



**TRANSPLANT UNWRAPPED
PRESENTS:**

A Parent and Caregiver's Guide to Medications



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Medication Basics

Children with intestinal failure as well as other gastrointestinal conditions, often require many medications. As a parent or caregiver of a child, it is important to speak with your child at an age-appropriate level about the following:

- Why he or she is taking the medication.
- How and when he or she needs to take the medication.
- The importance of taking his or her medications.
- Medication safety.

The older your child, the more he or she should know about his or her medications. For age-specific recommendations, refer to this [FDA article](#).

Medication Safety

- Store medications in a safe location that is out of reach for children.
- Never leave medications or vitamins out on a kitchen counter or at a child's bedside.
- Always relock the safety cap on a medication bottle. Make sure you hear the "click."
- **Never** tell children **medicine is candy**.
- Tell your children that medication and vitamins should only be given by a parent or adult caring for them.
- Educate your child on the correct use of his or her medication and the potential dangers of misuse.

Getting Your Child to Take Medication

General Tips:

- Remain calm when giving your child their medication. Your child models your behavior and feeds off of your emotions.
- Use positive reinforcement, such as creating a reward program. Consider using a reward chart (such as the one listed on the [Transplant Unwrapped Kid's site](#))
- Give your child a sense of control by offering them choices when taking his or her medicine. For example, ask them if they would like juice or water to wash down their medicine.
- If your child needs structure, use a timer during medicine time.

Getting Your Child to Take Medication

General Tips Continued:

- Use distraction: Allow your child to play with a toy or watch a TV show. Some kids who are learning to take pills or other medicines may need to avoid distractions.
- Assess your child's needs and make an individualized plan.

If possible, allow your child to **select the form** of their medication. Common forms:

- Liquid
- Pill
- Shots
- Sublingual (under the tongue)



Tips for Liquid Medications



- If your child does not like the taste of his or her liquid medicine, ask the pharmacist if a flavor can be added.
- If flavor can be added, allow your child to choose the flavor. This gives them a feeling of control and encourages them to want to take their medicine.
- Suggest your child hold his or her nose when taking the medicine to block the smell and taste.
- Chill the medicine. Some kids find chilled medicine more palatable.
- To help numb the taste buds, have your child suck on a Popsicle® or ice cube before taking medicine.



Tips for Taking Pills



- If your child cannot swallow a pill, ask if the pill can be crushed. Note that not all pills can be crushed. Mixing suggestions: applesauce, ice cream, juice, mashed potatoes, pudding.
- Children usually can start learning to take pills around 5-6 years old.
- When teaching to take pills, do so in a calm, quiet environment.
- It may be helpful to first model pill taking with a stuffed animal or doll. Your child should also watch you take a pill or vitamin.
- When ready, have your child start trying to mimic pill taking with small pieces of candy, such as mini M & Ms, Tic Tacs, or Nerds. Slowly increase the size until your child reaches nearly the size of the pill he or she will need to take.
- If the pill is extra-large, ask the pharmacist if you can split the pill in half.

Common Medications: Short Bowel Syndrome (SBS) and Intestinal Rehabilitation

- 1. Anti-Diarrheal Medication:** This slows down the movement of contents through the intestine. This increases the time contents spend in contact with the intestinal wall, thus, increasing absorption. Ex: Imodium®, Lomotil®, Tincture of Opium, Codeine
- 2. Anti-Acid Medications:** Decreases the amount of stomach acid the stomach produces. This helps reduce gastric hypersecretion commonly seen in kids with short bowel. Examples: famotidine (Pepcid®), ranitidine (Zantac®), omeprazole (Prilosec,® Losec®)
- 3. Bile Acid Binders:** These function to bind excess bile salts, which can worsen short bowel syndrome malabsorption. They can help with bile salt diarrhea but must be taken carefully because they can also affect your child's ability to absorb fat-soluble vitamins and nutrients. An example is cholestyramine.
- 4. Antimicrobials:** It is common for children with short bowel syndrome to get small intestinal bacterial overgrowth (SIBO). This is treated with an antimicrobial agent or regimen. Your child's team will recommend the best antimicrobial treatment. Probiotics may also be suggested to help with SIBO.
- 5. Growth Hormone:** Growth hormone, known as somatropin, is made by the pituitary gland in the brain. When released into the body, it promotes the growth and maintenance of organs and tissues. It has been made into a synthetic form. When injected into an individual's with short bowel, it has been shown to enhance intestinal adaptation and increase absorption of fluids and nutrients.
- 6. Glucagon-Like Peptide-2 (GLP-2) Analog:** GLP-2 is a substance usually produced naturally by the human body. Gattex® is an injectable analog that is FDA approved for children >1 year of age with short bowel syndrome and dependent on PN.
Function: Improves absorption of fluids and electrolytes by increasing the absorptive surface of the small intestine.

