

Boston Children's Hospital's Colorectal & Pelvic Malformation Center

BOWEL MANAGEMENT PROGRAM



**Boston
Children's
Hospital**

Until every child is well™



Welcome to the Bowel Management Program

Boston Children's Hospital treats children with bowel management issues by pairing surgery (when necessary) with proven techniques for bowel management, including enemas, medication and diet.

Boston Children's improves the lives of children born with:

- Anorectal malformations/ imperforate anus
- Hirschsprung's disease
- Inflammatory bowel disease
- Colonic dysmotility, such as idiopathic constipation
- A variety of other colorectal disorders

Our goal is to improve the quality of life for all children with colorectal problems. A team of health care professionals from across Boston Children's will teach your family how to regulate and control your child's bowels. Successful bowel management means that your child goes to the bathroom consistently and on a schedule, without bowel incontinence (your child poops unexpectedly). This offers your child the chance to live with a new sense of freedom and independence.

Recipe for success

Bowel management is not as simple as giving an enema, following a prescribed diet or taking a medication. It is a combination of enemas, colonic irrigations, diet and medication.

Remember:

- The success of any of these strategies depends upon collaboration among your family, your child and the health care team.
- There are many approaches depending on your child's needs. It takes dedication, determination, consistency and love by everyone involved.
- Children who have completed the bowel management program and remain clean for 24 hours experience a new sense of confidence.

To contact Boston Children's:

Phone: 617-355-8664 | Fax: 617-730-0477 | ColorectalCenter@childrens.harvard.edu

Visit us Online:

www.bostonchildrens.org/colorectalpelvic

Like us on Facebook!

www.facebook.com/BostonChildrensHospital

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FAQs

What is the right age for my child to be in the Bowel Management Program?

- The right time for bowel management is when your child needs to be clean and free of stool (poop) throughout the day, usually in time for preschool/ school.
- If your child is still in diapers, it is important to make sure your child does not get constipated (have a hard time pooping). The Bowel Management Program intends to keep your child pooping daily.
- Some children come to the program earlier if they have significant constipation or many urinary tract infections due to stool in the diaper. In these cases, the reason to start the program is not to prevent accidents. It is to have more control on the timing of bowel movements and to make sure they do not build up stool.

When should I toilet train my child?

- If your child has an anorectal malformation, toilet training and pooping is usually a long-term goal. We believe that all children deserve a chance to toilet train, but if they are not successful, it does not always mean they will not be able to toilet train in the future.
- We encourage families to toilet train at the same time as you would for a child without an anorectal malformation.
- The same is true for children with Hirschsprung's disease.
- For all children, the most important thing for successful toilet training is avoiding constipation and making sure the colon is stimulated.

What are some tips for toilet training?

- Keep it simple: When your child is 2-3 years old, sit your child on the toilet after every meal. Give your child positive feedback.
- Keep it light: The less stress you feel the less stress your child will feel during the process. If your child is not successful, do not view it as a failure.
- Keep it fun: Give your child a small reward or make a sticker chart to use when your child goes to the bathroom on the toilet.

Can my child go to school if toilet training is not working?

We usually recommend the Bowel Management Program by the time your child is 3-4 years old (at least 6-12 months before starting school). This way, if your child is not toilet trained, your child can still go to school clean and in normal underwear.

It is important to know that it is up to your family to decide when and how to start bowel management. The goal is to have your child in school wearing normal underwear.

What time of day should we do the enemas?

This depends on what works best for your family. Consider what time of day will work best. Try to do them at the same time every day to avoid accidents. Your child may have an accident if more than 24 hours go by between enemas. If you miss an enema one day, you may need to do 2 the next day to get back on track. You should not let more than 48 hours go by between enemas.

During bowel management week, we ask that the enemas happen in the morning so we can get an X-ray after the enema to see how well it worked.


How long does bowel management take each day?

Bowel management takes at least an hour. The enema runs for 5-10 minutes and your child holds it (if possible) for another 5-10 minutes. Then, your child sits on the toilet for 45-60 minutes to completely empty the bowels.

How can I make my child comfortable?

How well the enema works depends on making the process as comfortable and efficient as possible. Reading books, watching TV or playing with toys or an electronic device (or even homework!) can pass the time and make the process more pleasant. Your child can rest his legs on a footstool while sitting on the toilet to be more comfortable.

Let your child help with the process. Your child can help mix the enema, put in the catheter and decide what activity to do during the enema. This can give your child a sense of empowerment through the process.



What are the long-term effects of daily enemas?

- Enemas have been used for decades. Bowel management with daily enemas to keep clean has been in practice for more 20 years.
- As far as we know, there are no known negative effects caused by using saline and water or the additives (glycerin and Castile soap).
- If you make your own saline, we recommend following the recipe in this booklet in order to make sure it is not too concentrated. This can cause nausea, vomiting, dehydration and discomfort.
- We try not to use phosphate enemas (brand name Fleet®) in the long-term. It may cause electrolyte issues (especially in people with kidney problems). It can also sometimes irritate the colon.

Do enemas affect how my child absorbs nutrients and grows?

- The enemas only wash the colon. The colon's job is to absorb water and make solid stool. Most of the nutrients are processed higher in the digestive tract (small bowel).
- Your child may eat more after starting bowel management. This is because the tummy is no longer full of stool and your child feels hungrier instead of bloated.

What if my child starts having accidents again while doing the program?

