Understanding Your Ileostomy
This booklet can help you understand and manage your ileostomy. It is important to remember that you are not alone. Every year thousands of people have ileostomy surgery. For some, it is a lifesaving event. It may be performed to repair an injury or remove a diseased part of your bowel. Whatever the medical reason for your surgery, it’s natural to have questions and concerns.

The purpose of this booklet is to answer some of your questions and to ease some of your concerns about living with an ileostomy. This symbol indicates where detailed information is available about certain topics on our website www.hollister.com.

This booklet is provided to you by your healthcare team. It complements information given to you by your doctor and your Wound, Ostomy, Continence (WOC) Nurse or ET Nurse – a nurse who specializes in ostomy care. When you have questions, write them down on pages 24 and 25. You should discuss these questions with your doctor or WOC Nurse.

For a list of terms you may not be familiar with, but are used in this booklet, we have provided a glossary on page 23.
The colon is divided into four parts: the ascending colon, the transverse colon, the descending colon, and the sigmoid colon. As the stool moves through your colon, more and more water is absorbed until the stool becomes completely formed. When you have a bowel movement, stool and gas go from your colon into your rectum, and then out of your body through your anus. A muscle in your anus, called the anal sphincter, allows you to control when to have a bowel movement.

About Your Ileostomy

Before your surgery
Determining where the stoma will be placed on your abdomen is a very important part of the preparations for your surgery.

Generally, an ileostomy stoma is located on the abdomen in what is called the right lower quadrant. That is an area just below the waist, to the right of your navel – or belly button.

Before your surgery, your WOC Nurse and your surgeon will determine the best location for your stoma. Ideally, the stoma should be placed on a smooth skin surface. It should be located where you can see the stoma easily and take care of it yourself.

The gastrointestinal (GI) system
When you chew your food and swallow it, the food goes down your esophagus into your stomach. Stomach acids and chemicals called enzymes break down the food until it becomes a liquid mixture. From your stomach, the liquid food mixture goes into your small intestine.

The small intestine – which is about twenty feet long – is where most digestion takes place. Vitamins, minerals, proteins, fats, and carbohydrates are all absorbed into your body through your small intestine. Any food that is not absorbed in the small intestine goes into the large intestine as liquid waste or stool.

Your large intestine is also called the colon. It is generally five to six feet long. The colon has two main purposes:
1. to absorb water from your stool
2. to store your stool until you have a bowel movement

What is an ileostomy?
An ileostomy is a surgically created opening into the small intestine through the abdomen. The purpose of an ileostomy is to allow stool to bypass the colon.

An ileostomy may be temporary or permanent, depending on the medical reason for the surgery.

Because of an injury or disease – such as ulcerative colitis or Crohn’s Disease – the colon may be surgically removed, along with the rectum and anus.

Remember, the colon’s main purpose is to absorb water and store stool. Your body can continue to function even without a colon. When you have an ileostomy, stool is no longer eliminated through the anus. Instead, stool is eliminated through the ileostomy.
An ileostomy does not have a sphincter muscle, so you have no voluntary control over bowel movements. Instead, you will wear a disposable pouch to collect the stool.

An alternative to a permanent ileostomy is a procedure called ileal pouch anal anastomosis or ileal reservoir. After removal of the colon, the small intestine is used to create a reservoir pouch that is placed in the pelvis and connected to the anus. A temporary ileostomy is often needed while the reservoir heals.

The stoma
- Not painful
- Always red and moist
- May bleed easily

To construct an ileostomy, your surgeon brings part of the small intestine (ileum) through the abdominal wall. This new opening on the abdomen is called a stoma. Your stoma will probably be swollen for a period of time after surgery.

Each stoma is unique. Chances are, your stoma will look different from someone else’s. The stoma should not be painful. It is always red and moist – somewhat like the inside of your lip. The stoma may also bleed easily, especially if it is hit or rubbed. This type of minor, temporary bleeding is normal. (If the bleeding continues, or if the discharge (stool) is bloody, you should contact your doctor or your WOC Nurse).

Your stoma will probably be swollen after surgery. It may take several weeks for the stoma to shrink to its permanent size.

