SPINAL CORD MEDICINE

CLINICAL PRACTICE CONSUMER GUIDELINE: NEUROGENIC BOWEL

Neurogenic Bowel: What You Should Know

A Guide for People with Spinal Cord Injury

consortium for SPINAL CORD MEDICINE
CLINICAL PRACTICE GUIDELINES

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Who Should Read This Guide?

This Guide is for everyone who wants or needs to understand how spinal cord injury (SCI) can affect and change *bowel** function. The clinical name for this condition is *neurogenic bowel*. It's also for everyone who wants to learn about ways to deal with these changes in bowel function. That includes:

Adults with spinal cord injuries:

- People with a new SCI.
- People who've lived with SCI for years.

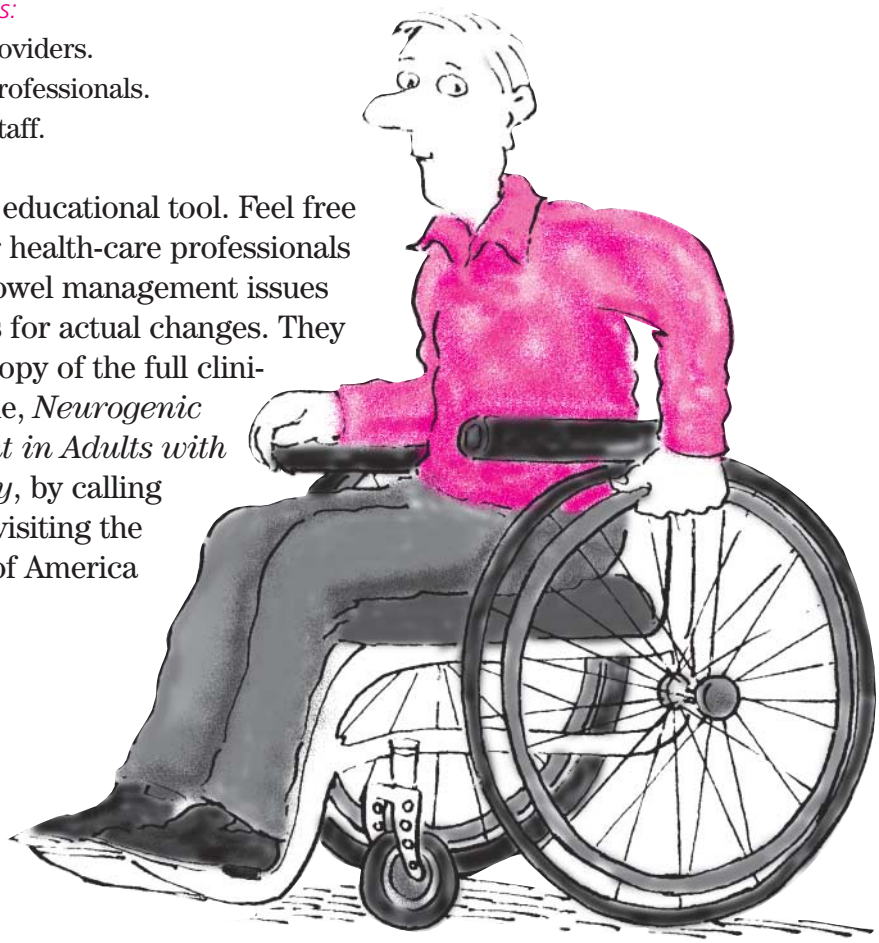
Caregivers:

- Family members.
- Friends.
- Personal care attendants.

Health-care professionals:

- Primary-care providers.
- Rehabilitation professionals.
- Other hospital staff.

This Guide is an educational tool. Feel free to share it with your health-care professionals when you discuss bowel management issues with them and plans for actual changes. They can also get a free copy of the full clinical practice guideline, *Neurogenic Bowel Management in Adults with Spinal Cord Injury*, by calling (888) 860-7244 or visiting the Paralyzed Veterans of America (PVA) web site at http://www.pva.org.



*Words in italics are explained in the Glossary on page 41.

Cliff

I'm an avid sportsman and can't get enough of the great outdoors. Since my SCI, I've been experimenting with new ways to do all the things I loved before my all-terrain vehicle (ATV) accident. I spend all my free time camping, whitewater rafting, kayaking, fishing, and hunting. I've got a T7 complete injury, so I needed some special adaptive equipment to continue my outdoor interests.

The biggest problem I had after my injury wasn't with changes to my sporting equipment or other gear, but in getting my body functions under control. I was worried that I'd have a bowel accident while I was on a camping or fishing trip, and that kept me from doing the things I really enjoyed.

So I talked with my doctor, rehabilitation nurse, and occupational therapist, and we developed a bowel program that's working well for me. Because I'm very physically active, we changed the frequency of my bowel care. The occupational therapist gave me some tips on positioning and disposal. My doctor also linked me to a dietitian, and we made some changes to my diet. It worked. I'm in control of my situation and that gives me confidence in other areas as well.

A **proper bowel program** promotes independence and thereby **improves quality of life.**

I met a young woman I really care for. We've been dating for a couple of months. Last month she began asking some personal questions about my injury, and I'm being really honest with her. I gave her a copy of PVA's *Yes, You Can!* book and marked some important sections for her to read. The bowel and bladder stuff is hard to talk about, but once she had read the book, it was easier.

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Why Is This Guide Important?

A spinal cord injury changes the way your body works and how you will care for yourself. One important change that may be difficult for many of us to talk about is how the bowel functions.

Before an SCI, people don't have to make special plans or schedules for bowel movements. They can feel the need to use a toilet, hold their bowels until the time is right, and then relax and let stool pass out at the right place.

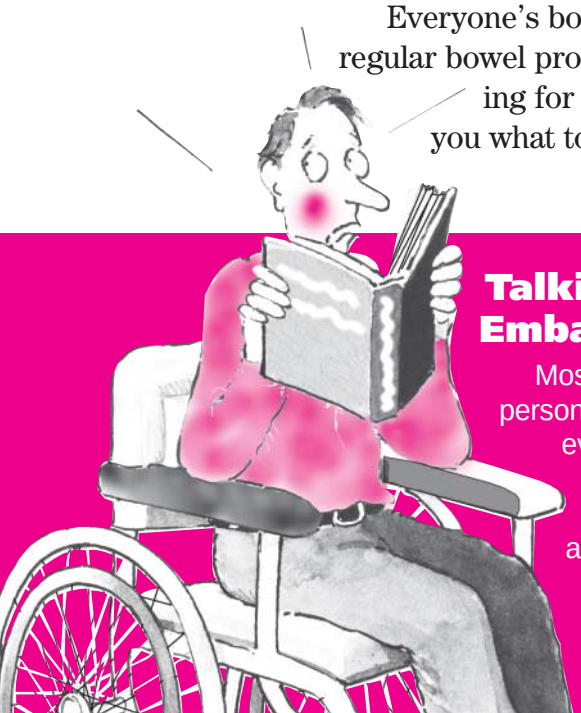
After an SCI, bowel movements require more time, thought, and planning. People with SCI usually can't feel when stool is ready to come out, and they need help expelling the stool. As people with SCI say, "**The bowel rules**."

A well-designed *bowel program* can help you lead a healthier and happier life after SCI. It can:

- Help prevent unplanned bowel movements (also called bowel accidents, *incontinence*, or involuntaries).
- Help avoid physical problems such as *constipation*.
- Put you back in control of a bodily function that, if neglected, can cause embarrassment.
- Improve your confidence in work and social situations.

This Guide will help you work with your family, caregivers, and health-care professionals to create a bowel program that fits your needs. After that, it's up to you to stick with it.

Everyone's body changes over time. Even if you've kept to a regular bowel program for months or years, it may stop working for you as well as it once did. This Guide will tell you what to do if that happens at any time in your life.



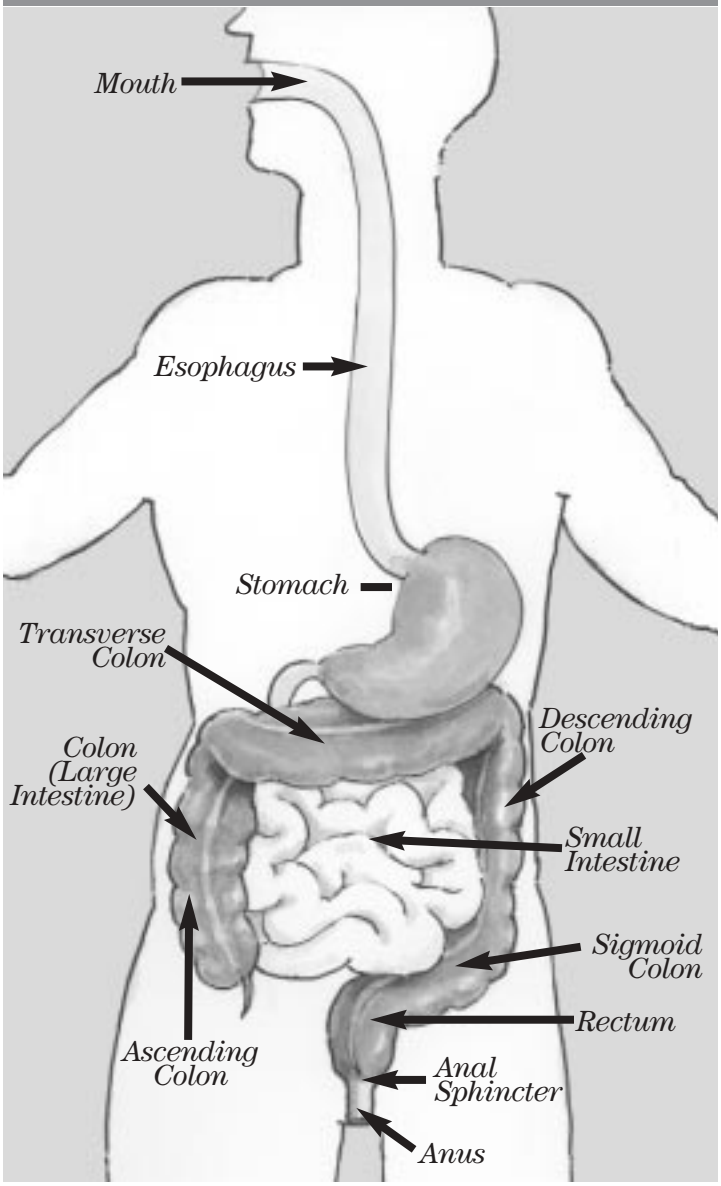
Talking About Embarrassing Subjects

Most of us consider bathroom functions private and personal. We're not comfortable talking about them, even with close family members or health-care professionals. That's one of the hardest changes after SCI: talking about bowel functions—and asking for help with them.

What Is the Bowel and Where Is It?

