

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. Feel free to write down any questions you may have for your physician or nurse.

To understand how your ostomy functions, you need to become familiar with the digestive tract.

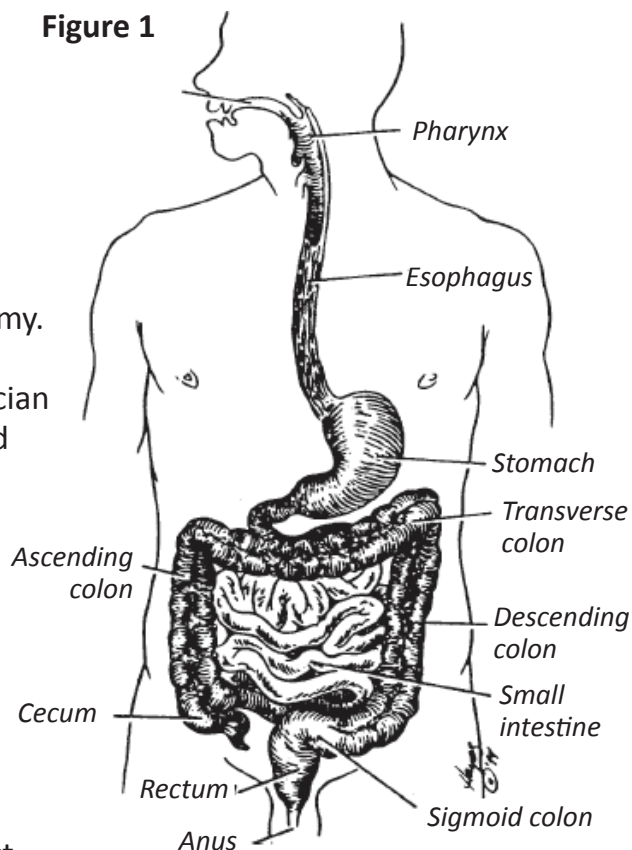
During your hospital stay, you will be visited by a wound, ostomy and continence (WOC) nurse. This nurse is trained and certified in complete care of patients with an ostomy. The WOC nurse will work with your physician and staff nurses to aid you in your recovery. Once you leave the hospital, the WOC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

The digestive system

To understand how your ostomy functions, you need to become familiar with the digestive tract (see Figure 1). When you eat, food travels from the mouth to the stomach. It then moves to the small intestine, where digestion is completed. Here, the nutrients from the food are absorbed for use by your body. The unused parts of the food will then pass into the colon, which collects the stool and absorbs water from the remaining material.

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

Figure 1



Digestive tract

Ileostomy – what is it?

An ileostomy is a surgical opening in the abdomen in which the lower end of the small intestine, called the ileum, is brought 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 called 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.

Since there is no muscle around the stoma, you are not able to control when stool passes out of your body. Therefore, an odor-proof pouch is applied to your skin, around the stoma, and collects the stool and gas. (Pouches will be discussed on page 7.) An ileostomy is done when part or all of the colon or rectum needs to be removed or bypassed. An ileostomy may be temporary or permanent.

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

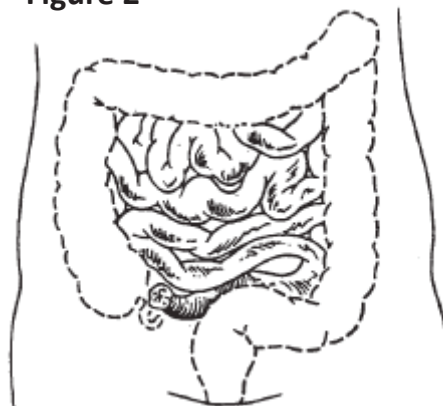
A temporary ileostomy may be needed for a period of time to allow a portion of the small or large intestine to heal. The colon may be rejoined in a later surgery. This could be weeks, months or years later. A permanent ileostomy may be needed for a variety of reasons. This type of ileostomy will not be closed in the future. The stoma will be the permanent exit for the stool. With an ileostomy, your stool will be a thick liquid.

Types of ileostomies

An ileostomy may be an **end** or a **loop**, depending on your surgery. In an end ileostomy, the bowel is cut and the end is brought to the skin surface (see Figure 2). The remaining bowel is either removed or sutured closed.

A loop ileostomy is formed by bringing a segment of the ileum to the skin surface and making an opening in the top. The opening is folded back like a turtleneck and is sewn to the skin. A plastic rod remains under the loop of the ileum for about 3 to 5 days (see Figure 3 on the next page).

Figure 2



End ileostomy

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 periodically. You will have the urge to have a bowel movement, and pass mucus-like drainage from the rectum. If your rectum has been removed, this will not occur.

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 color. 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. This change will be most noticeable 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.

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 large amount of bleeding, contact your physician.

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 such as seat belts and large belt buckles, which can cut into the stoma.

Activities

Work

Discuss with your physician when you can return to work. Most people are able to 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 gain confidence and security with the pouch remaining intact. You will be able to be independent in emptying and changing the pouch.

Clothing

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

Showering and bathing

The pouch is waterproof. You can wear it in the shower. Your pouch will remain intact underwater, while bathing or swimming. 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

There will be a short period of time when your activities will be restricted to allow your body to heal. These are some general guidelines to follow:

- No heavy lifting (more than 10 pounds) is allowed 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 resuming it.

