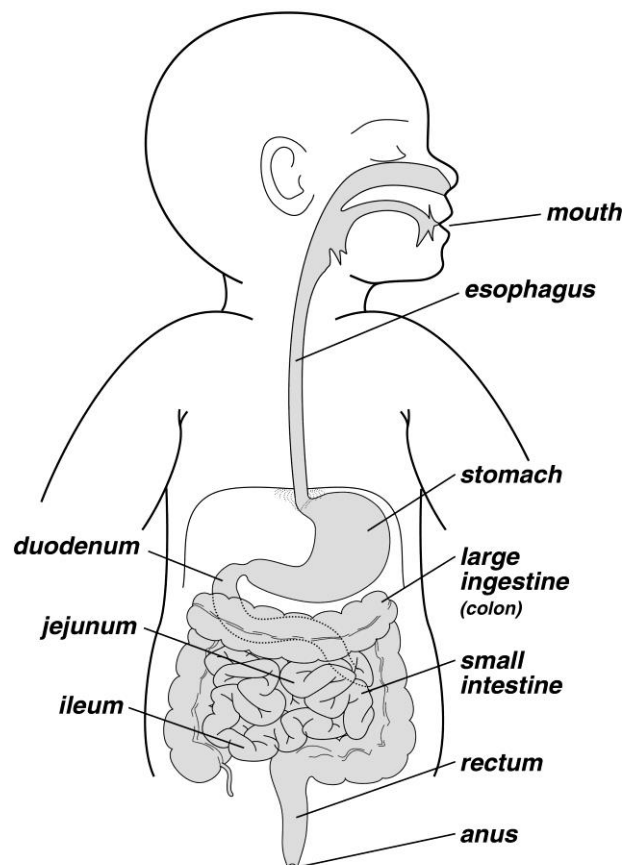


## Caring for Your Child's Ostomy

This guide will teach you what an ostomy is and how to care for it. You will learn about the care of an ostomy, changing ostomy appliances, and supplies needed for your child's ostomy.

### Normal Digestive System

Food passes from the mouth to the esophagus; or through a tube into the stomach, where it is broken down into small pieces. The food then moves into the small intestine where nutrients are absorbed. The rest of the undigested food moves into the colon where water is absorbed. It becomes stool and is passed through the rectum and comes out through the anus.

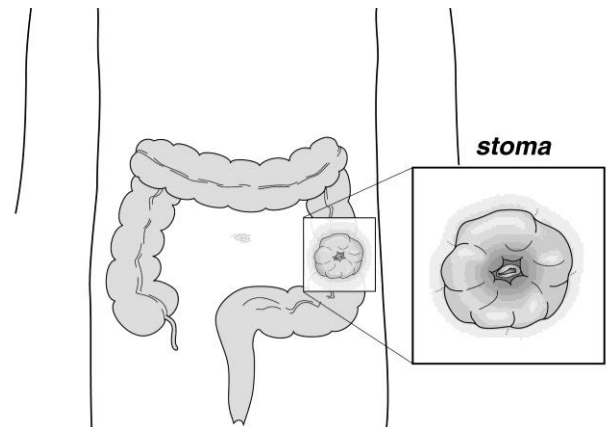


### What is an ostomy?

An ostomy is an opening created during surgery that brings the bowel from the inside of the body to the outside of the body on the abdomen. It may be temporary or permanent. There are different types of ostomies depending on what part of the bowel is used.

### What does the stoma look like?

The opening of the bowel on the outside of the body is called a stoma. The stoma can look different from child to child, but should look pink or red in color, moist, and round or oval in shape. The stoma may change in size or shape a few weeks after surgery.



### Why does my child need an ostomy?

An ostomy is usually needed when stool can no longer pass the normal way through the rectum. There are a variety of reasons why your child may need an ostomy. Your child's doctor will talk with you.