The enema plan that may be working well during the week may need to be changed once you get home. Accidents happen for usually 2 reasons:

- There is a build-up of stool and the enema needs to be stronger.
- The enema is too strong and over-stimulating the colon.

The best way to tell is by taking an X-ray of the belly. This can be ordered by us or your child's pediatrician. We can make changes to the enema as needed after seeing the X-ray.

Does the enema plan stay the same as my child grows?

Changes in your child's routine, diet, size and stress level can affect the plan. We usually know if things need to be changed if your child starts having accidents. We also take X-rays of the belly to check for a build-up of stool. Planning ahead can help make changes to the plan before accidents start to happen.

Will my child need bowel management for life?

Although it is different for every child, our philosophy is that we "never say never." Every child deserves a chance to go to the bathroom without enemas (as long as they stay clean). However, many children with a higher anorectal malformation, short sacrum and/or tethered cord may always need enemas.

Many children who might be able to control their bowels do not potty train until they are older because they need to learn to understand their body's signals letting them to know they need to stool. This may include a stricter diet and routine. Younger children may not want to cooperate with this and can be kept clean with enemas until they are ready to try it.

How will I know if my child is ready to stop daily enemas?

- Your child's routine works and your child is clean and not having accidents.
- Your child is cooperative, aware of his problem and motivated to work with you.
- Stopping enemas and switching to laxatives is usually done carefully with a "laxative trial."
- If the first laxative trial does not work, it does not mean it is a failure. It means your child is not ready or does not have the ability to completely control stooling.

Please save all your questions about your child's specific needs for your clinic visit with a doctor.

TALKING WITH YOUR CHILD ABOUT BOWEL MANAGEMENT

Be as honest as possible

- Children of all ages tend to cope best when they are told what to expect and why it is happening.
- Phrases you can use:
 - » “We don’t know why this happens to some kids and not to others. But it is part of what makes you so special, even if it is not fun.”
 - » “Your body is not able to (1) Get all of your poop out without help, or (2) Tell you when you need to go to the bathroom.”
 - » “We are going to use a soft, small tube (or straw), to put special water into your bottom to help you poop. Once all of the water is in your bottom, you will sit on the toilet for a while until all of your poop comes out.”
 - » “We will have to do the enemas every day to help keep you from having accidents because your body keeps making new poop that will need to come out.”

Do not apologize for the bowel management process

- This is a fact of life for your child and everyone in your family needs to see it this way.
- Realize that you are making the best decision you possibly can for your child and his or her quality of life.
- You may empathize with your child and validate his or her feelings (like frustration). But your child needs to understand that there are some things in life that are not fun, and we have to do them anyway.

Use words that are understandable for your child

- “Straw” or “Tube” instead of “Catheter”
- “Special Water” or “Flush” instead of “Enema Solution”
- “Potty” instead of “Toilet”
- “Poop” instead of “Bowel Movement”
- Decide what you want to call the enema. Other families use “Flush” or “Wishy-Wash”

You can help your child feel less alone

- Tell your child that there are lots of kids who have enemas to help them with accidents.
- Try to connect with other families who are learning about or practicing bowel management.
 - » There are always families looking to connect with each other during the bowel management week.
 - » Join the Colorectal Parent Group. See page 18 for a list of Facebook support groups.
 - » If you need personal help, please contact a Boston Children’s social worker.
- Help your child see that everyone has differences. All kids are unique in some way.

Examples:

 - » Some kids may not be able to eat certain foods because they make them sick.
 - » Some kids have to take medicine every day or they will get sick (like kids with diabetes).
 - » Some kids need wheelchairs.
- Consider a camp for children with similar medical conditions. Example: Youth Rally: www.youthrally.org.
- Remember that going to the bathroom is still a private matter. Keep this in mind when connecting your child with others.

Involve your child in the process

- Give your child simple tasks to help with the bowel management process. This gives your child some control and ownership over the process.

Examples:

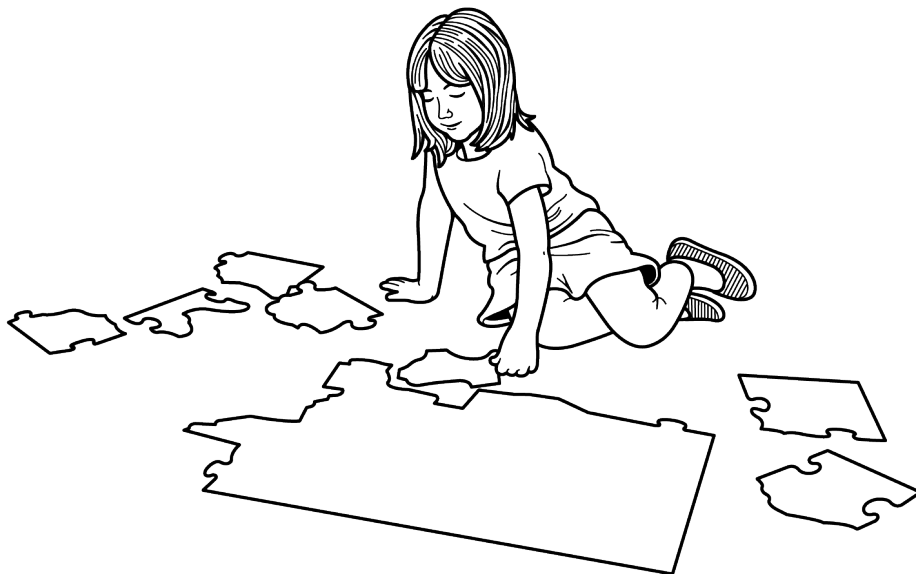
- » Help with set-up, like measuring the liquid.
- » Pick out an activity to do while sitting on the toilet.

