

## A Patient's Guide to Ileostomy Care

This information will help you understand your surgical procedure. It also will be a resource for your care after leaving the hospital. Write down any questions you may have for your physician or nurse.

During your hospital stay, a wound, ostomy and continence (WOC) nurse will visit you. A WOC nurse is trained and certified in the complete care of patients with an ostomy. The WOC nurse will work with your physician and staff nurses to help you in your recovery. Once you leave the hospital, the WOC nurse will continue to be a resource for you.

### The digestive system

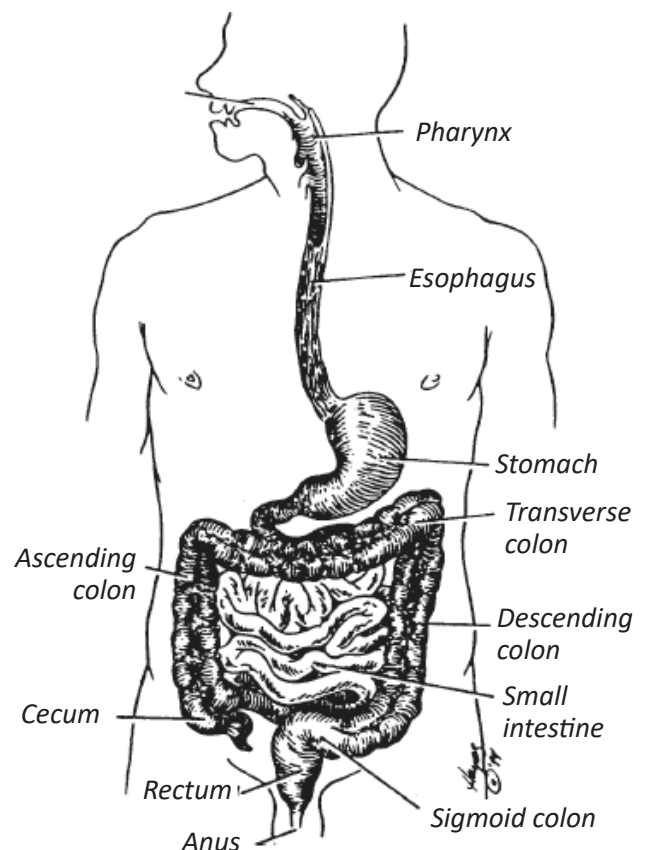
To understand how your ostomy works, get familiar with the digestive tract (Figure 1). When you eat, food travels from the mouth to the stomach. It then moves to the small intestine, for further digestion. The small intestine absorbs the nutrients from the food for the body to use. The unused parts of the food will then pass into the colon. The colon collects the stool and absorbs water from the remaining material.

By the time this waste reaches the rectum, it is in a solid form. The waste leaves the body, as a bowel movement (BM, stool, feces).

### Ileostomy – what is it?

An ileostomy is a surgical opening in the abdomen. The surgeon brings the lower end of the small intestine, known as the ileum, to the skin surface. The small intestine allows for normal digestion and absorption following bypass or removal of the large intestine, rectum and anus. The end of the ileum brought to the skin surface is known as the stoma, a Greek word for “opening.” The stoma becomes the exit for all bowel movements and gas. Having an ileostomy should not change your ability to eat and digest food.

**Figure 1. Digestive tract**



Since there is no muscle around the stoma, you are not able to control when stool passes out of your body. Therefore, you will apply an odor-proof pouch to your skin, around the stoma. The pouch collects the stool and gas. (See more information about pouches on page 7.) With an ileostomy, your stool will be a thick liquid.

A person may need an ileostomy when they have part or all of the colon or rectum removed or bypassed.

Some of the conditions that may lead to an ileostomy include:

- Injury, accidents or birth defects
- Inflammatory bowel disease (ulcerative colitis, Crohn's disease, toxic megacolon)
- Familial polyposis
- Cancer

### ***Temporary or permanent***

An ileostomy can be temporary or permanent.