Helpful Tip: Is your child struggling with his or her Gattex® shots? Try using our **shot hero rewards chart** on our For Parents Page to motivate and encourage them to keep on going!

Common Medications: Post-Intestinal and Multivisceral Transplantation

1. **Anti-Rejection Medication or Immunosuppression:**

- When your child receives an organ transplant, their body senses the new organ as foreign, and the body's immune system attacks it.
- Immunosuppressive medication helps reduce the risk of your child's body rejecting the new organ by lowering their immune response.
- Since your child has a lowered immune response, this also means that your child is more susceptible to all types of infections.
- **Common immunosuppressants include:** Tacrolimus (Prograf), Prednisone (steroid), Cyclosporine (Neoral, Sandimmune), Mycophenolate Mofetil (CellCept), Sirolimus (Rapamune), Thymoglobulin
- **Tip:** Explain the importance of these medications to your child at a level they can understand. Skipping doses of anti-rejection medications can lead to organ rejection and possible graft failure. Do not scare your child into taking the medication; rather, educate them on what the medication is for and the gift of organs they have received.

2. **Prophylactic Medications:** Medications given to prevent infection. Examples:

- Acyclovir (antiviral)
- Nystatin (antifungal)
- Clotrimazole (antifungal)
- Sulfamethoxazole/ Trimethoprim (Bactrim) (antibiotic)
- Pentamidine (alternative to Bactrim)
- Valganciclovir (antiviral)

3. **Anti-Acid Medications:** These help to decrease the amount of acid the stomach produces. Examples: pantoprazole (Protonix®), famotidine (Pepcid®), ranitidine (Zantac®), omeprazole (Prilosec,® Losec®)

4. **Metoclopramide (Reglan®):** Reglan (metoclopramide) increases muscle contractions in the upper digestive tract, which helps to increase the rate at which the stomach empties into the intestine. Your child's transplant team may prescribe this if they are having trouble with slow motility or nausea after their transplant.

5. **Anti-Diarrheal Medication:** This slows down the movement of contents through the intestine. It helps to decrease diarrhea and high ostomy output. Ex: Imodium®, Lomotil®, Tincture of Opium, Codeine

Tips on Post-Transplant Medications

- Immunosuppressants are usually taken at the same time every day, usually 12 hours apart (8 hours apart for small children). Please refer to your child's transplant team or pharmacist for dosing instructions.
- Many immunosuppressants and post-transplant medications interact with grapefruit. Avoid giving your child grapefruit or grapefruit-containing products.
- Ask your care team for their recommendation if your child misses a dose of their immunosuppression medications.

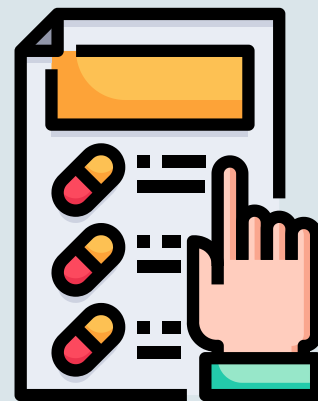
Keeping Track of Your Child's Medications

Always **have a list of your child's medications** with you.

Include:

- Name of the medication.
- Dose of the medication.
- The reason why your child is taking the medication.

Consider putting the list in a note on your phone and have a written hardcopy, so it is never lost.



Set alarms on your phone **for medication times**. Keep a regular schedule for medications. This will help you and your child stay on top of taking medications and create structure for your child.

If your **child experiences any side effects** from a medication, **contact your child's care team** immediately. Write down the date, time, medication, and side effects for your records.

Sample Medication Tracking Chart

Medication	Purpose or Reason to Take	Dose	Time(s) of Day	Form (liquid, pill, shot)	Special Instructions

Interested in learning more?

Visit us on our [Main Website](#), where you will find helpful webinars, downloads, and support systems. In addition, our [Parent's and Caregiver's Page](#) on the Transplant Unwrapped Kid's site also offers helpful downloads and information.

Get in Touch!



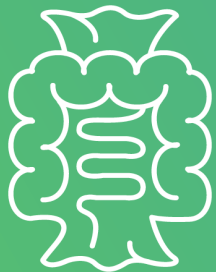
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