

Secondary Conditions
Preventions & Treatment:
B Series---N0.5

Bowel Dysfunction

**The Research
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Center on
Independent
Living**



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Abstract: Bowel irregularities may develop in the course of spinal cord injury or any other neurological challenge. Many people with spinal cord injuries report that bowel and other gastrointestinal (digestive) complications have a major impact on their lives. For example, more than a third of people with paraplegia list bowel and bladder problems as the major functional losses associated with their injury.

Non-neurological causes of bowel dysfunction include activity, medications, diet, stimulants, stress, and injuries. A bowel management program takes into account the injury, level of physical ability, diet, techniques and a schedule for bowel emptying, beneficial medications and supplements, and physical environment.

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In his book entitled ‘Human Being,’ Christopher Morley defined a person as “an ingenious assembly of portable plumbing.” Clearly, we are more than this. However, the importance of our “plumbing” must not be underestimated, as any- one with a bowel condition knows very well.

Bowel function and dysfunction

For most people living independently with SCI, bowel problems rank far from number one as a cause of death or serious disease. However, many people say these problems rank first as sources of physical and emotional discomfort, need for personal assistance, and social embarrassment. This booklet will explore the most common causes of bowel complications and their symptoms, discuss preventive measures that may help avoid some problems, and present effective strategies for increasing physical and personal comfort. Common bowel-related problems include: constipation, impaction, diarrhea, incontinence, and hemorrhoids. Information about each of these conditions can be found in the “Problem-solving” section of this booklet.

Clearly, bowel function is not only a physical phenomenon, but also a social one. As children, we learn the importance of having control over when, where, and how we eliminate feces. We learn that part of growing up is having control over our bowels, and that the sight, smell, and sounds of our waste products are not socially acceptable. For these reasons, bowel problems can affect not only health, but social and sexual relationships. When bowel irregularities develop in the course of SCI or any other neurological challenge, it is normal to feel disturbed by this turn of events.

“It is one of the most difficult problems to explain to new [people in my life] who don’t know about people with disabilities. . . but it’s a part of me and my disability.”

On the other hand, the different stages of digestion are just a part of life, like any other bodily function, and need not inspire shame or embarrassment. For this reason, we will present the topic of bowel challenges and management in as straightforward a manner as possible.

A focus group of people with spinal cord injury and various disabilities gave feedback on an earlier version of this booklet. Many of them emphasized the importance of communicating with others who have similar challenges. They communicated about everything from overeating to choosing a brand of diapers. Because the topic of defecation is considered “taboo” in our society, often people don’t feel comfortable speaking about it. Yet, solutions can only be found when people talk openly about the challenges they face.

Remember, many people with spinal cord injuries and other neurological challenges have bowel dysfunction: You are not alone. Situations that can feel extremely embarrassing at first, like having an accident with other people around, may be less disturbing when you hear how other people have had the same experience and lived to tell the tale. You will find quotes from our focus group members throughout this booklet. We hope they encourage you, in turn, to share your own information and feelings with others.

While some bowel problems cause only occasional discomfort, others require daily care or are serious enough to require medical attention. Knowing the language spoken by health professionals can help consumers to understand their situation and to negotiate effectively for the kind of care they want. For this reason, we have included in this booklet many of the technical terms used by medical professionals. Some of these terms are defined in the text. Terms also appear in the glossary. You may find it useful to use this booklet as a resource before or during visits to health professionals.

Keep in mind that most people with SCI who develop bowel conditions find strategies that work well for them. There is no “best” or “only” way to deal with a bowel problem, since everyone’s situation is unique. Finding the best solution for you will probably require time, experimentation, and the willingness to communicate clearly about your needs and problems to health professionals and other people in your life who can be of assistance.

How common are bowel problems for people with SCI?

Many people with SCI report that bowel and other gastrointestinal (digestive) complications have a major impact on their lives. For example, more than a third of people with paraplegia list bowel and bladder problems as the major functional losses associated with their injury. In acute and long-term care settings, complaints about digestive problems are common. Various studies report that approximately 25-30 percent of people living independently say their digestive problems have altered their lifestyle and/or required medical intervention. The good news is that from two thirds to three fourths of people with SCI do NOT list bowel dysfunction as a significant problem in their lives. The bad news is that many people who have bowel complications do not openly speak about them, so it is likely that many more than 25-30 percent of people with SCI have bowel troubles that significantly affect their lives.

People with complete lesions and people whose injuries occurred more than five years ago seem the most likely to experience complications. As greater numbers of people survive spinal cord injuries and thrive into older age, chronic bowel dysfunction becomes increasingly common.

In order to understand what can go wrong with the bowel and why complications occur, it will help to know what the bowel is and how it normally functions.

What is the bowel?

Often the butt (pun intended) of humor, the bowel is actually a magnificent organ. Before discussing what can go wrong with it, let us first examine its importance and the many excellent functions it serves in the community of the body’s digestive organs.

The bowels have an interesting linguistic history. According to the American Heritage Dictionary of the English Language, the archaic meaning for bowels was “the seat of pity or the gentler emotions.” This is the definition undoubtedly used in Lamentations 2: 11: “My bowels are troubled.” The dictionary also states that the word “bowel” is derived from the Old French “boiel,” which in turn is derived from the Latin “botellus,” meaning “sausage.”

Anatomically speaking, the bowel is just another name for the intestines. In everyday language and in this booklet, it refers in particular to the large intestine, also called the colon.

Digestion and the bowel

To better understand the colon's important functions, let's follow the process of digestion from the time food enters the mouth to the emergence of a bowel movement. Figure 1 provides a visual representation of the digestive system and the functions of its major parts.

Eating dinner. Imagine you have just eaten your favorite dinner, whether it be steak and potatoes, or a tofu burger with a crisp salad. As soon as food enters your mouth, digestion begins. Chewing breaks the food down mechanically. Saliva contains a substance that begins to break down the carbohydrates (starches) found in your potatoes or burger bun

The stomach. As you swallow, your meal begins its descent into the approximately 15 feet of "tubing" that make up the digestive tract of a living person. It

first passes down your pharynx (throat) and esophagus, the tube that leads from your throat down to your stomach. The stomach stores some of your dinner. It dissolves and partially digests the rest. In the stomach, acids and other chemicals begin to break down the protein in your steak or tofu. However, they are unable to break down fats. They are also unable to break down the fiber contained in your salad. The walls of the stomach do not absorb many of the nutrients contained in your food. This will happen at the next step.

By the time your stomach has its way with your dinner, it no longer looks like the dinner you enjoyed. If you saw in its present state you might never have eaten it. It has become a substance called "chyme," which consists of tiny pieces of protein, fat, and polysaccharides (chains of sugars).