If you have a temporary stoma, it may be a loop or double barrel. A loop ileostomy may have a supporting device that is normally removed after two weeks.

The skin around the stoma is called the peristomal skin. The skin next to your stoma should not have rashes or sores. The most important thing you can do to keep your skin healthy is to use ostomy products that fit well and stay in place.

Stool from an ileostomy
Just after surgery, the stool from an ileostomy is generally a steady liquid type of drainage. However, as the small intestine begins to adapt, the stool will become thicker and more paste-like.

Remember the stool from an ileostomy comes directly from the small intestine, so it contains digestive enzymes that can be very irritating to your skin. Because of that, the pouch you wear must have a protective skin barrier that fits closely around your stoma.
Ileostomy Pouching Systems

You can choose the kind of Hollister ileostomy pouch you want to use. The type most commonly used with a ileostomy is a drainable pouch. All pouching systems include a skin barrier. The skin barrier protects your skin and adheres your pouching system to your skin.

Your pouch may be part of a one-piece or two-piece pouching system. Many pouches have clear and beige options. You can also select pouches that have a soft cover, such as the Hollister ComfortWear panel, to increase your comfort.

You might choose a pouch with a filter if your drainage is mostly solid. The filter lets the gas out, but not the odor. It also prevents gas from building up, so the pouch does not inflate like a balloon.

Hollister provides odor barrier pouches to increase your confidence when wearing a pouch.

### Drainable pouch

Drainable pouches are best for managing your ileostomy. They have a clamp or closure, so emptying the pouch is quick and easy.

Left to right: One-Piece Drainable Pouch, Two-Piece Drainable Pouch and Two-Piece Skin Barrier
Skin care

It is very important for the skin around the stoma to remain healthy and free of irritation. The peristomal skin should look just like the skin elsewhere on your abdomen. To prevent skin irritation or other skin problems, you should have a skin barrier and pouch that fits properly. Each time you remove your skin barrier and pouch, look carefully at your peristomal skin. If you notice any swelling, redness, or rash, you could have irritated skin. Sometimes – but not always – irritated skin is painful. If the problem persists or gets worse, be sure to contact your WOC Nurse.

Bathing or Showering

With an ileostomy, you can shower or bathe just as you did before. Soap and water will not flow into your stoma or hurt it in any way. You may shower or bathe with your pouch on or off – the choice is yours. Soap residue can sometimes interfere with how well the skin barrier or adhesive sticks to your skin, so choose a soap or cleanser that is residue-free.

Diet

Immediately after surgery, you may be on a restricted diet. After your recovery from surgery, you should be able to go back to your usual diet unless you are otherwise instructed.

Remember, the actual digestion of food takes place almost entirely in the small intestine, not in the colon. There are some foods that can cause odor or gas in your system. If that is a concern for you, you may want to eat those foods in moderation.

Odor

Odor is a concern for people who have ostomy surgery. Today’s ileostomy pouches are made with odor-barrier film, so odor from the stool is contained inside the pouch. You should notice it only when you are emptying or changing your pouch. If you notice odor at any other time, check the pouch seal for leakage.

Lifestyle Tips

- Eat a balanced diet.
- Eat slowly and chew your food well.
- Add foods to your diet gradually, to see how those foods agree with your system.
- Drink plenty of water, juice or other fluids each day.
Empty your pouch when it is necessary and convenient; for many people with an ileostomy that means four to six times a day. Emptying your pouch regularly can help reduce the risk of leakage. It can also help to avoid a bulge from a pouch that is too full. Your diet can affect the odor of the stool. Some foods and nutritional supplements affect the odor of stool.

**Foods that may increase odor:**
- asparagus
- broccoli
- brussel sprouts
- cabbage
- cauliflower
- eggs
- fish
- garlic
- onions
- some spices

**Gas**
As your bowel begins to function after surgery, you will notice gas in your pouch. The amount of gas varies. If you experienced excessive gas before your surgery, you will likely have similar problems after your surgery.

Gas can be caused by the foods you eat. It can also be the result of swallowing air. Drinking carbonated beverages, smoking, chewing gum, and chewing with your mouth open can all increase the amount of air you swallow.

