



Guide for Bowel Management Week at the Colorectal and Pelvic Center

Bowel Management Week

Dear Caregiver,

Welcome to the Colorectal and Pelvic Center's Bowel Management Week. This week, we will work with you to create a plan for your child. The goal is to help them have regular bowel movements, completely empty their bowels, and have no accidents for a period of 24 hours. Our overall goal is to improve your child's quality of life, give them confidence, and a new sense of freedom. Please read through this guide to help prepare you for the week.

If you have any questions, please contact our team at Colorectal@childrens.com

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Introduction to Bowel Management Week

Bowel Management Week (BMW) is an 8-day program at the Colorectal and Pelvic Center at Children's Medical Center Dallas. It is for children who are born with a health issue such as:

- Imperforate Anus/Anorectal Malformation (IA/ARM)
- Cloacal exstrophy
- Hirschsprung Disease (HD)
- Pelvic tumors such as sacrococcygeal teratomas

It is common for children born with these health issues to have long term bowel problems such as:

- Severe constipation (hard poop they have difficulty passing)
- Stooling accidents (poop they cannot hold in)
- Chronic diarrhea (loose, watery poop).

Kids should start a bowel management program between the ages of 3-5 years old or when they start school so they can wear underwear without accidents.

The goal of bowel management week is to:

- Help patients empty their bowels fully every 24 hours (a 1-day period)
- Help them prevent accidents and stay clean in their underwear

Before your first visit:

- Your child will have a contrast enema (an x-ray of their tummy with a liquid used so we can see your child's large bowel). The liquid will be given through a small flexible tube inserted through their bottom.
- This will help show if their large bowel (where poop is stored) is larger than normal or moves too slowly or quickly.
- The contrast enema will be done the day before clinic unless your child has had this done in the last year.

We will work with you to decide which bowel management program fits best with your child's needs. This program may include enemas, laxatives, and changes to their diet.

We will teach you how to start the program at home, keep a diary and record important information to share with us at their visits over the next week. We will also show you how to set up a MyChart account if you don't have one. MyChart is how you can send messages to our team and how we can share any changes to your child's program. See Appendix A for MyChart information.

The next pages will review the schedule for the week and details about the 3 bowel management programs we offer.

Introduction to Bowel Management Week

On **Day 1** (Thursday), at your clinic visit:

- Your child will have an x-ray of the bowel.
- This x-ray will help to see how much poop is in the bowel and if there is any remaining contrast from the study completed the day before. This will also tell us how fast or slow the poop moves in your child's bowel.
- The health care team will review your child's tests, past medical and surgical records, do a physical exam, and decide on your child's bowel management program.

On **Days 2-4** (Friday, Saturday, and Sunday):

- You will start your child's bowel management program.
- You will keep a diary and record
 - any pain or problems your child has
 - the amount, type, and color of your child's poop
 - the time of any accidents your child has and how big they were
- It is important the treatment is given at the same time every day. This process takes commitment, patience, and hard work by everyone.

On **Day 5** (Monday):

- Your child will come back to the clinic.
- They will get an x-ray.
- The health care team will look over the diary and talk with you about how your child did over the weekend.
- Changes may be made to your child's bowel management program based on the results of the x-ray and how your child is doing.
- If needed, you and your child will be able to meet with our social worker, dietitian, and child life specialist.

On **Days 6-7** (Tuesday and Wednesday):

- Your child will come back each morning for an x-ray.
- Please send us a MyChart message or call by 10am telling us how your child is doing.
- Each day, the health care team will review the x-ray and the information you shared to make changes if needed.
- You will get a message or call back with these changes so you can start them with the next treatment.
- Changes might need to be made every day to find the right plan for your child's success.

On **Day 8** (Thursday), at the last clinic visit:

- Your child will get their last x-ray.
- You will meet with the health care team to finalize your child's bowel management program.
- Supplies will be ordered, and a follow-up clinic visit will be made.
- It is common to make changes to your child's plan as they get older and their body and life-style change.