A **temporary** ileostomy lets a part of the small or large intestine to heal. The surgeon can rejoin the colon in a later surgery. This could be weeks, months or years later.

A **permanent** ileostomy will not be rejoined in the future. The stoma stays open. It will be the permanent exit for the stool.

## **Types of ileostomies**

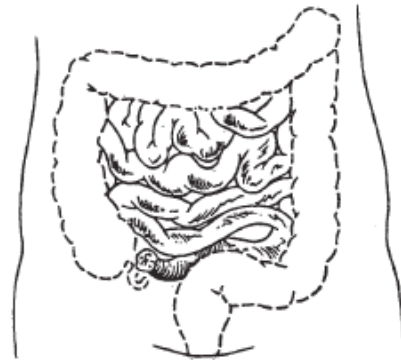
An ileostomy may be an **end** or a **loop**, depending on your surgery.

In an end ileostomy, the surgeon cuts the bowel and brings the end to the skin surface (Figure 2). They either remove the remaining bowel or suture it closed.

In a loop ileostomy, the surgeon brings a segment of the ileum to the skin surface. They make an opening in the top, fold the opening back like a turtleneck and sew it to the skin. A plastic rod stays under the loop of the ileum for about 3 to 5 days (Figure 3).

Depending on your surgery, the rectum may be left intact. In this case, it is normal for some form of drainage to come from the rectum at times. You will have the urge to have a bowel movement, and pass mucus-like drainage from the rectum. This will not happen if your rectum has been removed.

**Figure 2. End ileostomy**



**Figure 3. Loop ileostomy**



## About your stoma

Stomas come in all shapes and sizes. Some are round and others are oval. It may stick out (a budded stoma) or be flat (a flush stoma). The color should be a deep red or pink. The stoma is warm and moist like the inside of your cheek.

Your stoma will change in size throughout your life with weight gains or losses. You will see a big change in the first 6 to 8 weeks after surgery. Surgery causes swelling. As the swelling decreases, your stoma size becomes smaller. Therefore, every week, it is important for you to measure your stoma and fit the pouch opening according to size. Your WOC nurse will show you how to do this.

Your stoma has no nerve endings, so it is not painful when touched. You do not have to be afraid to touch it. However, you should protect it from sharp objects, seat belts and large belt buckles, which can cut into the stoma.

When you clean around your stoma, you may see a drop of blood on the washcloth. This is normal. (You may have noticed that your gums sometimes bleed slightly when you brush your teeth. This also is normal.) The stoma has many small blood vessels just like the inside of your mouth. Do not be afraid of your stoma, but if you notice a lot of bleeding, contact your physician.

## Activities

### **Work**

Talk with your physician about when you can go back to work. Most people can return to the work they were doing before the surgery. If your job requires heavy lifting, you need to talk with your physician about your options.

It will take time to adjust to your ileostomy. This is normal. Some people are afraid to face their co-workers and friends and tell them about having an ileostomy. Decide whom you want to tell. Do and say what makes you feel comfortable. It is your choice. Not everyone needs to know. You do not need to be embarrassed about your ileostomy; it is a part of you. Discuss your concerns with your nurse.

### **Social life**

You will be able to resume your social activities. Your ileostomy should not interfere. You will feel more confident and secure when the pouch stays intact. You will be able to empty and change the pouch yourself.

### **Clothing**

You will not need special clothing. If you feel your pouch shows, talk with your WOC nurse about other types of pouches. Tight clothes will not hurt the stoma. Tucking your pouch inside your underwear and wearing snug underwear will help hide the pouch.

### **Showering and bathing**

The pouch is waterproof. You can wear it in the shower. Your pouch will stay intact when it is underwater when you while bathe or swim. Remember to empty your pouch before swimming.

On the day you change the pouch, you can take the pouch/wafer off and shower. Water from the shower will not hurt your stoma. Dry your skin well with a towel and air dry.

### ***Exercise and sports***

You will need to restrict your activities for a short time after surgery to allow your body to heal. These are some general guidelines to follow:

- Do not lift anything more than 10 pounds (about the weight of a gallon of milk) for 6 weeks.
- Ask your physician when you may drive after surgery.
- If you had an exercise routine before surgery, please check with your physician before going back to it.