If you are concerned about gas, you can use a pouch with a filter. The filter lets the gas out of the pouch, but not the odor. It also prevents gas from building up, so the pouch does not inflate like a balloon. Filters work best with a more formed discharge.

**Foods and beverages that may increase gas:**
- beans
- beer
- beverages
- broccoli
- brussel sprouts
- cabbage
- carbonated beverages
- eggs
- fish
- garlic
- onions
- some spices

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**Understanding Your Ileostomy**

**Food Blockage**
If the drainage from your ileostomy suddenly stops or consists only of watery fluid and you have abdominal pain you may have a food blockage. This can occur when high fiber foods have difficulty passing through the intestine and exiting the stoma. The symptoms (cramping, stoma swelling, abdominal distension) are similar to bowel obstruction of other causes so it is important to contact your healthcare provider or seek care at an emergency room.

Foods that may contribute to blockage include high fiber foods such as: celery, Chinese vegetables, coconut, corn, nuts, dried fruit, and popcorn.

**Diarrhea**
Diarrhea can occur for a variety of reasons. With an ileostomy, you can still get diarrhea, just as before your surgery. It's normal for ileostomy output to be unformed. If your drainage changes to mostly fluid output and a marked increase in the volume of the drainage, you may have diarrhea. If you have diarrhea, you need to drink more fluids to prevent dehydration. During this time, avoid foods and beverages that cause loose stools.

**Foods that may help thicken your stool:**
- applesauce
- bananas
- cheese
- creamy peanut butter – not chunky
- noodles – any type
- pretzels
- white rice
- white toast
- yogurt

**Lifestyle Tips**
- Diarrhea can cause dehydration, so you may need to increase the amount of fluids you drink.
- If the diarrhea persists, call your doctor.
- Do not take laxatives unless prescribed by your physician.
- Other signs of dehydration include dry mouth, dark urine, reduced urine, weakness, muscle cramps, and feeling faint.
- Sports drinks will help prevent dehydration related to fluid loss better than water, juices and carbonated beverages.
Medication
Some medications or nutritional supplements may change the color, odor, or consistency of your stool. Even non-prescription medications, like antacids, can cause changes. Some medications may not be completely absorbed when you have had your colon removed. These types include:

- Enteric coated
- Timed-release
- Extended or sustained release

Before taking any medication, it’s a good idea to ask your doctor or pharmacist.

Maintaining Your Lifestyle

Clothing
After ileostomy surgery, many people worry that the pouch will be visible under their clothing. Some people think they won’t be able to wear “normal” clothes, or that they will have to wear clothes that are too big for them. You should be able to wear the same type of clothes you wore before your surgery. In fact, today’s pouches are low-profile and fit so close to the body, chances are no one will know you’re wearing a pouch – unless you tell them.

The pouch can be worn inside or outside your underwear, whichever is more comfortable. Women can wear panty hose or girdles. Choose a patterned swimsuit, instead of one with a solid color.

Returning to work and traveling
As with any surgery, you will need some time to recover. Be sure to check with your doctor before returning to work or starting strenuous activity.

Once you’ve recovered from the surgery, your ileostomy should not limit you. You should be able to return to work or travel just about anywhere. When you travel, take your ileostomy supplies with you. Take more than you think you will need. If you need to buy supplies while traveling, you will find that ileostomy products are available from select medical or surgical retailers throughout the world.

Lifestyle Tips
- When flying, pack your ostomy products in your carry-on bag.
- Pre-cut your products so you will not need to carry scissors in your carry-on bag.
- Fasten the seat belt above or below your stoma.
- Store your ostomy products in a cool, dry place.
- Plan ahead. Know where to contact a local WOC Nurse when traveling.
Activity, exercise and sports

A ileostomy should not prevent you from exercising or from being physically active. Other than extremely rough contact sports or very heavy lifting, you should be able to enjoy the same type of physical activities you enjoyed before your surgery.

People with ileostomies are able to swim, water ski or snow ski, play golf, tennis, volleyball, softball, hike, sail, or jog just as they did before their surgery. Please be aware that heat and moisture can reduce the wear time of the pouching system, so you may want to watch how your skin barrier performs under these conditions.