## Types of Ostomies

### Colostomy

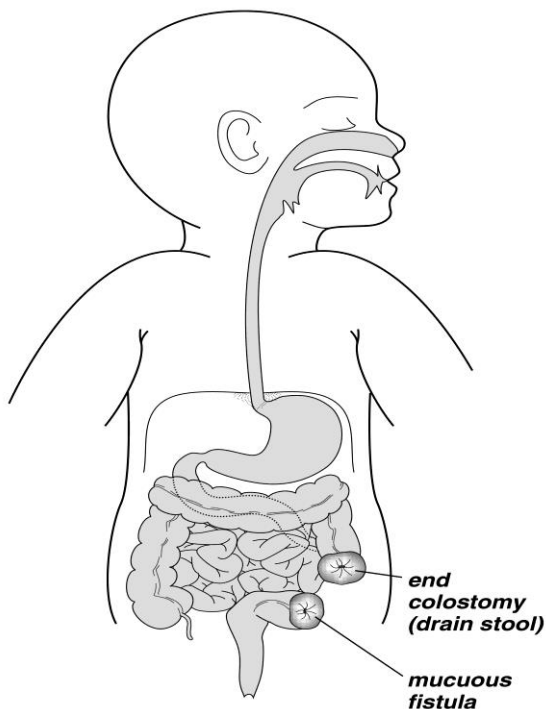
- A colostomy is created when a part of the large intestine called the colon is brought to the surface of the abdomen.
- Stool output from a colostomy may be thicker since more water is absorbed in the large intestine.

### Ileostomy

- An ileostomy is created when the end of the small intestine is brought to the surface of the abdomen.
- Stool output from an ileostomy may be loose since less water is absorbed in the small intestine.

### Mucous Fistula

- Your child may or may not have a mucous fistula in addition to the ostomy.
- The mucous fistula brings the remaining end of the colon up to the surface of the abdomen. This allows mucous, bile and gas to drain out of the bowel.



## What To Expect About Your Child's Stool

- Your child will not have control over passing gas or a stool because there is no muscle (sphincter) at the opening of the stoma.
- Ileostomy stool consistency depends on which part of the bowel is used. Stool is looser than colostomy.
- Certain foods may change the thickness of the stool.
- If there is a significant change in your child's stool output, call your doctor.
- Your child may have mucous or stool from the rectum. This may be normal.
- Over time, you will get to know what is normal for your child.

## Surgery

### Getting Ready for Surgery

- You and your child meet with the healthcare team for an appointment before surgery to answer any questions you may have.
- The healthcare team will give you specific instructions to prepare your child's bowel for surgery.
- Your child will not be able to eat or drink before surgery.
- Your child may be admitted to the hospital before surgery.
- Recovery from ostomy surgery may take 3-5 days. The length of time your child stays depends on the type of surgery, your child's needs, and the recovery process.

## What to Expect After Surgery

### Healthcare Team

You and your child will meet many people at the hospital including, nurses, nurse practitioners, residents and attending doctors, and case managers. We call these people “the healthcare team.”

### Monitoring

Your child’s vital signs, bowel function, and hydration are monitored in the hospital.

### Stoma

The stoma may be red and swollen after surgery. It will change size over time.

### Pain Control

The healthcare team will work with you to manage your child’s pain after surgery. There are no nerve endings in the stoma so your child will not feel pain when it is touched or when stool or gas pass through it.

### Diet

Your child will receive fluids through an intravenous (IV) until bowel function returns. The healthcare team will let you know when your child is able to start drinking and eating.

### Education

Your child’s health care team will teach you how to care for your child’s ostomy

## Taking Care of Your Child’s Ostomy

### Pouch System

The stool comes out of the stoma into a pouch. There are many types of pouches that come in different sizes and have different drainage options. The team will choose a pouch that is best for your child’s needs. You may need to try out several pouches before finding the best fit for your child.

## Types of Pouches

- One-piece pouches have the pouch and the skin barrier or wafer together as a one-piece unit. The skin barrier or wafer will be cut to fit your child’s stoma.



- Two-piece pouches have a skin barrier, also called a wafer, which sticks to the skin, and the pouch attaches to the wafer.



### Emptying the Pouch

- Empty the pouch when it is 1/3 full of stool or gas, and before bedtime. This prevents the pouch detaching from the skin causing leaks.
- To empty the pouch, open the tail end of the pouch and let the contents drain into a toilet, basin, or diaper.
- Clean the inside and the outside of the tail end of the pouch before closing it.
- Look at the stool and write down any changes in color, consistency or the amount that drains out of the pouch.

