

This information will help you on your journey as you learn to successfully care for your ileostomy.

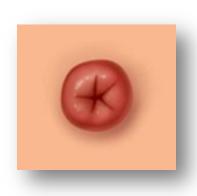
What is an ileostomy?

An ileostomy is a surgical opening in the abdominal (belly) wall. This opening is where the small intestine (bowel) is brought out to make a "stoma." Stoma is the Greek word for "mouth" or "opening." An ileostomy is made to bypass disease or injury in the intestines, making a new way to pass stool (bowel movements) when the lower bowel is injured or blocked.

When you have an ileostomy, stool does not pass through your anus, but goes through the stoma. Unlike the anus, you have no control over the stoma. You will wear a pouch under your clothes to collect the stool. Your ostomy nurse will help teach you how to empty and change the pouch.

Your stoma

- After surgery, your stoma may be swollen. It may shrink for the first six to eight weeks after surgery to a permanent size.
- A healthy stoma is pinkish red in color. A change in color, especially darkening should be reported to your doctor.
- Your stoma has no feelings so it will not hurt to touch it.
- Your stoma may bleed a little when it is cleaned. This is normal and the bleeding should stop quickly. If the bleeding continues let your doctor know.





Your ileostomy output

- The stool from your ileostomy may be liquid or like pea-soup.
- Stool will look different depending on what you eat.
- You must wear a pouch at all times to collect the stool.
- Your pouch will need to be emptied 5-7 times a day.

Bathing and Showering

Your pouch is waterproof so you may bathe, shower or swim with your pouch. You may choose to bathe or shower without your pouch. Soap and water will not hurt your stoma. There are swimsuits and board shorts that you can buy to support and hide the ostomy pouch. Ask your ostomy nurse for more information.



Clothing

You should be able to wear the same types of clothes you wore before your surgery except for tight belts that can stop the flow of stool in your pouch. If you wear a belt, you may need to loosen it or consider suspenders. The pouch is worn inside or outside of your underwear. You may choose to wear special ostomy underwear. Your ostomy nurse can give you more information about clothing.





Getting Back to Normal Activities, Work and Traveling

As with any surgery, you will need time to rest and recover. Your doctor will let you know when you can return to normal activities and work. Once you have recovered, your ileostomy should not stop you from having an active life. Always carry extra pouches with you in case of leakage. When you travel, it is a good idea to pack more supplies than you think you will need. When flying, pack your ostomy supplies in your carry-on bag, as sometimes luggage gets lost.



Relationships, Love, Sex and Helpful Tips



Because ileostomy surgery changes the body, some people worry about how this change will affect relationships and sexual activity. Having an ostomy does not change who you are as a caring and loving person. Talk with your partner and let them know sexual activity will not hurt your stoma. After recovery, it is still possible for most woman to have children and many men

become fathers. If you have questions or concerns about sex after surgery, it may be helpful to arrange for you and your partner to talk with your doctor or ostomy nurse.

- Empty your pouch before sex.
- Wearing a beige pouch will hide the pouch contents.
- You may want to wear a small beige closed pouch.
- A cummerbund or intimate underwear can help hide the pouch.
- Never use the stoma for sex.



Things to Remember About Your Pouch

- Change your pouch 2 times a week and for leaks.
- Pouches changed too often can cause skin irritation.
- Anytime your pouch leaks change it!
- Do not rinse your pouch out. Rinsing may cause your skin barrier to loosen and leak.
- Burning or stinging under your pouch may be a sign of skin irritation and the pouch needs to be changed.
- Empty your pouch when it is 1/2 full of stool. A pouch that is too full may leak.
- Look out for skin redness or irritation around your stoma and call your ostomy nurse or UCLA Ostomy Clinic if you are not sure how to take care of it.
- Do not use creams or ointments under your ostomy pouch. These will stop your pouch from sticking.





When to Call Your Doctor or Health Care Professional

- Feeling sick to your stomach (nausea), throwing up (vomiting) or have no stool in your pouch for 24 hours.
- Dark colored urine or little urine.
- Feeling very thirsty.
- Muscle cramps
- Increasing belly pain and bloating.
- Weakness, lightheadedness and feeling tired.
- Stool amount is greater than 1000ml (1 liter) a day.
- Blood in your stool
- Changes in the color of your stoma such as dark or black color.
- Changes in the look or length of your stoma.
- Pouch does not keep sealed.
- Rash or wound on your skin around your stoma that does not heal after 1 to 2 pouch changes.