Lifestyle Tips

- Empty your pouch before swimming.
- You may add tape to the edges of your skin barrier before swimming.
- You may need to change your pouch more often if you wear it in a hot tub or sauna.
- You may want to wear a small pouch (closed pouch) for swimming and active sports.

Sex and personal relationships

Because ileostomy surgery is a body-altering procedure, many people worry about sex and intimacy, and about acceptance by their spouse or loved one. For people who are dating, a big concern is how to tell someone about the ileostomy.

Supportive personal relationships can be major sources of healing after any type of surgery. The key, of course, is understanding and communication.

Ileostomy surgery affects both partners in a relationship, and it’s something to which both partners must adjust, each in his or her own way. Let your partner know that sexual activity will not hurt you or your stoma. If you have concerns about your emotional adjustment after surgery, be sure to talk about them with your doctor or WOC Nurse.

If you are concerned about having children, you will be happy to know that after a satisfactory recovery, it is still possible for a woman who has a stoma to have children. Many men have become fathers after having ileostomy surgery. If you have questions about pregnancy, be sure to ask your doctor or your WOC Nurse.

Maintaining Your Lifestyle

Lifestyle Tips

- Empty your pouch before having sexual relations.
- Sexual activity will not hurt you or your stoma.
- You may wear a small pouch or closed pouch during sex.
- A beige pouch or pouch cover can help hide the pouch contents.
- Intimate apparel can hide the pouch and keep it close to your body.
Routine Care of Your Ileostomy

Here are a few guidelines for successful care of your ileostomy.

- Empty your pouch when it is one-third to one-half full.
- Replace the skin barrier (the waxy part that sticks to your skin) every three to seven days.
- If you use soap, make sure your soap doesn’t contain oils or lotions that can interfere with adhesives.
- Rinse your skin with water, and dry it completely before you apply the new pouch.
- After you apply your skin barrier, hold it against your body for 30-60 seconds. The pressure and warmth help activate the adhesive.
- If you wear a two-piece system, try putting your skin barrier on at an angle, making a diamond shape, for a smoother fit.
- You can shower or bathe with your skin barrier and pouch in place, or you can remove them before bathing. Water will not harm or flow into your stoma.
- If your skin becomes red and sore, or your pouch is not staying in place, be sure to see your doctor or WOC nurse.

Follow Up Care

Following surgery: discharge information

Your WOC Nurse can help you keep a record of your surgery and recommend the right products to maintain the health of your ileostomy.

Type of ostomy: __________________________

Date of surgery: __________________________

Stoma size and shape: ______________________

Recommended pouching system: __________________________

Other recommended products:

Other suggestions:

You can get your ostomy products through the following retailer(s):

Retailer Name: __________________________

Retailer Address: __________________________

Phone: __________________________

Retailer Name: __________________________

Retailer Address: __________________________

Phone: __________________________

Your WOC Nurse: __________________________

Phone: __________________________
About Supplies
Ostomy products are specialized supplies that are not available through all pharmacies. You may choose to use mail order supply companies or purchase through a local retailer.

Most ostomy supplies are covered by private insurance plans, military benefits, Medicare and Medicaid. Check with your carrier to find out your level of coverage and if you must use a specific supplier.

If you need assistance in finding a supplier for Hollister products, contact us at 1.800.323.4060.

Call your WOC Nurse if you notice any of the following problems listed below:

- Skin irritation.
- Recurrent leaks of your pouch or skin barrier.
- Excessive bleeding of your stoma.
- Blood in your stool.
- A bulge in the skin around your stoma.
- Persistent diarrhea.
- Abdominal pain and/or vomiting.

Questions to ask my doctor or my WOC Nurse:

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Other questions related to living with an ostomy:

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Resources

Organizations that provide information
Your doctor and your WOC Nurse are very important resources. An annual physical with your doctor is something that should definitely be a part of your routine. It’s also a good idea to have an annual checkup with your WOC Nurse. For more information and a free catalog, contact Hollister Incorporated.

Hollister Incorporated
2000 Hollister Drive
Libertyville, IL 60048
1.800.323.4060
www.hollister.com

If your hospital does not have a WOC Nurse on staff, contact the Wound, Ostomy, and Continence Nurses Society, a professional organization. They can help you find a WOC Nurse close to where you live.

