

Ostomy Home Care Teaching Manual



Call 911 or an ambulance if your child:

- Struggles to take each breath
- Grunts with each breath
- Is unable to speak or cry
- Has blue or white lips or nails

Call the Surgery Team night or day if your child has any of the following symptoms:

- Has any bleeding from the stoma.
- Has dark, gray, or black coloring of the stoma.
- No stool output from the stoma for more than 4 hours.
- Urinates less than 4 times in 24 hours and is less than 12 months old.
- Urinate less than 3 times in 24 hours and is older than 12 months.
- Is crying without tears.
- Has a dry mouth or cracked lips.

Note: Call the General Surgery Office 314.454.6022 during office hours. If after hours (nights, weekends, and holidays) call 314.454.6000 and ask for the Surgery Resident on-call to be paged.

Date	Initials	Content
		Surgery office number 314-454-6022
		1. Caregiver/Child emptied bag: <input type="checkbox"/> <input type="checkbox"/> Demo <input type="checkbox"/> <input type="checkbox"/> Return Demo <input type="checkbox"/> <input type="checkbox"/> Independent
		2. Caregiver/Child changed bag: <input type="checkbox"/> <input type="checkbox"/> Demo <input type="checkbox"/> <input type="checkbox"/> Return Demo <input type="checkbox"/> Independent
		3. School note (if needed) <input type="checkbox"/> <input type="checkbox"/> Yes <input type="checkbox"/> <input type="checkbox"/> N/A
		4. Home Health <input type="checkbox"/> <input type="checkbox"/> Name of Home Care supplier _____ <input type="checkbox"/> <input type="checkbox"/> Phone number _____ <input type="checkbox"/> <input type="checkbox"/> Name of Nursing Agency _____ <input type="checkbox"/> <input type="checkbox"/> Phone number _____
		Follow-up appointment -- Date: _____ Time: _____

This handout is for your general information only. The lists above are guidelines and do not include all symptoms. This document is not a substitute for your child being seen by a doctor. Always call your child's doctor if you have any questions or problems. If your child's condition gets worse, call your child's doctor or go to the emergency department.

St. Louis Children's Hospital
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 St. Louis MO 63110
 R5417 03-2015

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A. What is an Ostomy?

An ostomy is an opening (*stoma*) in part of the digestive system (the small or large intestine) that is brought outside the body on your child's abdomen. The *stoma* (opening) is where your child will pass stool. The skin around the stoma is tender after surgery.

- After surgery, the stoma may be large but it will get smaller 3 to 4 weeks after surgery.
- The stoma has many tiny blood vessels (capillaries) that keeps the stoma healthy and causes the stoma to look dark pink or red. It is normal to see tiny spots of blood when cleaning the skin around the stoma because of all the capillaries.
- The stoma has no sensation and is not sensitive to pain.

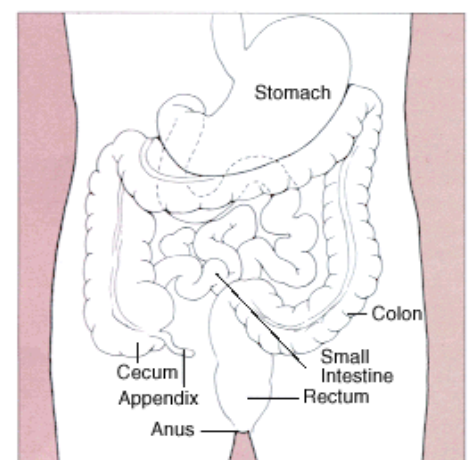
What is a mucus fistula?

Your child **may** have two openings on the abdomen after surgery. One opening is the ostomy that allows stool to pass through the stoma. The other opening may look like a stoma or a tiny hole on the abdomen. This is called the mucus fistula and allows mucus to drain from the rest of your child's intestines.

- The mucus secreted by the fistula helps keep it moist and healthy.
- After surgery, you may see a small piece of Vaseline gauze covering the mucus fistula.
- If the mucus fistula is close to the ostomy stoma, the Vaseline gauze may cause the bag slip off the skin. The nurse may remove the Vaseline gauze and replace with a small Band-Aid as needed.
- Mucus fistulas may not need to be covered if they don't rub on clothes or diapers.