Enema Program

For children who are unlikely to have bowel control (have frequent poop accidents) or who have severe chronic constipation, an enema program may be the right choice for bowel management. This program consists of a daily enema that will clean the bowel once per day. The recipe for the enema solution is made exactly to your child's needs so the bowel is emptied at the same time every day. This keeps your child completely clean in their underwear for 24 hours.

The enema is made up of a saltwater solution (normal saline) with other ingredients added such as glycerin or castile soap. These ingredients help the bowel empty fully. It is important to remember the enema solution is made special for each child and will take a few tries to find the right recipe.

If your child is started on an enema program, it is important to remember these things:

1. The goal of the enema program is that your child stays clean in their underwear for 24 hours or 1 full day.
2. The enema should always be given at the same time every day. For most families, this is usually in the evening when schedules are less busy. During bowel management week, we prefer the enemas to be given in the morning before getting the x-ray for the day.
3. Enemas can be frustrating, and they often need to be changed until we find a good solution that works for your child.
4. Expect to spend one hour per day on the entire process. This includes time for set up, giving the enema, and sitting on the toilet.
5. Your child should sit on the toilet for about 45 minutes to allow enough time to poop and get rid of the enema solution. You may give your child a toilet break for 5 minutes half-way through the process, to stand up and stretch but they should remain close to the bathroom.
6. Diet and fiber play a small part in this program; however, it is still important to offer a healthy, well-balanced diet with 3 planned meals per day, without snacks in between.
7. If your child can sometimes poop in the toilet on their own, we may be able to try a laxative program in the future. Every 6-12 months, we can try laxatives in hopes of stopping the enema program. As your child gets older and more mature, there is a higher chance they will be more interested and successful in being free of accidents. The laxative program is discussed on pages 7-9.

Enema Program

Enema solution ingredients

- **Normal saline**
 - You can buy normal saline already mixed at the pharmacy or with a prescription through a medical supply company.
 - You may mix your own normal saline by following the recipe attached as Appendix B. Be sure to follow the instructions exactly.
- **Glycerin**
 - Glycerin is a mild soap.
 - You may purchase glycerin in any pharmacy. You may also purchase it in a department or grocery store in the cosmetic aisle.
 - The easiest way to find it is by doing an internet search for “liquid glycerin”.
 - We often use between 10-30 ml.
- **Castile Soap**
 - Castile soap is a mild hand soap and not a pharmacy product.
 - You may find it in a department or grocery store in the cosmetic aisle. We suggest buying only castile soap without fragrance.
 - The easiest way to find it is by doing an internet search for “castile soap”.
 - It is available in packets and in bulk.
 - We often use between 9-27 ml. One packet is 9 ml.

Enema supplies

You will be provided your first enema kit. We will then order the following items through a medical supply company:

- Size 24 Fr Foley catheter with a 30 ml balloon
- Gravity feeding bag and tubing with a roller clamp
- 30 ml luer tip syringe
- 60 ml catheter tip syringe
- Water-soluble lubricant
- IV pole or a hook

Laxative Program

Laxatives are an important bowel management tool. We prefer laxatives with senna, which come in many forms, including liquids, tablets, and chocolate squares. Senna laxatives are stimulants which cause the movement of poop through the bowel; this helps with hypomotility (slow moving bowel). If we feel your child would do well with a laxative program, they will be prescribed a starting dose of senna and fiber. We will make changes throughout the week of bowel management until we find the right dose. Again, every child is unique, and we will make an educated guess on the right dose. This will take trial and error.

If your child is started on a laxative program, it is important to remember these things:

1. The goal is for your child to poop 1-2 times every day and stay clean in underwear for 24 hours or 1 full day.
2. Your child's poop should be soft and formed. Fiber will help with this.
3. Three meals a day should be offered at planned times without snacks in between. The same types of foods should be given every day until you know which foods may cause accidents or constipation.
4. Stay close to a bathroom during this week.
5. Have your child sit on the toilet for 10 minutes at regularly scheduled times. They should sit on the toilet after waking up, after every meal, after school and before bed. Sitting on the toilet after meals is best because a strong movement of the bowel happens after eating.
6. Give the senna in the evening or before bed. Senna will normally cause your child to poop within 6-8 hours. This will allow your child to poop in the morning before getting the x-ray.
7. After bowel management week, you may give the dose of senna at whatever time works best for your family. It is important to give the dose at the same time every day.
8. If one entire day goes by and your child does not poop, it means they did not receive enough senna the day before. In that case, you must give an enema to remove the stool and we will increase the dose of laxatives.
9. If your child gets loose/watery poop, it means that too much senna was given. In that case, we may decrease the dose of senna or increase fiber.
10. If your child sometimes poops in the toilet on their own but still has accidents often, we recommend going back to the enema program. Every 6-12 months, we can try laxatives in hopes of stopping the enema program. As your child gets older and more mature, there is a higher chance they will be more interested and successful in being free of accidents.

Laxative Program

Oral laxative (senna) products

The following is a list of laxatives you can find at a pharmacy or grocery store, without a prescription:

- Ex-Lax chocolate squares (15 mg per square)
- Ex-Lax tablets (15 mg or 25 mg per tablet)
- Senna liquid (8.8 mg per 5 mL)
- Senokot tablets (8.6 mg per tablet)
- Senokot Xtra (17 mg per tablet)

Fiber

Adding water soluble fiber to the diet, along with plenty of fluids, can make poop more formed without causing constipation. When poop is formed, rather than loose or watery, it is easier to "hold" so your child can make it to the toilet. Fiber will make the senna laxative work better.

The following is a list of soluble fiber supplements you can find at a pharmacy or grocery store without a prescription:

- Benefiber (3 grams per packet, 1.5 grams per 1 teaspoon powder)
- Metamucil (2 grams per 1 packet, 2 grams per 1 teaspoon powder)
- Pectin (2 grams per 1 tablespoon powder)
- Nutrisource (3 grams per 1 scoop powder)
- Citrucel (2 grams per 1 tablespoon powder, 1 gram per 2 tablets)

Fluids

It is very important your child drink plenty of fluids to help prevent constipation. Water helps keep food moving through the intestines and keeps poop soft and easier to pass. If your child experiences diarrhea, they will also need to drink plenty of fluids to replace the fluids lost.

Laxative Program

Foods for constipation

Below is a list of foods that will help control your child's constipation.

LAXATIVE DIET

Food group	Food recommended	Food to avoid or limit
Whole grains	Whole wheat breads, cereals and pasta, oatmeal, bran flake cereals, popcorn, brown rice, quinoa	White bread, white rice
Beans and legumes	Lentils, black beans, kidney beans, soybeans, lima beans, chickpeas, edamame, refried beans, hummus, navy beans	
Fruits	Berries, apples with the skin on, oranges, pears, blackberries, strawberries, raspberries, avocados, prunes, kiwis, ripe bananas, apricots, plums, raisins, peaches, grapes, watermelon	Unripe bananas
Vegetables	Carrots, broccoli, green peas, collard greens, potatoes, sweet potatoes, okra, kale, lettuce, spinach, swiss chard, artichoke hearts, asparagus, brussels sprouts, cabbage, squash, zucchinis, artichokes, turnip greens	Cauliflower, onions, garlic
Nuts and seeds	Almonds, peanuts, walnuts, pecans, flaxseed, pomegranate seeds, chia seeds	
Dairy products	Plant based milks, yogurt	Cheese, ice cream, milk, butter, sour cream
Meat	Turkey, chicken	Red meat, processed meat, eggs
Beverages	Water, fruit juice, vegetable juice, non-caffeinated herbal tea	Sodas, artificially sweetened drinks
Other foods	Peanut butter, olive, and flaxseed oils	Fast foods, frozen dinners, fried foods, cookies, cakes, caffeine, chocolate, sweeteners, potato chips, pizza, sugar

Hypermotility Program

Instead of constipation, a small number of children will have hypermotility (a fast-moving bowel that causes diarrhea). These children have either an overactive bowel, a short segment of bowel, or no bowel at all. Most of the time they have a lower chance for having bowel control. This means even when an enema cleans their bowel easily, new poop passes quickly through the bowel. This can be hard to manage and requires a strict diet, daily medications, and sometimes small enemas with little or no other ingredients.