After your recovery, the ileostomy should not interfere with exercise. Daily exercise is important for your body. Do not do contact sports, such as football, karate or wrestling. Doing these activities could injure your stoma. If you want to continue any contact sports, check with your physician. Non-contact sports should be OK.

### ***Travel***

You can travel. Just remember to bring extra ostomy supplies with you. Always carry your supplies with you when traveling. If you are flying, put supplies in carry-on luggage and not with checked luggage. In a car, store supplies in a cool spot. Do not put supplies in the trunk or on the back window ledge. If you take long vacations, ask your supply company to ship supplies to you along the way. Contact your WOC nurse if you have any questions.

### ***Sexual activity***

Many people have concerns about having intimate relationships after surgery. Your ability to love, care and be intimate with another person does not change. Expressing your feelings and talking with your partner are important. Sexual activity, hugging and affection will not hurt your stoma. Your partner may be concerned about hurting you and will need to know these activities will not harm you. After surgery, you will need time for your body to heal and adjust to this change.

Cisgender men, transgender women and some nonbinary people who have an ileostomy may have some changes in sexual function. Talk with your physician and WOC nurse about what to expect and ways to have a satisfying sexual relationship.

Cisgender women, transgender men and some nonbinary people of childbearing age who have an ileostomy need to plan for birth control. The body needs time to heal after surgery before getting pregnant.

Here are some helpful tips when engaging in sexual activities:

- Always empty the pouch first.
- Roll up and secure the end of the pouch with tape, a cummerbund or scarf.
- Use smaller pouches (drainable or closed-ended).
- Wear attractive sleep and intimate apparel.

Please ask questions. Your care team is here for you and want to help you return to your normal lifestyle.

## Medications

The small intestine absorbs most medications. You may not have total absorption of time-released and time-sustained medications. Therefore, these medications may not be as effective.

Follow these guidelines:

- Tell any physician who prescribes your medication that you have an ileostomy.
- Tell your pharmacist that you have an ileostomy.
- Do not crush or separate time-released or enteric-coated tablets without checking with a pharmacist or physician. You may get more medication in less time if time-released medication is crushed.
- When starting any new medication, check your pouch for the pill. Make sure your body absorbs the pill and that it does not pass into the pouch.
- Try to stay away from medications that can cause diarrhea. Before taking any medication routinely used to prepare or clear the bowel for X-ray or surgery, go over the instructions with your surgeon or physician.

Carry a MedicAlert® card in your wallet if your rectum has been removed. It should state you have an ileostomy and that you should not have rectal enemas, suppositories or rectal temperature checks.

## General dietary guidelines

If your medical condition required a special diet or restriction before surgery, you will need to continue on that diet. After surgery, your diet will progress from clear liquid to a bland, low-fiber or low-residue diet. On return visits to the physician, be sure to find out when you can start on a regular diet. Please refer to the Ileostomy Diet Guidelines patient education brochure for more detailed information.

Some food fibers are never completely digested by your body such as peanuts, corn and mushrooms. These same foods were not completely digested before your surgery. You may now notice them in your pouch. This is normal.

Chew foods well and eat moderate portions. Drink plenty of fluids. This is very important in hot weather or during heavy exertion, when perspiration (sweat) adds to the loss of body fluids. Since you no longer have the large intestine for reabsorption of fluids, you may get dehydrated.

Eat a well-balanced diet. Do not skip meals. Skipping meals will cause an increase in gas and watery diarrhea.

### ***Low-fiber diet***

Due to the nature of your surgery and/or physical condition, your physician may feel you should temporarily stay on a low-fiber diet. Refer to the Low-Fiber Diet Guidelines patient education brochure for more detailed information. Here are some general guidelines.

