



Understanding

Your Ileostomy



Ostomy Care
Healthy skin. Positive outcomes.



Life after ostomy surgery

As a person who lives with an ostomy, I understand the importance of support and encouragement in those days, weeks, and even months after ostomy surgery. I also know the richness of life, and what it means to continue living my life as a happy and productive person.

Can I shower? Can I swim? Can I still exercise? Will I still have a healthy love life? These are the questions that crossed my mind as I laid in my bed recovering from ostomy surgery. In the weeks following, I quickly discovered the answer to all of these questions for me was YES! I was the person who would empower myself to take the necessary steps and move forward past my stoma. Those who cared for and loved me would be there to support me through my progress and recovery.

Everyone will have a different journey. There will be highs, and there will be lows. Although our experiences will differ, I encourage you to embrace the opportunity for a new beginning and not fear it. Remember that resources and support are available to you — you are not alone. Our experiences shape our character and allow us to grow as people. Try and grow from this experience and embrace the world around you.

This booklet has been carefully crafted for you — the individual, the spouse, the parent, the grandparent, the caregiver, the person with a stoma.

Hopefully, it will help you obtain the knowledge and skills you need to move beyond your ostomy, and back into your life.

— BROCK MASTERS
TORONTO, CANADA

The information provided in this booklet is not medical advice and is not intended to substitute for the recommendations of your personal physician or other healthcare professional. This booklet should not be used to seek help in a medical emergency. If you experience a medical emergency, seek medical treatment in person immediately.



If you are about to have — or have recently had — ileostomy surgery, this booklet can help you understand your ileostomy and how to manage it. It is intended to help answer some of your questions, and to help ease some of your concerns about living with an ileostomy.

Remembering that you are not alone is important. Every year thousands of people have ileostomy surgery. For some, it is a lifesaving event.