The small intestine. From your stomach, the remains of your dinner move down into your small

intestine. The small intestine is about nine feet in length and is divided into three sections called the duodenum, the jejunum, and the ileum. Inside the small intestine, food is broken down into its basic units. Substances produced by the pancreas and liver flow into this area to aid in digestion. The nutrition that comes from your food, along with water, vitamins, and minerals, is absorbed through the intestinal walls. Blood and lymph carries it to areas of the body that need it.

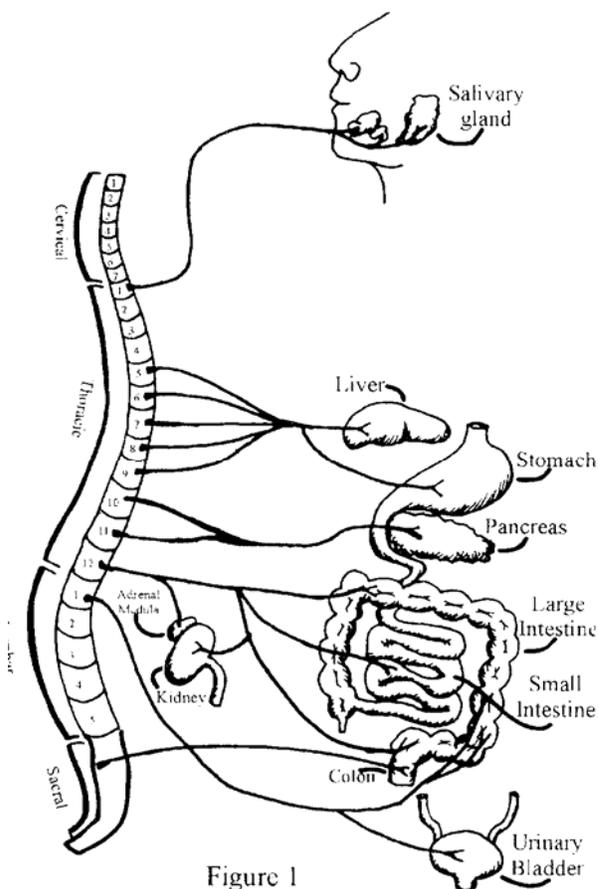


Figure 1

The small intestines move continually and regularly in wavelike contractions called peristalsis. They empty their contents into the colon.

The bowel. The bowel, also called the colon or large intestine, is described by the direction in which it lies in the abdomen. It is divided into the ascending, transverse, and descending colon. If you trace the outer edges of your abdomen from the lower right-hand corner, up several inches, across to the left, down to the lower left-hand corner then towards the center below your navel, you would be following the approximate position of the colon in the same direction that food and waste products move.

The descending colon continues downward into the sigmoid colon. “Sigma” is a Greek letter that is usually written as “s” in English. The sigmoid colon is indeed shaped a bit like the letter “s.” It leads to the rectum, the final section of the bowel. The rectum, in turn, terminates in an opening called the anus.

Many bacteria, called E. coli live inside the colon and aid in digestion. These bacteria are normal and harmless when properly contained inside the colon. However, they can cause serious infection if they travel elsewhere in the body such as the urinary tract.

Your colon has several major tasks. Its first task is to reabsorb water and electrolytes (such as salts) from the remains of your once-delicious dinner. These substances can then be recycled and used elsewhere in the body. When either not enough or too much water remains inside the colon, involuntary bowel movements (sometimes called invols) can result.

The colon’s other major tasks are to store and then let go of bowel movements, or feces. The rectum, that part of the colon nearest the anus, has the job of storing fecal matter until it is time for it to pass out of the body in a bowel movement.

Inside the colon, strong peristaltic movements called mass movements push the final remains of your dinner further towards the rectum. Mass movements occur several times a day. Starting the digestive process again stimulates the entire digestive tract, so mass movements tend to occur following a meal — especially the first meal of the day. When beginning a bowel management program, this is good to know since it can help you schedule your bowel care at an appropriate time following a meal.

The sphincters. Two sphincters, or muscular rings, ordinarily control the anal canal. One is located just inside the anus, and the other is the visible portion of the anus. Reasonably enough they are called the internal and external anal sphincters.

The internal sphincter is different from many other muscles in an important way: It is not under voluntary, or conscious, control. Usually, in order to tighten a muscle, you must decide to do so. For example, when you decide to open your jaws, one set of muscles contracts. When you close your mouth, other muscles contract to pull the jaws together. The muscles you are NOT using relax.

This is not the case with the internal sphincter. It is connected to the autonomic (or automatic) nervous system part of the nervous system that generally functions independently of conscious control. When the nervous system is working as it should, the internal sphincter generally remains contracted to keep the anal canal closed and its contents inside the body. This sphincter must receive additional information to relax in order to allow the anal canal to open.

The external anal sphincter can either relax or contract voluntarily, provided that the pathways in the nervous system that give it these messages are intact.

What is a bowel movement?

As the remains of a meal travel slowly through the colon, they become less liquid and more solid. As feces accumulate towards the bottom of the colon, the colon distends (stretches out), then automatically contracts to propel the feces into the rectum. For a person without spinal cord injury or other neurological impairment when the rectum fills, the urge to defecate is automatically stimulated. The internal sphincter begins to relax. However, if the time and place are not convenient, the external sphincter contracts to prevent a bowel movement from occurring. When the time and place are right, the person allows the external sphincter to relax and the lower part of the colon contracts, expelling the feces in a bowel movement. Spinal cord injury and other challenges to the nervous system can affect this process in a number of ways.

Spinal cord injury and the “neurogenic bowel”

Nerves at many levels ordinarily communicate with the digestive organs. With injury, messages can no longer pass between the brain and the area below the injury. SCI can affect the bowels at any of the steps of digestion outlined above. For example, the intestines may not properly move waste products down into the lower colon and rectum. The signal of fullness in the rectum may no longer reach the brain, so a person may not be able to feel when the bottom of the colon is distended and a bowel movement is about to occur. The anal sphincters may be chronically loose, or chronically contracted.

Several factors affect how the bowel will be affected by spinal cord injury. Among these are: how recently the injury occurred, the area of the spinal cord affected by the injury, and the severity of the injury.

A bowel that has lost some of its function due to neurological trauma or disease is often referred to as a neurogenic bowel. Spinal cord injury is not the only cause of neurologically-based bowel impairment. Nerve damage from a disease such as multiple sclerosis or a congenital condition like spina bifida can also result in a neurogenic bowel. Anyone with a neurologically-based disability can benefit from the information contained in this booklet.