Everything you eat and drink travels from your mouth through your *digestive system*—also called the gastrointestinal tract or GI tract (see Figure 1). The GI tract includes the mouth, esophagus, stomach, small intestine, and colon (also called the large intestine) and ends at the anus. The colon is about 5 feet long and forms a question mark shape in the abdomen. Together, the large and small intestines are called the *bowel*.

FIGURE 1



There's no getting around it: Life **is** different now. Practice helps. The more you talk about bowel issues, the easier it gets. Remember that other people (except health-care professionals) are likely to be just as uncomfortable with bowel discussions as you are at first.

Humor can be a good way to relieve embarrassment. If you try to put other people at ease, you'll feel less embarrassed too.

How Does the Bowel Work?

The digestive process breaks down what you eat and drink into nutrients your body uses and waste that you eliminate. A wave-like action called *peristalsis* propels food through your GI tract. The undigested food, waste your body doesn't use, moves into the colon from your small intestine. The colon takes the moisture out of the waste and stores it. The waste follows the question-mark shaped pathway of the colon: up the ascending colon, across the transverse colon, down the descending colon through the sigmoid colon, and into the *rectum* on its way out of the body (see Figure 1, page 5).

People use many words to describe these wastes. Health-care professionals call them bowel movements (BM), stool, excrement, fecal matter, or feces. Your family and caregivers may be more comfortable using terms like BM. (Liquid wastes are eliminated as urine.)

How Does SCI Change the Way the Bowel Works?

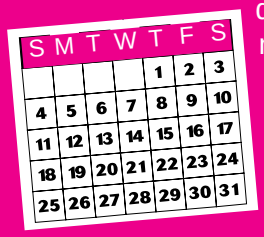
Neurogenic bowel is a condition that affects the body's process for storing and eliminating solid wastes from food. After SCI, the nervous system can't control bowel functions the way it did before.

For most people, the digestive process is controlled from the brain by *reflex* and voluntary action. SCI interferes with that process by blocking messages from parts of the digestive system to and from the brain through the spinal cord. How it interferes depends on where along the spinal cord the injury is.

Here's what normally happens. The colon stores stool until it's propelled out as a bowel movement. When the stool is

Tips for Following a Regular Bowel Care Routine

- Stick with a consistent schedule. That means every day or every other day, depending on your needs.



- Find a convenient time of day. That means always in the morning or always in the evening—whatever works for you, but always the same time of day.

pushed into the rectum, it triggers a reflex action. This action contracts the *anal sphincter*, keeping it closed so that stool doesn't slip out. Without SCI, people can feel stool in the rectum and voluntarily contract the anal sphincter to hold in the stool. They then find a toilet, relax the anal sphincter, and have a bowel movement.

SCI can keep you from feeling stool in the rectum and from controlling your anal sphincter. It can also affect peristalsis—how stool moves through your colon.

Generally, two basic patterns of neurogenic bowel occur after SCI, depending on which part of the spinal cord is injured.

Reflexic Bowel

This usually results from SCI at the cervical (neck) or thoracic (chest) level. This type of SCI interrupts messages between the colon and the brain that are relayed by the spinal cord. Below the injury, the spinal cord still coordinates bowel reflexes. This means that although you don't feel the need to have a bowel movement, you still have reflex peristalsis. Stool buildup in the rectum can trigger a reflex bowel movement without warning. Between bowel movements, your anal sphincter will remain tight, and your colon will respond to *digital rectal stimulation* and *stimulant medications* with reflex peristalsis that pushes the stool out.

Areflexic Bowel

This results from SCI that damages the lower end of the spinal cord (the lumbar or sacral level) or the nerve branches that go out to the bowel. This means that you have reduced peristalsis and reduced reflex control of your anal sphincter.

- Try to do bowel care after a meal or a hot drink. That may help stimulate your bowel to push stool out.
- Find a comfortable place and positions.
- **Privacy helps.**

Your bowel isn't controlled by reflexes from the spinal cord. You can't feel the need to have a bowel movement, and your rectum can't easily empty stool by itself.

The location of your SCI also has a great deal to do with the bowel program that will work best for you. (See pages 14-18 for information about bowel care for reflexic and areflexic bowel.)

What Is a Bowel Program?

A bowel program is a total plan for regaining control of bowel function after SCI. It deals with several aspects of your life, including:

- Diet and fluids—what, how much, and when you eat and drink.
- Activity level—how active you are: for example, how often you get a full *range of motion* of your joints, how many different positions (sitting, standing, lying) you are in during the day and for how long.
- Medications—what products you take for bowel care and for other reasons. These include oral medications you take to improve bowel function, rectal medications you use to stimulate a bowel movement, and medications you take for other reasons that affect bowel function.
- Bowel care—frequency and technique of scheduled, assisted bowel movements.

A bowel program is designed to help you improve your quality of life:

- Prevent or cut down on bowel accidents.
- Eliminate enough stool with each bowel care session at regular and predictable times.
- Make bowel care go smoothly, allowing you to finish within a reasonable time.
- Keep bowel-related health and other problems to a minimum.

You and your health-care professionals will work together to design a bowel program that fits your needs.

What Is Bowel Care?

Bowel care is the term for assisted elimination of stool, and it's part of a bowel program. It begins with starting a bowel movement. That's usually done with digital rectal stimulation and/or a stimulant medication. After the bowel movement starts, intermittent digital rectal stimulation can also be used to speed up defecation. (See page 18, "Are There Other Ways To Improve a Bowel Movement?")

Important:
People with SCI need to stick with a **regular** schedule and technique of bowel care. You may have to revise your bowel program over time, but keeping a regular schedule for doing bowel care at a regular time is one of the best things you can do for your health and well-being after SCI.

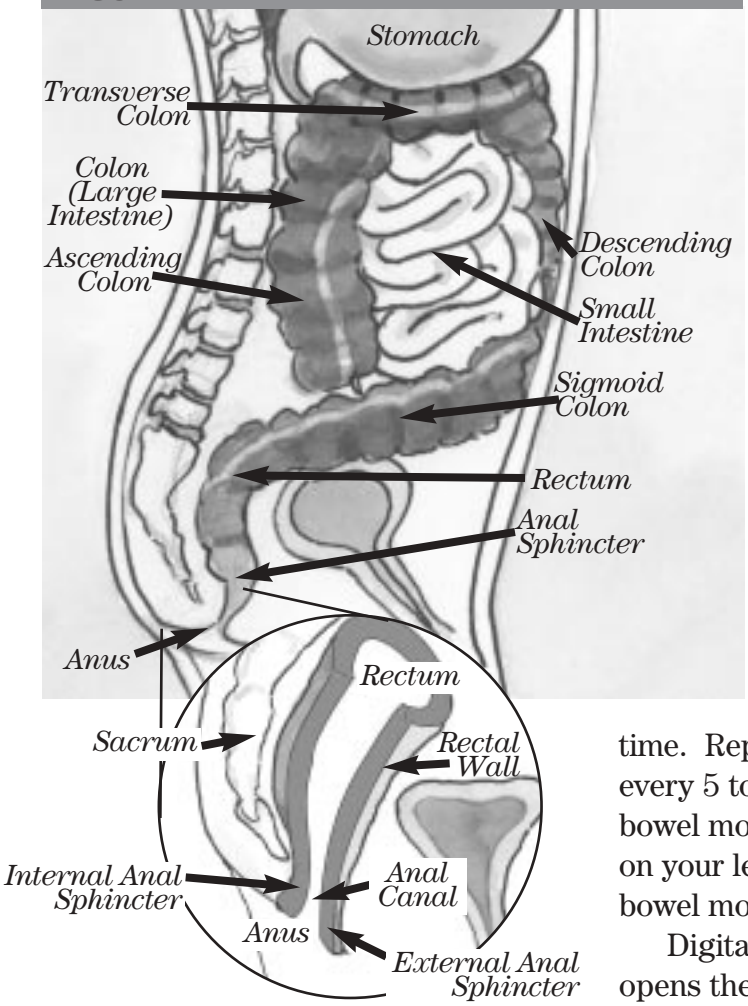
What Is Rectal Stimulation?

It's a way to turn on peristalsis in the colon, start a bowel movement, and keep it going. Most people need to start bowel care by stimulating the rectum to eliminate stool. There are two main types of rectal stimulation:

- *Mechanical stimulation*. This method uses a finger or a stimulant tool. It includes *digital rectal stimulation* and *manual evacuation*.
- *Stimulant medications*. This method uses a *suppository* or *mini-enema* (also called a liquid suppository).

Important:
If your SCI is at T6 or higher, stool in the rectum or any method of rectal stimulation may cause *autonomic dysreflexia*. This is a potentially life-threatening emergency medical condition! A fast, major increase in your blood pressure is the most dangerous sign of autonomic dysreflexia. Learn more about it and how to prevent it. Read the guide called *Autonomic Dysreflexia: What You Should Know*. For a free copy, call (888) 860-7244 or visit the PVA web site at http://www.pva.org.

FIGURE 2

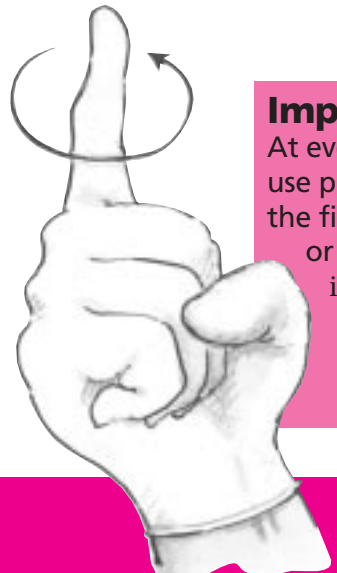


How Is Digital Rectal Stimulation Done?

Insert a gloved, well-lubricated finger **gently** into the rectum. Direct the stimulating finger toward the belly button and follow the anal canal (see Figures 2 and 3). When the finger is inserted, digital rectal stimulation can begin. Move the stimulating finger **gently** in a circular pattern, keeping the finger in contact with the rectal wall. Digital rectal stimulation usually takes 20 seconds and should be done no longer than 1 minute at a time. Repeat the digital stimulation every 5 to10 minutes until you have a bowel movement. Sitting up or laying on your left side may help stimulate a bowel movement.

Digital stimulation relaxes and opens the external anal sphincter (see Figure 2), straightens the rectum, and triggers peristalsis. From the time you start digital stimulation, it should take only a few seconds to a few minutes for stool to enter the rectum and come out.

FIGURE 3



Important:
At every stage of digital rectal stimulation, it's important to use plenty of lubricant and to be gentle. Pushing or rotating the finger too roughly can irritate or tear the rectal lining or anus and trigger autonomic dysreflexia. (For more information about autonomic dysreflexia, see the glossary and the guide called *Autonomic Dysreflexia: What You Should Know*. For a free copy, call (888) 860-7244 or visit the PVA web site at http://www.pva.org.)

