Bowel Control in Children with Spinal Cord Injuries and Spina Bifida
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Bowel Control
in Children with Spinal Cord Injuries and Spina Bifida

What is bowel control?

Some people cannot control their bowels because they cannot feel when it is time to go to the bathroom. They cannot feel when they leak stool or soil themselves. **Bowel control** means having a stool around the same time each day. The goal is to let out stool at a planned time, and not to leak or soil.

How do you do it?

You can get bowel control through a **bowel management program**. This program is different for each person, and may include:

- diet
- activity
- medicine
- things to do every day

Why is it important?

Controlling your bowels helps to avoid:

- stool soiling
- loose stool (**diarrhea**)
- dry, hard stool (**constipation**)
- infections of the bladder and kidney

Children who can control their bowels feel better about going to school and being with friends.
How the bowels work

When we eat food we digest it. **Digestion** separates the nutrients from the waste. The nutrients go into the blood and feed the body. The waste goes out of the body as stool or urine.

**Here’s how it works:**

1. You chew food, and mix it with the liquid in your mouth (saliva). This starts to break down the food into its parts.

2. The food then passes down a tube (esophagus) into your **stomach**. Your stomach holds the food there for a while and breaks it down some more.

3. The food then moves into the **small intestine**. Most food is digested in the small intestine. Here, food is broken down more, and the nutrients (vitamins, minerals, protein and other things) move into the blood. The blood takes these nutrients to the rest of the body, where they are used.

4. By the time this food moves from the small intestine into the **large intestine**, it is becoming stool and is very watery. The large intestine takes the extra water from the stool. This turns the stool more solid. The nerves tell the muscles of the large intestine to move the food forward. The muscles squeeze the large intestine.
5. When the stool reaches the rectum, it stays there until you have a bowel movement.

6. When the amount of stool in the rectum is right, nerves in the walls of the rectum help you feel the need to go to the bathroom.

7. You walk to the toilet, sit down, then tell other nerves that control the opening (inner and outer anal sphincter) to relax and let the stool move out, into the toilet. If you can’t get to a toilet right away, you can tighten the outer anal sphincter to keep stool from oozing out.

**Two systems work together to control bowel movements:**

1. The parts of the gut (anatomic): small intestine, large intestine, rectum, inner (internal) anal opening (sphincter), outer (external) anal sphincter and the muscles of the pelvic area.

2. The nerves (neurologic)
   
   In the nervous system, there are special nerves that help move the bowels.
   
   — Some of these nerves are in our control (voluntary),
   — Some the body takes care of without our thinking about it (autonomic), and
   — Some are in the walls of the intestines (enteric).
Neurogenic Bowel

When it is hard to control bowel movements because there is a problem with the nervous system, it is called neurogenic bowel. This may happen to children who:

- are born with a problem in the spinal cord
- get an injury to their spinal cord
- have a tumor on the spinal cord.

The spinal cord starts at the bottom of the brain and travels down the back. Messages travel along the nerves in the spinal cord. The type of problem depends on where the injury (lesion) is. The higher the spinal cord injury, the more parts problems it can cause.

The message travels from the intestine through the spinal cord to the brain back down to the rectum telling the bowels to empty.

When pressure increases in the rectum, a message is sent to the brain that tells the bowels to empty. You can increase the pressure by putting a suppository into the rectum, so the person moves stool out.

On the other hand, children with spina bifida or myelomeningocele cannot send messages up and down the spine like this. They have more trouble emptying their bowels. They are more likely to be constipated because:

- they can't feel the stool in the rectum
- their intestines don't work as quickly
- the walls of the rectum are so weak and soft, they can hold a lot of stool
- the muscles at the opening of the rectum (sphincters) can become loose, and stool may ooze out.
How to Create a Bowel Program

The emptying of your child’s bowel needs to fit your family’s routine. Your child needs a bowel program that works for the whole family.

