing lesson. I told my grandmother she could stay, and my nurse just pulled the curtain, so while I transferred onto the commode, with my grandmother just sitting a couple of feet away, I cathed successfully, and proudly my 80-year-old grandmother started singing the rap song "Whomp!"

(There It Is).” It was hilarious until the catheter sort of pointed the wrong way and shot out my pee on my grandmother’s feet.

Although, we got quite a chuckle out of it, I never thought that would be my last memory of my grandmother. Two days later, she passed away. I bet most people can’t say that the last time they ever saw their grandmother they peed on her foot. Sounds disgusting? Well, it gets worse: the following Monday at her funeral, I had a bowel accident, right in the middle of her service. My grandmother always had a sense of humor, and she was probably trying to teach me to accept what my new life was going to be like.

My discharge from rehab was just a few days after my grandmother’s funeral. While I was happy to be going home, I was sad because of my grandmother’s death. I was nervous because I was still not independent in many things, among them catheterizing myself, and I was going to be returning to high school. Most people have fond memories of their senior year. I don’t. I only went to school for two hours in the morning and then had physical therapy in the afternoon. Around my friends I was always nervous that I was going to pee in my pants or have a bowel accident. I had a close-knit group of friends who knew about my spinal cord injury and would often come to my house to visit because it was easier. I really cut myself off from people the first years after my injury because I was always afraid to go out for fear of having an accident. I planned everything around my cathing schedule. I couldn’t even sleep through the night because I would have to wake up every 4 to 6 hours and catheterize myself. I knew I was not drinking enough liquids, which sometimes led to infections, and since I only have one kidney, dehydration was especially bad for my health.

I was isolating myself from the world, and not because I used a wheelchair and couldn’t walk anymore but because I could not control my bladder and bowels. I was obsessed. In my head, over and over, I would try to do everything I could do to avoid having a bladder or bowel accident, but it didn’t matter. They both still happened. Then I met a girl who had the answer:

She was similar in age, and injury, and we totally hit it off. She understood what I was dealing with. She told me about a surgery where they use part of your intestines to make your bladder bigger, and create a little hole in your stomach, called a stoma, in which they would create a canal using your appendix, and it would connect to your bladder. I just couldn’t imagine it at first, but she said it was hopefully going to change her life. In fact it did! She had

the surgery and one day at the mall we both went into the gigantic handicap bathroom stall together. She sat in her wheelchair, pulled out a long catheter, lifted up her shirt just a little bit, inserted the catheter into the stoma (which looked like a little belly button), and drained the urine into a bottle held between her legs.

I was amazed! She was peeing out of her stomach. How could that be? Meanwhile, I had to transfer onto the toilet, pull down my pants, get out all of my cathing supplies, and try to catheterize myself on a public toilet in the mall and keep everything as sterile as I could. After that, I knew I wanted this surgery.

I waited about a year to get the surgery. I needed to do my research on it, talk to my doctors, and see the surgeon to make sure it was the best decision for me. It wasn't just a little procedure. The entire process from start to finish, including healing after being discharged from the hospital, was going to be a few months.

The end result was amazing! After about four months of healing, I slept an entire night without having to wake up or worry about peeing in my bed. I slowly kept trying new things that I was missing out on before because I was always worried about whether or not I would pee in my pants. I was more active, I felt confident again, I started dating more, I went to live at college, and I traveled. Overall, I started living again. If I went somewhere with friends, I didn't have to stress about what time it was or where I would catheterize myself. I could just go with the flow of the day, not having to preplan everything. I didn't have to worry anymore.

This surgery changed my life. I can now have a job, remain off bladder medications, and go on road trips. I believe I would not be living the quality of life that I am without this surgery. In 13 years I have had fewer infections, and I can drink a lot more because they increased my bladder 10 times the size. In the long run this surgery has kept my one kidney healthier as well because before the surgery I was always so dehydrated.

I can't say that everything in my life has changed because of the bladder surgery—because just like with other issues related to my spinal cord injury, I have had to get used to things—but it has made my life a lot less stressful. I do truly think, though, that if I had not gotten this surgery done, I can almost say for certain that I would not have gone to college, dated, socialized, or had a full-time job, among many other things that everyone has in life. I know so many people that are afraid to leave the house and try to work full time and do all the extra things in life because they are bound to a life revolving around their cathing schedule. I understand because I have been there, too!