What Does My Health-Care Professional Need To Know?

No single bowel program is right for everyone. Every person with SCI has a different diet, activity routine, need for medication, and life schedule that regular bowel care has to fit. A normal schedule for passing stool is whatever is usual for you. That's usually once a day or every other day. To find what works best for you, tell your health-care professional about:

Any new problems with bowel function:

- Does your bowel care produce poor results, or no results?
- Do you have rectal bleeding?
- Does your bowel care routine take longer than before?
- Do you have a lot of gas or feel bloated?

Your medical history. In addition to information about your SCI:

- Do you have, or have you had, diabetes?
- Do you have digestive problems, such as *irritable bowel syndrome*, *inflammatory bowel disease*, or *colitis*?
- Have you had any bowel surgery?

Medications you're taking:

- What prescription products are you taking and for what?
- What nonprescription products, such as *laxatives*, are you taking and how often do you take them?

Alcohol and other drugs:

- Do you drink alcoholic beverages? If so, what do you drink, how much, and how often?
- Do you use, or have you ever used, any "street" drugs? If so, which ones, how much, and how often?
- Do you use, or have you ever used, any alternative medicines? If so, which ones, how much, and how often?

Important:
Alcohol and drugs can affect bowel function. If you use alcohol or drugs, your health-care professional needs to know, to be able to design a bowel program that will work for you.

Your Bowel Program Is as Individual as You Are

The location of your SCI affects the amount of control you have over your bowel and determines which methods will work best for you. Work with your health-care professional to create a bowel program that fits, for example:

- **Work and home situations.** These help determine the best time and place for bowel care. They also affect meals and food preparation.
- **Supplies and equipment.** They need to be affordable, available, and accessible for you.

Your bowel habits before the SCI:

- How often did you have bowel movements?
- At what time of day did you have bowel movements?
- Did you have recurring problems with constipation or diarrhea?

Your diet:

- How much do you drink every day and what do you drink?
- What sorts of food do you usually eat, how much, and how often?
- Do any foods affect your bowel movements?
- Do you have problems with dairy products (*lactose intolerance*)?
- Do spicy foods give you loose stool?

Your stool:

- Is it hard, soft, or diarrhea (liquid that takes the shape of any container it goes in)?
- How much stool usually comes out during one of your bowel movements? For example, if your stool were formed into a ball, would it be a golf ball, a tennis ball, a softball, or, heaven forbid...a basketball?

If you have a bowel program now, your health-care professional will need to know:

- When and how often do you do bowel care?
- Which bowel care techniques do you use?
- How do you start a bowel movement?

  —Digital stimulation?

  —Stimulant medications (suppositories, mini-enemas)?

- **Bowel care.** You need to be able to perform the techniques yourself or direct an attendant or other caregiver on when and how you need help. Discuss whether you need an assistant with your health-care professional and if so, how to tell the assistant what to do.

- **Insurance.** Find out what your insurance covers. If some products aren't reimbursed, advocate for yourself—explain why the product is needed. *Involve your health-care professional in any decisions about what products you use.*

- How long does it take for the stimulants to work?
- Have you changed what you eat or drink?
- Has your activity level changed?
- Have any of your medications changed (medications you take for bowel care or anything else)?
- Are you having problems with any part of your bowel program?

Important:
Bowel care needs to be done regularly to help prevent accidents! **If you're having problems sticking with your program, tell your health-care professional**. Together, you can help identify the problem by talking about your history of bowel care, performing a physical examination, and taking tests to explore why you're having problems. Then, changes can be made—one element at a time—that will help you follow a regular routine. (See page 29, "What Should I Do if My Bowel Program Isn't Working?")

How Do I Do Bowel Care?

If I Have a Reflexic Bowel

The goal of a reflexic bowel program is soft, formed stool that can be passed easily with minimal rectal stimulation. The bowel care routine usually starts with a stimulant medication or with digital stimulation.

Getting ready and washing hands. Empty your bladder or move your urinary drainage equipment away from the anal area. Whoever performs bowel care—you or an *attendant*—should wash their hands thoroughly.

Setting up and *positioning*. Prepare for a bowel movement by getting on or ready for a transfer to a toilet or commode. If you're sitting up, gravity helps empty your rectum. When sitting, keep your feet on the floor or on a footstool or on the footrest of your commode chair, with your hips and knees flexed. If you need help with a transfer, position yourself before bowel care. If you don't sit up, lie on your left side.

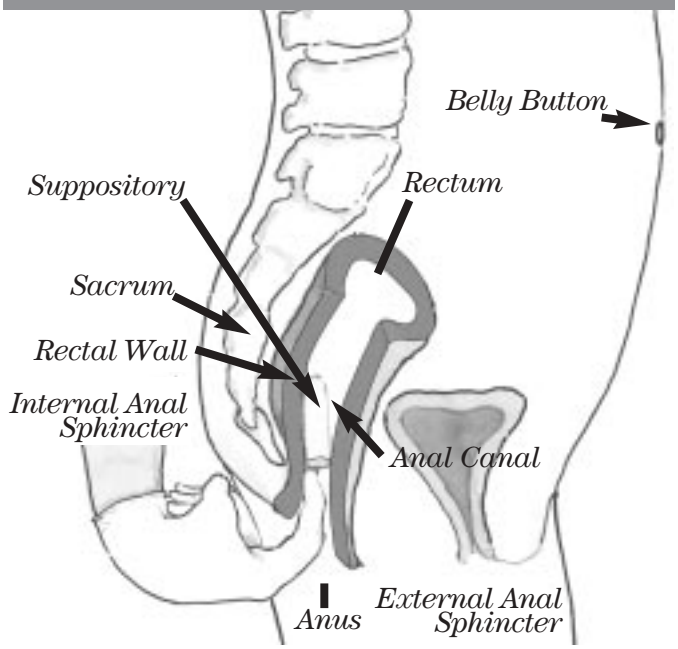
STEP R3

Checking for stool. Check for stool by sliding a gloved, well-lubricated finger into the rectum. Remove any stool that would interfere with inserting a suppository or mini-enema (manual evacuation). Use one or two gloved and lubricated fingers to break up or hook stool and gently remove it from your rectum.

STEP R4

Inserting stimulant medication. (If you don't use a suppository or mini-enema, go directly to step R6.) To start a bowel movement, insert a lubricated suppository or squirt a mini-enema high in your rectum. (The suppository should be coated with a water-soluble lubricant.) Use a gloved and lubricated finger or *assistive device*. Place the medication right next to the rectal wall (see Figure 4).

FIGURE 4



Waiting. Wait about 5 to 15 minutes for the stimulant to work. If you pass gas or some stool, it's a sign that the stimulant is beginning to work.

Starting and repeating digital rectal stimulation. Use digital rectal stimulation or other techniques. To keep stool coming, repeat digital rectal stimulation every 5 to 10 minutes as needed, until all stool has passed. (See page 10, "How Is Digital Rectal Stimulation Done?")

Recognizing when bowel care is completed. To make sure the rectum is empty, do a final check with a lubricated and gloved finger or assistive device. You'll know that stool flow has stopped if:

— No stool has come out after two digital stimulations at least 10 minutes apart.

— Mucus is coming out without stool.

— The rectum is completely closed around the stimulating finger.

Cleaning up. Wash and dry the anal area.

If I Have an Areflexic Bowel

The goal of an areflexic bowel program is firm, formed stool that: (1) can be passed manually with ease, and (2) doesn't pass accidentally between bowel care routines. Bowel care doesn't usually require chemical stimulants because the response would be very sluggish.

Getting ready and washing hands. Empty your bladder or move your urinary drainage equipment away from the anal area. Whoever performs bowel care—you or an attendant—should wash their hands thoroughly.

Setting up and positioning. If possible, sit up. If you're sitting, gravity helps empty your rectum. When sitting, keep your feet on the floor or on a footstool or on the footrest of your commode chair, with your hips and knees flexed. If you don't sit up, lie on your left side.

Starting and repeating digital rectal simulation. Use digital stimulation or other techniques. To keep stool coming, repeat digital rectal stimulation every 5 to 10 minutes as needed, until all stool has passed. (See page 10, "How Is Digital Rectal Stimulation Done?")

Doing manual evacuation. Use one or two gloved and well-lubricated fingers to break up stool, hook it, and gently pull it out.

Use repeated Valsalva maneuvers. (See page 18.) Use gentle *Valsalva maneuvers* to bring stool down before and after each manual evacuation. Breathe in and try to push air out, but block the air in your throat to increase the pressure in your abdomen. Try to contract your abdominal muscles as well. This technique can help you increase pressure around the colon to push stool out. Repeat it for 30 seconds at a time on and off as long as you need to expel all stool.

Bending and lifting. If you have good torso stability, lift yourself as if doing a pressure release or do forward and sideways bending with Valsalva maneuvers. This helps change the position of the colon and expel stool.

Checking the rectum. To make sure the rectum is empty, do a final check with a gloved and well-lubricated finger. If stool is present, repeat Steps A4-7.

Cleaning up. When you are confident all stool has passed, wash and dry the anal area.

Whether you have a reflexic or an areflexic bowel, you may be able to rely on diet, fluids, and regular activity to give your stool a healthy texture for bowel care. If these don't work by themselves, your health-care professional may suggest medications. (See page 27, "What Medications Are Used in Bowel Programs?")

Are There Other Ways to Improve a Bowel Movement?

Once you have a regular bowel program that works, you and your health-care professional may want to explore ways to simplify it: doing bowel care less often, changing the stimulant you use, or trying digital stimulation without a suppository or mini-enema. Remember, before making any of these changes, discuss them with your health-care professional.

Your health-care professionals may suggest a number of *assistive techniques* or tips to improve your bowel care results. The most common ones are:

- **Positioning**. Sitting upright in a cushioned commode chair or padded toilet seat may help gravity to empty the lower bowel. Placing your feet on footrests or footstools also gives you support while you bear down (see Valsalva maneuver, below) to push stool out.
- **Abdominal massage**. Rubbing or running a hand firmly over the abdomen in a clockwise motion from the lower right across the top and down the left helps move stool through the colon to the rectum.
- **Forward or sideways bending**. For this, you need either a lap safety belt if you're using a commode chair or enough control of your upper body to be able to return to a sitting position after you bend forward or side to side at the waist. These maneuvers also help move stool through the colon to the rectum.
- **Push-ups**. If you have strong upper arms, you can raise your hips off the commode chair seat. Put yourself down in a slightly different position to vary the pressure against your skin. Push-ups also help move stool into the rectum.
- **Valsalva maneuver**. This technique works best for people with areflexic bowel who have control over their abdominal muscles and can help push stool out. Before doing Valsalva maneuvers,

check with your health-care professional, especially if you have a history of heart problems. (See A5 on page 17 under "If I Have an Areflexic Bowel.")