Emphasize the positives

- Examples:
 - » Let your child pick out “big kid” underwear.
 - » Your child can now go to school, sleepovers, play sports, etc. without worrying about accidents.
 - » No more bad smells from accidents.
- You have to believe in the process yourself or you will not be able to convince your child.

Create an enema “fun” kit

- Put together a box of special activities or movies that your child can choose from when it is time for the enema.
- These activities should only be used during the enema. If you let your child watch these movies or play the games at other times, they lose their special appeal and your child will not look forward to them.
- Some suggestions of fun distraction toys:
 - » Light spinners
www.amazon.com/Awesome-Lighted-Spinning-Party-Disco/dp/B003AGIJ86
 - » I-Spy Books
www.amazon.com/Spy-Treasure-Hunt-Picture-Riddles/dp/0439042445
 - » Fun craft projects
www.orientaltrading.com
 - » Puzzles
 - » Movies/cartoons
 - » What else does your child enjoy?




GUIDELINES FOR THE WEEK OF BOWEL MANAGEMENT

After meeting with the team, you will get the enema/laxative dose to start with.

For Enemas

Give the enema every morning. We will take an X-ray after your child has done the 45–60 minutes sit time. The goal is to see how the enema works and how it empties the colon.

 **If your child is on enemas, please report the following information every day:**

Soiling between enemas:

Number of accidents _____

Number of hours after the enema the accident happened _____

Amount _____

Consistency/color _____


Difficulty with the enema:

Leaking _____

Not able to hold the enema fluid for 10 minutes, etc. _____

For Laxatives

Give the laxatives either in the morning or in the evening before bed. It usually takes 8–12 hours for the laxatives (taken by mouth) to take effect.

 **If your child is on laxatives or stopping enemas, please report the following information every day:**

Was there a bowel movement in the last 24 hours? _____

How many bowel movements in the last 24 hours? _____

Did your child know he had to have a bowel movement? _____

Did he make it to the bathroom or did he have an accident? _____

What is the consistency of the bowel movement? _____

Are there any changes made to the prescribed regimen? _____

Important To-Do's

- Schedule an X-Ray for your child Monday–Thursday before 11 a.m. Call 617-355-8664 or e-mail your nurse after the X-Ray is taken for an update. Your nurse will tell you about any changes in the plan. You do not need to give a report on the weekend since we will not change anything until after the X-ray on Monday.
- Always carry your cell phone with you so we can reach you. Please check your messages throughout the day.
- Questions? Please leave a message stating your concerns on our voicemail or e-mail. After hours, please call 617-355-8664 and ask for the General Surgery doctor on call.

ENEMA INGREDIENTS



Normal Saline Solution

You can buy this pre-mixed online or through your pharmacy.

You can make your own using these exact measurements:

- Mix 500 mL water and $\frac{3}{4}$ teaspoons of salt, or
- 1,000 mL water and 1 $\frac{1}{2}$ teaspoons of salt

Be sure to use a measuring spoon for accuracy.

You can measure out the right amount of solution and pour it into the enema bag.



USP Vegetable Glycerin

Glycerin is a mild soap that can be added to the saline solution.

You can buy it at a pharmacy.

You can buy it in a department store or supermarket in the cosmetics aisle with fragranced hand soaps.

The easiest way to find it may be searching online for "USP vegetable glycerin."

The amount of glycerin ranges from 5–30 mL.



Castile Soap

Castile is a mild kind of hand soap

This is not a prescription. You can buy it in a pharmacy, department store, supermarket or online.

The easiest way to find it may be by doing a search online for "castile soap."

It comes in packets or in bulk.

In general, we use between 9–27 mL, because the packets come in a volume of 9 mL.



Phosphate

This is also called the Fleet® brand.

You can buy this at a pharmacy or supermarket.

It comes in a prefilled bottle of 66 mL or 122 mL.

Fleet® brand also makes plain saline enemas. Be sure to check the active ingredient list. The active ingredient should list phosphate.

We try to avoid giving daily phosphate enemas long-term.

ENEMA ADMINISTRATION

Normal Saline Recipe

Use the ratio of 1 1/2 teaspoons (7.5 grams) of table salt to 1,000 mL of warm tap water. Do not change this recipe.

Equipment You Need

Enema bag (Kangaroo feeding bag)
22fr or 24fr silicone catheter with 30 mL balloon
30 mL syringe (slip tip) to inflate the balloon
Water soluble lubricant (Surgi-lube packets or KY Jelly)
Saline solution
Additives as ordered by your child's physician
60 mL syringe (catheter tip) for cleaning the catheter

Steps

1 Test the balloon:

Inflate the balloon with the 30 mL syringe. Withdraw the plunger. The balloon should be fully deflated. This tests the balloon to be sure it is functioning before you put it into the rectum.

2 Prime the tubing

Clamp the tubing of the enema bag. Pour the amount of warmed normal saline and additives (as prescribed) into the bag. Mix well. Open the clamp and allow the fluid to flow out of the bag. Squeeze the drip chamber on the tubing until it is halfway filled with fluid. Fill the entire tubing with fluid (this is called priming) before you insert the tube into the rectum.

3 Position your child

These are the most common positions. Use what is most comfortable for your child. Keeping the knees up (see below) positions the anal opening so you can see it well. It also helps relax the sphincter.