A bowel program is different for each person, and may include:
— diet
— activity
— medicine
— things to do every day

Medicines and special ways to clean out the bowel need to be done within an hour after a meal. Some families like to do it in the morning. Others find their mornings are busy, and they prefer to do it in the evening.

As the child gets older, he or she may do more of the tasks in the bowel program. In time, the child will be able to take care of him or herself.

Your child should help with the bowel program as well as he or she can. How old is your child? What is your child able to do? What does your child understand?

Some things your child can do includes:
— get the supplies
— wash his or her hands
— get on the potty chair
— clean up after

A child should not go longer than two days without having a good sized bowel movement.
Bowel Management

Diet: Fluids and Fiber

Drinking plenty of fluids helps a child pass stool easily. The more your child weighs, the more fluid he or she needs.

<table>
<thead>
<tr>
<th>Weight of child</th>
<th>Amount of fluid to drink each day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 22 pounds</td>
<td>3 to 4 measuring cups (24 to 32 ounces)</td>
</tr>
<tr>
<td>23 to 44 pounds</td>
<td>4 measuring cups (32 ounces) plus fluid in food</td>
</tr>
<tr>
<td>45 to 99 pounds</td>
<td>6 measuring cups (48 ounces) plus fluid in food</td>
</tr>
<tr>
<td>100 or more pounds</td>
<td>7 measuring cups (56 ounces) plus fluid in food</td>
</tr>
</tbody>
</table>

Fiber acts to bulk up the stool. Bulky stool is easier to move along the intestine. Include foods with fiber in every meal. Choose foods that are higher in fiber whenever possible. Here is a list of high fiber foods.

Foods High in Fiber

The most fiber

Vegetables
Artichokes, raw
Carrots, raw
Corn, raw or cooked
Parsley, raw
Potatoes, baked with skin
Turnip greens, cooked

Brussel sprouts, boiled
Chives
French fries, frozen
Peas, canned
Sweet potatoes, raw or cooked
Mixed vegetables, frozen or cooked
**Fruits**
- Apricots, dried
- Peaches, dried
- Raisins
- Figs, dried
- Prunes, stewed or dried

**Grains, Cereals, Legumes, Nuts, Seeds**
- Almonds
- Barley Beans, raw
- Bulgur
- Bread, high-fiber, whole wheat
- Cereal, bran flakes
- Cereal, granola
- Cornmeal, whole germ
- Crackers, rye
- Cracker, whole wheat
- Flour, rye
- Lima beans, raw
- Pistachios
- Rice bran, crude
- Spaghetti, whole wheat, dry
- Wheat bran, crude
- Wheat germ, toasted
- Amaranth or amaranth flour
- Great Northern, raw
- Bread, crisp, rye
- Cereal, bran, high fiber
- Cereal, fruit with fiber
- Cereal, oatmeal corn bran, crude
- Cowpeas, raw
- Crackers matzo whole wheat
- Flour, corn
- Flour, whole wheat
- Oat bran
- Popcorn
- Spaghetti, spinach, dry
- Triticale or triticale flour
- Wheat germ, crude

**A lot of fiber**

**Vegetables**
- Broccoli
- Cauliflower, raw or cooked
- Onions, spring, raw
- Potatoes, hash browned
- Squash, winter, cooked
- Turnip greens, raw
- Water chestnuts, canned
- Cabbage, red or white, raw or cooked
- Mushrooms, boiled
- Peas, podded, raw or cooked
- Spinach raw or cooked
- Tomato puree
- Turnips, boiled
- Watercress

**Fruits**
- Apples, raw with skin
- Kiwifruit, raw
- Oranges, raw
- Strawberries
- Blueberries, raw
- Olives
- Pears, raw
Grains, Cereals, Legumes, Nuts, Seeds

Baked beans, canned
Bread, bran
Bread, Hollywood-type, light
Bread, pita, whole wheat
Bread, rye
Bread, whole wheat
Cashews
Cereal, wheat or malted barley
Chips, corn
Chips, tortilla
Cornmeal, degermed
Crackers, Matzo egg or onion
Fig bars
Flour, rice, brown
Hazelnuts
Lima beans, cooked
Melba toast
Mixed nuts
Muffins, oat bran
Noodles, spinach
Rice, wild, raw
Taco shells
Walnuts