To better understand how neurological problems can affect bowel function, it is useful to have some sense of how the nervous system works.

The nervous system

The nervous system branches out to all parts of the body. Nerves enter and leave the spinal cord between each pair of vertebrae in the spinal column. These nerves send information to or receive information from all parts of the body including muscles, skin, and the internal organs. Some messages travel up to the brain, while others start in the brain. All messages either directly or indirectly affect or bring information from our muscles, glands, and organs.

The central nervous system (CNS) consists of the brain and the spinal cord. Nerves elsewhere in the body are called the peripheral nervous system (PNS). More complicated actions, such as typing or dictating a letter, require the brain's input. Other actions like the reflex that occurs when our hand jerks away from a flame, can occur without input from the brain itself.

Spinal nerves are identified by the area of the bony spine they are associated with and their position relative to other nerves. The higher the number, the lower on the spine

the vertebrae or nerve is located. Moving from the head to the feet, there are 8 sets of nerves (C1-C8) associated with the cervical (neck) vertebrae, 12 (T1-T12) associated with the thoracic (upper back) vertebrae, 5 (L1-L5) associated with the lumbar (lower back) vertebrae, and 5 (S1-S5) associated with the sacrum (the triangular, ridged bone at the bottom of the spine). Nerves at higher levels control and bring feedback from higher areas of the body (e.g., arms) while nerves at lower levels connect with lower areas of the body (e.g., legs).

An injury at a particular level of the spinal cord interrupts communication between the brain and the area of the cord below the injury. However, neurological functions (such as reflexes) that do not require input from the brain may remain intact. Figure 1 shows the different levels of spinal nerves responsible for the colon. The primary nerves responsible for bowel function are found between the very bottom of the spine to the T12 level. This is referred to as the sacral region.

How spinal cord injury can affect bowel function?

Fortunately, the intestines can perform many of their basic functions well without central nervous system input. Their basic ability to contract and release, to absorb, and to secrete can remain intact even with severe spinal trauma, since many of these abilities are controlled locally either by healthy sections of the spine or by the digestive organs themselves.

Even though these basic digestive processes continue, the “fine tuning” of digestion and defecation often suffers due to neurological damage. Imagine the members of an orchestra (the parts of the digestive system) trying to play an important symphony (a bowel movement) without a conductor (the CNS). The performance will most likely suffer without the conductor’s influence.

The effects of injury higher in the spinal cord: Reflex bowel

When a spinal cord injury occurs above the T12 level, the bowel that results from this level of injury is called a reflex bowel, upper motor neuron bowel or spastic bowel. With this level of injury, the internal anal sphincter retains its tone. Local nerves that connect with the rectum are still able to communicate with one another. The reflex that causes the colon to begin a bowel movement remains intact. Thus, as the rectum expands from the pressure of feces inside, the bowel senses this pressure and may empty. This is called reflex defecation. Since the anal sphincter retains its ability to hold the feces inside the body, leakage between bowel movements is not common. However, the person is not consciously aware of when the colon is full, and may not realize when reflex defecation is about to happen.

A good bowel management program can help time this reflex so that it happens when and where you want it to. If you have a reflex bowel, a program in which you move your bowels every one to three days may be sufficient.

The effects of injury to the lower spinal cord: Flaccid bowel

A person with a spinal cord injury below the T12 level may cause a flaccid bowel, also sometimes called a lower motor neuron or relaxed bowel. “Flaccid” means relaxed or flabby. In a person with SCI lower down in the spine, the anal sphincter may remain chronically relaxed. The defecation reflex may not be present. This means that the colon

does not contract normally when the rectum is full. In general, the lower down in the spinal cord the injury is, the less bowel control the person has. The risk of impaction, incontinence, and leakage between bowel movements is greater. A bowel management program can still be effective. However, the person with a lower spinal cord injury may need to plan bowel movements at least once a day.

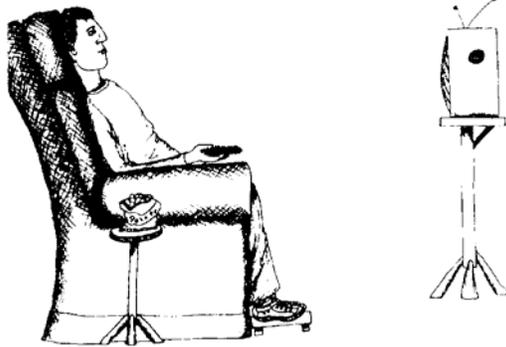
Complete versus partial injury

Often when an injury to the spinal cord is not complete, nerve impulses above and below the injury are only partially affected. In this case, the person may have at least some sensation of when the rectum is full and more control over the course of a bowel movement in general than a person with a complete injury.

Non-neurological causes of bowel dysfunction

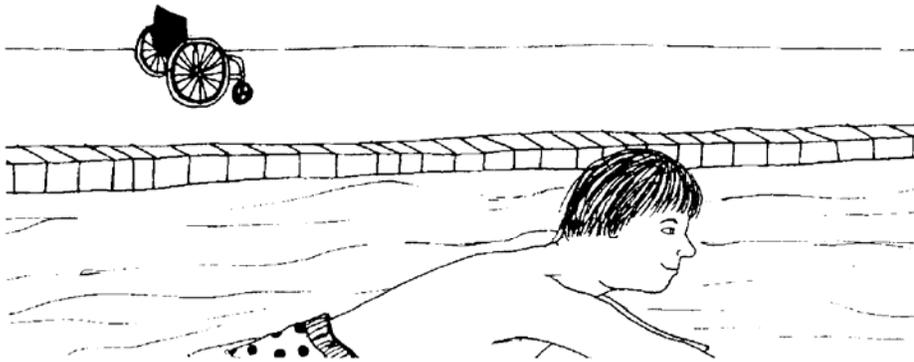
Bowel function can be affected by:

- *Activity.* Decreased activity can lead to a sluggish bowel.
- *Medications.* Certain antacids, iron, other medications or supplements cause constipation in some people. Other medications such as antibiotics are potential causes of diarrhea. If you have any questions about whether a medication may be causing bowel complications for you, it is a good idea to discuss the issue with a health professional familiar with the neurogenic bowel.
- *Diet.* Not eating enough foods with fiber can lead to constipation. Like medications, some foods and drinks have been found to cause constipation or diarrhea in some



Decreased activity can lead to a sluggish bowel. Surfing the channels will not keep you active. Be sure to stay active as possible.