Wound, Ostomy, and Continence Nurses Society (WOCN)
15000 Commerce Parkway
Suite C
Mt. Laurel, NJ 08054
1.888.224.WOCN (9626)
Fax: 866.615.8560
www.wocn.org

Another important source of information and support is the United Ostomy Associations of America, Inc. (UOAA) an organization of people with ostomies. There are chapters of the UOAA in nearly every major city in the country, and there is a national conference each year.

United Ostomy Associations of America, Inc. (UOAA)
1.800.826.0826
www.uoaa.org
Additional Resources
American Cancer Society (ACS)
1599 Clifton Road NE
Atlanta, GA 30329
1.800.ACS.2345
www.cancer.org

Crohn’s & Colitis Foundation of America, Inc. (CCFA)
National Headquarters
386 Park Avenue South, 17th floor
New York, NY 10016-8804
1.800.932.2423
www.ccfa.org

You can get more educational materials and product information from Hollister. Ask your WOC Nurse or call Hollister Incorporated at:
Hollister Incorporated
2000 Hollister Drive
Libertyville, IL 60048
1.800.323.4060
www.hollister.com

In Canada:
Hollister Limited
95 Mary Street
Aurora, Ontario L4G 1G3
1.800.263.7400

Educational Resources

All of these Hollister educational materials listed and others are available on our website:

www.hollister.com

Ostomy Educational Theatre (available in DVD or VHS) Literature Number
How to Choose an Ostomy System (English) 907186 (DVD)
How to Use Ostomy Products (Spanish) 907383 (DVD)
Managing Your Ostomy
How to Choose an Ostomy System (English) 907184 (VHS)
How to Use Ostomy Products (Spanish) 907382 (VHS)
Managing Your Ostomy 907185 (VHS)
Ostomy Educational Theatre Checklist - New 907430

Stoma Sizing Guide 903515

Instruction Materials Literature Number
Understanding Your Colostomy Booklet - Updated 907411
Understanding Your Ileostomy Booklet - Updated 907412
Understanding Your Urostomy Booklet - Updated 907413
What’s Right?–Colostomy (English) 906596
What’s Right?–Colostomy (Spanish) 907242
What’s Right?–Ileostomy (English) 906597
What’s Right?–Ileostomy (Spanish) 907243
What’s Right?–Urostomy (English) 906598
What’s Right?–Urostomy (Spanish) 907244
What’s Right?–Pediatric (English) 906624

Ostomy Care Tips (Pads of 25) Literature Number
Adapt Barrier Rings and Convex Barrier Rings 907392
Adapt Lubricating Deodorant - New 907428
Adapt Paste 907249
Adapt Powder Coming Soon
Colostomy Irrigation - New 907254
One-Piece Pouching System - New 907251
Patient Anatomy Guide 907414
Peristomal Skin Care/Complications - New 907253
Glossary

**Anus**
The opening of the rectum; the last section of the digestive tract where waste is expelled.

**Colon**
Another term for the large intestine or last portion of the gastrointestinal tract.

**Ileostomy**
An ostomy (surgical opening) created in the ileum, part of the small intestine.

**Enzymes**
Digestive enzymes break down the food we eat so it can be used as a source of nutrition.

**Large intestine**
Another term for the colon or the last part of the gastrointestinal tract.

**One-Piece**
The skin barrier is attached to the pouch.

**Peristomal skin**
The skin area around the stoma.

**Pouch**
The bag that collects the discharge from the ostomy.

**Rectum**
The lower end of the large intestine, leading to the anus.

**Skin barrier**
Part of the pouching system; it protects your skin and adheres your pouch to your skin.

**Small intestine**
The portion of the gastrointestinal system that first receives food from the stomach. Divided into three sections: duodenum, jejunum and ileum.

**Sphincter**
A muscle that surrounds and closes an opening. An ostomy does not have a sphincter.

**Stoma**
Another term for ostomy, a surgically created opening.

**Stool**
Waste material from the bowel. Also known as feces or bowel movement.

**Two-Piece**
The skin barrier is separate from the pouch. Both pieces are needed to create a complete pouching system.