ADVICE FOR PEOPLE WITH SCI WHO ARE ON OR ARE CONSIDERING A BLADDER MANAGEMENT PROGRAM

- Try to keep up to date with new medical procedures. You can do this by reading professional or SCI magazines, such as *PN* or *New Mobility*; by talking to your doctor and friends who also deal with SCI; or by searching the Internet. The important thing is to be comfortable asking your health-care team about new ideas or procedures that may be helpful.
- Before you decide to have any surgical procedure, do as much research as you can, ask as many questions as you can think of, and get a second expert opinion. Always ask how many of these procedures the surgeon has done in the past and if he or she has experience working with SCI patients and treating autonomic dysreflexia. If possible, talk to one or more previous patients who also have a spinal cord injury.
- Be careful with new procedures. Don't make snap decisions. Feel free to take the time to feel comfortable with your decision before making a change.
- If you wish to participate in a clinical research trial, be sure to get all the relevant information so that you can make an informed decision. Ask about the potential risks and benefits, the number of people participating, and the expected outcomes. Discuss any clinical trials with your doctor, family, and/or friends.
- Follow your doctor's instructions carefully. Take medications as directed, drink the recommended amounts of fluids, and take care of any urinary drainage and collection devices exactly as your doctor prescribes.
- Be aware of physical signs and symptoms that might be telling you something is wrong with your bladder function or that something has changed. Sometimes your bladder will physically change over time, possibly necessitating a change in your bladder management program.

- Be aware of physical signs that tell you when you need to urinate. These may be new sensations that are completely different from those you had prior to your spinal cord injury (e.g., tingling in the toes or hands). These kinds of sensations may prove helpful over time.
- Don't necessarily base your decisions on what works for others. While it is a good idea to get information from others who use bladder management programs, a program that works for someone else may not be right for you.
- Choosing a bladder management program is a personal choice. Try to get to know your post-spinal cord injury body as well as possible to help you choose the program that is most in tune with your needs.
- Be patient. Don't set your expectations too high, especially at first. Bladder management may require some trial and error. If you are not completely successful at first, or need to change your method of management, don't get discouraged. This is normal and a good way to gauge your needs, likes, and dislikes.
- Continually discuss your bladder function with your health-care providers. Small changes in what you observe may help your doctor determine what you need.
- Get regular checkups with your doctors to evaluate your urinary system and bladder management method. You can have major problems and no symptoms. Problems are best treated when they are caught early.

Useful Terms

Alpha blockers: Medications that can relax the urinary sphincter and prostate and therefore allow better bladder emptying.

Augmentation cystoplasty: A surgery that enlarges the bladder by sewing a piece of intestine onto the top of the bladder.

Autonomic dysreflexia: A sudden rise in blood pressure that can occur in SCI individuals with injuries at T6 and above if their body experiences any type of painful stimulation below the level of injury. The most common reason for autonomic dysreflexia is the bladder becoming overfilled with urine or the urinary sphincter contracting with too much force. Symptoms of autonomic dysreflexia include headache, sweating, flushing, goose bumps, chills, anxiety, and a slower pulse rate. However, about 30 percent to 40 percent of people at risk for autonomic dysreflexia have elevated blood pressures with few if any symptoms (silent dysreflexia). You can find clinical guidelines for both yourself and health-care professionals at www.pva.org/cpgs.

Bladder augmentation: Another term for augmentation cystoplasty.

Bladder outlet obstruction: Any type of blockage that restricts urine from flowing freely from the bladder. In older males this is frequently from an enlarged prostate. In SCI individuals it may be from detrusor sphincter dyssynergia or scar tissue.

Computerized Tomography (CT scan) of the abdomen and pelvis: A special type of X-ray procedure that uses computers to give a detailed picture of the internal organs in your abdomen and pelvis. This test is very helpful to see if there are problems, such as stones, tumors, or inflammation of the kidneys, ureters, or bladder.

Continent urinary diversion: A surgical procedure to bypass the bladder. This is made possible by using a section of the stomach or

intestine to create an internal pouch. The ureters are sewn into the pouch.

Credé maneuver: A bladder management method involving pushing into the lower abdomen directly over the bladder with enough force to squeeze urine out of the bladder.

Cutaneous ileovesicostomy: A surgical procedure in which a piece of the intestine (ileum) is attached to form a tube from the bladder to an opening in the skin (stoma) on the lower abdomen. Urine is thus able to drain from the bladder, avoiding the urethra.

Cystogram: A test in which X-ray material is used to fill up the bladder to determine whether or not urine flows backward from the bladder to the kidneys.

Cystoscopy: An examination of the urethra and bladder using a small, circular instrument called a cystoscope. It is used to check for inflammation, bladder stones, tumors, or foreign bodies.

Detrusor: The muscle that forms the bladder.

Detrusor sphincter dyssynergia (DSD): A loss of coordination between the urinary sphincter and the bladder.

Epididymitis: An infection of the tubes that surround the testicles. If the testicle also becomes infected the condition is called epididymo-orchitis.

Hydronephrosis: The stretching of the kidneys due to back pressure from the bladder, urine backflow (reflux), or blockage of the tube (ureter) that goes from the kidneys to the bladder. This stretching can result in kidney damage, kidney stones, and kidney infections.