Bread, Boston brown
Bread, cracked wheat
Bread, mixed grain
Bread, pumpernickel
Bread, white, high fiber
Bread crumbs
Cereal, wheat flake
Chickpeas, canned
Chips, potato
Coconut Corn, toasted
Cowpeas, cooked,
Crackers, wheat
Flour, oat
Granola bars
Ice cream cones
Macaroni
Millet, hulled or raw
Muffins, English, whole wheat
Noodles, Japanese, udon or somen, dry
Peanut butter peanuts pecans
Sunflower, seeds
Tortillas, corn

Some fiber

Vegetables

Beans, snap, raw or canned
Cabbage, Chinese, raw or cooked
Celery, raw
Cucumbers, raw
Mushrooms, raw
Peppers, sweet, raw
Potatoes, raw, flesh or skin
Potatoes, boiled, flesh
Squash, winter, raw
Tomatoes, raw

Beets, canned
Carrots, canned
Corn, canned
Lettuce
Onions, raw
Pickles
Potatoes, baked, flesh
Squash, summer, raw or cooked
Sweet Potatoes, canned
Turnips, raw
### Fruits
- Apples without skin
- Bananas
- Nectarines, raw
- Pineapple, raw or canned
- Applesauce
- Fruit cocktail, canned
- Peaches, raw or canned
- Prune juice

### Grains, Cereals, Legumes, Nuts, Seeds
- Bagel, plain
- Bread, Italian
- Bread, Vienna
- Bread, white toasted
- Brownies with nuts
- Cereal, farina, dry
- Cookies, butter
- Cookies, chocolate sandwich
- Cornbread
- Crackers, matzo
- Doughnuts, leavened
- Flour, rice, white
- French toast, frozen
- Hominy, canned
- Noodles, chow mein
- Pie, pecan
- Pretzels
- Rice, white, glutinous
- Semolina Spaghetti, dry
- Waffles, frozen
- Bread, French
- Bread, oatmeal
- Bread, wheat
- Bread stuffing
- Cereal, cornflakes plain or frosted
- Cereal, oatflakes
- Cookies, chocolate chip
- Cookies, oatmeal
- Crackers, graham
- Crackers, saltine
- Flour, arrowroot
- Flour, wheat, white
- Fruitcake
- Muffins, blueberry
- Noodles, egg
- Pie, pumpkin
- Rice, brown, longgrained, raw
- Rolls, dinner, made with egg
- Tortillas, whole wheat

Watch how your child’s bowel responds to certain foods. Some foods may stimulate the bowel and cause accidents. Examples of these may be candy, chocolate, Kool-Aid, tomatoes, pizza, and corn.
Activity

Activity is important to promote good bowel movements.

Increased activity helps to move food through the intestines. Encourage your child to move as much as possible. Your child may add activity through play, exercise, or physical therapy.

Medicine

Sometimes your child may need medicine to increase the bulk of stools. This is more likely if your child has a lower spinal cord problem, such as spina bifida.

A clean out program may include one or more of these medicines:

**Bulking agents**
- Benefiber
- Citrucel
- Fibercon
- Metamucil

**Stool Softeners**
- Docusate sodium (Colace)

**Stimulant laxatives**
- Senna syrup (Senokot)
- Castor Oil
- Bisacodyl suppository (Dulcolax)

**Lubricants**
- Glycerin suppository
- Mineral oil (Agoral)

**Osmotic laxatives**
- Milk of Magnesia
- magnesium citrate
- Miralax

You don’t need a prescription for these medicines. However, some of these may cause leaking, soiling, or staining. Work with your health care team to choose the right medicine, and the right amount.
What to do every day

Bowel readiness

Your child needs to understand that emptying the bowels is normal. Before you start the bowel program, you might want to read a fun book with your child: *Everyone Poops*. This book shows how all living creatures have to poop. You may find this book is at The Emily Center, your public library, or your local bookstore.