4 Insert the catheter

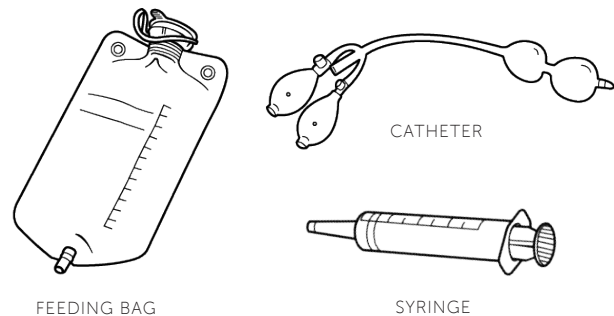
Lubricate the catheter well. Place the catheter into the rectum about 4-5 inches.

- Fill the syringe with air or water and attach it to the small port of the catheter. Gently inflate the balloon. Once the air is in, take the syringe off right away.
- Pull gently on the catheter until you feel some resistance. This resistance is the balloon around the rectal wall. It will keep the solution from leaking during the enema.

5 Give the enema

Continue to gently pull on the catheter to keep the enema from leaking. Give the enema over 2-5 minutes.

To slow down the fluid: Use the roller clamp on the tubing or lower the level of the enema bag to lessen the gravity flow. If the enema leaks, it is usually because there is not enough constant tension or the balloon is not inflated properly.



6 Hold time/toilet sitting

Your child needs to hold the solution for 10 minutes after the enema is given for it to work well. Leave the tubing connected to the catheter until the catheter is removed.

When hold time is up, place your child on the toilet. Deflate the balloon. This lets the catheter slip out.

Most children need a sit time of 45 -60 minutes.

If your child is young, try having special toys and books to use only during the enema for distraction. If your child is older, he could read a favorite book or do homework while sitting.

7 Clean up

When finished, rinse the bag with water and flush the catheter with soapy water using the 60 mL syringe. You can reuse the catheter as long as the balloon is intact.

RECTAL ENEMA PRODUCTS

Only use as told by your child's doctor.



Pedia-Lax

liquid glycerin suppository

Dosage:

2.8 grams glycerin per
liquid suppository

Some solution may still be in bottle
after you give it.



Pedia-Lax

solid glycerin suppository

Dosage:

1.2 grams glycerin per
solid suppository



Dulcolax

(bisacodyl) suppository

Dosage:

10 mg bisacodyl
per suppository



Dulcolax

(bisacodyl) enema

Dosage:

10 mg bisacodyl per
30 mL enema

Some solution may still be in bottle
after you give it.



Fleet

pediatric phosphate enema

Dosage:

monobasic sodium phosphate 9.5 g,
dibasic sodium phosphate 3.5 g per
59 mL enema

Do not use if your child has kidney
problems. For 2–11 years of age.
Some solution may still be in
bottle after you give it.



Fleet

adult phosphate enema

Dosage:

monobasic sodium phosphate
919 g, dibasic sodium phosphate
heptahydrate 7 g per 118 mL enema

Do not use if your child has kidney
problems. For 12 years and older.
Some solution may still be in bottle
after you give it.

LAXATIVE TRIAL

The goal of laxatives is to manage constipation to prevent stool from backing up.

- 1 Laxatives are used instead of enemas if your child might have the ability to control his bowels. The enemas stop and laxatives start to help a bowel movement happen.
- 2 The goal is to have 1-2 soft bowel movements a day.
- 3 The first amount of laxatives your child is prescribed is based on your provider's experience with other children, your child's history and previous laxative or enema requirements. The final dose of laxatives is based on trial-and-error through the week.
- 4 The trial is centered around stimulant laxatives. The most common stimulant laxative is Senna. Another stimulant laxative is Bisacodyl.
- 5 A laxative is different than a stool softener. A stool softener just softens the stool but does not stimulate the colon to produce a bowel movement.
- 6 In order for your child to control the stool, your child needs the right amount of stimulation and the right consistency. The consistency may be changed by adding soluble fiber (Pectin, Citrucel, fiber gummies, Benefiber). **See below for more information.**

For best results during laxative week:

- 1 Stay close to a bathroom. Since this is like toilet training, your child should have easy, quick access to the bathroom.
- 2 Have your child sit on the toilet 15-20 minutes after meals. Your child will probably have the urge to poop after eating.
- 3 If your child does not have a bowel movement after 24 hours, it means that he did not get enough laxative the day before. To reset your child's system, you will give an enema and the dose of laxatives will go up (by 1 square).
- 4 If your child has more than 3-4 loose/watery stools, it means that too much laxative was given. The dose is lowered (by 1/2 a square).
- 5 Try to keep your child's diet the same through the week: 3 meals and snacks given at the same time.
- 6 If your child has regular accidents at the end of the week, your child may not be ready for laxatives. We may suggest giving daily enemas. It does not mean that laxatives are not possible. Your child may just need more time before laxatives will be successful.

WATER SOLUBLE FIBER SUPPLEMENTATION

Water soluble fiber adds form to the stool, making it easier for your child to sense when it is time for a bowel movement and to hold it until your child reaches the bathroom.



Pectin

Also called Sure Jell, Ball, Certo or generic brands

Adds bulk to the stool without causing constipation

Can be found in grocery stores with canning supplies

Binds with liquid to make it a solid

Either non-flavored or sour with sweet aftertaste

You can mix it with foods like yogurt, applesauce, orange juice, slushies or smoothies or small amount of a drink. Like all medications, your child must finish the entire serving to make sure it is the right dose.