Indwelling catheter: A tube (catheter) that remains in the bladder providing constant drainage of the bladder to a collecting bag. If the tube enters through the urethra, it is called an indwelling urethral catheter. If the tube enters by way of a surgical opening in the

lower abdomen, it is called a suprapubic tube. An indwelling catheter is held in place in the bladder by a small balloon inflated with a small amount of water.

Intermittent catheterization: A method whereby a catheter is passed through the urethra to drain the bladder. Once the bladder is drained, the catheter is removed.

Intravenous pyelogram: A test to determine kidney anatomy and function. It involves an injection of a liquid contrast followed by an X-ray.

Neurogenic bladder: A bladder that does not function normally due to nerve damage related to spinal cord injury, multiple sclerosis, or a stroke.

Overactive bladder (detrusor): A bladder that has uninhibited (involuntary) bladder contractions. These contractions may cause a feeling of needing to urinate and may also cause leakage (urinary incontinence). An uninhibited contraction may cause autonomic dysreflexia in a person with a spinal cord injury at T6 or above.

Posterior (dorsal) rhizotomy: A surgery to cut nerves that communicate with the sacral cord so that the bladder no longer contracts. This is often done at the time of a bladder electrode implant procedure so that the stimulator device will control bladder contractions rather than the bladder contracting on its own.

Postvoid residual: The urine left in the bladder after voiding.

Renal scan: A test to determine kidney function. It involves the injection of a liquid into the vein that passes through the kidneys and down into the bladder. If the kidneys are weak or there is a lot of back pressure from the bladder, the liquid will not pass down to the bladder with its normal speed.

Renal ultrasound: A renal ultrasound is a safe and painless test that uses sound waves

to make images of the kidneys, ureters, and bladder.

Sphincterotomy: A permanent surgery that involves cutting the urinary sphincter with a special knife or laser so that urine can more easily flow out of the bladder. This surgery may be used when the sphincter does not relax at the same time the bladder is contracting (also see: detrusor sphincter dyssynergia).

Stoma: A surgical opening that provides an alternative path for urine to exit the body (see ileovesicostomy).

Stoma stenosis: Narrowing of the stoma. The stoma can get narrow enough so that it is difficult for urine to pass out of it.

Underactive bladder: A bladder that has weak or no bladder contractions, resulting in incomplete bladder emptying. This may occur when a person is first injured (spinal shock) or with an injury lower on the spinal cord (the signals that tell the bladder to contract are on the lower spinal cord).

Urethra: The opening through which urine exits the body. In females it is located between the clitoris and the vagina. In males it is located at the tip of the penis.

Urethral diverticulum: A small pocket in the urethra that can interfere with insertion of a catheter. If the catheter gets caught in the pocket and a person continues to push on the catheter, it can enlarge the pocket, making it even harder to insert the catheter the next time (also see: urethral false passage).

Urethral false passage: A small pocket in the urethra that is usually narrower, deeper, and longer than a urethral diverticulum. It is often created by a catheter that is forcibly pushed into the urethra near a tight urinary sphincter. It can also result from a catheter balloon that is accidentally inflated in the urethra or by a surgical procedure in the urethra. If the catheter gets caught in the pocket and a person continues to push on the catheter, it can enlarge the pocket, causing bleeding and

making it even harder to insert the catheter the next time (also see: urethral diverticulum).

Urethral stent: A tubular device made of wire mesh. It is placed in the urethra to hold the external sphincter open.

Urinary sphincter: The muscles that relax when urinating and tighten when not urinating to prevent leakage.

Urinary tract infection (UTI): An infection caused by bacteria of the urethra (urethritis), bladder (cystitis), or kidney (pyelonephritis), causing such symptoms as cloudy or strong-smelling urine, blood in the urine, or sudden increase in spasticity. The presence of bacteria in the urine in the absence of symptoms usually does not require treatment.

Urodynamics: A test that involves filling the bladder through a catheter passed into the bladder. The catheter is attached to special equipment that can determine how well the bladder and sphincter are working.

Valsalva maneuver: A bladder control method involving bearing down with your abdominal muscles in order to push urine out of your bladder.

Vesicoureteral reflux: Urine flows backward from the bladder up to the kidneys. This can cause a bladder infection to spread up to the kidneys or cause stretching of the kidneys (hydronephrosis).

Voiding: Eliminating urine through the bladder.

Resources

Books:

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

Organizations:

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

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

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


Christopher and Dana Reeve Paralysis Resource Center
www.paralysis.org
800-539-7309

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

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

Paralyzed Veterans of America
www.pva.org
800-424-8200 or 202-872-1300

Spinal Cord Injury Information Network, University of Alabama at Birmingham
www.spinalcord.uab.edu
205-934-3283

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



Administrative and financial
support provided by

PARALYZED VETERANS OF AMERICA
801 Eighteenth Street, NW
Washington, DC 20006-3517
www.pva.org

ISBN 978-0-929819-23-5
June 2010