- people. In general, foods that are spicy and/or high in fat may cause diarrhea. A lack of fiber in the diet can lead to either constipation or diarrhea.
- *Stimulants.* Many people find that stimulants such as caffeine and nicotine irritate the intestines and lead to diarrhea.
- *Stress and mood.* Emotional stress affects people differently. Some people tend to become more constipated when they are under pressure, upset, or sad, while for others stools becomes softer.
- *Non-neurological injuries.* Other parts of the body affected by trauma may in turn affect digestion. For example, damage to the teeth is quite common in a traumatic accident. When a person can't chew well, the digestive organs must work harder to break food down. For this reason, dental care following an accident is very important. Also, as mentioned in the discussion of digestion, organs such as the pancreas and liver contribute substances that are necessary for digestion. If these organs are injured, digestion will be adversely affected. Finally, physical injury to the digestive organs themselves can result from a traumatic accident.



Swimming is an activity that persons with various levels of physical ability may be involved in.

Neurogenic bowel: What can I do that will be of help?

The problem that most often causes people social concern and embarrassment is the loss of control over when and where a bowel movement (BM) will occur. To review, neurological damage sometimes results in the following:

- A decrease or loss of sensation, so that the person is not aware when a bowel movement is about to occur.
- A decrease or loss of control over the anal sphincters, the rings of muscle that allow or stop the passage of a bowel movement. This can make it difficult or impossible for a person to control the time and place of a bowel movement.

Introducing bowel management

With loss of muscular control and/or sensation, the truth is that a person's bowel control will never be perfect. However, many people have found effective ways to minimize bowel problems by exploring and adopting an effective bowel management program. A bowel management program takes into account:

- Your injury and level of physical ability
- Your diet
- Techniques and a schedule for bowel emptying that fits into your lifestyle as well as possible
- Beneficial medications and supplements
- Your physical environment

With the right bowel management program you can achieve the following goals:

- The ability to have regular, planned bowel movements
- A decrease in the number of involuntary bowel movements
- Fewer problems secondary to bowel dysfunction (such as constipation, compaction, and diarrhea).

The importance of communication

A recent study found that, for the most part, people with SCI were coping very well with tasks of daily living. The area in which they reported having the greatest problems was bowel care! The most frequently cited reason for bowel care problems was lack of education and instruction. Unfortunately, a specialist who really knows about the challenges of the neurogenic bowel is difficult to find and many health professionals know very little about bowel care. This is why it is important for YOU to become an expert in your own bowel care and to actively seek out resources in your community. Your local independent living center (ILC) may be a good source of information. A peer counselor dealing with similar issues at your local ILC might be a good place to start.

No matter how much written information you have, nothing can substitute for working closely with a knowledgeable health professional to explore bowel management in more depth and detail. Communicating with peers informally or in a support group setting can give you new ideas. Each person has slightly different challenges and your program will need to be individualized.

If during hospitalization and rehabilitation you were not properly instructed in bowel care, it is never too late to seek the information you need. Or, if your bowel condition has changed or worsened over the years following your injury, it may be time to update your information or bowel management skills. Even for people who do not have a neurogenic bowel, certain digestive problems such as constipation tend to increase with age and dietary changes may be needed.

Many people are embarrassed at first to ask questions about bowel care or even to admit that they have a problem. However, allowing embarrassment to stop you from getting the help you need now may only cause more embarrassment later if a bowel problem persists or worsens. Also, while bowel problems are usually not life-threatening, they can BECOME life threatening when ignored. Infection, dehydration, autonomic dysreflexia, and perforation (puncture or tear) of the bowel's lining are just a few of the serious problems that can occur when effective bowel management is not practiced.

Bowel emptying

Bowel emptying, also called bowel evacuation, is one of the main parts of a bowel management program. It is possible to learn how to time bowel movements so that they occur at a time and place that you choose.

The bowel evacuation program outlined below will generally not take more than 30-60 minutes to complete. Each person is different, so you will have to experiment with your own body to find what works best.

The "normal" frequency of bowel movements differs from person to person. It can be anywhere from several times a day, to just two or three times a week. It is generally not recommended to wait more than three days for a bowel movement. If your spinal injury is below T12 (see Figure 1, page 3), it is a good idea to move your bowels at least once each day. Generally, the longer a person waits between bowel movements, the greater the chance there is for constipation and impaction.

The type and frequency of bowel movements are affected by mealtimes, nutrition, fluid intake, and stress. Women sometimes find that their menstrual cycle affects the consistency of their stool. Regular mealtimes and many high fiber foods are recommended.

The role(s) of fiber. Fiber is a substance found only in plants. People cannot digest most of the fiber they eat. Instead, it travels through the digestive tract. Fiber helps people to have healthier stool in two ways that, at first glance might seem to be contradictory. Because fiber helps to retain water in the stool, it helps guard against constipation and impaction, and helps the stool to move smoothly through and out of the digestive tract. Because fiber provides bulk, it helps keep the stool from being too soft and runny. Thus, as far as a bowel movement is concerned, fiber can be thought of as “the great balancer.” Good sources of dietary fiber are vegetables, fruit, whole-grain breads, and cereals. Supplemental bran in the form of cereals or unprocessed bran flakes (available in many grocery stores) can also be added to the diet.

Movement. Movement and exercise are also important for healthy bowel activity. A good rule of thumb is if you are able to move it, then move it! If you can't, get help with range-of-motion exercises when possible. A range-of-motion exercise is when someone gently assists you in moving a part of your body that you might not be able to move yourself. Movement helps increase your circulation, which is beneficial for all the body's systems. It is good not only for the health of your bowels, but for your muscles, your joints, your heart, and your spirit! The best movement or exercise routine will differ from person to person. and should never leave you feeling exhausted or in pain.

Individual differences

Your knowledge of your own body will be your best teacher in finding a program that works well for you. If you are just beginning a bowel program, it is important to take detailed notes about the time, frequency, and consistency of your bowel movements. Also note the effects of any' foods that appear to stimulate or inhibit bowel action. You are also the best source of information about the best time of day to do your bowel program. It's good to think ahead. Once you establish your program at one time of the day, it may take several weeks to readjust your schedule if you decide to change it. Because eating a meal tends to stimulate the entire digestive tract, it's usually best to plan bowel stimulation 30 to 60 minutes after eating breakfast or dinner, or drinking coffee.



Wheelchair sports may be an option to try. It's one way to keep active and healthy!

Because people are so different from one another, there is no “right” schedule for everyone. The frequency of a person's bowel movements prior to SCII is often, but not always, a good predictor of their frequency afterwards. Especially in the beginning of your bowel management program, finding the best schedule for you will require some trial and error. The goal is CONSISTENCY. Bowel movements should be scheduled at regular intervals and at the same time of day each time.