B. What Happens in the Digestive Tract?

- Food goes through a complex journey when it enters the mouth and finally leaves through the anal opening.
- Food passes through the esophagus into the stomach and into the small intestine.
- The small intestine has three sections: the first section is the duodenum, followed by the jejunum and then the ileum. The small intestine breaks down nutrients, vitamins and minerals so they can be absorbed by the body.
- The stool is very watery when it completes its travel through the small intestine.
- Water and salt are absorbed in the large intestine (colon), allowing us to have formed stool when it passes through the rectum out the anal opening.



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Where is my child's stoma?

- Depending on the child's disease process or condition, the surgeon creates an ileostomy *stoma* (opening in the ileum) or a *colostomy stoma* (opening in the colon).
- Children with *ileostomies* are more at risk for dehydration and skin breakdown from their watery stools since water cannot be absorbed by the colon and may benefit from extra salt and water. Discuss this with the Dietician or your child's primary physician.

C. How Do I Take Care of My Child with an Ostomy?

Accepting the need for an ostomy is the first step for successful learning for the caregiver and the child. Many children learn ostomy techniques with their parents and often enjoy telling adults how to change the ostomy bag correctly.

- The goal is to find a bag system that fits your child to help prevent leaking of stool and protect the skin from irritation and break down.
- Most parents and children want to find the smallest bag to place over the stoma; however, a small bag can easily "pop off" causing leaking.
- Your nurse or APN will instruct you on the proper bag to use at home. The surgery nurses will continue to respond to your questions about ostomy care after your child is discharged from the hospital.
- The nurses will contact the Home Care Supplier if another bag system is necessary.

D. General Guidelines to Follow For Any Bag System

- The ostomy bag should be changed as soon as leaking is noticed.
- How long the bag has been staying on in the hospital probably indicates how long it may stay on during the first few weeks after discharge.
- After the stoma matures, bags usually last longer but should be changed by 5 to 7 days.
- Ostomy bags on infants and toddlers may only last 1 to 3 days since they have a smaller space on their abdomen for the bag to stick and/or are quite active.
- Babies should wear "onsies" to cover the ostomy bag.
- It is best to change the bag one hour before the child eats or 3 to 4 hours after eating.
- It can be frustrating to apply a new bag when stool continues to ooze from the stoma: Try placing a wash cloth over the stoma to absorb some of the drainage before applying the new bag.

E. Emptying the Bag (one or two piece):

Empty the bag when it is 1/3 full, before feeding, or before changing bag. Always empty gas from the bag or the gas may cause the bag to “pop off”. To empty the gas, unclamp the bag and smooth out the bag so gas is pushed out.

Gather supplies:

- basin, toilet or diaper
- toilet paper or tissue
- disposable wet wipes or baby wipes
- GU syringe

1. Place basin under bag or place bag over toilet or diaper.
2. Put toilet paper or tissue into toilet bowl to prevent splashing when emptying the bag.
3. Slowly unclamp the bag and smooth it with your hand to completely empty the bag.
4. If stool is thick, rinse the bag with the GU syringe and water.
5. After emptying the bag, dry the end of the bag (inside and outside) with a tissue or a wet or baby wipe and close the bag.
6. Wash hands.

F. Types of bags: *The steps to apply different bags are the same.*

- One piece bag: bag is attached to a stoma wafer
- Two piece bag: the bag and wafer are separate. The bag attaches to the wafer.

Using a Skin Barrier Wipe (skin prep) before applying a new bag

- Skin barrier wipe or “skin prep” is a small pad that is applied to the skin around the ostomy before putting on the bag.
- Apply some skin prep on your hand and wait until it gets a sticky film.
- This sticky film helps the bag stick and creates a protective skin covering.
- Stool can roll over the film instead of sitting directly on the skin.
- When tape is removed, it pulls up the skin prep and not the top layer of your child’s skin.