A typical dose is 1 Tablespoon with all 3 meals



Citrucel

Adds bulk to the stool without causing constipation

You can buy it in a drugstore or pharmacy

Binds with liquid to make it a solid

Orange flavored

You can mix it with foods like yogurt, applesauce, orange juice, slushies or smoothies or small amount of a drink. Like all other medications, your child must finish the entire serving to make sure it is the right dose.

A typical dose is 1 Tablespoon with all 3 meals

ORAL LAXATIVE PRODUCTS

Only use as told by your child's doctor.



Ex-Lax squares

Dosage:

15 mg per square



Ex-Lax tablets

Dosage:

15 mg per tablet

There are several doses of tablets. Be sure to read the label carefully.



Ex-Lax tablets

Maximum Strength

Dosage:

25 mg per tablet

There are several doses of tablets. Be sure to read the label carefully.

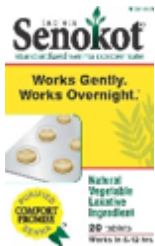


Senna syrup

or liquid

Dosage:

8.8 mg per 5 mL
(1 teaspoon)



Senokot tablet

Dosage:

8.6 mg per tablet

There are several doses of tablets. Be sure to read the label carefully.



Senokot Xtra

Dosage:

17 mg per tablet

There are several doses of tablets. Be sure to read the label carefully.



Dulcolax

(bisacodyl)

Dosage:

5 mg per tablet

There are several doses of tablets. Be sure to read the label carefully.



Miralax

or generic polyethylene glycol 3350

Dosage:

17 grams per cap/scoop
depending on brand

NUTRITION THERAPY FOR COLORECTAL PATIENTS

Foods High in Fiber

Fruits: pears, berries, apples with skin, citrus fruits, bananas, skin of fruits

Vegetables: green leafy vegetables, broccoli, peas, spinach, potatoes with skin, corn.

Grains: whole wheat or whole grain bread, bagels, pasta, cereal and English muffins, brown rice, oats and oat bran, barley

Other: popcorn, beans and legumes, nuts and seeds

Foods Low in Fiber

Fruits: apples without skin, applesauce, fruit juice

Vegetables: white potatoes without skin, iceberg lettuce

Grains: white bread, bagels, pasta, crackers and English muffins, white rice

Meat: chicken, fish and eggs

Dairy: yogurt, milk and cheese

Other: candy, oils and butter

Fluids

It is important that your child drink enough fluid to prevent constipation. All liquids count toward your child's daily total fluid goal. This includes beverages and food. About 20% of fluids come from foods. Types of fluid include water, milk, formula, low-calorie sport drinks, broth, popsicles and gelatin.

It is important to remember that not all children react to foods the same way. If you have questions about your child's nutritional needs or would like more information, please ask to meet with our outpatient registered dietitian.

NUTRITION THERAPY

Follow this diet to help control your child's diarrhea/constipation.



Dairy

Non-Constipating Foods

- Soy, rice, or almond milk
- Use lactose-free milk if diarrhea is the result of lactose intolerance

Constipating Foods

- Half-and-half, cream
- Sour cream
- Whole milk and whole milk ice cream
- Yogurt with berries, dried fruits or nuts



Fruits

Non-Constipating Foods

- All raw fruits except melons, bananas and berries
- Dried fruits, including raisins and prunes
- Fruits in heavy syrup
- Fruit juice with pulp

Constipating Foods

- Applesauce
- Apples without skin
- Bananas
- Canned soft fruit
- Melons



Grains

Non-Constipating Foods

- Barley, oats
- Brown or wild rice
- Cereals made from whole grains or bran
- Cereals or bread made with nuts and seeds
- Flax seed
- Popcorn
- Whole wheat or whole grain breads, rolls, crackers or pasta

Constipating Foods

- Grain foods should have less than 2g of fiber per serving
- Products made with white flour, like noodles, white rice, saltines, pretzels and cold cereal
- White bread



Vegetables

Non-Constipating Foods

- All raw vegetables
- Beans
- Fried vegetables
- Sweet potatos and potato skins

Constipating Foods

- Mashed potatoes without skin
- Most well cooked vegetables without seeds or skin
- Strained vegetable juice



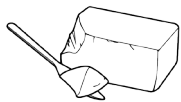
Meat
and Other Protein

Non-Constipating Foods

- Eggs
- Fish
- Smooth nut butter
- Soft well cooked meats

Constipating Foods

- Fatty meats (sausage, bacon, hot dogs)
- Luncheon meat such as bologna or salami
- Nuts and chunky nut butter
- Red meat, fried meat, poultry, or fish



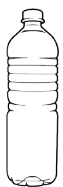
Fats and Oils

Non-Constipating Foods

- None

Constipating Foods

- High Fats
- Oil, butter, margarine and cream cheese



Beverages

Non-Constipating Foods

- Commercially available rehydration beverages (not homemade)
- Drinks with caffeine*
- Water

Constipating Foods

- Drinks with caffeine*
- Sorbitol or high fructose corn syrup

*Note: Caffeine is a stimulant so it can cause you to have a bowel movement. But it can also cause dehydration, which can lead to constipation. Talk with your doctor about whether or not your child can have caffeine.