**Signs of bowel readiness are:**

— Your child at least two years old, and is able and ready to do the program.
— Your child can sit on a potty chair or be held up sitting.

Doing the same thing every day at the same time makes the bowel care program work.

1. Give your child a stool softener every day.

One example of a stool softener given by mouth is docusate sodium (also called *Colace*). You may need to use other medicines, too.

If your child is constipated, he or she may need a clean out program before you can start the daily bowel program. To find out more, talk to your child’s doctor or nurse.

2. Place the child on the potty at the same time everyday

- Position on the toilet.
  — Have safety straps and arm rests on the potty chair if necessary
  — Make sure the child can place both feet firmly on the floor. If your child’s feet don’t reach the floor, use a small stool.
• Never leave the child alone on a potty.

• Never leave the child sitting on a potty for more than 15 minutes.

Establishing good bowel habits is not easy. It usually takes months. Keep working at it! Praise your child and yourself for a job well done.
The Bowel Program — Empty the Bowel

Supplies
- non latex glove
- KY jelly or other water soluble lubricant
- underpad
- suppository

What to do

1. Just before your child eats a meal, take a suppository out of the refrigerator. This will let it warm up to room temperature before you use it.

2. Have your child eat a meal and drink something warm.

3. Find a private place. About 30 minutes after the meal, put your child on top of the underpad, on his or her left side, with the knees pulled up towards the chest.

4. Put on the gloves.

5. Take the foil off the suppository. Put some KY jelly on the suppository. Put the suppository up past your child's inner sphincter of the rectum against the rectal wall.

   If there is a lot of stool in the rectum, you may need to remove some stool before putting in the suppository.

6. After putting in the suppository, your child should stay lying down for about 15 minutes. Then help your child to sit on the toilet or potty chair.

7. Encourage your child to bear down. Activities that teach your child to bear down include:
   - blowing a pinwheel
   - blowing bubbles
   - blowing party favors
   - pretending to blow up a balloon (don’t use a real balloon)
8. After complete emptying, if possible, help your child
   — clean him or herself up
    (girls should wipe from the front to the back)
   — put clothing back on
   — wash his or her hands

9. Wash your hands.

10. Thank your child for helping.

Rewards

When you start the bowel program, help your child enjoy it. Reward your child when he or she helps. Keep a calendar or a chart and glue or draw a star on it for each day your child helps. At first, reward every helpful effort. When your child sits on the potty, reward this. Later, when your child is able to empty his or her bowel when sitting on the potty, reward that.

Keep the rewards simple. The best rewards are not money or food. Use a sticker book or chart. Do something together. Go to the park, or do an art or craft project.
Keep Records

Every child is different. We need to find out what works for your child and what doesn’t work. The best way to do this is to write down the details. Bring these notes with you when you see your child’s health care provider. You will be able to talk about ways to make your child’s bowel program work better.

Date:
Time:
Was clothing soiled?
Amount and type of stool:
Medicine:
Progress:
Problems:

Date:
Time:
Was clothing soiled?
Amount and type of stool:
Medicine:
Progress:
Problems:

Date:
Time:
Was clothing soiled?
Amount and type of stool:
Medicine:
Progress:
Problems:

Date:
Time:
Was clothing soiled?
Amount and type of stool:
Medicine:
Progress:
Problems:
Spinal Cord Injury (SCI)

In a spinal cord injury (SCI), stool passes through the body just as it does in a person with normal bowel control. However, the person with spinal cord injury cannot control emptying the bowel. The person doesn't know when the rectum is stretched. When the rectum is stretched or stimulated, the bowel will empty.

When pressure increases in the rectum, a message is sent to the brain that tells the bowels to empty. You can increase the pressure by putting a suppository into the rectum, so the person has a stool. When your child has a spinal cord injury, stimulating or stretching the rectum can make stool pass.

Tips for bowel control in spinal cord injury:

• Keep stools soft with fiber, fluids, and stool softener. Soft, formed stool passes most easily.