After your recovery, the ileostomy should not interfere with exercise. Daily exercise is important for your body. Contact sports, such as football, karate or wrestling, are a concern. Injury to the stoma could occur. If you are interested in continuing any contact sports, check with your physician. Any non-contact sport should not be of concern.

Travel

You can continue to travel. Just remember to bring extra ostomy supplies with you. If you are flying, put supplies in carry-on luggage and not with checked luggage. In a car, store supplies in a cool spot, and avoid the trunk and back window ledge. If you take long vacations, arrangements can be made to have supplies shipped along the way by your supply company. Contact your WOC nurse with 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.

Males having an ileostomy may note some changes in sexual function. Talk to your physician and WOC nurse about expected changes and ways to maintain a satisfying sexual relationship.

Women of childbearing age who have an ileostomy need to plan for birth control. The body needs time to heal after surgery before pregnancy occurs.

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).
- Make use of attractive sleep and intimate apparel.

Please feel free to ask questions. Your care team is available and want to help you return to your normal lifestyle.

Medicines

Most medicines are absorbed in the small intestine. You may not have total absorption of time-released and time-sustained medicines. Therefore, these medicines may not be as effective. You need to notify any physician who treats you that you have an ileostomy. The following are suggested:

- Inform any physician who prescribes your medicine that you have an ileostomy.
- Inform 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 receive more medicine in less time if time-released medicines are crushed.
- When starting any new medicine, check your pouch to see that it is being absorbed and not expelled in the pouch.
- Medicines that cause diarrhea are not suggested.
- Before taking any medicine routinely used to prepare or clear the bowel for X-ray or surgery, verify the instructions with your surgeon or physician.

Carrying a MedicAlert® card in your wallet is suggested if your rectum has been removed. It should state you have an ileostomy and that rectal enemas, suppositories or rectal temperatures should not be attempted.

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 especially important in hot weather or during heavy exertion, when perspiration adds to loss of body fluids. You no longer have the large intestine for reabsorption of fluids; therefore, dehydration is possible.

Eat a well-balanced diet and avoid skipping 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 remain on a low-fiber diet. Please refer to the Low-Fiber Diet Guidelines patient education brochure for more detailed information. Here are some general guidelines.

Low-fiber foods*

- 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 beverages (check with your physician first; alcohol should not be mixed with some medicines)

*Remember to cut food into small bites and chew it thoroughly.

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 tend to clump together to form a mass that is difficult to digest or expel. 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 should occur, the following can be done in the early stages of a food blockage:

- 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 pouches available. Several types may be tried 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 wish to change to a pre-cut pouch system (already cut to fit your stoma size). Your WOC nurse will show you how to size your pouch for a correct fit. Pouches can be purchased 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. When 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 and empty the pouch. Clean the end of the pouch with toilet paper and roll up closure at the bottom of the pouch.

Your pouch will need to be changed routinely twice a week and when any of the following occur:

- Leakage
- Itching under the pouch
- Burning under the pouch

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

If you routinely change your pouch twice 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 leaking occurs. It also is important to bring an extra pouch anytime you visit the physician, hospital or WOC nurse.

How to change your pouch

1. Assemble your supplies.

- Scissors
- Measuring guide
- Wash cloths or soft paper towels
- Non-moisturizing soap (optional)
- Towel
- Paste or ring (optional)
- Paper towel rolled into a wick

2. Remove the old pouch.

Remove pouch gently by lifting up on tape while pressing underneath on skin. Do not rip or tear the pouch off, as this can irritate the skin. If 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 and rinse well with water. Allow skin to dry well. **Do not** use wipes that have lotion in them. Check your skin for any changes. Refer to skin irritation section if changes are seen.

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.

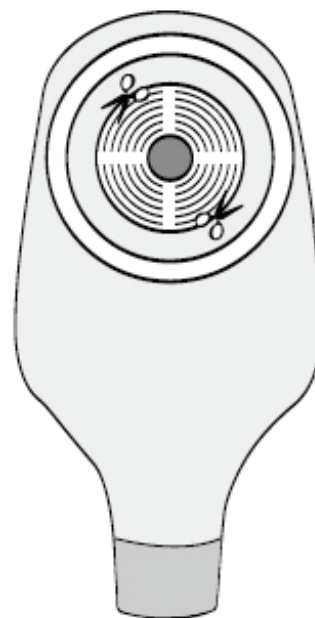
5. Prepare wafer/pouch.

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

6. Apply 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. Cleanse with a wet wash cloth.
3. Gently dry surrounding skin.

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 a protective barrier wipe on top of the powdered skin.
7. Recheck the size of the opening used. 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 various reasons. It is important to have equipment that fits and works well for you and allows you to lead a normal, active life. Remember to bring an extra pouch when you visit the physician, hospital or WOC nurse. The appointments with your WOC nurse can be made to coincide with a visit to your physician whenever possible.

Call your physician

Check with your physician if any of the following occur:

- Change in stoma color from pink-red to purple-black
- Excessive bleeding from stoma opening
- Continuous bleeding between stoma and skin
- Unusual bulging around your stoma
- Any unusual problems with abdominal pain, or continuous nausea and vomiting, 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 leakage.
- For additional information or questions about activities of daily living.

Where to buy supplies

Look in the Yellow Pages or on 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 assist you with insurance forms. Contact your WOC nurse for information. Many pharmacies carry or will order supplies, but there may be added charges. Price comparison is strongly suggested. A prescription from your physician may be required to obtain 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 individualized 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 persons with ostomies and for their spouses/significant others. 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
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

Notes