Other

Non-Constipating Foods

- None

Constipating Foods

- Chocolate
- Iron and calcium supplements

Laxative Trial Sample Day

	Day 1	Day 2
Breakfast	Rice Krispies cereal or any puffed rice cereal 1/2 ripe banana Rice, soy, or almond milk	Plain white bagel with minimal amount of spread (butter, margarine, smooth nut butter) Scrambled eggs 1/2 ripe banana Rice, soy or almond milk
Snack	Water Hard-boiled egg Graham crackers	Water Vanilla wafers
Lunch	Chicken rice soup 1 slice white toast 1/2 cup applesauce Water	Plain hamburger with white bun 1/2 cup applesauce Peeled baked potato wedges Water
Snack	Saltine crackers Water or decaffeinated drink	Pretzels Water or decaffeinated drink
Dinner	Baked chicken White pasta Peeled apple slices Water or decaffeinated drink	Baked fish White rice Peeled apple slices Water or decaffeinated drink
Snack	Vanilla wafers and/or Sugar-free hot chocolate made with water or a milk alternative (such as soy milk)	Angel food cake and/or Sugar-free hot chocolate made with water or a milk alternative (such as soy milk)

TIPS FOR CONTROLLING DIARRHEA

Not every child tolerates food the same way, so learning to identify the foods that control your child's diarrhea best is very important. A great way to do this is by keeping a food journal and recording what your child eats and when he or she has bowel movements for at least 3–7 days. If possible, review your child's food journal with a registered dietitian who can help evaluate their diet and identify foods that could be contributing to their diarrhea.

Once diarrhea goes away or your child has not had accidents for 24–48 hours, you can begin to incorporate more foods. Introduce 1 new food at a time every 2–3 days. If your child soils after eating a newly introduced food, remove that food from his diet and introduce other new foods.

Drink plenty of fluids

Avoid drinks high in sugar (like juice)

Smaller, more frequent meals may help

Avoid foods high in fat, fiber and sugar

Avoid spicy foods

Avoid foods that are very hot or very cold

The sugar in milk (lactose) may increase diarrhea in some children. Try lactose-free products such as rice, soy or almond milk instead of milk and dairy

RULES FOR CHILDREN WITH HYPERMOTILITY

We recommend following these rules.

- 1 The goal is that your child stays clean 24 hours a day.
- 2 Your child may need may need 1 or all of the following: medication, enemas, water soluble fiber (Pectin or Citrucel) and a constipating diet.
- 3 Loperamide (the generic name for Imodium) may be ordered to slow the colon. **See below for information.**
- 4 The constipating diet should be very strict to start. You child should take a multivitamin daily while on this diet unless otherwise recommended by the pediatrician.
- 5 If your child stays completely clean, add 1 food at a time to the diet. Give that same food 3 days in a row to see how it affects your child. If your child stays clean, you can add that food to the diet. If there is soiling, do not give that food again.
- 6 Your child's stool should be soft and formed. Water soluble fiber will help get the right consistency of the stool.
- 7 Your child should eat meals at the same time every day. Do not give any snacks.
- 8 Stay close to a bathroom while we are forming your child's bowel management plan.
- 9 Have your child sit on the toilet after meals. This is the time that movement of the colon happens, which can cause a bowel movement.
- 10 Your child may have occasional voluntary bowel movements but still soil a lot. If this happens, give enemas for 6 months to 1 year. Every 6 months to 1 year, we can try stopping the enemas and try potty training.

GENERAL INFORMATION ABOUT LOPERAMIDE

What is Loperamide?

This medicine treats diarrhea and decreases the amount of drainage in patients who have ostomies.

Should my child take this medication?

Your child should not take this medicine if he or she has ever had an allergic reaction to loperamide or if he has severe colitis, diarrhea caused by antibiotics or dysentery (inflammation of the intestines and bloody diarrhea). Do not give it to your child if he is under 2 years old.

How do I give this medication?

- Loperamide is give by mouth as a liquid-filled capsule, tablet, capsule or liquid.
- Your doctor will tell you how much to give and how often.
- Have your child drink plenty of water while using this medicine.
- Your child can take it on an empty or full stomach.
- Your child should take it 1 hour before meals

What if I miss a dose?

- Give the missed dose as soon as possible.
- If it is almost time for your child's next regular dose, wait until then and skip the missed dose.
- Your child should not have 2 doses at the same time.

How should I store this medicine?

- Store it at room temperature, away from heat and moisture. Do not freeze it.
- Keep all medicine out of the reach of children.

What warnings come with this medicine?

- Do not give loperamide to your child unless your doctor tells you to.
- Make sure your doctor knows if your child takes any antibiotic drugs.
- Loperamide solution (liquid) contains alcohol.
- If your child is still having diarrhea after using this medicine for 2 days, call your doctor.
- Ask your doctor or pharmacist before using any other medicine, including over-the-counter medicines, vitamins and herbal products.

Are there possible side effects?

Call the doctor right away if you notice any of these side effects:

- Constipation with nausea and vomiting
- Bloating

If you notice these less serious side effects, talk with your doctor:

- Stomach pain, cramps
- Loss of appetite
- Dry mouth
- Changes in vision, such as trouble focusing
- Drowsiness or dizziness

Note the different dosages. Be sure that the dose in mg is correct. Please ask your nurse or pharmacist for help if you need it.

Loperamide (Imodium)

Caplet or tablet: 2 mg

Liquid: 1 mg/5 mL

Imodium AD: 1 mg/5 mL

PROBLEM SOLVING AT HOME

For Constipation

Follow these instructions if your child is constipated or if you are not sure if your child is constipated.

If your child is constipated:

Give 2–3 enemas a day for 3 days. Then make the enema stronger or increase the dose of laxative.