### ***Low-fiber foods***

These foods are low in fiber:

- Cooked fruits and vegetables
- Bananas, applesauce, asparagus tips (not stalks), canned vegetables
- Low-pulp juice
- Eggs
- Fish and meat without casings
- White bread, flour tortillas (not corn), pancakes, pastries
- Dairy products
- Potatoes without skin, white rice, pasta
- Plain cakes, cookies, candy without nuts
- Carbonated beverages
- Alcoholic drinks (Check with your physician first. You should avoid alcohol if you take certain medications.)

Remember to cut food into small bites and chew it well.

### ***Foods to avoid***

- Uncooked fresh fruits (except bananas) and fresh vegetables
- Fresh coconut
- Nuts, seeds and kernels, including popcorn
- Whole grain
- Meat in casings (such as bratwurst)
- Dried beans
- Most Chinese food

Some foods may clump together to form a mass that is difficult to digest or get rid of. Partial obstruction of the small intestine can cause watery output or cramps. A complete obstruction can cause no output for 5 hours, with cramping, nausea and vomiting.

If this happens and the blockage is in the early stages, do the following:

- If you have increased watery output with cramping, change to a clear liquid diet.
- If you have no output with cramping, nausea or vomiting, do not eat or drink.

To relieve an obstruction, try the following:

- Get into a knee-chest position and rock back and forth.
- Take a warm bath to help relax the abdominal muscle and then try the knee-chest position again.

If cramping and/or nausea and vomiting continue without relief for 4 to 6 hours, call your physician.

## **Ileostomy care**

### ***Pouches***

There are many types of pouches. You may need to try several types to find the best pouch for you. You will leave the hospital with a cut-to-fit pouch (you cut it to fit your stoma size). Later, when your stoma size stabilizes, you may want to change to a precut pouch system (already cut to fit your stoma size). Your WOC nurse will show you how to size your pouch for a correct fit. You can buy pouches from local medical/surgical suppliers, mail order or online companies. If you are interested in trying a company's product, contact them for free trial packets.

It is best to empty your pouch when it is about half full of either air or stool. This will prevent the pouch from getting too full and pulling off. Before you empty your pouch, place toilet paper in the toilet to prevent splashing. Then, sit down and empty the pouch between your legs. You may also stand facing the toilet to empty the pouch. Clean the end of the pouch with toilet paper, then fold up the closure at the bottom of the pouch.

You will need to change your pouch routinely 2 times a week, and when any of the following happen:

- Leaks
- Itching under the pouch
- Burning under the pouch

Your pouch system prevents stool from getting on your skin. Stool is irritating to your skin. If any of the above conditions happen, remove the pouch and check your skin.

If you routinely change your pouch 2 times a week, you can feel comfortable that it will not leak. Whenever you leave home, carry an extra pouch already cut to fit. This will make you feel more secure if it leaks. It also is important to bring an extra pouch anytime you visit the physician, hospital or WOC nurse.

## How to change your pouch

### 1. Gather your supplies.

- Scissors
- Measuring guide
- Wash cloths or soft paper towels
- Non-moisturizing soap (optional)
- New pouch (Figure 4)
- Towel
- Paste or ring (optional)

### 2. Remove the old pouch.

Remove the pouch gently by lifting up on the tape while pressing underneath on skin. Do not rip or tear the pouch off. This can irritate the skin. If the pouch is sticking too well, use a wet wash cloth to press on the skin behind the barrier.

### 3. Clean the skin.

Wet a washcloth or soft paper towel with tap water and clean the skin around the stoma. You may use a non-moisturizing mild soap. Rinse well with water. Allow the skin to dry well. Do not use wipes that have lotion in them. Check your skin for any changes. If you see changes, read the “How to treat irritated skin” below.

### 4. Measure the stoma.

Before applying the pouch, remeasure the stoma with a guide. Make a note of the new size opening. Trace the new opening on the back of the wafer and cut it out. For the first 2 months after surgery, measure the stoma whenever you change your pouch. Adjust the size as needed.