Even people who don't have normal sensation in the bowels can sometimes find ways to predict when a bowel movement will occur. Examples of sensations that might signal a bowel movement are a sense of fullness in the lower abdomen or a restless feeling. People who have any rectal sensation at all can sometimes help a bowel

movement along by giving themselves (or having another person give them) abdominal massage in a clockwise direction (from the right to the left side of the abdomen), and/or by using the Valsalva maneuver. People who do not have the abdominal strength to perform this maneuver can sometimes get a similar effect by leaning forward with the arms crossed over the belly. Either technique can help push a bowel movement downward.

The Valsalva maneuver helps to increase pressure in the rectum. This pressure forces stool into the rectum. To do the Valsalva maneuver, take a deep breath and hold it while tightening the abdominal muscles. Some people also call this bearing down. People whose lower thoracic cord (T6-T12) is intact will usually be able to do this well. People with injury to this area may not have the necessary abdominal control to squeeze strongly enough. People with cardiac problems should avoid this maneuver. This technique is frequently referred to as “straining” and is a technique that nearly everyone uses, whether they are nondisabled or not.

When possible, the sitting position is best so that gravity can help. Whether or not a raised toilet seat is needed is a matter of individual preference and degree of mobility. A raised toilet seat can sometimes give more access to the anal area and make transfers easier. However, using a higher seat may also make it more difficult to bend forward, which some people find helps them to empty their bowels. If sitting is not possible, lying on your left side can also be an effective position.

Let the emptying begin

Once you have decided on a schedule for emptying your bowels, stick with it as much as possible. As you prepare to empty your bowels, make sure the materials you need are handy. Commonly-used items include disposable gloves, lubricant, soap and water or other cleanser, disposable washcloths, toilet paper, plastic bags, and Chux or other pads.

Stimulation of the rectum: Digital stimulation

Sometimes it's necessary to provide a stimulus to begin the bowel movement. Forms of stimulation include very gentle rectal stimulation with a gloved finger, use of a suppository, a mini-enema or an enema. Of these, enemas should be avoided when possible. Long-term use of enemas can make the walls of the bowels more sluggish and/or increase the possibility of impaction. Some of the ingredients used in enemas can also irritate the lining of the bowels.

For hygiene, digital stimulation is done using a gloved, lubricated finger. It can also be done with the assistance of a medical aid called a digital stimulator (see Figure 2.). If gloves are not available, some focus group members suggest disposable plastic sandwich bags can be used. Finger cots can also be used. These are disposable coverings that fit over one finger. Both gloves and finger cots are available in drug stores. They are often made of a material called latex. Unfortunately, many people are allergic to latex. If you experience any allergic symptoms (such as rash, wheezing, or watery eyes) after touching latex, ask your health care professional or pharmacist where to find gloves that are made of vinyl or other non-latex material.

Gently insert your finger 1/2 to 1 inch into the rectum. Most people use the index finger for this job. The skin around the anus and in the rectum is very sensitive, so your

finger nail should be short, and lubrication should always be used. Some lubricants that people have found effective include KY Jelly, Surgilube, and Preparation H. If you have a tendency to experience autonomic dysreflexia or painful hemorrhoids, an anesthetic lubricant might work best for you.

For some people, insertion alone will stimulate the external sphincter to relax and allow a bowel movement to occur. Others may need to gently move the finger in a circular motion or from side to side, until relaxation of the sphincter occurs. Sometimes it helps to pull gently towards the back of the rectum while doing the Valsalva maneuver or leaning forward. Slow motions get the best results.

Sudden movements of the finger may cause the anus to contract, clearly defeating the purpose. As you feel your sphincter relax, gently remove your finger. Once the bowel empties, wait a few minutes and try the same thing again. This will help ensure that all the stool has passed.

Digital stimulation should not be done for more than one minute at a time. If the bowel does not empty, wait a few minutes and try again. Unfortunately, digital stimulation can sometimes trigger autonomic dysreflexia, a potentially dangerous condition. If you notice signs of autonomic dysreflexia, stop the stimulation and monitor your blood pressure or have someone else monitor it for you.

“One of the things I have learned is to take my time when I do my bowel program. It seems like I am always behind in what I have to do, but since my accident I have had to listen to my body, slow down, and do what it needs first. I used to watch the clock so I didn’t go too long between bathroom trips, but now it’s a habit to try to go no matter where I am so I won’t suffer later.”

Other sources of stimulation

Mild stimulants, such as prunes or prune juice, may be helpful prior to bowel emptying. It is best to stay away from commercial laxatives except as a last resort. They can be habit-forming and can result in more frequent involuntary bowel movements. Some laxatives are recommended as good and some are not recommended to be used at all.

Suppositories can be helpful and many people use them instead of or in addition to digital stimulation. When used with digital stimulation, wait at least 15 minutes after taking the suppository to begin stimulation.

Another infrequently used technique is electrical stimulation. It is new in the treatment of bowel dysfunction, although electrical stimulation in other forms has been used for some years with persons with SCI to stimulate specific muscle sites. For more information on this subject, a rehabilitation hospital near you may be able to direct you.

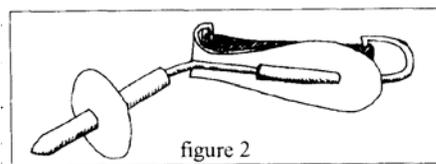


figure 2

Flaccid versus reflex bowel

People with lower spinal cord injury, have a stronger tendency to become constipated or suffer impaction. Because of decreased tone in the rectal sphincters and pelvic floor (perineal) muscles, feces tend to leak when the person lifts or strains. For this

reason, bowel emptying may be necessary on a more frequent basis. While digital stimulation or suppositories often work well for those with reflex bowel, people with flaccid bowel will usually have to manually evacuate the feces with a gloved hand or device. Before, or in addition to resorting to manual evacuation, some strategies that might bring on a bowel movement are doing the Valsalva maneuver, massaging the abdomen, leaning forward (if possible), and using a suppository in conjunction with manual evacuation.

Bowel management and independence

Paraplegia. While it requires training and practice, people with paraplegia can generally become completely independent with all aspects of bowel care and management. An occupational or physical therapist can be particularly helpful in determining what alterations need to be made in your bathroom and what supplies you will need.

Quadriplegia. Posing additional challenges, paraplegia often results in lack of control and strength in the arms and hands. It may be difficult for the person to balance on the toilet seat. For independent bowel care, you must be able to either transfer to a toilet or commode, or move into a side-lying position in bed, with a Chux or similar pad placed beneath the buttocks. Lying on the left side is best, since food and waste products travel through the abdomen from right to left. There are many helpful devices available, but to use them at least some wrist strength or splinting is required.