If your child is started on a hypermotility program, it is important to remember these things:

1. The goal is that your child stays clean in underwear for 24 hours or 1 full day.
2. Your child may need a combination of a constipating diet, medications, fiber, and enemas. The right combination is found through trial-and-error and may require frequent changes.
3. The constipating diet should be very strict at first. If your child stays completely clean (no accidents), you may add one food at a time from the Phase Two group . Give that same food three days in a row to see its effect. If your child stays clean, that food may be added to their diet. If your child has an accident, that food should not be part of their diet.
4. Sugar can be a problem for these children, and in some cases, medications that have sugar may need to be changed.
5. Give a daily multivitamin to your child because this is a very limited diet.
6. Your child's poop should be soft and formed. Fiber will help with this. When poop is formed, rather than loose or watery, it is easier to "hold" so your child can make it to the toilet.
7. Three meals a day should be offered at planned times, without snacks in between. The same types of foods should be given every day, until you know which foods may cause accidents or diarrhea.
8. Stay close to a bathroom during this week.
9. Have your child sit on the toilet for 10 minutes at regular scheduled times. They should sit on the toilet after waking up, after every meal, after school and before bed. Sitting on the toilet after meals is best because a strong movement of the bowel happens after eating.
10. Imodium (Loperamide) is used to slow down the bowel, so poop does not move through it as quickly. Your child may be started on this medication. They will be prescribed a starting dose and we will make changes throughout the week of bowel management until we find the right dose.
11. Imodium should be given one hour before meals. You should see a change in how often your child poops within 48 hours of starting Imodium.
12. Imodium should not be taken if your child has diarrhea with fever, vomiting or a possible viral or bacterial infection.

Hypermotility Program

13. If your child has loose/watery poop, we may increase the dose of Imodium or fiber, or see if there is something in the diet that needs to be removed.
14. If one entire day goes by and your child does not poop, we may decrease the dose of Imodium or be less strict on the diet. We may also recommend giving an enema to help your child poop.
15. If your child sometimes poops in the toilet on their own but still has accidents often, we recommend continuing the use of daily enemas. Every 6-12 months, we can try to stop the enemas. As your child gets older and more mature, there is a greater chance they will be more interested and successful in being free of accidents.

Medications for diarrhea

The following is a list of medications your child may be prescribed:

- Imodium liquid (1mg per 5ml) – available without a prescription
- Imodium AD liquid (1 mg per 7.5ml) – available without a prescription
- Imodium (Loperamide) tablet (2mg) – available without a prescription
- Levsin (Hyoscyamine) tablet (0.125mg)
- Cholestyramine powder (4g per packet)
- Lomotil liquid (2.5mg per 5ml)
- Lomotil tablet (2.5mg)
- Clonidine patch (0.1mg patch/24 hour)

Hypermotility Program

Foods for diarrhea

Below is a list of foods that will help control your child's diarrhea. In Phase One, eat strictly constipating foods to slow down the bowel. You may move to Phase Two after three days of no poop accidents.

HYPERMOTILITY / CONSTIPATING DIET – PHASE ONE

Food group	Food recommended	Food to avoid or limit
Milk	Plain rice milk	All others
Vegetables	None	If vegetables are eaten, make sure they are cooked and not raw
Fruits	Applesauce, apples without skin, bananas	Avoid raw fruits
Starches, grain	White and refined flour, bread, crackers, pasta/noodles, white rice, white potatoes (without skin), dry cereals	All others
Meat, seafood, legumes	Baked, broiled, or grilled meat, poultry, fish, lean deli meats, eggs	Avoid beans
Fats and oils	Non-stick spray, non-fat butter spray	Limit butter, margarine, and oils; no fried foods
Sweets	Sugar free gelatin, popsicles, jelly, syrup, or ice cream	All others
Beverages	Water, Gatorade, sugar-free Crystal Light, and sugar-free Kool-Aid, Pedialyte	Avoid carbonated beverages, soda, juices, high-sugar drinks