Fluid and Diet Tips

- For the first 6-8 weeks after surgery, your doctor may tell you to follow a diet low in fiber (without raw vegetables, corn, beans, and nuts) to give your bowel time to heal. After recovery most patients can eat a normal diet.
- If you have swelling of your belly or diarrhea after eating a new food, stop it and try again in 2 weeks. It can help to try those foods again in smaller amounts or cook them longer.
 Writing down the foods that are bothering you in a food diary can help. See the Food Guide Chart below for more tips.



- Take small bites of food and chew well until food is soft like pudding. Swallow food completely after each bite.
- Make time for meals and snacks. Eat at the same times and do not rush when you eat.
- Try small frequent meals instead of large meals. Have your largest meal in the middle of the day to reduce your stool amount at night.
- Drink fluids between meals.





Not Getting Enough Water (Dehydration)

Dehydration is when you do not get enough water or fluids. You have a greater risk of losing water from your stool with an ileostomy. It is very important to get enough fluids every day.

Signs of dehydration

- Dark or little urine.
- Feeling weak, very tired, or confused.
- Dry mouth and skin.
- Muscle cramps, numbness or tinging in arms or legs.
- Your stool is 1,000 ml (1 liter) or more a day.



Call your doctor if your stool output is more than 1,000 ml (1 liter) in 24 hours. Your doctor may want you to take the following medications:

- Imodium (1-2 tablets) take 30 minutes before each meal, and every night before you go to sleep (do not take more than 8 tablets of Imodium in 24 hours).
- If your stool output is still high, add Lomotil (1-2 tablets) in between Imodium doses (do not take more than 8 tablets of Lomotil in 24 hours).

Note: Lomotil may need a doctor's prescription.

• If your stool output continues to be high you can add Metamucil (1-2g) 3 times a day.



Tips to prevent dehydration

- Drink plenty of fluids, at least 8-10 large (12oz) glasses of water or other liquid a day, unless your doctor tells you otherwise. Drink more if you sweat or vomit or any time you lose extra fluids.
- Drink fluids between meals instead of with meals.
- Avoid drinks with caffeine such as coffee, cola and some teas.
- Eat foods that are high in potassium such as bananas, fruits (no skin or seeds), potatoes (no skin), yogurt, and potato chips.
- Be careful of sweet drinks, juices and sweet desserts that can give you loose stools. See more tips below.
- Eat foods that make your stool thick. See more tips below.
- Measure your stool and record it. Bring your record with you when you come to clinic.
- Call your doctor for signs of dehydration. Ask your doctor if you should start *Homemade Drinks to Help with Dehydration* recipes (page 13).

More Food Tips

Food that may make stools thick	Applesauce, bananas, cheese, yogurt, pasta, rice, tapioca, bread, bagels, crackers, pretzels, potato (without skin), creamy peanut butter, and marshmallows.	
Food that may make stools loose	Green beans, raw vegetables, spinach, broccoli, fruit juices such as grape juice and prune juice (also prunes), fried food, spicy food, chocolate, ice cream, high sugar foods, caffeine, beer.	



Preventing Food Blockage

Surgery on the intestines may cause swelling. Large pieces of food could become stuck causing a blockage.

Signs of a blockage

- Little or no stool in your pouch.
- Stool is watery with a bad odor.
- Belly cramps
- Swelling of your belly.
- Let your doctor know if you have signs of a blockage.



Limit or try to avoid these foods that may cause a blockage

Raw celery, raw cabbage, coleslaw, lettuce, brussels sprouts, corn, popcorn, oranges, pineapples, grapefruit, dried fruit, coconut pieces, nuts, seeds, meats in casings such as hot dogs, fruit and vegetable skins and peels, berries, dried fruit, legumes.



Preventing Gas

As your bowel begins to function after surgery, you may see gas in your pouch. Most pouches today have a filter that lets gas out but not the odor. Gas can be caused by the foods you eat and swallowing air.