Examples of helpful aids include suppository inserters, a loop attached to a wrist device that can isolate the middle finger for insertion into the rectum, and a “dil stick” for digital stimulation. An adaptive holder can help with toilet paper use. A knowledgeable occupational or physical therapist can be of great help in alerting you to the aids that are available, the alterations that might be required in your home, and the techniques required for bowel care.

When deciding what is possible to do on your own and what will require help from others, let safety and practicality be your guides. For example, if you have no sensation in your finger, there is greater potential to injure yourself during digital stimulation.

Even if you rely on others to help you with bowel care, knowing as much as you can about your bowel management and emptying is extremely important. Even experienced and professional caregivers often do NOT get proper training about bowel dysfunction and the neurogenic bowel. Chances are that you will have to instruct your caregivers about what to do. For bowel emptying, the methods will be the same as what we’ve described, except that the caregiver will be doing the work.

Problem-solving strategies in bowel management

Bowel management is a challenging and imperfect discipline. The following are some common problems, and potential solutions. Improvement can almost always be attained through communication and experimentation. When you are experimenting to see which aspect of your bowel program to change, alter only one aspect of your bowel program at a time so that you can be sure any change that occurs is due to your new practice.

“I am lucky where I work because our plant nurse gave me a drawer to keep my medical supplies in and I can keep extra pants, etc. there in case of an accident. The nurse talked to my supervisor and helped explain things, so I have to leave my machine at any time it is not a problem.”

Involuntary bowel movements (invol and accidents)

Involuntary bowel movements occur occasionally for many people with neurogenic bowels. However, if this is a common occurrence, it may be necessary to schedule more frequent bowel movements. It may also indicate that the lower bowel is not emptying completely. You may need to set aside additional time for each bowel movement. Some people benefit from checking with a gloved finger to make sure the bowels are empty even after having a bowel movement.

Another strategy is to notice if accidents seem to occur after particular foods are eaten, and to avoid these foods. Caffeine, nicotine, and chocolate, and spicy foods are commonly known to stimulate the bowels. People also have reactions to foods that are very individualized. Keeping a food diary for several weeks will help you determine what foods may be worsening your bowel problem. Once you suspect a food or food group (such as dairy products) is adversely affecting your bowels, cut it out of your diet for several days and see if there is improvement.

“Carra Foam is a skin and perineal cleanser that can be put on a paper towel and used to wipe up accidents. Also, if one uses a glove and needs to re-insert to finish the bowel program, Carra Foam can be sprayed on it and wiped off. Baby wipes can be kept in your bag or the trunk of your car along with extra clothing to just be prepared for accidents. Always get cleaned up as fast as possible to prevent skin breakdown.”

What about the occasional accident that occurs in spite of your best efforts? Sometimes it’s just necessary to realize that you won’t feel embarrassed forever, that others have had the same experience and survived, and that you will, too. When friends, family, or coworkers are aware of an invol they may simply take the problem in stride. After all, a bodily function you cannot always control does not define who you are as a human being. Some people who have had occasional invols in public are even able to approach the topic with some humor. When asked “What do you do?” one member of our focus group replied, “Escape as soon as possible.”

“I have this little tote bag with extra things just in case something goes wrong. I even have soap and a wash rag. You may never have to use your emergency bag, but it is there and makes you feel safer.”

Diarrhea

This is the nightmare of every person with bowel problems. Unfortunately, no matter how consistent your bowel management program is, diarrhea leads to incontinence.

Diarrhea can sometimes be caused by medications, particularly antibiotics. Following a course of antibiotics, it is helpful to eat yogurt with live culture or to ingest acidophilus (available in health food stores and some pharmacies) for several days to help restore the balance of healthy bacteria in the colon.

Liquid stools can sometimes result from fecal impaction. At first glance. This may not seem to make sense, because impaction is the buildup of hard stool. However, behind

this “plug” lurk watery wastes that leak around it. If impaction is the cause of liquid discharge, checking for and removing the impaction will help clear up the problem.

Sensitivity or allergy to particular foods or stimulants can also cause diarrhea. In this case, a bit of detective work can usually uncover the culprit(s).

Soft, poorly-formed stool

Sometimes the distinction between “soft stool” and “diarrhea” is in the mind of the beholder, so the above section is relevant to this problem too. Adding more constipating-type foods to the diet is often of benefit. These include cheese, meat, and starches. Experiment with the amount of fiber you are ingesting daily.

Constipation

Constipation is when feces move through the colon more slowly than is healthy or normal for an individual. The longer it continues, the more likely it is that the stool will lose water and harden, becoming an impaction. Constipation affects people of all ages, particularly the elderly. Signs and symptoms of constipation include loss of appetite, generalized abdominal discomfort, or referred pain. The abdomen may feel hard or distended. People often feel irritable or nauseous, or develop a headache. Any time you have not defecated for more than two or three days, constipation must be suspected. Scheduling more frequent bowel movements may be helpful especially if your current program is less frequent than every other day.

Even the most mild laxative can mess me up. For me it works best to change my diet, eat more salads, etc.”

Eating enough dietary fiber and drinking enough water are essential to prevent constipation. The average recommended daily fiber intake is 40 grams. To see if constipation is fluid-related, you can experiment with how much water and other liquids you drink to see if this makes a difference. Ideally, a person should take in between 2000 and 3000 ml. (approximately 8-12 cups) of fluid each day. Sometimes people with SCI have reduced their fluid intake as part of bladder management. In this situation, it may take some time to find a workable balance between bowel and bladder needs.

“Drinking enough fluids is hard because the more I drink, the more chances I have at bladder spasms and accidents.”

Constipation can be a side effect of many medications, especially some pain medications (including aspirin), bladder medications, and antidepressants. A careful review of medications being taken (including non-prescription drugs) with the help of a knowledgeable pharmacist or doctor, can help determine if this is the case. Sometimes a medication that is causing constipation can be stopped or a different one can be substituted.

Impaction

Impaction occurs when hardened feces collect in the colon. It should be suspected when there has been no bowel movement for three or more days. Impactions will

generally require medical attention. Treatment includes taking a strong laxative orally, yet mineral oil for this procedure should be avoided as it may lead to a long-term case of diarrhea.

The removal of an impaction should be followed with an effort to establish a regular bowel program at least every two days with increased fiber intake. Lactulose syrup is available by prescription and may soften and mobilize the impaction. Like many laxatives, it tends to cause accidents, so use it only with your doctor's supervision.

With an impaction, it is important to seek medical help. An impaction can have serious consequences. Occasionally impaction or its removal can cause a tear in the lining of the bowel, allowing bacteria that should only live inside the colon to cause serious infection in other areas of the abdomen. For this reason, it's particularly important to remove an impaction carefully. Impaction can also cause autonomic dysreflexia.