Remember that you can only give 1 phosphate Fleet enema in 24 hours. If you see a large amount of stool or hard stool after the second or third enema, your child is constipated.

It will never hurt to give an extra enema.

We need to take an X-ray to make sure the colon is emptying.

Signs of constipation:

Little or no results from the enema despite normal activities and diet

Hard pieces of stool

Smear of stool in the underwear

For Soiling or Diarrhea

Remember that soiling may be a result of impaction, rather than the following causes.

Possible causes of soiling or diarrhea:

Virus: Has your child been around anyone else with symptoms (diarrhea, fever, vomiting)?

- Your child may have more severe symptoms with a virus and symptoms may last longer than with other children.
- Watch for dehydration and see your local physician if you have concerns about dehydration.
- If your child has severe diarrhea, you can wait to give the enema or laxative until it gets better.

Antibiotics may cause diarrhea.

The enema may be too strong or the laxative dose may be too high.

WHY ARE X-RAYS NEEDED?

The Bowel Management Program is considered successful once your child can keep a clean colon and can wear normal underwear all the time.

You will continue the program when you return home. After days, weeks, months or years the program may no longer work. This can happen because the enema or laxative is no longer cleaning the colon or because the colon is moving too fast because of dietary or other problems.

In order to make small changes to your child's program, we will need an X-ray of your child's belly when your child has accidents or gets constipated. This helps to us find the specific reason why the bowel management is no longer working. For instance, if the X-ray shows that the colon has a large amount of stool, we may recommend a larger dose of laxatives, using a larger enema or a more concentrated enema. On the other hand, if we see an empty colon, your child may need a less concentrated enema, a smaller dose of laxatives or a diet change.

NETWORKING RESOURCES

Bowel Group for Kids

The Bowel Group for Kids (BGK) is a registered, Australian-based charity dedicated to providing emotional support to families of children born with Hirschsprung's disease, imperforate anus/ano-rectal malformations and associated conditions.

www.bgk.org.au

Healing Helpers

Healing Helpers are comfort stuffed animals that physically relate with the person who adopts them, with a zipper pouch in the place of a scar and a mended organ representing their own. They are intended to bring hope, comfort and happiness to children and families that live with difficult medical and emotional circumstances.

www.healinghelpers147.com

Hirschsprung's & Motility Disorders Support Network (HMDSN)

Hirschsprung's & Motility Disorders Support Network (HMDSN) is an organization that connects families that have a child suffering from Hirschsprung's Disease and other Gastrointestinal motility disorders for support

www.hirschsprungs.info

Parents Helping Parents

Parents Helping Parents meets the needs of individuals and their families with any special needs, including illness, accidents, birth defects, neurological conditions, learning or physical disabilities, mental health issues, etc.

www.php.com

Pull-thru Network

Pull-thru Network (PTN) is one of the largest organizations in the world dedicated to the needs of those born with an anorectal malformation or colon disease and any of the associated diagnoses.

PTN offers a private Yahoo email group just for girls ages 11–13. Please contact PullthruNetwork@gmail.com for more information.

www.pullthrunetwork.org | PullthruNetwork@gmail.com

Sibling Support Project

The Sibling Support Project is the first national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental and mental health concerns.

www.siblingsupport.org

The Spina Bifida Association

The Spina Bifida Association (SBA) serves adults and children who live with the challenges of Spina Bifida. SBA is the only national voluntary health agency solely dedicated to enhancing the lives of those with Spina Bifida. Its tools are education, advocacy, research and service.

www.spinabifidaassociation.org

TEF/VATER Support Network

TEF/VATER Support Network offers support for families with babies born with a tracheo-esophageal fistula with esophageal atresia. They provide long term support to parents and families, information about the different birth defects, the operations to correct them, the problems before and after surgery, as well as coping skills.

www.tefvater.org | info@tefvater.org

United Ostomy Associations of America, Inc

The United Ostomy Associations of America, Inc. (UOAA) is a nonprofit organization that supports, empowers and advocates for people who have had or who will have ostomy or continent diversion surgery.

www.ostomy.org

Wrightslaw

Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law, education law and advocacy for children with disabilities and medical needs at school.

www.wrightslaw.com

FACEBOOK SUPPORT GROUPS**Bladder & Cloacal Exstrophy: My Son Has Exstrophy**

This is a group for boys and men living with bladder or cloacal exstrophy.

www.facebook.com/group/595040753883250

Bladder & Cloacal Exstrophy: My Daughter Has Exstrophy

This is a group for girls living with bladder or cloacal exstrophy.

www.facebook.com/groups/230137903813818

Bladder Exstrophy

This is a group for anyone living with bladder exstrophy or for anyone who knows people born with this birth defect. It supports people dealing with the issues brought about by bladder exstrophy.

<https://www.facebook.com/groups/2261346099>

Bowel Management for Spina Bifida

The purpose of this group is to allow people with Spina Bifida and parents of children with Spina Bifida to share information, tips, pointers and tricks regarding bowel management programs.

www.facebook.com/groups/729598100490391

Imperforate Anus/Bowel Management

This is a group for parents/guardians of children born with IA to talk about issues related to imperforate anus and bowel management. To join, you will need to email bowelmanagement@aol.com and explain why you are interested.