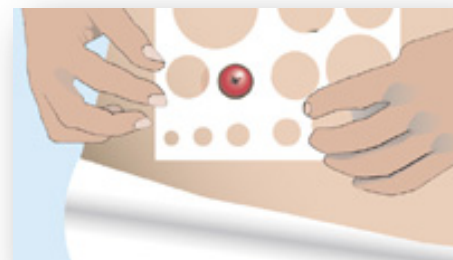
G. Changing the Bag: (One-Piece Bag)

Gather supplies:

- basin of warm water
- wash cloth (baby washcloths if desired)
- scissors
- mesh-like tape (i.e. hypafix) if needed
- ostomy supplies: one piece bag, skin prep, adhesive remover, clamp if the bag does not have a Velcro closure



1. Measure the stoma if the ostomy is new or use the previously cut pattern.
2. Place pattern on the back of the ostomy bag and draw the proper size opening. *Do not cut more than one bag for next ostomy change if the stoma is still shrinking.*
3. Place a finger inside the bag to prevent cutting through the bag when cutting the hole into the wafer. The wafer should fit just around the stoma in order to minimize the amount of skin exposed.
4. You should not apply the wafer if too much skin is left exposed to stool drainage. You can always cut the wafer larger if it is too small at first.
5. Empty contents of bag.
6. Remove old bag and stoma wafer, by using adhesive remover or gently pulling bag away from skin and placing your hand on the skin to decrease pulling on the skin.
7. The skin may look dark pink when the bag is first removed. This fades quickly.
8. Discard the bag. Put the bag in a small "baggie" before putting it in the trash.
9. Pat the skin around the stoma with a damp wash cloth. You do not need to remove all sticky material left on the skin from the old bag.
10. Inspect the skin for signs of rash, irritation or breakdown.
11. When skin is clean and dry, apply skin prep around the stoma site and let dry until it gets sticky.



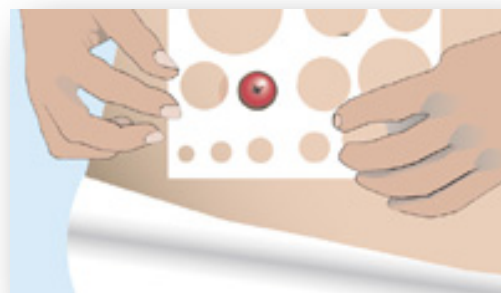
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12. Warm the wafer attached to the bag by gently rub it between your hands to help the wafer mold to the skin. **Do not use a microwave or hairdryer to warm the wafer.**
13. Touch the skin around the stoma. Reapply the skin prep if the skin is longer sticky.
14. Take the paper off the back of the wafer and place the bag around the stoma.
15. Gently press the bag in place with your hand to help the wafer mold to skin.
16. Smooth out end of bag, fold it two times and put on the clamp if the bag does not have a Velcro closure.
17. If the edges of the wafer are not sticking to the skin:
 - Rub skin prep on the edges of wafer.
 - Use mesh tape (Hypafix) to tape the edges of the wafer to the skin.

H. Changing the Bag: (Two-Piece Bag)

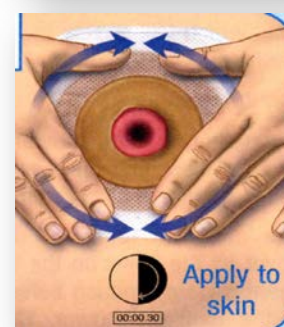
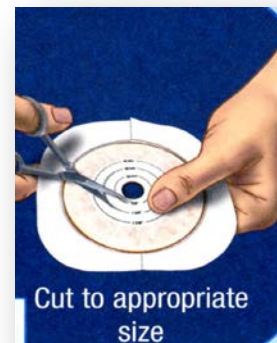
Gather supplies:

- basin of warm water
 - wash cloths (baby washcloths if desired)
 - scissors
 - mesh-like tape (i.e. Hypafix) if needed
 - ostomy supplies: two-piece bag system, skin prep, adhesive remover, clamp if the bag does not have a Velcro closure
1. Measure the stoma if the ostomy is new or use the previously cut pattern.
 2. Place the pattern on the back of the wafer and draw the proper size opening. *Do not cut more than one bag for next ostomy change if the stoma is still shrinking.*
 3. Cut the hole into wafer. The wafer should fit just around the stoma in order to minimize the amount of skin exposed.
 4. You should not apply the wafer if too much skin is left exposed to stool drainage. You can always cut the wafer larger if it is too small at first.