- Foods that can cause gas are: broccoli, brussels sprouts, cauliflower, spinach, peas, corn, mushrooms, cucumbers, beans, milk products, fried and fatty foods, sugary food, carbonated soda, and beer.
- Avoid chewing gum, drinking with a straw, chewing tobacco, and smoking.
- Skipping meals and eating too fast can cause gas.

Preventing Odor

You should only notice odor when you are emptying the pouch. If you notice odor at any other time, check the pouch for a leak. Empty your pouch when it is 1/2 full of stool. Changing and emptying your pouch at regular times can help stop leaks. Your diet can also affect the odor of the stool. You can purchase deodorant drops to place in your pouch. Drops are purchased where you buy your ostomy supplies. Ask your ostomy nurse for more information.



Foods that may increase odor	Asparagus, broccoli, brussels sprouts, cabbage, cauliflower, beans, eggs, fish, some spices, beer, and alcohol.
Foods that may decrease odor	Buttermilk, yogurt, parsley, and cranberry juice (but not too much).



Food Guide Chart

Use this chart to choose foods to eat for the first 6-8 weeks after surgery. After that, you can start to slowly add more foods.

Food Group	Choose more	Choose less
Grains	Wheat or white bread, English muffins, pasta, rice, couscous, bulgur, crackers, biscuits, pancakes or waffles (no syrup), unsweetened cereals (wet or dry), or any other grains with less than 1-2 grams of fiber per serving.	 Sweet rolls, pancakes or waffles with syrup, sweetened quick breads, sweetened muffins, pastries, or sweet croissants, sugary cereals, high fiber cereals, bran cereals, flavored hot cereals. Tip: Slowly add back foods with higher fiber content (3-5 grams of fiber per serving) so that half of your grains are whole grain.
Dairy and non- dairy replacements	Cottage cheese, cheese or non-dairy 'cheeses', plain yogurt or kefir, unsweetened cream cheese, unsweetened soy milk or other dairy replacements (such as almond, cashew, hazelnut, and coconut milks). Tip: Some people may be lactose intolerant for a time after surgery. Slowly add back milk and dairy. If you have too much gas or diarrhea, stop dairy for a few days and then try a small amount again.	Very sweet yogurts or kefir, chocolate or other flavored milks, cream, half and half, flavored soy or other non-dairy milks.

Food Group	Choose more	Choose less
Meats, Chicken, Fish and other protein foods	Fresh or frozen meat, turkey and roast beef, poultry, fish, canned tuna or salmon, unsweetened and smooth peanut butter (or other nutbutters), eggs, tofu, 100% plain whey protein powder or other plain, unsweetened vegetable-based protein powder. • Tip: Try one at a time to see how you do.	 Meat with casings. Heavily fried meat, fish, or poultry, sweetened protein powders or protein shakes. Tip: Try to avoid or limit gravies and sauces and cook meats in their natural juices instead.
Vegetables	Fresh or frozen, well-cooked vegetables, canned vegetables, potatoes, sweet potatoes, or yams. • Tip: You may do better with soft or mashed vegetables in the beginning.	Creamed vegetables, legumes (i.e. lentils, kidney beans, pinto beans, lima beans). • Tip: Try one at a time and in small amounts to see how you do. Be careful, you don't want to get a blockage. See Preventing Food Blockage above.
Fruit	Bananas, melons, unsweetened canned fruits such as applesauce, pears, peaches, apricots, and plums packed in water or their own juice. Cooked or soft fruit.	 Dried fruits, fruits canned in syrup, fruit juices, high fructose syrup in drinks. Tip: Slowly add back fresh fruit without seeds or skin. See <i>Preventing Food Blockage</i> above.
Condiments	Butter, margarine, olive oil or raw/virgin coconut oil (MCT), salad dressing, mayonnaise, salt, pepper, lemon juice, salsa, fresh and dried herbs, spices as tolerated, vinegar, garlic, soy sauce, ketchup, mustard	Any sweetened sauces or marinades, ketchup with high fructose corn syrup, sweet chili sauce, sweetened barbecue sauce, tartar sauce, pickle relish. • Tip: Do not eat too much fat. Be careful with spices.