<https://www.facebook.com/groups/99804044741>

Imperforate Anus in Greece Support Group

This group is intended to provide support and information for residents of Greece dealing with imperforate anus (IA) or related issues.

www.facebook.com/groups/imperforateanusgreece

Imperforate Anus International Support Group

This group is intended to provide support and information for international residents dealing with imperforate anus (IA) or related issues.

www.facebook.com/groups/IASupports

Imperforate Anus USA Support Group

This group is intended to provide support and information for residents of the U.S dealing with imperforate anus (IA) or related issues. They welcome family members of children with the condition as well as adults who have grown up with IA.

www.facebook.com/groups/IA.USA.Support

Persistent Cloaca

This is a forum for families and girls with cloaca to learn from and support each other through all the challenges they have to overcome.

www.facebook.com/groups/153812524718254

VACTERL Association

The VACTERL Association group is a place for individuals and families, affected by VACTERL, to share information and resources and provide support. To join, please find the Admin of the group and send them a brief private message on why you would like to join.

www.facebook.com/groups/VACTERL

Women with Spina Bifida, Cloacal Exstrophy or OEIS

This group is for women with Spinal Bifida, Cloacal Exstrophy or Omphalocele Exstrophy Imperforate Anus (OEIS) and moms with daughters that have SB, OEIS or CE. You must be at least 15 to join. Men are not allowed to join this group.

www.facebook.com/groups/679538932082253

CAMPS**Youth Rally**

Youth Rally helps teens who have a bowel or bladder dysfunction or ostomy prepare for independence and build a personal support network.

www.youthrally.org

Victory Junction

Victory Junction enriches the lives of children with serious illnesses by providing life-changing camping experiences that are exciting, fun and empowering, at no cost to children or their families.

www.victoryjunction.org

The Center for Courageous Kids

The mission of The Center for Courageous Kids is to uplift children who have life-threatening illnesses by creating experiences year-round that are memorable, exciting, fun, build self-esteem, are physically safe and medically sound.

www.thecenterforcourageouskids.org

Camp John Marc

Camp John Marc offers several camps for sibling of children, teens and young adults with Spina Bifida and other chronic illnesses.

www.campjohnmarc.org

VIDEO RESOURCES

Enema administration

<http://bit.ly/2eil8N0>

Irrigations:

<http://bit.ly/2e5Q9Zg>

 DAILY ENEMA PROGRESS CHART

You should expect the phone call from your nurse between 2–5 p.m.

Day 1

Report on any special instructions you were given.

Day 2

Enema solution used: _____

Time given: _____

Any leaking: _____

Good results: _____

Any accidents? If so, how many hours after the enema? Description?

Day 3

Enema solution used: _____

Time given: _____

Any leaking: _____

Good results: _____

Any accidents? If so, how many hours after the enema? Description?

Day 4

Enema solution used: _____

Time given: _____

Any leaking: _____

Good results: _____

Any accidents? If so, how many hours after the enema? Description?

Day 5

Enema solution used: _____

Time given: _____

Any leaking: _____

Good results: _____

Any accidents? If so, how many hours after the enema? Description?

Day 6

Enema solution used: _____

Time given: _____

Any leaking: _____

Good results: _____

Any accidents? If so, how many hours after the enema? Description?

Day 7

Enema solution used: _____

Time given: _____

Any leaking: _____

Good results: _____

Any accidents? If so, how many hours after the enema? Description?

Day 8

Enema solution used: _____

Time given: _____

Any leaking: _____

Good results: _____

Any accidents? If so, how many hours after the enema? Description?

 LAXATIVE DOSE CHART

	Laxative Amount (mg)	Loperamide (Imodium) (mg and how often)	Fiber (Pectin) (Tablespoon)	Diet (Type)	Number of Voluntary Bowel Movements (your child knows he/she has to go to the bathroom and makes it to the toilet)	Number of Accidents/Soilings	Accidents/Soiling: Amount and description
DAY 1							
DAY 2							
DAY 3							
DAY 4							
DAY 5							
DAY 6							
DAY 7							
DAY 8							

 **DAILY LAXATIVE PROGRESS CHART**

You should expect the phone call from your nurse between 2–5 p.m.

Day 1

Laxative used and dose given: _____

Number of voluntary bowel movements: _____

Description: _____

Number of accidents: _____

Description: _____

Any fiber given? If so, how much and how often?

Day 2

Laxative used and dose given: _____

Number of voluntary bowel movements: _____

Description: _____

Number of accidents: _____

Description: _____

Any fiber given? If so, how much and how often?

Day 3

Laxative used and dose given: _____

Number of voluntary bowel movements: _____

Description: _____

Number of accidents: _____

Description: _____

Any fiber given? If so, how much and how often?

Day 4

Laxative used and dose given: _____

Number of voluntary bowel movements: _____

Description: _____

Number of accidents: _____

Description: _____

Any fiber given? If so, how much and how often?

Day 5

Laxative used and dose given: _____

Number of voluntary bowel movements: _____

Description: _____

Number of accidents: _____

Description: _____

Any fiber given? If so, how much and how often?

Day 6

Laxative used and dose given: _____

Number of voluntary bowel movements: _____

Description: _____

Number of accidents: _____

Description: _____

Any fiber given? If so, how much and how often?

Day 7

Laxative used and dose given: _____

Number of voluntary bowel movements: _____

Description: _____

Number of accidents: _____

Description: _____

Any fiber given? If so, how much and how often?

Day 8

Laxative used and dose given: _____

Number of voluntary bowel movements: _____

Description: _____

Number of accidents: _____

Description: _____

Any fiber given? If so, how much and how often?



**Boston
Children's
Hospital**

Until every child is wellSM

BOWEL MANAGEMENT PROGRAM