### Changing the Pouch

- Change the pouch when there are signs of leaking. Most pouch systems last 3-4 days.
- The best time to change the pouch is before breakfast and before activity because these are times when less stool is coming out of the stoma.
- The pouch can be changed while your child is sitting, standing or lying down.

### Ostomy Supplies

You will need to gather the supplies you need before changing the pouch.

- One or two piece ostomy pouch system
- Stoma measuring guide
- Pen
- Scissors
- A washcloth or soft cloths.



### How to Change the Pouch System

1. Wash your hands with soap and water.
2. Prepare pouch system. Cut-to-fit trace template and cut starter hole just slightly bigger than the stoma size. Choose the correct wafer size. The healthcare team will help you figure out the best fit. The size of the stoma may change over time. Use the measuring guide that comes with your other ostomy supplies.
3. Gently peel the old wafer away from the skin. You may use alcohol free adhesive remover or a warm wet washcloth to help loosen the wafer to remove it.
4. Look at the stoma and the skin around it. The stoma should be red or pink and moist. The skin should look smooth without open areas.
5. Clean the skin around the stoma with lukewarm water. Do not use oils, cleansing baby wipes, soaps, or lotion on the skin. This may prevent the wafer from sticking to the skin.
6. Pat the skin dry.
7. Center the cut hole over the stoma. It should fit close to the stoma but not be too tight or scrape the edges of the stoma.

### Bathing and Skin Care

Keep the pouch on for baths. You do not need to cover the pouch for bathing. Your child may shower with the pouch on or off. Use a towel to dry off the pouch.

### **Skin Irritation**

Skin irritation may be from leaking stool, sensitivity to the ostomy products used, or from adhesives tearing off the top layer of skin.

- Always change the pouch right away if it is leaking. Do not try to patch a leak.
- Use alcohol free adhesive remover to remove pouch if needed. Gently lift off pouch from skin.
- Check if wafer system is the right size. Stoma size can change over time.

### **Hydration and Nutrition**

Encourage your child to drink fluids. A child with an ostomy may become dehydrated more easily. If you notice dark urine, it may mean your child needs to drink more fluids.

After surgery, the doctors will tell you when your child can start to eat food. Some foods may cause increased gas. The pouch is odor proof, but gas may need to be emptied more often.

Some foods may cause a blockage in the stoma opening, others may cause loose stools, and others may thicken stools. Below are lists of foods and how they affect your child's ostomy.

#### **Foods That May Decrease Gas and Odor**

- Yogurt, buttermilk, cranberry juice, and parsley

#### **Foods to Avoid to Prevent Blockage of the Stoma**

- Nuts, seeds, and hulls

#### **Foods That Need to be Eaten in Small Amounts and Chewed Well to Prevent Blockage of the Stoma**

- Raw fruits and vegetables, dried fruits, fatty foods and meats, popcorn, carbonated drinks, broccoli, cabbage, beans, onions, cucumbers, corn, and dairy products

#### **Foods That May Cause Loose Stools**

- Fruit juices, baked beans, tomatoes, chocolate, dairy, fried foods, licorice, spiced foods, and leafy green vegetables

#### **Foods That May Cause Thicker Stools**

- Applesauce, bananas, cheese, rice, mashed potatoes, peanut butter, soda crackers, tapioca, and weak tea

### **Nutrition for Infants**

- Breastfeeding is always encouraged for infants. Infant formula can be given and is easily digested. Talk to your doctor or dietician if your infant has special formula needs.

### **Activity/Clothing/School/Travel**

#### **Activity**

A child with an ostomy can do most activities that other children can. Talk to your child's doctor before starting exercises.

- For the first few weeks after surgery, avoid abdominal exercises or heavy lifting.
- Avoid contact sports with a risk of getting hit in the abdomen.
- Wear the pouch to swim. Many types of bathing suits can hide the pouch. To make sure there is a good seal, put the pouch on a few hours before your child gets in the water. Water resistant tape may add extra security.