• Empty the bowel at the same time every day. Make sure all the stool comes out.

• The bowel will empty best about 30 minutes after eating.

• The bowel will empty best if you give your child a warm drink, such as hot cocoa, tea, or warm lemonade.
Lower Spinal Cord Problems or Spina Bifida

In lower spinal cord injury (SCI) and spina bifida, the bottom of the spine and the spinal cord has a problem. This makes the stool pass through the body much slower than normal. Because the stool is in there longer, more water is pulled out of the stool. This makes the stool hard and dry. The rectum stretches easily, and can store a lot of stool. Children with this problem need to take stool softeners every day, and use suppositories. They also need to eat a lot of fiber and drink a lot of fluid.

Tips for bowel control in lower spinal cord problems:

• Soft stool passes most easily. Keep stools soft with fiber, fluids, and stool softener. If you don’t, your child will become constipated quickly.

• Give the suppository 30 minutes after eating.

• Have your child sit on the toilet or potty chair with his or her feet up on a stool. Keep the knees higher than the hips.

• Sometimes hard stool gets stuck in the rectum, and only loose stool can get out around it. If your child's stool becomes too loose, check the rectum for stuck stool.

• If your child's stool becomes too loose, give less stool softener.

• If your child is constipated, you may need to give an enema.
For Spinal Cord Injury (SCI), Lower Spinal Cord Problems and Spina Bifida

The child will not know when there is too much stool in the rectum. The stool may come out (overflow soiling) and the child will not be able to stop it. A bowel program gets the stool out every day or two. This keeps too much from building up and spilling out when you’re not ready for it.

Problems

Any bowel program can have some problems: constipation, diarrhea, and urinary tract infection.

Constipation

Takes longer for the stool to pass through the large intestine, so more water is taken out of the stool.

If the bowel isn’t emptied on time, even more water is removed from the stool. This makes it dry and hard. Hard stools can cause sores around the anus.

☐ yes ☐ no See the handout: Constipation (#8)

Diarrhea

Diarrhea can be caused by illness, or too much medicine that loosens stools.

Sometimes hard stool gets stuck in the rectum, and only loose stool can get out.
around it. It may look like diarrhea, but your child may really be constipated. This is called encopresis.

If your child has too much diarrhea, your child could become dehydrated.

☐ yes  ☐ no  See the handout: Dehydration (#13)

**Urinary tract infections**

- Urinary tract infections are often seen with chronic constipation.

- The amount stool in the rectum, puts pressure on the tubes that drain urine

- Bladder isn’t always completely emptied

- Urine that can’t get out of the bladder has too much bacteria and can cause an infection

☐ yes  ☐ no  See the handout: UTI or Urinary Tract Infection (#409)

**Now that you’ve read this:**

☐ Tell your nurse or doctor why your child needs to be on a bowel program.  
  (Check when done.)

☐ Describe your child’s bowel program to your nurse or doctor. (Check when done.)
If you have any questions or concerns,
☐ call your child’s doctor or     ☐ call ______________________

If you want to know more about child health and illness,
visit our library at The Emily Center at Phoenix Children’s Hospital
1919 East Thomas Road
Phoenix, AZ 85016
602-546-1400
888-908-5437
www.phoenixchildrens.com

Disclaimer
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Family Review of Handout

Health care providers: Please teach families with this handout.
Families: Please let us know what you think of this handout.

Would you say this handout is hard to read?  Yes  No
          easy to read? Yes  No

Please circle the parts of the handout that were hard to understand.

Would you say this handout is interesting to read? Yes  No

Why or why not?

Would you do anything differently after reading this handout? Yes  No

If yes, what?

After reading this handout, do you have any questions about the subject? Yes  No

If yes, what?
Is there anything you don’t like about the drawings?  

☐ Yes  ☐ No

If yes, what?

What changes would you make in this handout to make it better or easier to understand?

Please return your review of this handout to your nurse or doctor or send it to the address below.

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Thank you for helping us!