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5. After stoma size remains stable, you can cut the pattern on a bag to use for the next bag change.
6. Empty contents of bag.
3. Remove old bag and stoma wafer, by using adhesive remover or gently pulling the wafer away from skin and placing your hand on the skin to decrease pulling on the skin.
4. The skin may look dark pink when the bag is first removed. This fades quickly.
5. Discard bag and wafer. Put the bag system in a small "baggie" before putting it in the trash.
6. Pat the skin around the stoma with a damp wash cloth. You do not need to remove all sticky material left on the skin from the old bag.
7. Inspect the skin for signs of rash, irritation, or break down.
8. When skin is clean and dry, apply skin prep around the stoma site and let dry until it gets sticky.
9. Warm the wafer by gently rub it between your hands to help the wafer mold to the skin.
10. Touch the skin around the stoma. Reapply the skin prep if the skin is longer sticky.
11. Remove paper from the wafer and place it around the stoma. Gently press the wafer with your hand wafer to help it to mold to the skin.
12. Attach bag to wafer.
13. Smooth out end of bag, fold it two times and put on the clamp if the bag does not have a Velcro closure.
14. If edges of stoma wafer are not sticking:
 - Rub skin prep on the edges of wafer.
 - Use mesh tape (Hypafix) to tape the edges of the wafer to the skin.



I. If Your Child's Skin is Broken Down

- Stomahesive powder
- Stomahesive paste
- Barrier ring

Stomahesive powder

Leakage of stool may cause the skin to become red, irritated or broken down. Skin prep is still necessary so the bag can stick to prevent further skin breakdown. However, skin prep contains alcohol and **should not** be applied directly on broken down skin.

- Stomahesive powder is sprinkled on the skin before applying skin prep to decrease the child's discomfort and help the bag to stick.
- **Directions for applying the stomahesive powder:**
 1. Pat the skin around the stoma with a damp wash cloth.
 2. Sprinkle the powder over the affected areas of skin. Pat off excess powder until it looks like a fine dusting of snow
 3. Gently pat the skin prep over the powder until you no longer see the powder. Wait until the skin prep is dry and apply the bag.

Always apply the powder first and then the skin prep!

Stomahesive paste (putty)

Stomahesive paste acts like a putty to "fill in" uneven areas on your child's skin around the ostomy. **Note: Use the paste only if directed by the surgery team.**

- A little stomahesive paste works well when needed. Too much stomahesive will flatten under the bag and become hard causing the bag to not stick.
- The paste contains alcohol and **should not** be applied directly on broken down skin.
- Always apply stomahesive powder **first** if the skin is broken down.
- **Directions for applying the stomahesive paste:**
 1. Pull the plunger out of a small syringe and squeeze a small amount of the stomahesive paste into the syringe.
 2. Replace the plunger
 3. Gently squeeze a tiny amount of paste where it is needed.

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Barrier rings

- The rings look similar to stomahesive putty but are molded into a circle.
- The rings may be used whole to fit around the stoma or cut to fill in spaces on the skin around the stoma.

J. Emergency Care

Call the Surgery Team night or day if your child has any of the following symptoms:

If your child's stoma is:

- Black or dark gray in color (necrotic):** this usually indicates a lack of adequate blood supply to the stoma and requires immediate intervention.
- Bleeding:** the stoma may have suffered trauma or your child may have internal bleeding.
- Obstructed:** blockage of ostomy seen by a small amount to no stool.