Gas

Gas is a natural by-product of digestion. Gas buildup can lead to pain and bloating. The longer feces remain inside the digestive tract, the more time gas has a chance to develop. Preventing constipation and increasing the frequency of your bowel evacuations may help. Avoid foods such as beans and cabbage that tend to form gas. Some medications are available to help relieve discomfort from gas.

Hemorrhoids

Hemorrhoids are dilated (varicose) blood vessels in the area of the rectum and anus. They are common, especially with chronic constipation. The likelihood of developing hemorrhoids increases with age. They can be caused by remaining in one position for an extended period of time, straining to evacuate, rough manual stimulation of the anus, and giving birth. The first sign of hemorrhoids may be rectal bleeding following a bowel movement, or blood that is visible in the stool. By themselves, hemorrhoids are more an uncomfortable inconvenience than a serious challenge to health. However, if left untreated they can cause infection. Increasing circulation in the buttocks area will help avoid hemorrhoids.

Circulation can be increased by changing position at least a little every half hour, and by doing pressure lifts if you are able to perform them. Warm baths can also be helpful. When applying digital stimulation, always use lubrication and always be gentle. A number of hemorrhoidal creams that are sold over the counter can serve two roles at once; as medication for the hemorrhoids and as a lubricant.

To avoid further irritation, be especially careful to clean and dry the rectal area each time you have a bowel movement. A perineal cleanser like Carra Foam and damp paper towels may do the trick. Treatment for hemorrhoids includes anti-inflammatory suppositories and topical ointments. Medical procedures include cutting or injecting the hemorrhoidal tissue, or banding. Banding is a procedure in which an elastic band is tied around external hemorrhoids. The pressure of the band cuts off the blood supply and the hemorrhoidal tissue dies and falls off.

Autonomic dysreflexia (AD)

Autonomic dysreflexia (AD) is also known as autonomic hyperreflexia. It is a complication in which blood pressure can rise very high. While often the condition will

resolve itself, at times it can require emergency medical care. Since AD only occurs in people who have spinal cord injury, many health professionals do not know how serious it can be or even what it is. Therefore, the more you know about it, the more you will be able to give yourself the proper care and/or get it from others.

AD has many causes aside from bowel dysfunction. The symptoms of autonomic dysreflexia differ from person to person. If you have experienced AD several times, you may find that you tend to have certain symptoms and not others. Learning to listen to your body for signs of AD could save your life! Common symptoms of mild AD include:

- Sweating above the level of the injury
- A mild increase in blood pressure. (For example, a person with quadriplegia whose usual blood pressure is 90/60 should suspect AD if blood pressure rises to about 120/80. A person with paraplegia whose usual blood pressure is slightly higher might suspect AD if blood pressure rises to around 140/90. The important thing is to be aware of what your own resting blood pressure usually is.)

Symptoms of more severe AD include:

- Extremely high blood pressure (200/100 or higher)
- A pounding headache
- Changes in heart rate (either faster or slower than is normal for you.)
- Reddening of the face and neck while skin below the SCI gets paler and feels cold.

Some people will experience difficulty breathing, goosebumps, blurred vision, anxiety, nausea, and/or nasal congestion. However, these symptoms alone do not mean you have AD.

Unfortunately, autonomic dysreflexia is common. It occurs in more than 80% of people whose SCI is at or above the T6 level. The first episode could occur as early as two months or as late as 12 years after injury. Most commonly, if a person is going to develop this condition, the first episode will occur between four and six months after the injury. Some people might have only one or two experiences with AD in their lives, while others tend to experience it on a regular basis.

Causes. AD is generally “triggered by a stress on the body that can be very localized. For example, a bladder that is too full and fecal impaction are considered two of the most common causes of AD. Other causes include pressure on the skin, spasm or stress in the rectal area due to digital stimulation, bloating due to gas, urinary tract infection, etc.

Solutions. If you begin to feel symptoms of AD while lying down, change to a seated position. Make sure you have your own blood pressure equipment and learn how to take your own blood pressure. If this is not possible, make sure that the people who are around you most frequently know how to take our blood pressure.

If the cause of the AD can be found and eliminated as soon as possible, you may not need medication or medical attention. For example, if you begin to feel AD symptoms and find that you have an impaction, blood pressure will often return to normal when the impaction is removed.

Once you eliminate the cause of the AD (e.g., remove an impaction, loosen clothing, or empty the bladder), monitor your symptoms and take your blood pressure every 3-5 minutes to make sure it is returning to normal.

If the cause of the AD is not obvious and your blood pressure is high, take medication to lower your blood pressure and monitor your blood pressure as described above. There are several prescription medications available to lower blood pressure, and a knowledgeable doctor can help you choose one and tell you how much and how often to take it.

Make sure all the health professionals and caregivers you work with are knowledgeable about AD. Remember that this condition is particular to SCI and many people are not familiar with it,

If your blood pressure does not return to normal within an hour or if it rises as high as 200/100 seek emergency medical help. If left untreated, AD can have life-threatening consequences that include seizures, cerebral hemorrhage, and heart attack.

When to seek medical help

Even though long-term bowel management programs are highly successful, almost everyone who has a neurogenic bowel will need follow-up medical care at some point in time.

- Prolonged constipation and/or impaction always requires medical attention since the danger is great for perforation, infection, and/or autonomic dysreflexia.
- Diarrhea that lasts more than 24 hours requires medical attention.
- Blood in or around the stool is a common symptom of hemorrhoids. Digital stimulation can also cause rectal bleeding. Unfortunately, blood in the stool can also be a sign of cancer of the colon. If you have experienced rectal bleeding or if your feces have recently become darker in color, make sure your doctor is aware of this.
- The incidence of colon cancer rises dramatically with age. A program of screening sigmoidoscopy is recommended every three to five years for people over 50 years of age.
- Autonomic dysreflexia that does not quickly begin to resolve, or blood pressure that reaches 200/100 or higher may be life-threatening. Seek medical assistance immediately.
- Any obvious change in your bowel habits or in the level of pain or abdominal hardness you feel or notice merits at least a phone call to a health professional. Stool that is unusually foul-smelling can signal infection or parasites, and fever should also call for investigation as to its cause.
- If a successful bowel program stops working even though you have had no recent change in your lifestyle (such as a new diet, or added stress or activity), enlist the help of your doctor to uncover the source of the problem.

Colostomy: A treatment of last resort?

In situations where bowel complications repeat themselves again and again and bowel management is unsuccessful, people sometimes turn to a procedure called a colostomy. It should be stressed here that this treatment is sought only after careful consideration of the many effective alternatives that have been described in this booklet. It does involve a surgical procedure and lifelong effects that should be weighed in the consideration of this treatment. Many persons with SCI do have colostomies and are glad for the benefits of this procedure.