Hypermotility Program

HYPERMOTILITY / CONSTIPATING DIET – PHASE TWO

Food group	Food recommended	Food to avoid or limit
Milk	All milk products allowed, but limit to 16 oz total per day	Any milk or cheese products (such as ice cream) with nuts or seeds
Vegetables	Vegetable juice without pulp, vegetables that are well cooked; Green beans, spinach, pumpkin, eggplant, potatoes (without skin), asparagus, beets, carrots	Raw vegetables, vegetables with seeds
Fruits	Applesauce, apples (without skin), banana, melon, canned fruit, fruit juice (without pulp)	Fruit juice with pulp, canned pineapple, prunes, dried fruit, jam, marmalade
Starches, grain	Bread, crackers, cereals made from refined flours, pasta or noodles made from white flours, white rice, pretzels, white potatoes (without skin), dry cereal	Whole-grain or seeded breads, whole-grain pasta, brown rice, oatmeal, bran cereal, whole-grain cereal
Meat, seafood, legumes	Meat, poultry, eggs, seafood; baked, broiled, or grilled are preferred cooking methods	Beans, fried or greasy meats, salami, cold cuts, hot dogs, meat substitutes
Fats and oils	All oils, margarine, butter, mayonnaise, salad dressings	Chunky peanut butter, nuts, seeds, coconut
Sweets	Jelly, Rice Dream frozen desserts, sugar, marshmallows, angel food cake	Anything containing nuts, coconut, whole-grains, dried fruits, or jams
Beverages	Water, Gatorade, sugar-free Crystal Light, sugar-free Kool-Aid, Pedialyte	Juice, regular soda, regular Kool-Aid, or powdered drinks
Miscellaneous	Salt, ground or flaked herbs and spices, vinegar, ketchup, mustard, and soy sauce	Popcorn, pickles, horseradish, relish, jams, preserves

Frequently Asked Questions

What are the benefits of a Bowel Management Program?

- It will help your child to go to school, join in activities, and play with friends without having to worry about having accidents.
- It will help your child have a better quality of life, more self-esteem, and confidence.

How should I prepare my child?

Be honest with your child. Children cope better if they know what to expect and why things happen.

Things you can say to help your child cope:

- “We don’t know why this happens to some kids and not others, but this is part of what makes you so special, even if it’s not fun.”
- “Your body is not able to tell you when you need to go to the bathroom or get all of your poop out without help.”
- “We are going to use a soft, small tube (or straw) to put special water into your bottom to help you poop. Once all the water is in your bottom, you will sit on the toilet for a while until all of your poop comes out.”
- “You will have to put the special water in your bottom each day to help keep you from having accidents because your body keeps making new poop that will need to come out.”

Use words that match your child’s age and developmental level, like:

- Straw or tube instead of catheter
- Special water or flush instead of enema solution
- Potty instead of toilet
- Poop instead of bowel movement (or whatever word your family uses)
- Come up with a special name for the enema, such as “flush”, “wishy washy”, or “poopy bye-bye time”

Do not apologize for the process.

- You are making the best choice you can for your child’s quality of life, self-esteem, and self-confidence.
- You should validate your child’s feelings but help them understand some things in life are not fun. Some things need to be done to help them feel better.
- Let your child know their condition is not their fault, and their treatment is not a punishment.
- Be patient with your child and keep calm during the process. Your child may cry, whine, have a temper tantrum and act out. These are common responses that will be for a short time. Setting rules and limits will help handle these responses.

Frequently Asked Questions

Help your child feel less alone.

- Tell your child many other children must use enemas to help them with accidents. It helps to connect with other families in the bowel management program. However, when connecting your child with other children, keep in mind that using the bathroom is still a private matter.
- Join a colorectal parent group, or if your child is old enough, think about going to a camp for children with similar health problems.
- Tell your child all people are different. Some kids can't eat certain foods, some kids must take medicine each day (like kids with diabetes), and some kids can't walk and use wheelchairs.

There are things you can do to make your child more comfortable.