Symptoms of Blockage	Cause of Symptoms
Output becomes watery	Food is blocked but water can pass around it
Output increases and becomes continuous	Intestines become hyperactive to relieve obstruction
Objectionable odor	Bacterial overgrowth occurs at site of food blockage
Cramping	Increase bowel activity to rid itself of blockage
Distended abdomen and abdominal pain	The blockage traps gas and liquids in the bowel
Vomiting	Body tries to rid of blockage through stomach
No ostomy output	Complete blockage

- **Or if your child is dehydrated:**
 - Has not urinated in more than 8 hours.
 - Cries without tears.
 - Feels dizzy
 - Has a very dry mouth or cracked lips.
 - Has a sunken soft spot on the top of the head in a child less than 1 year.
 - Less active (lethargic) or more sleepy than usual

Note: Call the General Surgery Office 314.454.6022 during office hours. If after hours (nights, weekends, and holidays) call 314.454.6000 and ask for the Surgery Resident on-call to be paged.

K. Non-Emergent Care

CALL THE SURGERY OFFICE:

If your child's stoma is Prolapsed.

- Prolapse of the stoma occurs when the stoma begins to protrude from the abdomen.
- The stoma may slide out and eventually go back in.
- As long as the stoma looks healthy (red or pink in color) and your child's stool output is normal, everything is fine.
- The surgery office will monitor the progress of the stoma and suggest modifications in care if needed.

If your child's stoma is Retracted

- Retraction of the stoma occurs when the stoma shrinks or retracts into the ostomy opening on the skin.
- As long as the stoma looks healthy (red or pink in color) and your child's stool output is normal, everything is fine.
- The main concern with this condition is making sure the bag is still able to stay attached.

If your child's skin is: irritated, bloody, broken down, or has a rash because a yeast rash may occur on the skin around the ostomy. Your child's medical provider will prescribe a powder to treat this condition.

L. Tips

- Always have an extra bag system and ostomy supplies with the child *at all times*.
- Carry your child's ostomy supplies when traveling. Do not put them in the luggage in case the luggage gets lost.
- If you need supplies when traveling, look in the yellow pages under "Surgical Supplies". Some ostomy suppliers will air mail equipment if they are called.

Infant Tips:

- **Your child can take a bath with or without the bag.**
- If your baby wakes up crying because of hunger or a leaking bag: change the bag before your baby is fed. Changing the bag after feeding can cause vomiting or increase output during bag change.
- Clothes: One-piece outfits, such as onesies, are nice to use. Avoid two piece outfits that have a snug elastic band that rubs on the ostomy. The elastic may pull on the bag or stoma.
- Try taping the edges of the bag to the skin with mesh tape (hypafix).

Older Children and Teens:

- **Your child can take a bath with or without the bag.**
- Apply the bag when your child is standing, lying down, or sitting. Make sure that the skin is smooth or this will break the seal when he/she straightens out.
- A hand mirror will let the child get a better view of the stoma.
- Your child should wear the bag inside his/her underwear for support.
- Your child can go swimming. Before going swimming, reinforce the stoma wafer with waterproof tape in the form of a picture frame. Ostomy belts can be used for swimming and other activities.

M. Guidelines for Eating After Surgery

Your child should:

- Eat meals regularly.** For the first few weeks after surgery your child may feel better eating 6 small meals. Your child should always eat three or more times a day. An ostomy works best this way and produces less gas.
- Chew food well.** Chewing food well will help to avoid a blockage in the intestine, be especially careful when your child chews foods that may be hard to digest or have high fiber content.
- Try new foods one at a time.** Watch what foods give your child excess gas, constipation, looser stools, or odor. If a new food seems to give your child problems, eliminate it for a few weeks, but try it again later. You may find something else was causing your problem.
- Drink a lot of fluid daily.** Children lose more body fluids than usual through the stoma, so it's important to drink a lot of fluid. Children with ileostomies and children with colostomies who have lost a large part or all of their large intestine will have more fluid loss. This is because most of the body's fluid is normally reabsorbed in the large intestine.
- Above all, remember that no two children will react the same to foods.** You will learn through experience which foods, if any, you should have your child avoid.

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Preventing Blockage:

Use caution when giving the following foods to your child. These foods cannot be completely digested and could cause blockage. Your child does not need to avoid these foods. Just eat small amounts and be sure to chew them well.