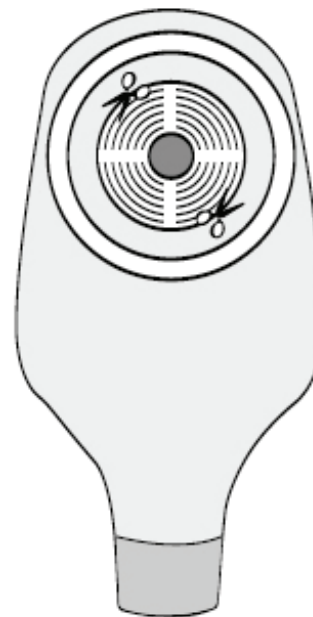
### 5. Prepare the wafer/pouch.

Remove the paper backing from the barrier wafer. (If you use a 2-piece system, remove the backing from the wafer.) You can use paste, a paste ring or strip paste on the sticky side of your wafer/barrier around the opening edge to fill in minor creases. This will make a flat surface and improve the fit and seal of your pouch. Your WOC nurse will show you how to do this.

### 6. Apply the pouch.

Center opening in wafer/barrier around the stoma and apply sticky side to skin. Press down to ensure all edges are sealed. To close the bottom of the pouch, fold up the lower edge 3 times and pinch to close.

Figure 4. Ileostomy pouch



## How to treat irritated skin

1. Remove the pouch gently.
2. Clean the skin with a wet wash cloth.
3. Gently pat your skin dry.



4. Sprinkle ostomy protective powder on reddened skin.
5. Dust off excess powder with a dry cloth. The powder will stick only to where the skin is irritated. The powder provides a dry surface so the wafer is able to stick.
6. Dab the powdered skin with a protective barrier wipe.
7. Recheck the size of the stoma. Be sure the opening in the wafer is the same size as your stoma.
8. Prepare and apply your wafer and pouch as usual.

## **Follow-up visits**

Your physician will tell you when to schedule a follow-up visit. Stomas change for many reasons. It is important to have equipment that fits and works well for you and lets you to lead a normal, active life. Remember to bring an extra pouch when you visit the physician, hospital or WOC nurse.

## **Call your physician**

Contact your physician if you have these symptoms:

- Change in the stoma color from pink-red to purple-black
- Bleeding from the stoma
- Bleeding between the stoma and skin that does not stop
- Unusual bulging around the stoma
- Any unusual problems with abdominal pain, nausea and vomiting that does not go away, or severe diarrhea (total volume of output increases and functions almost constantly)
- No output for longer than 5 hours

## **Call your nurse**

Contact your WOC nurse:

- If you have any skin redness, itching or burning lasting for more than a few days.
- If you have any questions or problems with pouching or leaks.
- For more information or questions about activities of daily living.

## **Where to buy supplies**

Search the internet under “medical/surgical supply companies.” Choose one close to you. Also, there are several mail-order and online companies that have free delivery and may help you with insurance forms. Contact your WOC nurse for information. Many pharmacies carry or will order supplies, but there may be added charges. You should compare prices. Sometimes you may need a prescription from your physician to get supplies. Talk with your physician about this.

## Insurance coverage

Most ostomy supplies are covered partially under Part B of Medicare and may be covered under Medicaid. Social Security disability benefits are available to those who qualify. Insurance coverage is different for each policy. We suggest saving receipts and asking your insurance company or third-party payor if coverage is available.

## Organizations

There are groups that provide support and information for people with ostomies and their spouses/partners. For example, the United Ostomy Association of America has programs that have educational, business and social components. Contact the following organizations for more information.

United Ostomy Association of America, Inc.  
800.826.0826  
**ostomy.org**

Wound Ostomy and Continence Nurses Society  
888.224.9626  
**wocn.org**

American Cancer Society  
312.372.0471  
**cancer.org**

Crohn's and Colitis Foundation of America (CCFA)  
800.932.2423  
**crohnscolitisfoundation.org**

CCFA Illinois Carol Fisher Chapter  
847.827.0404  
**ccfa.org**

MedicAlert cards and/or bracelets are recommended and available by calling:

MedicAlert  
800.432.5378  
**medicalert.org**

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