To perform a colostomy surgery, an incision (cut) is made in the colon and connected to another opening (stoma) in the abdominal wall. The lower end of the colon is sewn shut. Instead of proceeding all the way down to the rectum, feces exit out of the stoma. A bag attached to the stoma outside the body collects the feces.

Colostomy has both risks and advantages. Because it is surgery, it carries with it all the attendant risks such as the trauma of hospitalization, potential negative reactions to anesthesia, and possible infection. Many people hate the idea of having a feces-filled colostomy bag attached to them that must be emptied at regular intervals. Others see it differently. As one focus group member wrote, "It is preferable to frequent unpredictable bowel accidents!"

It appears that people who undergo this procedure often find it has simplified and improved the quality of their lives. Two studies asked people who had gotten colostomies how they felt about their choice. Although they suffered some complications and needed to adjust to and learn how to care for their stomas, the majority were much happier with their bowel care after surgery. Some of the major reasons they gave for having colostomies were: repeated infection, too much loss of time over bowel management, chronic leakage, bloating, lack of enjoyment in eating, and loss of mobility in their social lives and work. After their colostomies they reported improvements such as decrease in or reversal of fecal leakage, decrease in gas and abdominal pain, and increased independence.

Because a colostomy is a surgical procedure and because a regular bowel management program works well for so many people, a colostomy is usually considered only as a last resort. Whether or not a colostomy is right for you can only be determined by you in conjunction with a qualified health professional such as a gastroenterologist or physiatrist.

Sharing information: Comments from our readers

"Since I am not in a wheelchair with my SCI, sometimes standing over the toilet and hearing down will work the stool down so I can use digital stimulation and also press on the left side of my belly."

"I've gained about 35 pounds in the six years since my accident. If I eat, I go, so I end up overeating to keep from being constipated all the time. I've tried fiber, tried certain fruits, and medications, but still have problems."

"I'd suggest to people to not use the "Depends" brand due to being so expensive. I have used a cheap brand (extra large or large size) and they don't take up much room

in underwear and don't crinkle or show in clothing. I also use cheaper bed-pads or "Chux" to sleep on in case of accidents."

"I have a lot less trouble at home because I can exercise and work at my own rate. I can drink and go to the bathroom when I want. At work, it's a different story and I have to keep after myself to get enough fluids."

"I also realize the problem has kept me from dating some and even desiring to date and have to explain things. What's also been funny is explaining to my 3 1/2 year old why her mom buys diapers and wears them."

"I use Therevac S B. mini enemas, which the hospital started me on. I use them when I am really full and things don't seem to be moving down like they should."

"Carra Foam is a skin and perineal cleanser that can be put on a paper towel and used to wipe up accidents. Also, if one uses a glove and needs to re-insert to finish the bowel program, Carra Foam can be sprayed on it and wiped off. Baby wipes can be kept in your bag or the trunk of your car along with extra clothing to just be prepared for accidents. Always get cleaned up as fast as possible to prevent skin breakdown."

"One of the main things a person has to do is to just keep working at it. Not to be afraid that what you do with digital stimulation or anything else is going to hurt you. I talked to my doctor a lot and asked many questions'. Now he is learning from me."

Glossary

Accident: What many use to describe an involuntary bowel movement or instance of incontinence.

Autonomic dysreflexia: Complication of spinal cord injury that can have serious consequences if unattended or untreated.

Autonomic hyperreflexia: Same as autonomic dysreflexia.

Autonomic nervous system: Division of the central nervous system that is generally not under conscious control.

Banding: Procedure to eliminate hemorrhoids.

Bearing down: Tightening the abdominal muscles in a manner that helps move along a bowel movement.

Bowel emptying or bowel evacuation: Having a bowel movement as part of a bowel management program, often spurred on by digital stimulation, bearing down, and/or suppositories.

Bowel management program: Regular bowel care that includes nutrition, bowel emptying, hygiene, and sometimes medication.

Colon: Also called the bowel or large intestine, it is the final segment of the digestive tract.

Colostomy: Procedure that enables feces to collect outside of the colon.

Constipation: Retention of feces longer than is healthy or customary for an individual.

Defecation: Act of having a bowel movement.

Dehydration: Lack of sufficient fluid in the body.

Digital stimulation: Common method of stimulating bowel evacuation.

dil: Digital stimulation; the letters stand for “dilation procedure.”

Feces: Same as stool, the material that makes up a bowel movement.

Flaccid bowel or flaccid colon: Type of colon that often is the result of damage to the lower spinal cord. Muscle tone is lost and the anal sphincter cannot contract.

Gastric: Relating to the stomach.

Gastrointestinal: Relating to the stomach and the intestines.

Impaction: Collection of hard stool in the intestines.

Incontinence: Inability to stop an involuntary bowel movement from occurring.

Invol: A term many people use for an involuntary bowel movement.

Involuntary bowel movement: Bowel movement that is unplanned, not under a person’s control.

Neurogenic bowel: Medical term for a bowel whose function is affected by neurological (nerve-related) trauma or disease.

Neuron: A cell of the nervous system that receives and conducts impulses that can cause or stop actions.

Neurological: Relating to the nervous system.

Peristalsis: Wavelike motions of the digestive tract that help move food and waste products down into the rectum.

Perineum: Area of skin between the genitals and anus.

Rectum: Final segment of the bowel, terminating in an opening called the anus.

Reflex: Reaction to a stimulus that occurs quickly and without direct input from the brain.

Reflex defecation: Type of defecation in which the pressure of feces in the colon causes the colon to contract, helping to produce a bowel movement, generally possible for people whose spinal cord is damaged above S2.

Reflex bowel or reflex colon: Type of colon that results from an injury higher on the spinal cord. Also sometimes called a “spastic” colon.

Relaxed bowel: Same as flaccid bowel.

Sacrum: Triangular-shaped bone at the bottom of the spine. Its ridges are reminders that embryologically it, like the rest of the spine, was once composed of separate bones.

Screening sigmoidoscopy: Exploratory procedure to help test for colon cancer. spastic bowel or spastic colon. See reflex bowel. This term can be misleading. since it is used for other conditions that are not related to spinal cord injury.

Sphincter: A ring of muscle.

Stoma: Opening, hole.

Ulcer: Open sore or inflamed area on an inner or outer surface of the body.

Upper motor neuron bowel: Same as reflex bowel.

Valsalva maneuver: A maneuver that can help in pushing feces towards the anus.

Vertebrae: Bones that make up the spine.