Homemade Drinks to Help with Dehydration (ORAL REHYDRATION SOLUTION RECIPES) *

Be sure to check with your doctor first to see if these drinks are right for you and how much to drink.

Ingredients

3/8 teaspoon - Table Salt (Sodium Chloride) (3/8 tsp = 1/4 tsp + 1/8 tsp)

1/2 teaspoon - Morton® Salt Substitute (Potassium Chloride)

1/2 teaspoon - Baking Soda (Sodium Bicarbonate)

2 tablespoons + 2 teaspoons - Table Sugar (Sucrose)

Add tap or filtered water to make 1 liter

Directions

Measure and add the first four ingredients to a large container (1 liter or larger).

Fill container with 1/2 liter of water and stir to mix well. When the mixture is well-mixed, add the rest of the water and stir again. Drink slowly over a period of time. Throw out what is left after 24 hours. Drink tastes best if it is cold. You can add Splenda or another non-calorie sweetener for flavoring.

<u>Ingredients</u>

2 cups - Gatorade

2 cups - Water

2 tablespoons - Salt



Directions

Measure and stir all ingredients together in large container. Drink slowly over a period of time. Throw out what is left after 24 hours. Drink tastes best if it is cold.

* Adapted from the World Health Organization guidelines, and the book A Patient's Guide to Managing a Short Bowel, by Carol Rees Parish, MS, RD.



Steps to Changing Your Pouch

Get together all your supplies:

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Paper towels	Strip paste or ring of pa	ste			
☐ Plastic bag	Stomahesive® Powder	Stomahesive® Powder & barrier film (if needed)			
Scissors	Marker	or	pen		
Pouch					

Tip: It may be helpful to change your pouch in front of a mirror. You can change your pouch while standing or sitting.

Remove Pouch, Clean & Check Skin:

- 1. Gently pull the old pouch away from the skin.
- 2. Clean stoma and skin with warm water and pat dry well.
- 3. Check the skin around stoma for irritation or rashes. Contact your ostomy nurse or UCLA Ostomy Clinic for problems.
- 4. For skin rash, sprinkle skin with Stomahesive powder then brush off extra powder. Apply barrier film on top of powder.

Measure & Trace:

- 1. Measure the stoma with old pattern or measuring guide.
- 2. Trace measurement onto back of the skin barrier.
- 3. Cut out the pattern with scissors.

Tip: Measure stoma weekly for the first 6 to 8 weeks after surgery as size of stoma may shrink as swelling decreases.



Apply Pouch:

- 1. Remove release backing from skin barrier.
- 2. Apply strip paste or ring of paste to cut edge.
- 3. Apply pouch over stoma, and press down gently to seal
- 4. Close the end of the pouch.





Discarding & Emptying the Pouch:

- 1. Place used pouch and paper towels into plastic bag and throw away in regular trash.
- 2. Empty your pouch when 1/2 full and before bedtime.
- 3. Change your pouch every 3 to 4 days, or if your pouch leaks.





How to Empty Coloplast Pouches with a Velcro Closure

1.) Open the Velcro tabs and unfold the closure flap.



2.) Connect the white dots with the tan dots on the back of the closure flap.



3.) Squeeze edges to empty. Clean the inside edge of closure with toilet paper.



4.) Separate the white and tan dots on the back of the closure flap.



5.) Starting with the released closure flap, fold up and close the Velcro tabs.



UCLA Health

Ronald Reagan

Outpatient Ostomy Clinic

Pfleger Liver & General Surgery Clinic

200 Medical Plaza, Suite 214

Los Angeles, CA 90095

310-794-7788

Open Monday and Wednesday mornings

9:00 am-12:00 pm

By appointment only

Please call to schedule an appointment and ask for a

"Ostomy Nurse Appointment"

When visiting the clinic remember to bring extra ostomy supplies with you, as the supplies you are using may not be available

Support Organizations

- United Ostomy Association of America, www.uoa.org 800-826-0826
- Ostomy Association of L.A., <u>www.oa-la.com</u> 818-337-8416
- Crohn's and Colitis Foundation of America, <u>www.ccfa.org</u> 888-224-9626
- American Cancer Society, <u>www.cancer.org</u> 800-227-2345
- Wound, Ostomy and Continence Nurses Society, www.wocn.org 888-224-9626