- **Gastrocolonic response or reflex**. Eating a meal or drinking warm liquids before bowel care may help some people with SCI stimulate a bowel movement. Starting your bowel care within 30 minutes after you eat or drink may help it go faster and produce more results.

Important:
People with SCI need to stick with a **regular** schedule and technique of bowel care. You may have to revise your bowel program over time, but keeping a regular schedule for doing bowel care at a regular time is one of the best things you can do for your health and well-being after SCI.

What Is a Bowel Care Record?

A Bowel Care Record helps you and your health-care professional see whether your bowel program is working. It's most helpful the first weeks after you leave the hospital, whenever you're having problems, and a few weeks before your annual checkup.

Use the Bowel Care Record at the back of this Guide. Every time you do bowel care, write down:

- **Date**.
- **Start time**. The hour and minute you start stimulation or try to start a bowel movement.
- **Position**. Left side lying, right side lying, sitting.
- **Stimulation method**. Stimulant medication, digital rectal stimulation, or other technique you use to start a bowel movement.
- **Assistive techniques**. Methods used to promote bowel emptying and the number of times used during bowel care, e.g., abdominal massage, bending, push-ups, Valsalva maneuver.

Bowel Care Record

Date	Start Time	Position	Stimulation Method	Assistive Techniques	Time of Results First/Last	Stool Amount, Consistency, Color	Comments

- **Times of results**. The time when the first stool begins to come out of the anus and the time when the last stool comes out.
- **Stool amount, consistency, and color**. Amount: if stool were formed into a ball—golfball, tennis ball, softball. Consistency: hard, firm, soft, liquid. Color: especially anything unusual for you.
- **Comments**. Problems such as any unplanned bowel movements, abdominal cramps, pain, muscle spasms, pressure ulcers, hemorrhoids, or bleeding.

If your bowel program is going well, there's no need to keep a Bowel Care Record.

Important:
If you see any blood in your stool or any discoloration in your stool, too dark or light, call your health-care professional right away. It might indicate a medical problem. For example, stool that's dark, black, or tar-like could be a sign of bleeding in the GI tract, like an ulcer. **But be aware that iron supplements will turn your stool black, and that's not a problem**. (See page 29, "What Should I Do if My Bowel Program Isn't Working?")

Can I be Independent in My Bowel Care?

That depends on many factors: the level and completeness of your SCI, your body type and general health, how strong you are, and how much you want to be independent.

For complete independence, your arms and fingers need to be strong enough to manage your clothes, get you into a bowel care position, place stimulant medication, and do digital rectal

Alcohol and Drugs: What You Need To Know

Alcohol and drugs can affect bowel function and cause additional problems for people with SCI.

- **Alcohol**. Alcohol, even beer, can change your habits. It can reduce your appetite, making it hard to stick with the diet part of your bowel program. It can also cause problems in keeping up with your bowel care schedule. If you're having trouble following your bowel program because of alcohol use, your health-care professional needs to know, to be able to help.

- **Drugs**. Many street drugs, as well as prescribed pills for pain, cause constipation. Because of that, many people

stimulation. Most people with a thoracic, lumbar, or sacral SCI are strong enough and have enough balance. Some people with a cervical SCI at C6, C7, or C8 levels may not have enough finger strength or sitting balance to independently insert a suppository or mini-enema or do digital rectal stimulation. Special devices like a digital stimulator and suppository inserter can help with these activities.

Even if they can do bowel care themselves, some people choose to have a caregiver do it. They find that it takes too long, or it simply takes too much energy that they'd rather use doing other things.

Whether or not you do your own **bowel care**, you still need to manage your **bowel program**. That means watching what you eat and drink, your activity level, your medications, and the results of your bowel care routine. If you need assistance with your bowel care, learn the process so that you can teach it to caregivers and supervise your care. It's your body and you are the boss.

Why Do I Need to Watch What I Eat and Drink?

What you eat and drink can affect your bowel movements, but everyone responds a bit differently to different foods. The best way for you to learn how different foods affect you is to keep a Food Record and Bowel Care Record. For about a month, write down what you eat and drink each day and describe your bowel movements. (See the Food Record and Bowel Care Record at the back of this Guide.)

who use drugs end up overusing laxatives—and that can cause more problems. If you use drugs and don't tell your health-care professional, there's a very good chance that the bowel program you create together won't work. It's also a good idea to discuss any alternative medicines you use.

- **Your bowel function is your responsibility**. It's up to you to give your health-care professionals the information they need to help you rule your bowel—not the other way around.

Foods That Can Keep Stool Solid but Soft

Foods that have a lot of fiber can absorb liquids and help make your stool solid but soft and easy to pass. High-fiber foods are fresh fruits and vegetables, dried peas and beans, and whole grain cereals and breads. It's best to get the dietary fiber you need from a variety of food sources. A starting goal of at least 15 grams of fiber each day is recommended as part of a healthy diet. An increase in fiber is recommended only if it is necessary to produce a soft-formed stool. Table 1 gives a general idea of how much fiber is in different types of food. It's a good idea to increase this amount gradually over a 6-week period to prevent a bloated feeling and too much gas.

If you can't eat as much fiber as your health-care professional suggests, you may want to try fiber supplements—natural vegetable powders, like psyllium. You can get them at your local drugstore and supermarket. **If you take fiber supplements, be sure to drink plenty of fluids.** That means at least 64 ounces a day. (Drinks with alcohol or caffeine don't count toward that total.) Remember, if you use fiber to vary the consistency of your stool, you will have more total stool and may need to do bowel care more often.

Important:
Not everyone with SCI benefits from a high-fiber diet. You need to recall how much fiber you usually had in your diet before the SCI and how much you eat now. Talk with your health-care professional about the amount of fiber in your diet before and after your SCI.

Foods That Can Cause Gas

Gas in the digestive tract may cause uncomfortable feelings of fullness, bloating, and pain. If you're having problems with too much gas, you may want to cut back on or cut out foods associated with gas. These include beans, broccoli, cabbage, cauliflower, corn, cucumbers, onions, and turnips. (See Table 2. What You Can Do About Excessive Gas, page 24.) If your Food Record shows that some of these foods cause problems with gas, consider eliminating them from your diet.

TABLE 1

How Much Fiber Is in Different Types of Food?

Food Type	Quantity	Grams of Fiber/Serving
LEGUMES		
Baked beans	1/2 cup	8.8
Dried peas, cooked	1/2 cup	4.7
Navy beans, cooked	1/2 cup	6.0
Lima beans, cooked	1/2 cup	4.5
CEREALS		
Oatmeal	3/4 cup	1.6
Bran flakes	1/3 cup	8.5
Shredded wheat	2/3 cup	2.6
Raisin-bran type	3/4 cup	4.0
FRUIT		
Apple (w/ skin)	1 medium	3.5
Banana	1 medium	2.4
Orange	1 medium	2.6
Prunes	3	3.0
BREADS		
Whole wheat bread	1 slice	1.4
Pumpernickel bread	1 slice	1.0
Bagels	1 bagel	0.6
Bran muffins	1 muffin	2.5
MILK	*ANY AMOUNT*	*0.0*
MEAT		
Beef	Any amount	0.0
Pork	Any amount	0.0
Poultry	Any amount	0.0
Lamb	Any amount	0.0
Fish	Any amount	0.0
Seafood	Any amount	0.0
FATS	*ANY AMOUNT*	*0.0*

Certain foods may cause gas, so substitutions may be necessary.

Foods That Can Cause Diarrhea

There are no foods that cause *diarrhea* in everyone. Some people find fatty, spicy, or greasy foods seem to be related to diarrhea. Other people report that caffeine—found in coffee, tea, cocoa, chocolate, many soft drinks—appears to cause diarrhea. Diarrhea-causing bacteria can contaminate different foods as well. If you have episodes of diarrhea, keep a Food Record of what you eat and drink to help you identify what you're sensitive to.

TABLE 2

What You Can Do About Excessive Gas

CAUSES	*SOLUTIONS*	*FOODS THAT CAN CAUSE GAS*
Food Constipation Swallowing air while you're eating or drinking More bacterial breakdown of bowel contents than is usual for you Lactose intolerance	Think about **how** you eat: 1. Eat your food slowly. 2. Chew with your mouth closed. 3. Try not to gulp your food. 4. Don't talk with food in your mouth. Experiment with foods that can cause gas: 1. Remove specific foods from your diet, one at a time. 2. Do this for your favorite foods until you've learned which, if any, cause you to have gas. 3. Cut down on those foods. Think about your surroundings: 1. Ceiling fans help remove odors. 2. Good ventilation, such as plenty of windows or table-top fans, also helps. 3. Deodorant spray can mask the odor. Release gas at appropriate times and places: 1. Do digital rectal stimulation in the morning or evening daily. 2. Do push-ups or lean to the side to release gas when alone or before meeting with people. 3. The bathroom is an appropriate place to release gas.	**Vegetables:** • Beans: kidney, lima, and navy • Broccoli • Brussels sprouts • Cabbage • Cauliflower • Corn • Cucumbers • Kohlrabi • Leeks • Lentils • Onions • Peas: split and black-eyed • Peppers • Pimientos • Radishes • Rutabagas • Sauerkraut • Scallions • Shallots • Soybeans • Turnips **Fruits**: • Apples (raw) • Avocados • Cantaloupe • Melons: watermelon and honeydew

