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A Patient’s Guide to Ileostomy Care

This information is designed to 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 doctor or nurse.

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 ostomy patients. The WOC nurse will work with your doctor and staff nurses to aid you in your recovery. Once you leave the hospital, the WOC nurse will continue to be a resource person 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. There, 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.

**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 1 week to 10 days (See 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 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.

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, it is important for you to measure your stoma and fit the pouch opening according to size weekly. Your WOC nurse will show you how to do this.

When you clean your stoma, you may see a drop of blood as you wash it. 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 to wash your stoma. However, if you notice a large amount of bleeding, contact your WOC nurse.

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

Your nurse will give you a publication called A Patient’s Guide to Surgery. It will answer many of your questions about what will happen before, during and after surgery.

Work

Discuss with your doctor 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 doctor 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. After bathing or showering with the pouch, you can activate the wafer adhesive for a tight seal. Follow these steps:

- Dry the skin well.
- Turn a hand-held hair dryer to the lowest setting (warm).
- Direct the dryer air flow along all the edges of the wafer.

Always:

- Keep the hair dryer at least 6 inches away from the body.
- Use the dryer for a total of no more than 5 minutes.
- Do not use the dryer if your skin is red or sores are present.

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. Remember to empty your pouch prior to swimming.

**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. Do not drive for 3 weeks from the date of surgery. No heavy lifting (over 10 lbs.) for 6 weeks. If you had an exercise routine before surgery, please check with your doctor 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 doctor or WOC nurse. 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.

**Sex Life**

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 doctor 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 suggested by ostomy patients are:

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

Please feel free to ask questions. Your doctor and WOC nurse are 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 doctor who treats you that you have an ileostomy. The following are suggested.

- Inform any doctor 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 doctor. Some medicines can become inactive in the stomach. 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 doctor.

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 doctor, be sure to find out when you can start on a regular diet.

Some food fibers are never completely digested by your body (e.g., peanuts, corn and mushrooms). These 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. Also, eat regularly 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 doctor may feel you should temporarily remain on a low-fiber diet. 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 doctor first; alcohol should not be mixed with some medicines)

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

**Foods to avoid**
Fresh fruits (except bananas) and fresh vegetables
Fresh coconut
Nuts, seeds and kernels, including popcorn
Whole grain
Meat in casings (e.g., 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 increase in watery output, with cramping, is noticed, change to a clear liquid diet.
- If no output with cramping or nausea or vomiting is noted, do not eat or drink.

To relieve obstruction try:
- Knee-chest position while rocking back and forth.
- A warm bath to help relax the abdominal muscle and then the knee-chest position again.

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

**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 supply companies or discount catalogues. 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 one-third to one-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 replace the clip on the pouch. Some pouches are now made with a velcro-like closure.

Your pouch will need to be changed routinely every 4 to 7 days 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 every 4 to 7 days, 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 an accident occurs. It also is important to bring an extra pouch anytime you visit the doctor, hospital or WOC nurse.

**How to Change your Pouch**

- Assemble your supplies.
  - Scissors.
  - Measuring guide.
  - Wash cloths or wipes.
  - Towel.
  - Paste (optional).

- **Prepare wafer/pouch**
  Trace the opening on back of the wafer and cut it out. Snap the pouch to the wafer and remove paper backing. Paste may be placed on sticky side of wafer around the inner edge for minor creases. (Your WOC nurse will show you how to do this.)

- **Remove old pouch.**
  Remove the pouch gently by lifting up on tape while pressing underneath on skin. Do not rip or tear pouch off, as this can irritate the skin. If the pouch is adhering too well, a wet washcloth may be used to press on the skin behind the barrier.
- **Clean the skin.**
  Cleanse skin around the stoma with a wet wash cloth or wipe. Soap may be used but must be rinsed well. Allow the skin to dry. Check for skin changes. Refer to the skin irritation section below if changes are seen.

- **Measure the stoma.**
  Before applying the pouch, re-measure your stoma with a guide. Make a note of the new size opening. If the stoma is larger, take the prepared pouch and re-cut it. If smaller, apply the pouch and at next pouch change adjust the size. For the first 2 months after surgery, measure the stoma whenever you change your pouch. Adjust the size as needed.

- **Apply pouch**
  Center the opening in wafer over the stoma and apply sticky side to the skin. To close the bottom of the pouch, fold up the lower edge 3 to 4 times. Then pinch the entire bottom edge.

**How to Treat Irritated Skin**

1. Remove 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 or blot with a damp wash cloth. It will look like most of the powder has been removed. The powder will seal in to allow the irritation to heal. It also will provide a dry surface for the pouch to seal on the skin.
6. Dab a protective barrier wipe on top of the powdered skin.
7. Dust off or blot with a damp wash cloth. It will look like most of the powder has been removed. The powder will seal in to allow the irritation to heal. It also will provide a dry surface for the pouch to seal on the skin.

**Follow-up Visits**

Your doctor will tell you when to schedule a follow-up visit. We suggest regular yearly visits with your WOC nurse because manufacturers develop newer, more effective equipment. 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 doctor, hospital or WOC nurse. The appointments with your WOC nurse can be made to coincide with a visit to your doctor.
Call Your Doctor
Check with your doctor 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 under Medical/Surgical Supply Companies. Choose one close to you. Also, there are several mail-order companies that have free delivery and may assist you with insurance forms. Contact your WOC nurse for mail-order information. Many pharmacies carry or will order supplies, but there may be added charges. Price comparison is strongly suggested.

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 their spouses/significant others. For example, the United Ostomy Association of America (UOAA) has programs that have educational, business and social components. Contact the following organizations for more information.
United Ostomy Association of America, Inc. (UOAA)
800-826-0826
www.uoaa.org

Wound Ostomy and Continence Nurses Society
888-244-9626
www.wocn.org

The American Cancer Society
312-372-0471
www.cancer.org

Crohn’s and Colitis Foundation of America (CCFA)
Illinois Carol Fisher Chapter
847-827-0404
800-886-6664
www.ccfa.org

MedicAlert cards and/or bracelets are recommended and available by calling:
MedicAlert
888-633-4298
www.medicalert.org

Health Information Resources

For more information, visit one of Northwestern Memorial Hospital’s Health Learning Centers. These state-of-the-art health libraries are located on the third floor of the Galter Pavilion and on the first floor of the Prentice Women’s Hospital. Health information professionals are available to help you find the information you need and provide you with personalized support at no charge. You may contact the Health Learning Centers by calling 312-926-LINK (5465) or by sending an e-mail to hlc@nmh.org.

For additional information about Northwestern Memorial Hospital, please visit our Web site at www.nmh.org.