- Have your child rest their feet on a stool when sitting on the toilet.
- Give your child easy tasks to do, like helping mix the enema, or picking out an activity to do while sitting on the toilet. Giving your child something to do will give them ownership in the process.
- Make a special fun kit of toys, movies, and activities. This kit should only be used during the enema, so your child can look forward to it.

Point out the positives.

- Remind your child this will help them stop accidents in school, with friends and during other activities.
- Allow your child to pick out "big kid" underwear.
- Believe in yourself or you will not be able to convince your child.

Are there any long-term effects of daily enemas or laxatives?

Your child was born with a condition that needs enemas and/or laxatives to help them properly empty their bowel. Their normal growth and development should not be changed by daily use of enemas or laxatives.

- Enemas only wash the bowel and do not flush out nutrients.
 - Nutrients are processed higher in the digestive tract (in the small bowel).
- Your child may start to eat more after starting bowel management since their tummy is no longer full of stool.
- Eating a balanced diet and drinking plenty of liquids is very important to your child's health.
- Enemas and laxatives are not addicting.

Will the bowel management program change as my child grows?

Sometimes a bowel management program stops working and needs to be changed. If your child starts having accidents, please call our office.

Resources

Children's School Services

214-456-7733

Consults to patients during hospitalization or while receiving outpatient treatment. Support with 504 plan/School accommodations, special education services, behavior intervention plans, mental health needs, and more.

Transportation

Medical Transportation Program and gas reimbursement

877-633-8747

[Medical Transportation Program | Texas Health and Human Services](#)

DART Bus System

214-749-3278

214-979-1111

214-515-7272

<https://www.dart.org/>

Lodging/Medicaid Lodging

You may be able to get help with lodging and/or meals if your child is having to stay away from home for treatment or appointments. Contact your managed care on the back of your insurance card to request hotel accommodations or meal assistance.

Ronald McDonald House Dallas <https://rmhdallas.org>

***Social work referral needed.** With approximately 78,000 square feet, the House offers 79 private bedrooms, 4 extended stay suites and 6 transplant apartments. Additionally, the House contains multiple playrooms for kids of all ages and interests, a library, media room, craft room, chapel, meditation garden, and outdoor play areas. Two large communal kitchens and dining room provide opportunities for the families to share meals, which are provided 3 times a day by community volunteers, or to prepare their own food if they choose. Donations are always accepted from families, but no one has ever been turned away because of an inability to pay. The actual cost per night to house a family is approximately \$130 - a cost largely covered by individual and corporate donors, community organizations, and special events.

Pull-Thru Network <https://www.pullthrunetwork.org>

Pull-thru Network, Inc. is a volunteer-based, non-profit organization dedicated to providing information, education, support and advocacy for families, children, teens, and adults who are living with the challenges of congenital anorectal, colorectal, and/or urogenital disorders and any of the associated diagnoses.



Resources

One in 5000 Foundation www.onein5000foundation.org

The ONE in 5000 Foundation website is dedicated to being a worldwide resource for the Imperforate Anus (IA) / Anorectal Malformation (ARM) community. Their vision is to ensure that within the next 5 years, every child born with (IA) / (ARM) around the world is guaranteed the following four outcomes, they call it the AIMS program, which focuses on AWARENESS; INFORMATION; MEDICAL; SUPPORT.

United Ostomy Associations of America, Inc. <https://www.ostomy.org>

United Ostomy Associations of America, Inc. (UOAA) is a 501©(3) nonprofit organization that supports, empowers, and advocates for people who have had or who will have ostomy or continent diversion surgery.

Youth Rally <https://youthrally.org>

Each year, the Youth Rally hosts kids and teens living with conditions of the bowel and bladder at a college campus for a 5 night, one of a kind, camp experience that promotes independence, self-esteem, learning, friendship, and FUN!

Imperforate Anus USA Support Group

<https://www.facebook.com/groups/IA.USA.Support>

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.

Terminology and treatments for those with IA differ from country to country, and this group is solely for those in the U.S. The purpose in this is not to be exclusionary; the purpose is to create a group in which those dealing with the same healthcare system can speak to one another.