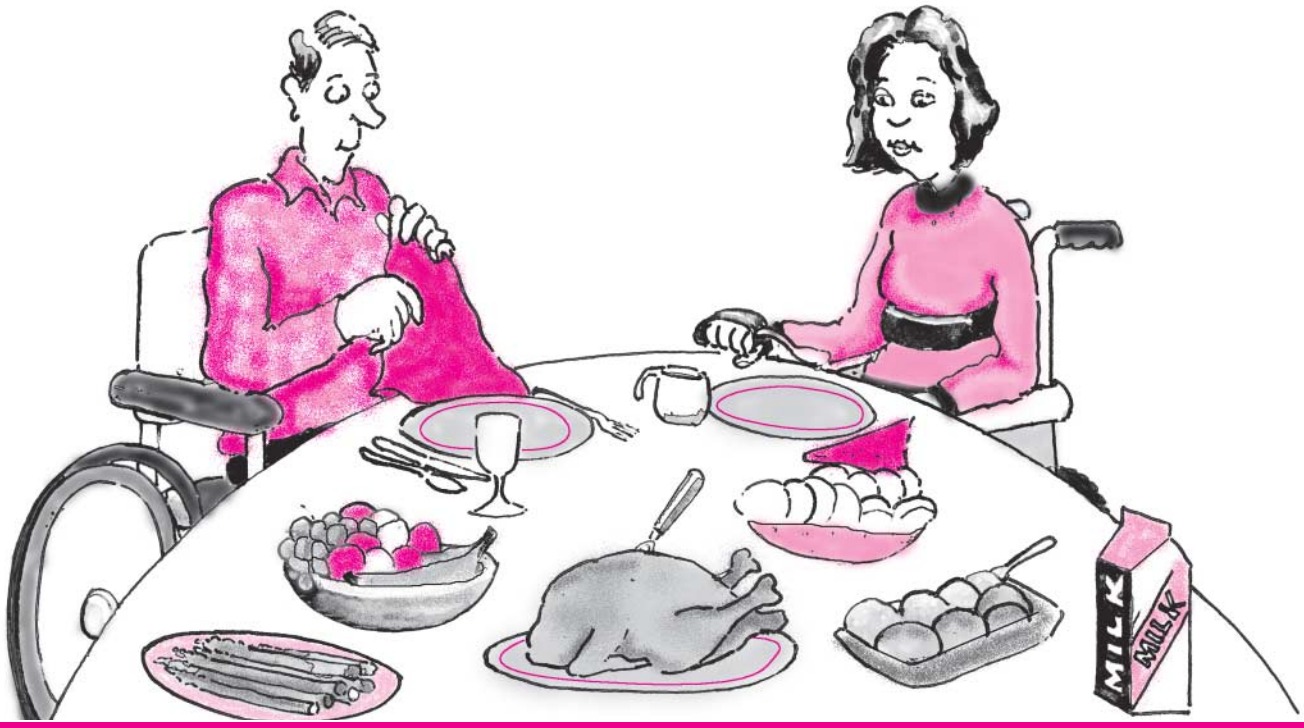
Table 2 was adapted from Yes You Can! A Guide to Self-care for Persons with Spinal Cord Injury *(Second edition). Paralyzed Veterans of America, 1993.*

How Much Should I Drink Every Day?

You need to drink plenty of fluids every day to keep your stool soft and to prevent constipation. Drinking enough is especially important if you're trying to eat more fiber. A good guideline is 64 ounces every day (drinks with alcohol or caffeine don't count). If you exercise a lot or the weather is hot, drink more.

Some people may need to limit how much they drink because of their bladder program. If that's true for you, talk with your health-care professional about a good daily fluid goal that will work for both your bladder program and your bowel program.

Important:
If you enjoy drinks like coffee, tea, cocoa, or soft drinks, there's something you should know. All these drinks contain caffeine, and caffeine is a diuretic. That means it may suck the fluid out of your body. In fact, diuretics can cause you to lose even more fluid than you drink. Caffeine is also a stimulant. For these reasons, you may want to consider keeping caffeine drinks to a minimum.



What Medications Are Used in Bowel Programs?

Like the foods you eat, the medications you take can affect your bowel activity. Some can help your body pass stool regularly. Others can make regular bowel movements difficult. Table 3 lists the different types of bowel medications and examples of each and describes what they do. For most people, the goal is to have a successful bowel program without medications or with the fewest medications possible.

Before taking any of the products in Table 3 regularly, discuss them with your health-care professional to learn how to use them safely for the best results.

Tips for Safe Bowel Care

To prevent falls and pressure ulcers, follow these tips for the safe use of equipment during bowel care. Don't hesitate to ask your health-care professional to show you how to use assistive devices and stimulant medications correctly.

Toilets and Commode Chairs

- Use seats carefully to avoid skin problems. If you can, consult an occupational therapist before you buy such equipment.
- Make sure that seats and chairs are padded; seams shouldn't touch your skin.
- Don't use a chair that has cracked or broken vinyl; it can hurt your skin.
- Keep correct posture the whole time you're on a toilet or commode seat.
- Keep your weight evenly balanced over the seat.
- Do pressure releases every 15 minutes to prevent skin problems. That means lifting yourself off the seat and shifting your position to keep from putting pressure on the same skin area too long.
- Be careful not to forcibly separate your buttocks or squeeze them together when you're sitting.
- Check your skin after using your bowel care equipment. Report any changes to your health-care professional.

TABLE 3

Bowel Medications

ORAL LAXATIVE MEDICATIONS

Stimulants

Increase the wave-like action of peristalsis to move stool through the bowel faster and keep it soft.

- bisacodyl
- cascara
- castor oil
- senna

Osmotic laxatives

Increase stool bulk by pulling water into the colon. If you take these medications, you need to drink extra fluids.

- lactulose
- magnesium citrate
- magnesium hydroxide
- magnesium sulfate
- sodium biphosphate
- sodium phosphate

Bulk-forming laxatives

Add bulk to stool. If you take these natural vegetable fiber medications, you need to drink extra fluids.

- hydrophilic muciloid
- methylcellulose
- psyllium

Stool softeners

Help stool retain fluid, stay soft, and slide through the colon.

- docusate calcium (Doss)
- docusate potassium
- docusate sodium
- mineral oil

Prokinetic agents

Stimulate bowel peristalsis.

- cisapride
- metoclopramide

RECTAL STIMULANTS

Suppositories

bisacodyl	Increases colon activity by stimulating the nerves in the lining of the rectum.
CO_2	Produces carbon dioxide gas in the rectum, which inflates the colon and stimulates peristalsis.
glycerin	Stimulates peristalsis in the colon and lubricates the rectum to help pass stool.

Enemas

mineral oil	Lubricates the intestine.
mini-enema	Stimulates the rectal lining and softens stool.

To prevent falls, be especially careful when you're:

- Transferring to and from a toilet or commode chair.
- Doing forward or sideways bending.
- Bending to insert stimulant medication, do digital rectal stimulation, or remove stool.
- Reaching for supplies.

Safety Straps

- Chest straps help people who have poor or no chest balance.
- Lap or waist straps help people who have spasms or tire easily.

Stimulant Medications

- Use plenty of water-based lubrication. Oil-based products, such as petroleum jelly, can prevent stimulant medications from working.
- Insert suppositories using lubrication, gently and correctly.
- Punch a hole in mini-enemas with a pin. Cutting them with a knife creates a sharp edge that can slice or scrape your skin.

How Often Should My Bowel Program Be Reviewed?

Your bowel program should be reviewed at least once a year to make sure that it's working well for you. Your Bowel Care Record is a key part of this review. Keep your completed Bowel Care Records in a notebook, folder, or other handy place and take them with you when you visit your health-care professional. Ask your health-care professional how long you should record your bowel care results.

Maintaining Bowel Care Equipment

If you use a commode chair or padded toilet seat, avoid unpleasant surprises. It's a good idea to record the date you get your equipment; cushions and pads tend to wear out in about 18 months. Inspect all your bathroom equipment every month:

- Check screws and other hardware for loose or missing pieces.
- Lubricate axles to prevent rust.
- Check for cracks or splits in vinyl covering. If cracks develop, ask a member of your rehabilitation team to inspect the equipment to consider replacement or repair.

Important:
If you're having constipation or other bowel problems (see Table 4 on page 31, Frequent Bowel Accidents: Possible Causes and Solutions), don't wait for your annual bowel program review. Call your health-care professional to discuss the problem and what you can do about it.

What Should I Do if My Bowel Program Isn't Working?

If there is a problem, you have to get to the bottom of it immediately. If you're having bad reactions with your bowel program, call and work with your health-care professional right away. Bad reactions include:

- Fainting or loss of consciousness.
- Symptoms of autonomic dysreflexia, like a pounding headache during bowel care. (For more information about autonomic dysreflexia, see the glossary and the guide called *Autonomic Dysreflexia: What You Should Know*. For a free copy, call (888) 860-7244 or visit the PVA web site at http://www.pva.org.)
- Blood in your stool, on your rectum, or on your clothes.
- Any sudden change in the color of your stool—if it becomes lighter, red, or black.

You may be able to take care of other problems yourself. The most common bowel problems after SCI are:

- Repeated bowel accidents.
- Delayed results from bowel care.

- Check for water-logged or soggy cushions or padded seats. Pushing on the cushion or seat can squeeze out extra water.
- Watch for worn-out cushions and padded seats. If they stay flattened after you get off, they're probably worn out.
- Replace worn, frayed safety straps and broken buckles.

- Prolonged bowel care (lasts more than 1 hour).
- Constipation.
- Inadequate or no stool results after two bowel care sessions.
- Diarrhea.
- Hemorrhoids.
- Too much gas or a bloated feeling.

Table 4 lists possible causes of and solutions to frequent bowel accidents (more than once a week). Table 5 on pages 32-33 describes other problems, their possible causes, and solutions. For many people with SCI, gas is a cause of embarrassment in public and private situations. Table 2 on page 24 provides information about excessive gas.

If you visit your health-care professional to discuss changing your bowel program, bring your Bowel Care Record with you. Be ready to discuss anything that might have changed in your bowel program. Even one change in what you usually eat or drink, for example, can affect how your program works for you. Figuring out what's changed and switching back to your previous habits may correct the problem.

If that doesn't work, or if there's a good reason for you not to return to your previous routines, your health-care professional will help you modify your bowel program. **It's important for you to change only one of the following components of your bowel program at a time**:

- Diet.
- Fluids.
- Activity.
- Bowel care schedule.
- Position during bowel care.
- Rectal stimulant medications.
- Mechanical stimulation.
- Assistive techniques for bowel care.
- Oral medications.

With this approach, you can see which changes improve your results.

TABLE 4

Frequent Bowel Accidents: Possible Causes and Solutions

NOTE: When changing your bowel program, change only ONE COMPONENT at a time, such as frequency of bowel care, time of bowel care, or diet, so that each change can be fully evaluated.

POSSIBLE CAUSE	*SOLUTIONS*
Stools are too soft and are oozing out.	If you are taking stool softeners, cut down on quantity and/or frequency or stop taking them altogether. Look at your diet to: (1) make sure you're eating enough high fiber foods, and (2) check for too many foods that can soften stools (such as spicy or greasy food).
You are eating more food than you did before.	Try doing your bowel care routine more often. For example, if your bowel care schedule is every other day, you may need to do it every day.
Overuse of laxative medications to help food move through your stomach and bowel (peristalsis).	If you are more active than you used to be or if you are eating more fiber, you may not need bowel medications anymore. Cut down on the number of laxatives you take each day until you have: (1) stopped having accidents, or (2) stopped taking the laxatives.
Bowel care sessions are not emptying your bowel well enough.	Consider: (1) taking an oral laxative medication to help move food through your digestive system, (2) using a stronger rectal stimulant and more frequent digital stimulation, and (3) discussing the problem with your health-care professional.

Information in table 4 was adapted in part from Educational Guide for Individuals and Families Following SCI. *Rehabilitation Institute of Chicago, 1995.*

Checking for Colorectal Cancer

SCI may make it more difficult to spot symptoms of colorectal cancer. That's why your health-care professional may want to do tests for this condition, especially if you're 50 or older and have (1) a positive test for unseen blood in the stool (fecal occult blood test) or (2) a change in the way your bowel works that doesn't improve after treatment.