Foods That Can Cause a Blockage

Celery	Chinese Vegetables	Pineapple
Coconut	Coleslaw	Nuts
Raisins & other dried fruits	Seeds	Peas
Popcorn	Relishes	Corn
Fruit & vegetable skins	Mushrooms	Salad greens

Foods That Can Cause Odor

Asparagus	Coffee	Garlic	Prunes
Beans	Cucumber	Green peppers	Radishes
Brussel sprouts	Eggs	Milk	Turnips
Cabbage	Fish	Onions	Certain vitamins
Cauliflower	Broccoli	Cheese (Certain types)	

Foods That Can Decrease Odor

Buttermilk	Yogurt
Cranberry juice	Spinach
Parsely	

Foods That Can Produce Gas

Gas at night can be very controlled by not eating after 8:00PM. This lets the intestine to "quiet down" by bedtime.

Apples (raw)	Carbonated drinks	Eggs & Milk	Onions
Asparagus	Cauliflower	Melon	Radishes
Beans & peas	Chewing gum	Mushrooms	Spicy foods
Broccoli	Corn	Nuts	Spinach
Cabbage	Cucumber	Brussel sprouts	Fish

Note: Chewing bubble gum or drinking with straws causes you to swallow more air and increases gas ("air in pouch").

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Foods That Can Cause Loose Stools

Apple juice	Highly seasoned foods	Chocolate
Grape juice	Licorice	Broccoli
Prune juice	Fried foods	
Green beans	Soups	
Fresh fruits	Beans	

Foods That Can Thicken Stools

Applesauce	Marshmallows
Bananas	Milk
Breads	Peanut butter (creamy)
Cheeses	Starchy foods (rice, pasta, potatoes, tapioca)
Yogurt	Weak tea

Foods That Can Color Stools

Some food and drinks with red dyes do not lose their color during digestion. They may cause a red color to your child's stool may. Do not mistake this for blood. Examples:

- Beets
- Red liquids such as Jell-O[®], Kool-aid[®], Hawaiian punch and popsicles

N. Quotes from Former Patients

Krista, age 16, says "Living with an ostomy is not hard at all. You can still wear clothes you like, take showers, swim, and do all the activities you did before having an ostomy. It's important that they (your friends) know that when you need to go to the restroom or need something to drink to let you go any time." Krista gives some important tips about living with an ostomy:

- drink plenty of water and healthy juices
- eat lots of protein
- always make sure your bag is kept clean and is sticking
- if you start having problems with your stoma or bag, call your doctor
- you do not have to tell everybody because it is not noticeable
- having an ostomy does not make you different--you can still have fun

Ryan, age 11, says "Make a list of things you eat in case certain things bother you. Don't eat too much before going to bed. Wake up a little earlier to empty it in the morning. Empty it right before you go to bed. Your friends do not have to know about the ostomy unless you tell them. I chose to tell my friends. They were fine with it."

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Joshua, age 12, says "You can do almost anything after surgery. After my surgery I could play baseball, basketball, go swimming, almost anything. The kids in my class reacted fine to my bags when I showed them. I just took an extra bag in my backpack just in case I had problems. Don't be scared."

Shirley, age 9, says "Every time you empty it, you should get a syringe and fill it with warm water if the poop is thick (if it is watery, you don't have to)."

O. Where to Find More Information

United Ostomy Association (UOA)

(Parents of Ostomy Children (POC) is a sub group of UOA. To find out if your community has a local chapter, write or call the UOA)

19772 MacArthur Blvd, Suite 200

Irvine, CA 92612-2405

1-800-826-0826

www.uoa.org

Pull-thru Network

www.pullthrunetwork.org

Crohn's & Colitis Foundation of America, Inc. (CCFA)

386 Park Avenue South

New York, NY 10016-8804

1-800-343-3637

www.cdfa.org

For General Health Information and Resources:

Call or visit the **Family Resource Center**, a health information library on the 3rd floor of the hospital. Call 314.454.2350, email at frc@bjc.org, or check out the FREE **St. Louis Children's Hospital Kid Care App**.



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