## **Clothing**

Your child does not need any special clothing, but when buying clothes avoid tight clothes, belts, and waistbands that may rub on the stoma area. Young children may play with or pull on the pouch. One-piece outfits help to hide the pouch to avoid having the pouch pulled off.

## **School**

Your child may return to school about 2-4 weeks after surgery.

- Ask the healthcare team for guidelines and activity restrictions to give to the school nurse and other staff at school.
- Ask about keeping extra ostomy supplies and a change of clothes at school.
- Talk about your child's needs with the school nurse.

## **Travel**

Ask your doctor for a letter describing your child's special needs.

- Cushion the seat belt if it rests on the stoma.
- Pack extra supplies.
- Keep extra supplies in carry-on luggage for air travel. If flying, pre-cut pouches at home and keep in zip lock bags since scissors are not allowed in carry-on bags.
- Keep extra supplies in a cool spot in the car to avoid damage by excessive heat.
- Bring zip-top bags to dispose of used pouches.

## **Getting Ready to Go Home**

- Before your child goes home, we want you to feel comfortable changing the pouch and emptying the bag on your own. Your health care team will guide you as you learn these cares.

- Before your child goes home, a pharmacist teaches you about any medicines your child needs and why your child needs each medicine. Talk to your child's doctor before giving any over-the-counter medicines or home remedies.
- Your child will have follow-up clinic visits with the healthcare team to assess the ostomy function and answer your questions. Bring any medicines your child is taking with you to the clinic visits.

## **Discharge Supplies**

The healthcare team will let you know which supplies your child needs before going home.

- The hospital gives you a small number of supplies to take home; enough to see you through your child's first appointment after surgery.
- Do not order supplies before the first appointment. Stoma size may change.
- Before the first appointment call your insurance provider and ask for a list of places you may get an ostomy supply prescription filled.
- Provide the name of the preferred provider to your health care team at your first appointment. Your prescription will then be sent to the preferred provider. You will be sent home with enough supplies until the ordered supplies arrive.

## **Complications**

**Look at** the skin around the stoma and incisions **and watch for these complications.**

- **Stoma retraction:** The stoma will be lower than the surface of the skin.
- **Stoma prolapse:** The stoma may look longer or higher.

- **Dehydration:** Stool in the pouch may look thicker or more dried up when your child is dehydrated. Also, your child may become dehydrated if you commonly see loose or watery stool in the pouch.
- **Obstruction:** A blockage in the stoma or somewhere else in the bowel. There may be a decrease in the amount of stool coming out of the stoma or no stool at all. There may be nausea or vomiting or abdominal pain that doesn't go away.
- **Infection:** Redness, warmth, swelling and pus-like drainage from the ostomy.
- **Bleeding:** A small amount of bleeding may be normal if the stoma is bumped or scraped.

#### When to Call

- If there is a big increase or decrease in the amount of stool from the pouch.
- If there is a big change in the consistency of the stool from the pouch such as more liquid.
- If the skin around the stoma becomes red or irritated or appears infected. Signs of infection are redness, warmth, swelling and pus-like drainage from the ostomy and a fever over 101.5°F that doesn't go away.
- Abdominal pain, cramping or vomiting that doesn't go away.

- If you have any questions or problems with putting the pouch on or keeping it on.

#### When to Go to the Emergency Room

- If the stoma is dark and discolored (dusky blue, grey, brown or black).
- Bleeding from the stoma that doesn't stop with pressure.

#### Who to Call

If you have questions or concerns the first 6 months after the surgery call:

- During weekdays from 8:00 am to 4:30 pm call the Pediatric Specialty Clinics at **608-263-6420**. Ask for the General Surgery Nurse Practitioner.
- After 4:30 pm, on weekends, and holidays, call the hospital operator at **608-262-2122** and ask for the pediatric general surgery resident on-call.

If you have questions or concerns after 6 months please call your child's primary care provider at \_\_\_\_\_.

If you are a patient receiving care at UnityPoint – Meriter, Swedish American or a health system outside of UW Health, please use the phone numbers provided in your discharge instructions for any questions or concerns.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 12/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#7652