Ask your doctor to help you follow current recommendations about checking for colorectal cancer. If you're 40 or older, it's recommended that you have a rectal exam and fecal occult blood test every year. Other tests may include using a special flexible scope to view the inside of the colon.

TABLE 5

Common Bowel Problems: Solutions and Possible Causes

Note: When changing your bowel program, change only ONE COMPONENT at a time so that each change can be fully evaluated.

PROBLEMS	SOLUTIONS	POSSIBLE CAUSES
Delayed Results Bowel movements start 1-6 hours after you begin your bowel care.	If you are not already doing digital stimulation, start; if you are already doing it, try to do it more often. If you can, sit up on the toilet or commode for bowel care techniques. Consider taking an oral laxative 6-8 hours before starting bowel care (talk with your health-care professional first). Try eating more fiber and drinking more liquids. Consider using a strong rectal stimulant medication: (a) if you are using a glycerin suppository, try a bisacodyl suppository or enema, and (b) if you are using a bisacodyl suppository, try a stimulant mini-enema, or a polyethyene glycol-based bisacodyl suppository.	Stool is too dry. Stimulant is too weak or you're not using enough. Medications such as narcotics, iron, aluminum hydroxide. Not enough fiber in diet. Inadequate rectal stimulation. Performing bowel care in a lying position. Digested food moving too slowly through the GI tract.
Constipation or hard stools Less than normal amounts of stool for at least 3 days (and it's usually hard); small or no bowel movements for 24 hours or 2 or more bowel care routines. May cause rectal bleeding that you can see as bright red blood on your stool, toilet paper, or glove. *If you get constipated every few weeks, you may need to change your bowel program.* **IMPORTANT**: If you are constipated **and** you have (1) abdominal pain, (2) autonomic dysreflexia* that doesn't go away after stool is removed from your rectum, or (3) sudden swelling in your abdomen, **call your health-care professional right away!**	Do a rectal check. —If you feel stool: (a) remove it **gently** with a gloved and well-lubricated finger, using an anesthetic cream or jelly, and (b) do your regular bowel care (suppository or mini-enema). —If you do not feel stool: (a) take a laxative or take more of the one you've already taken, and (b) wait 6-8 hours and do your regular bowel care (suppository or mini-enema). Increase the frequency of your bowel care to daily until normal volumes of stool results return. If the above steps do not produce a bowel movement, call your health-care professional. Suggestions may include taking a product to add bulk to your stool or a laxative at least 8 hours before you do your bowel care routine.	Not following a regular bowel program. Incomplete passing of stool. Not enough fiber in diet. Bed-rest or not much physical activity. Medications such as narcotics, iron, aluminum hydroxide.

**Autonomic dysreflexia* *is a life-threatening condition. For more information, please refer to the consumer guide* Autonomic Dysreflexia: What You Should Know, *August 1997, Consortium for Spinal Cord Medicine. To order your free copy, call toll-free (888) 860-7244 or visit the PVA web site at http://www.pva.org.*

PROBLEMS	SOLUTIONS	POSSIBLE CAUSES
Fecal Impaction See **Constipation**, but usually happens over a longer period of time. You also may have small amounts of liquid or watery stools.	Start with the first step, and try others ONLY if previous steps do not help: Do a rectal check; if you feel stool, remove it **gently** with a gloved and lubricated finger. Use an anesthetic cream or jelly. Drink 1 ounce of mineral oil to make the stool easier to eliminate. Take 1 or 2 tablets of senna or bisacodyl (bisacodyl is stronger) to help move the stool down into your rectum. Wait 6-8 hours and do your bowel care routine. If the above steps do not produce a bowel movement, call your health-care professional.	Not following a regular bowel program. Incomplete passing of stool. Not enough fiber in diet. Bed-rest or not much physical activity. Medications such as narcotics, iron, aluminum hydroxide.
Diarrhea Loose watery stools, usually 3 or more times a day. **IMPORTANT**: **Call your health-care professional right away** if you have any of the following: (1) abdominal pain, (2) dehydration (dry or chapped mouth or lips, a lot less urine than usual, or dark urine with a strong smell), or (3) diarrhea that lasts 3 or more days.	Stop taking any bowel medications. After the diarrhea stops, you may start taking them again slowly. Stay away from foods that can irritate your bowel (such as spicy, fried, and greasy foods). Eat foods that help make your stools hard (such as yogurt with fruit, whole grain breads and cereals, rice, and bananas). Drink plenty of water, estimating what you are losing with the loose stools and replacing it. Make sure it is not a fecal impaction. If you do have an impaction, your diarrhea may be very watery. If you are taking antibiotics, try eating yogurt every day. If you have diarrhea anyway, don't stop taking the antibiotics but do call your health-care professional.	Spicy or greasy foods. Drinks with caffeine (coffee, tea, cocoa, many soft drinks). Overuse of laxatives and bowel softeners. Severe constipation or impaction. Viral infection, flu, or intestinal infection. Stress. Antibiotics.
Hemorrhoids The first signs may be bright red blood on your clothes, glove, or toilet paper after a bowel movement. You may also see or feel bulging areas outside your rectum. **IMPORTANT**: Hemorrhoids are the most common problem in bowel programs. You can help prevent them by preventing constipation. Keep your stools soft but formed.	After each bowel movement, use a cream or suppository made for hemorrhoids as recommended by your health-care professional. If you have active hemorrhoids (bleeding, swelling, pain): (a) try to avoid or minimize digital stimulation and manual removal until the tissue heals, or (b) increase the amount of stool softener or take them more often. Use more lubricant.	Persistence of hard stools. Rectal straining. Too vigorous digital stimulation or manual evacuation. Suppositories, enemas, and digital stimulation can irritate and worsen hemorrhoids.

Information in table 5 was adapted in part from Educational Guide for Individuals and Families Following SCI. *Rehabilitation Institute of Chicago, 1995.*

Answers to Commonly Asked Questions

Q: What should I do if I have a bowel accident at school, work, or a movie?

If you have an accident, don't just sit there! If you can, leave wherever you are and find a bathroom. Here are three good reasons for you to deal promptly with the situation:

- Blocking stool flow can cause autonomic dysreflexia.
- Allowing your skin to be in contact with stool too long can cause skin problems.
- Putting others at ease and calmly doing what you have to do can help everyone get past the awkwardness. Accidents can be touchy situations, not just for you but for other people.

A regular bowel program can help you take charge of your bowel function and cut down on accidents. But accidents do happen; be prepared. Many people keep a change of clothes with them in a gym bag or overnight bag, just in case. The bag might contain some toilet paper, moist wipes, exam gloves, a diaper, clean underwear, loose-fitting pants, a water proof pad, and a plastic bag for storage of soiled clothes. Some people use disposable undergarments when they know they might be away from a bathroom for a long time.

When you have to talk about bowel management, it may help you and others if you are calm and matter of fact. As you learn to live with SCI, it'll become easier to discuss uncomfortable subjects like bowel functions and habits with your family and friends, attendants, and health-care professionals.

Preventing Bowel Problems

The best things you can do to prevent bowel problems are to:

- Stick with your bowel program. If you're having trouble following any part of your program, call your health-care professional. Together, you should be able to adapt your program to your life demands, privacy needs, and tolerance for various treatments.
- Pay attention to your body, your stool, and your bowel care routine. You know yourself best; you'll be the first to notice changes that may be important.
- If you need to change any aspect of your bowel program, change only one component at a time. And give yourself plenty of time to decide if the change has helped. A good rule is to

Q: What should I do if I pass a lot of gas? Passing gas in public is embarrassing, especially if it smells.

Have a frank talk with your health-care professional. You might be referred to a dietitian in case the gas and odor are related to foods you're eating. Think back to what you'd have done before the SCI. Whatever you do, don't try too hard to hold in the gas. That can give you a stomachache or headache.

And remember: Passing gas means your digestive system is working right. *It was OK to pass gas before your SCI; it's still OK to pass gas now*.

Passing gas and odor are just as embarrassing now as they were before the SCI. With or without SCI, most people aren't comfortable with their bodily functions.

Some gas smells bad, and some gas doesn't. Your gas will probably smell bad after you eat food that's high in protein, such as meat, fish, or eggs. If you eat a vegetarian diet, your gas probably won't smell so bad, but you'll have a lot of it. Increasing the frequency of bowel care may reduce the amount of stool you store in your colon to produce gas.

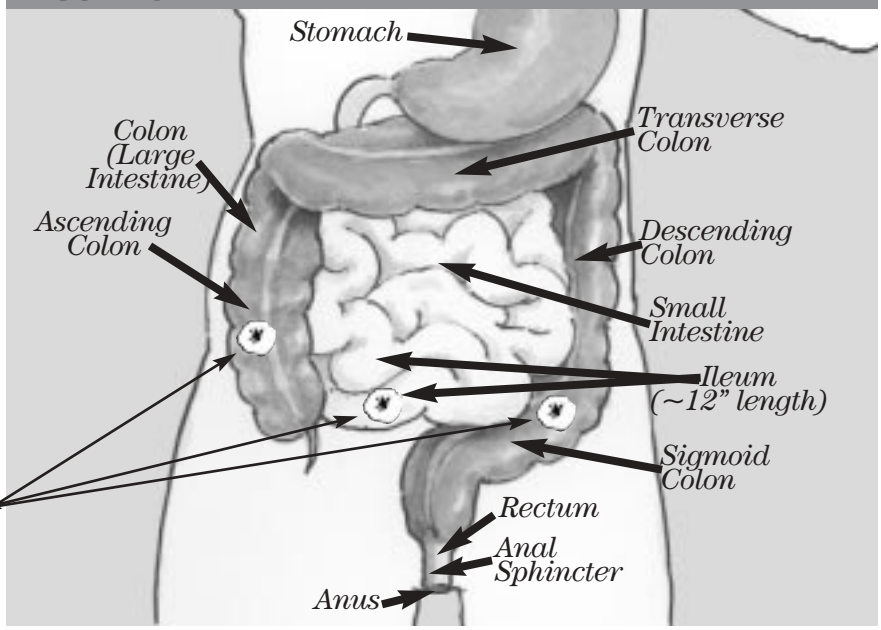
What did you do about gas odor before the SCI? Ventilation is a good idea; fans and open windows help. Some people keep room deodorizers or air fresheners in their office, home, and bathroom.

allow 1 week or 3 to 5 bowel care cycles before you make more changes.

- If you're having problems keeping a healthy weight (you're gaining or losing too much), talk to your health-care professional. Information about diet and exercise and an evaluation may be helpful.
- Get a checkup at least once a year. Bring a completed copy of the Bowel Care Record at the back of this Guide, and review it with your health-care professional.