Research, Education & Awareness for Children with Hirschsprung disease (REACH) <https://www.reachhd.org/>

Reach is a non-profit organization committed to improving the lives of children and families affected by Hirschsprung Disease by increasing awareness, promoting education, connecting families, and supporting various research around the world.

Hirschsprung's Disease Help Group

<https://www.facebook.com/groups/142815342419165>

This private group is for parents and medical professionals caring for children with Hirschsprung's Disease. The group was created by Nicole Baxter after her son was born with Hirschsprung's Disease.

Bowel Management Team Contacts

TEAM MEMBER	CLINIC LOCATION Children's Health Specialty Center Dallas (Pavilion) 2350 N. Stemmons Frwy Dallas, TX 75207	CONTACT NUMBERS
<u>General Surgery Clinic</u> Colorectal Nurse Practitioner	5 th floor F5200	214-456-6040 Office 214-456-6320 Fax 214-456-3406 Office
<u>Psychology</u>	4 th floor F4500	214-456-8000 Office
<u>Radiology Scheduler</u>	1 st floor Pavilion 1 st floor Main Campus C203	214-456-2849 Office
<u>Nutrition Clinic</u>	4 th floor F4170	214-456-8950 Office 214-456-2003 Fax
<u>Social Services</u>	L level of Tower C, Main Hospital Room CL240	214-456-2300 Office 214-867-2061 Fax
<u>Child Life</u>		214-456-8113 Office
<u>Program Manager</u>		214-456-8546 Office

Appendix A

Are you on "MyChart"? MyChart is the online access to your child's medical record. MyChart also offers communication with our staff via MyChart email.

During this week, the providers will discuss and formulate a collective plan for your child's bowel management. MyChart is an excellent way for you and your provider to communicate about any questions or concerns you may have and for the provider to convey adjustments to the regimen. If you do not have MyChart, please use the instructions below to register. If you have any questions, please give us a call, or send us a message to discuss further.

Benefits to MyChart:

- Access to medical records and recent lab results
- Communicate via secure messaging to their care team
- Request follow up appointments
- Access school and work letters
- View their bill online
- View medication list
- Access online communities
- Access education tools
- Appointment reminders

How to sign up for MyChart:

Please go to www.childrens.com, click on "Register", and use the patient's MRN and Date of Birth to register for MyChart. There are also downloadable applications available with iPhones and iPads.

MyChart help desk 1-866-499-2742.



Appendix B

Instructions for Homemade Normal Saline for Enteral Use.

Your child has a GI (gastrointestinal) procedure done at home that requires the use of Normal Saline. These are instructions to make and store Normal Saline at home. This solution should **not** be used for other purposes such as IV (Intravenous).

Supplies

Normal Saline solution can be stored at room temperature for 3 days in a closed container or up to 2 weeks in the refrigerator. The refrigerated solution would need to be out of the refrigerator for 1 hour to allow it to come to room temperature before using.

You will need

- Plain table salt from the store, any brand (not sea salt)
- Water from the sink or distilled drinking water from the store, any brand
- If you have well water, use distilled drinking water (if using well water, you will have to boil it for ten minutes, let cool for one hour, and then boil another ten minutes before mixing with salt.)
- A clean container with a lid
- Measuring teaspoon (tsp)

Recipe & Instructions

Wash your hands. Use a clean container with a lid. Measure 4 cups of warm or room temperature water and place into the container. Add 2 teaspoons (tsp) of table salt. Mix well with large spoon. Label the container **Normal Saline** and the **date/time** it was prepared.

- 4 cups of water
- 2 teaspoons of table salt
 - The salt dissolves in the water better if the water is warm

Storage of Normal Saline

The prepared Normal Saline can be stored on the kitchen counter for 3 days or in the refrigerator for up to 2 weeks. If stored in the refrigerator, take the amount of normal saline that you need out of the refrigerator and allow it to come to room temperature before using (1 hour).

Reference:

Fellows, J., & Crestodina, L. (2006). Home-prepared saline. *Journal of Wound, Ostomy and Continence Nursing*, 33(6), 606–609.

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