These steps can't prevent all bowel problems related to SCI. If the tips in Tables 2, 4, and 5 don't help, talk with your health-care professional.

FIGURE 5



Stoma—always moist and red

What Should I Know About Surgical Options?

One common surgical procedure creates a new opening (called a *stoma*) on the abdomen where stool can be pushed into an attached, disposable bag. This surgery is called *colostomy* or *ileostomy*, depending on where the opening is made. The choice between a colostomy or an ileostomy should depend upon the results of studies examining how your stool moves through your colon and consultations with your health-care professionals. The site on your abdomen for the stoma placement should maximize both your functional independence and your body image (see Figure 5).

An important goal of this type of surgery is to improve your quality of life by:

- Making you more independent in bowel care.
- Reducing the time and effort bowel care requires.
- Preventing bowel accidents.

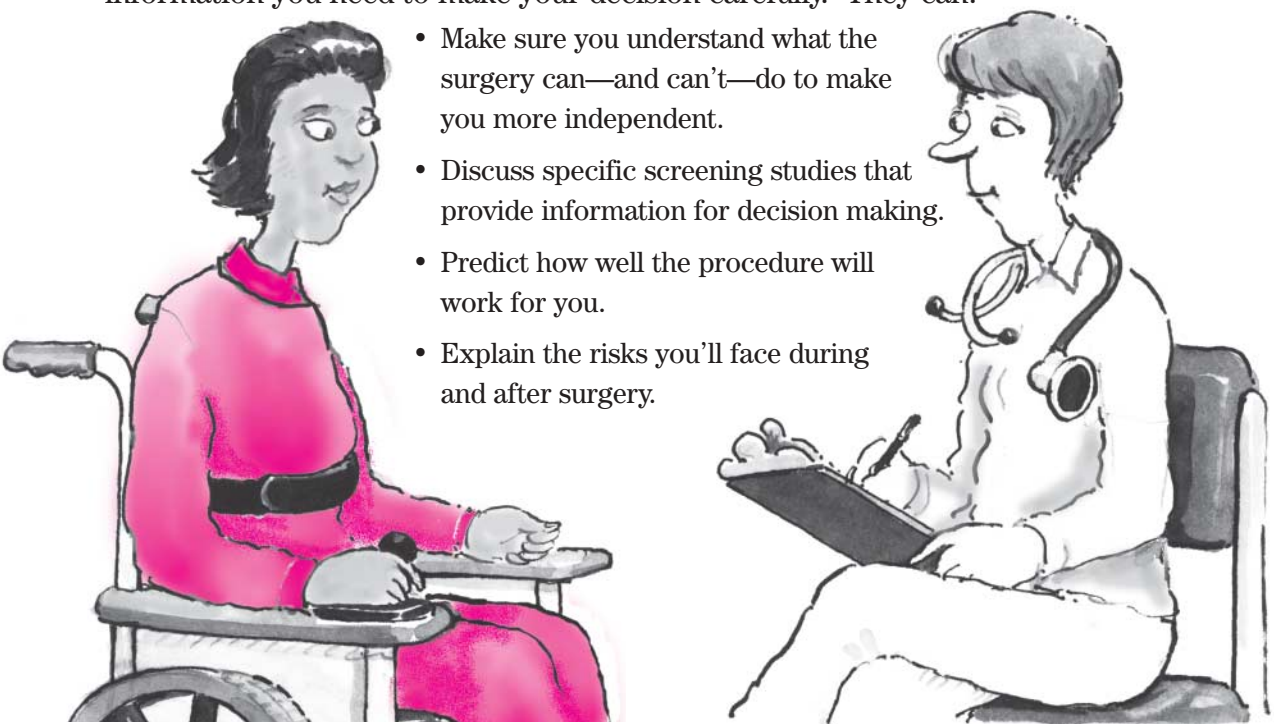
People consider surgery for many reasons, including some or all of the following:

- BM accidents or leaking of stool.
- Recurring pressure ulcers.

- Persistent pelvic or rectal infections.
- Safety issues (transferring accidents).
- Skin problems from a toilet or commode seat.
- Bleeding hemorrhoids.
- Sweating.
- Nausea.
- Anorexia.
- Fatigue.
- Effects of aging.
- Abdominal pains.
- Too much time spent on bowel care.

Surgery is a serious matter. **Before deciding if it's the right choice for you, you need to consider all other medical therapies thoroughly**. If they don't work, discuss surgical options with members of your rehabilitation team: your primary care practitioner, psychologist, occupational therapist, rehabilitation nurse, family members, and other people who are important in your life. Different team members can give you the information you need to make your decision carefully. They can:

- Make sure you understand what the surgery can—and can't—do to make you more independent.
- Discuss specific screening studies that provide information for decision making.
- Predict how well the procedure will work for you.
- Explain the risks you'll face during and after surgery.



If you're considering surgery, team members may suggest a conference to discuss important issues. These include how to take care of the opening, use of bags and other equipment, and where on your abdomen the opening should be. Things you need to consider in choosing a stoma site:

- Your preference (where you want it to be, and why).
- Your body image (how your clothes will fit and how you'll feel about the way you look).
- Independence in bowel care (how easy it is to reach and care for).

This type of surgery is intended to produce permanent changes in how the colon empties. It can be reversed, but only in some circumstances. If you aren't happy with the results, you may be able to go back to your previous bowel care routine. **Even though you can change your mind, reversing the procedure requires more surgery**. That's why you should ask as many questions as you need, to feel comfortable with your choice before anything is done.

Even though surgery is seldom required, the decision should include careful consideration of all alternatives. There are a variety of surgical options available to improve management of the neurogenic bowel. Evaluation of options should include contact with a spinal cord center and, if possible, discussion of the outcome with someone who has had the procedure.

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Bridget

I'm 24. Three years ago I had a spinal cord injury at C6. They sent me home from the hospital too fast. I didn't have time to learn much about bowel care and neither did Mom, who had to do all my attendant care. I wouldn't do pressure releases in public because I was afraid of having an accident or passing gas. It got so I was afraid to leave the house. My bowel program was a mess, and I was embarrassed and worried all the time.

Fortunately, I started working with a home health nurse who really cared and understood my fears and my dreams. She helped my mom and me train an attendant to help me with bowel care. Having that taken care of gave me enough confidence to move out of my parents' house. Now I live in a dormitory at school and "have a life!"

Having the right information and **sharing it** with family and significant others **can improve understanding** about embarrassing matters.

Regular bowel care really cut down on all the gas I was passing, I have more confidence in myself, and feel comfortable doing pressure releases in public.

At first I was afraid to tell my boyfriend the details of my bowel care needs and what could happen. As it turns out, he finds how I overcome problems very interesting. Our relationship has grown, and we've been physically close often. It helps that we talk about it.

A successful bowel program has made a big difference in my quality of life. It's not foolproof, but I have the assurance that others will understand if there are problems.

Glossary

anal sphincter—A circular band of muscle that keeps the colon closed, like a drawstring on a purse.

areflexic bowel—A pattern of bowel dysfunction caused by injury to the nerves that travel from the spinal cord to the bowel. No reflex bowel processes are possible. Also called flaccid bowel or lower motor-neuron (LMN) bowel. A person with this condition can't feel the need to have a bowel movement, the rectum doesn't empty by an automatic reflex action, and the anal sphincter doesn't close as tightly as it did to keep stool in.

assistive device—Any device that increases the independence of a person with a disability. An example is a digital stimulator, which helps a person with limited hand function to be more independent with bowel care. Also called adaptive device.

assistive technique—Any movement that increases the speed of bowel care or the amount of stool produced. Includes *digital rectal stimulation*, abdominal massage, *manual evacuation*, forward and sideways bending, and push-ups.

attendant—See *personal care attendant*.

autonomic dysreflexia—An abnormal response to a problem in the body below a spinal cord injury that causes high blood pressure. It's most likely to happen if the SCI is at or above the 6th thoracic vertebra (T6). See *Autonomic Dysreflexia: What You Should Know*, a free guide you can get by calling (888) 860-7244 or visiting the PVA web site at http://www.pva.org.

bowel—The intestines, tube-like structures that propel and store food (small intestine) and waste (large intestine).

bowel care—The process of triggering and assisting a bowel movement. Bowel care is part of a *bowel program*. Bowel care can include any or all of the following steps: getting ready, *positioning*, checking for stool, inserting *stimulant medications*, performing *digital rectal stimulation* or *manual evacuation*, recognizing when done, and cleaning up.

bowel program—A total treatment plan designed to prevent or cut down on bowel accidents (unplanned bowel movements), to eliminate stool at a regular and predictable time through *bowel care*, and to keep bowel-related health and other problems to a minimum. The components of a bowel program are diet and fluid, activity level, medications, and a consistent routine schedule for *bowel care* (including *rectal stimulation*).

colitis—Inflammation of the colon.

colostomy—A surgical opening from the intestine through the abdominal wall that allows stool to be pushed out into an attached, disposable bag. This opening is built by disconnecting the colon from the rectum and connecting it to the abdominal wall.

constipation—A condition in which stool does not pass as often, as fast, or as completely, and it's hard and dry.

defecation—Elimination of fecal matter from the bowel through the anus; bowel movement.

digestive system—The mouth, esophagus, stomach, small intestine, colon (or large intestine), *rectum*, and anus. Also called the *gastrointestinal tract*, GI tract, or gut (see *bowel*).

digital rectal stimulation—The process of inserting a gloved, well-lubricated finger into the *rectum* and moving the finger in a circular funnel-shaped pattern, keeping contact with the rectal wall. This technique helps trigger *peristalsis* in people with *reflexic bowel* and helps remove stool from people with *areflexic bowel*.

gastrointestinal tract—See *digestive system*.

ileostomy—A surgical opening from the ileum (the end of the small intestine) through the abdominal wall that allows liquid stool to be pushed into an attached, disposable bag. This opening is built by disconnecting the ileum from the colon and connecting it to the abdominal wall.

impaction—A collection of hard stool located within a segment of the colon that is obstructing peristalic stool movement.

incontinence—Involuntary passage of stool or urine. Also called an accident.

inflammatory bowel disease—A chronic condition associated with abdominal cramping, frequent stools, and diarrhea.

irritable bowel syndrome—A condition associated with colon cramping and alternating *constipation* and diarrhea.

lactose intolerance—Sensitivity to lactose, a sugar in dairy products. People with this condition can't digest lactose properly and may experience abdominal discomfort ranging from gas and bloated feelings to pain and diarrhea.

laxatives—Medications and substances found in certain foods or herbs that stimulate bowel movements.

lower motor-neuron bowel—See *areflexic bowel*.

manual evacuation—Use of one or two gloved and lubricated fingers to break up or hook stool and remove it from the *rectum*. This is the standard way to empty the *rectum* for people with *areflexic bowel*. People with *reflexic bowel* also use it sometimes to remove stool before they insert a rectal stimulant medication.

mechanical stimulation—Use of the fingers or other mechanical device (such as a digital stimulator) to remove stool from the *rectum*. *Manual evacuation* and *digital rectal stimulation* are two methods used by people with SCI to empty the *rectum*.

mini-enema—Medication in a small amount of liquid (usually 1 ounce or less) that's injected into the *rectum* to stimulate a bowel movement. Also called a liquid *suppository*.

neurogenic bowel—A medical condition caused by an injury to the spinal cord that damages the nervous system's control of the colon and interferes with the body's natural process for storing and eliminating solid wastes. There are two patterns of neurogenic bowel: *reflexic* and *areflexic*.

peristalsis—A wave-like action of the muscular gut wall that moves food through the gastrointestinal tract.

personal care attendant—A person—such as a family member, friend, or hired helper—who assists with personal care or household tasks on a routine basis.

positioning—Putting a person with SCI into a posture for skin protection, comfort, and efficiency of bowel care. A cushioned commode chair or padded toilet seat helps empty the lower bowel by taking advantage of the effects of gravity. Lying on the left side (for people who can't sit up) takes advantage of gravity in moving waste through the transverse colon.

range of motion—An arc of movement of a joint of your body.

rectal stimulation—Treatment of the *rectum* to encourage elimination of stool. There are two types of rectal stimulation: *digital rectal stimulation* is a manual or mechanical technique, and use of rectal *stimulant medications* in a *suppository* or *mini-enema* form is a chemical technique.

rectum—the last segment of the colon that ends just inside the anus.

reflex—An automatic (requiring no conscious thought) response coordinated by connections between nerves. An example is an increase in *peristalsis* in the colon caused by *digital rectal stimulation*.

Douglas

This spinal cord injury is old news for me. I was on patrol near Da Nang, Vietnam, when I was wounded in action. It's hard to believe I've been living with a T5 SCI for more than 30 years now. Those first couple of years were rough, but little by little, I was able to get my life back on track.

The VA's SCI system has been great to me and my family. I don't know what I'd have done over the years if these services weren't available. During rehab at the VA hospital in Sunnydale, California, I adopted a bowel care routine that worked well for 27 years.

Aging can bring on **changes** in an individual's bowel care program **that must be identified** and thoughtfully resolved.

There was one phase in my life when I did have a lot of accidents. I was drinking my share of beer and had a lot of fun. Even though I had bowel accidents on a regular basis after I drank, it took me a long time to make the connection between the accidents and the beer. I'm not saying that beer is responsible for all accidents, but if you're having a similar problem, you may want to consider that drinking beer and other alcohol may be a cause.

My biggest problem came about 3 years ago when my body seemed to be going through some changes. Bowel care was like mission impossible every time. So I called the VA SCI center near my home and scheduled an appointment. VA's SCI staff are really professional and know their stuff. In a short time we worked out some new procedures for my routine, and I've been on the go ever since.

reflexic bowel—A pattern of neurogenic bowel dysfunction that affects storage and elimination of stool that results from an injury to the spinal cord in the cervical (neck) or thoracic (chest) area. Also called spastic bowel and upper motor-neuron (UMN) bowel. A person with this condition may or may not be able to feel the need to have a bowel movement. In either case, the *rectum* will still empty by an automatic reflex action, the same as it did before the SCI.

spastic bowel—see *reflexic bowel*.

stimulant medications—Substances given rectally as a *suppository* or *mini-enema*.

stoma—An opening on the abdomen created by surgery for removal of stool.

suppository—A solid form of medication (usually small and bullet-shaped) that's inserted in the *rectum* to stimulate a bowel movement.

upper motor-neuron bowel—see *reflexic bowel*.

Valsalva maneuver—Breathing in and trying to push air out while at the same time blocking the air in your throat to increase the pressure in your abdomen. For people with *areflexic bowel*, gentle Valsalva maneuvers can help push stool out.

Food Record

For about a month, write down what you eat and drink each day and describe your bowel movements.

Food Category	DESCRIPTION AND QUANTITY FOR EACH MEAL CATEGORY				Successful Bowel Care?
	Breakfast	Lunch	Dinner	Snacks	
MONDAY					
Starch					
Vegetables					
Fruits					
Milk					
Meat					
Fat					
TUESDAY					
Starch					
Vegetables					
Fruits					
Milk					
Meat					
Fat					
WEDNESDAY					
Starch					
Vegetables					
Fruits					
Milk					
Meat					
Fat					

THURSDAY					
Starch					
Vegetables					
Fruits					
Milk					
Meat					
Fat					
FRIDAY					
Starch					
Vegetables					
Fruits					
Milk					
Meat					
Fat					
SATURDAY					
Starch					
Vegetables					
Fruits					
Milk					
Meat					
Fat					
SUNDAY					
Starch					
Vegetables					
Fruits					
Milk					
Meat					
Fat					

Medical History

Complete the following. Share this information with your health-care professionals.

Name: _____

Date of Birth: _____ Sex: M or F

Date of Spinal Cord Injury: _____

Neurologic location of injury: ☐ Complete_____ ☐ Incomplete_____

Description of bowel function before spinal cord injury (include usual frequency, time of day, problems such as constipation, hemorrhoids, etc.):_____

_____

_____

_____

Sensation around the anus? ☐ Yes ☐ No

Sensation of stool in the rectum? ☐ Yes ☐ No

Ability to contract the anal sphincter? ☐ Yes ☐ No

Reflexic or areflexic bowel? _____

Allergies?_____

Poorly tolerated foods? _____

Oral medications? ☐ Yes ☐ No

If yes, please complete the following section.

List medications taken regularly: _____

List medications taken as needed: _____

Rectal stimulants? _____

EMERGENCY INFORMATION

In case of emergency, call: _____

Relationship: _____ Phone number: ( ) _____

INSURANCE INFORMATION

Name of insurance company: _____

Identification number: _____

Group number: _____ Phone number: ( ) _____

Bowel Care Record

Every time you do bowel care, write down:

- **Date**.
- **Start time**. The hour and minute you start stimulation or try to start a bowel movement.
- **Position**. Left side lying, right side lying, sitting.
- **Stimulation method**. Stimulant medication, digital rectal stimulation, or other technique you use to start a bowel movement.
- **Assistive techniques**. Methods used to promote bowel emptying and the number of times used during bowel care, e.g., abdominal massage, bending, push-ups, Valsalva maneuver.
- **Times of results**. The time when the first stool begins to come out of the anus and the time when the last stool comes out.
- **Stool amount, consistency, and color**. Amount: if stool were formed into a ball—golfball, tennis ball, softball. Consistency: hard, firm, soft, liquid. Color: especially anything unusual for you.
- **Comments**. Problems such as any unplanned bowel movements, abdominal cramps, pain, muscle spasms, pressure ulcers, hemorrhoids, or bleeding.

Date	*Start Time*	*Position*	*Stimulation Method*	*Assistive Techniques*	*Time of Results First/Last*	*Stool Amount, Consistency, Color*	*Comments*

continued on back

Date	Start Time	Position	Stimulation Method	Assistive Techniques	Time of Results First/Last	Stool Amount, Consistency, Color	Comments

Orville

It's been over a year since the parachute accident that left me a paraplegic at the T6 chest level. One of the biggest challenges I've had is bowel management. I wanted to be as independent as possible, so I worked closely with my rehab team to learn how to take care of bowel care myself. I follow my bowel program like a flight plan.

Knowing your own body and being prepared can allow you to **have an active full life** with lots of independence.

As a young, single, career guy, the last thing I want to worry about is an unplanned bowel movement. If accidents happen, I handle them myself because I live alone and really feel this is something I need to take care of.

Now for the challenge. I work for a major airline, and my job has me traveling all over the country. Staying in hotels makes my bowel program a little different from how I manage at home. While I try to keep the same schedule, access to a toilet and bathroom conditions often change. At home, things are pretty routine. But on the road, I never know what facilities I'll find at different hotels. Sometimes the bathroom accommodations just don't work for me and I'm forced to do my bowel care in bed using the side-lying technique. When I fly, I do my bowel care at least 6 hours before I need to be at the airport. I think it's important for people with SCI to know it's OK to use whatever method works best for them.

Things are going OK for me. I watch what I eat and drink and have a regular schedule for my bowel care. I carry a backup bag with a change of clothes, just in case. It's like my parachute; I hope I don't have to use it, but it's there when I need it. My life is on course.

Acknowledgments

The Consortium for Spinal Cord Medicine Clinical Practice Guidelines is composed of 18 organizations interested in spinal cord injury (SCI) care and treatment. The Consortium Steering Committee established a guideline development panel to make recommendations on the management and rehabilitation of neurogenic bowel dysfunction in individuals with SCI. The recommendations within this consumer guide are based on scientific research compiled from 1966 to 1997 and used in the Consortium's clinical practice guideline (CPG) *Neurogenic Bowel Management in Adults with Spinal Cord Injury*. The CPG development panel was assisted by an expert team from the University of North Carolina at Chapel Hill who reviewed the literature and determined the quality of the research. The Paralyzed Veterans of America (PVA) provided financial support and administrative resources for all aspects of guideline and consumer guide development.

The consumer panel was chaired by Steven A. Stiens, MD, MS, and consisted of five members with experience in the management and treatment of the neurogenic bowel in individuals with SCI. For many with SCI, bowel dysfunction is a major life-limiting problem. Creation of a consumer guide that addresses the problems of, and the solutions for, living with a neurogenic bowel required a diverse, experienced, and sensitive panel. The Consortium thanks all members of the consumer guide panel for providing the essential ingredients of knowledge, experience, empathy, and practicality.

The Consortium is also appreciative of the outstanding work of the entire PVA publications support team. In particular, the Consortium would like to recognize the professional writer Barbara Shapiro, the PVA senior editor Patricia E. Scully, DesignS by Sarah for the graphic design, and the illustrators who made our concepts of characters come alive as figures.

In the end, it is those with SCI who are living with and learning about neurogenic bowel who are the best evaluators of a teaching tool such as this consumer guide. The Consortium thanks the consumer focus group for their critical review and comments on the manuscript, including ***Frank W. Anderson***, ***Victoria Christensen***, ***Edward R. Jasper***, ***Joseph A. Kiren***, ***Patrick J. Marron***, ***Delatorro L. McNeal***, and ***Charles J. Sabatier, Jr.*** Their varied life experiences with SCI provided wise perspectives that refined and improved the consumer guide.

Finally, it is essential to recognize all investigators studying the effects of SCI on the digestive system. Research is the source of solutions; there is still much to be done in the future. Bowel dysfunction continues to be a fertile area for research!

The Consortium will continue to develop clinical practice guidelines and consumer guides on topics in spinal cord injury care. Look for consumer guides on other topics in spinal cord injury.

consortium for

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