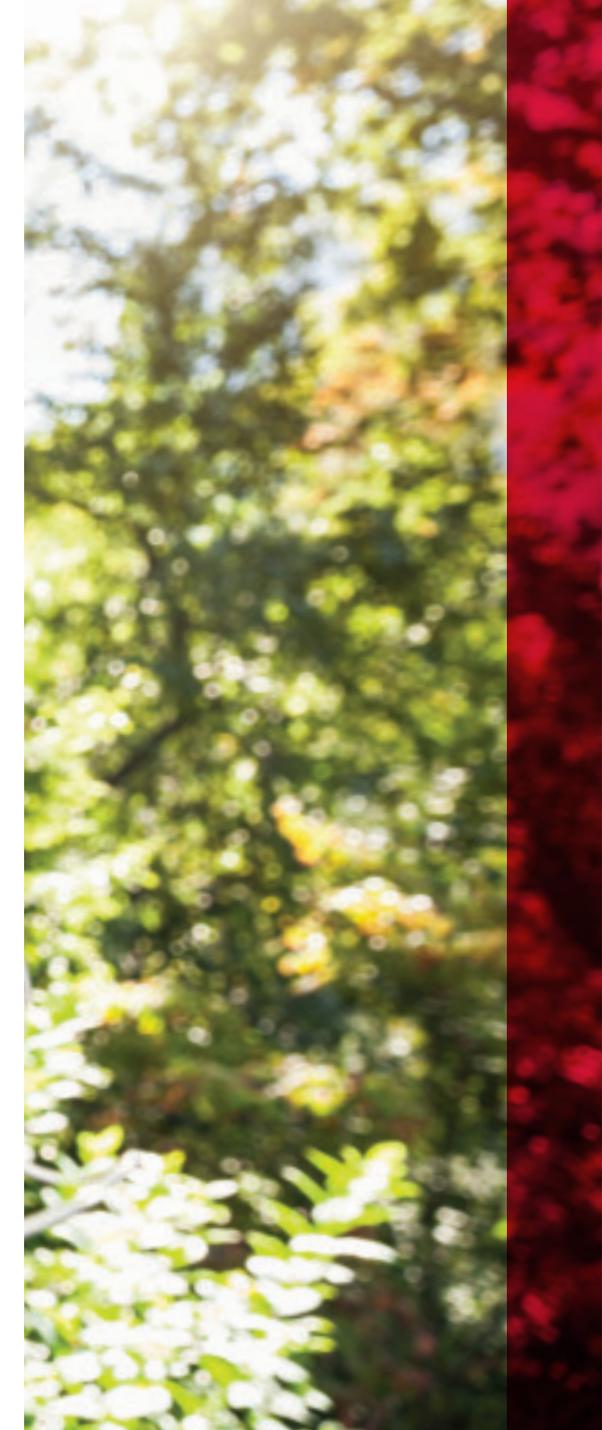


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It may be performed to repair an injury, or remove a tumor. Whatever the medical reason for your surgery, it is natural to have questions and concerns.

This booklet is provided to you by Hollister Education. It supports information given to you by your healthcare professional, and your Wound, Ostomy, Continence (WOC) nurse, or Enterostomal Therapist (ET) nurse — a nurse who specializes in ostomy care.

A glossary is included at the back of this booklet to help with some terms you may not be familiar with.



Getting Prepared

for 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. It is an area just below the waist, to the right of your navel, or belly button.

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

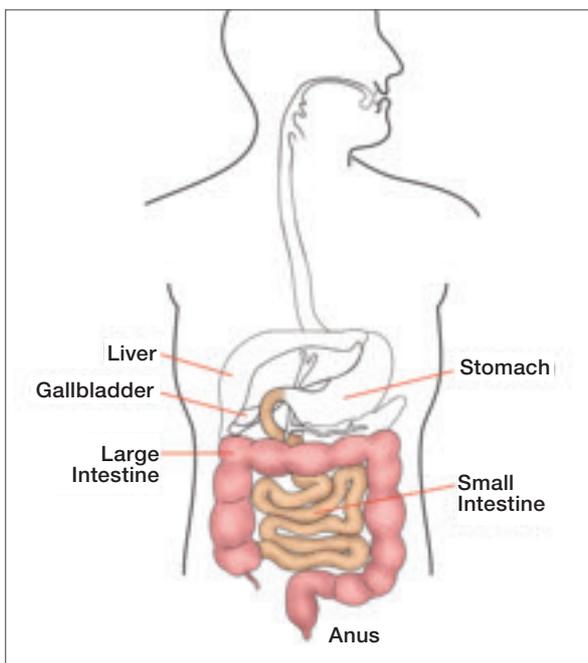
The gastrointestinal (GI) system

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 20 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.

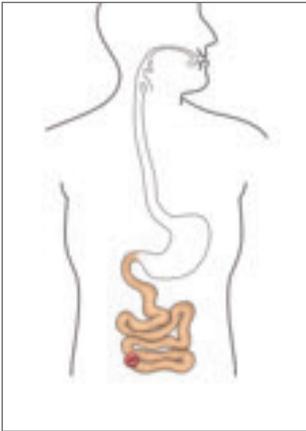
Your large intestine, also called the colon, is divided into four parts: the ascending colon, the transverse colon, the descending colon, and the sigmoid colon. It is generally five to six feet long and has two main purposes:

1. To absorb water from your stool
2. To store your stool until you have a bowel movement

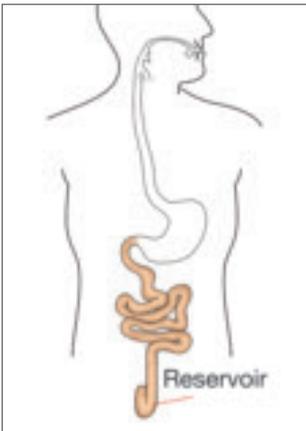


As the stool moves through your colon, more and more water is absorbed until the stool becomes more formed. When you have a bowel movement, stool and gas go from your colon into your rectum, and then out of your body through your anus. A muscle in your anus, called the anal sphincter, allows you to control when to have a bowel movement.

The GI system



Ileostomy



Ileal Reservoir

What is a ileostomy?

An ileostomy is a surgically created opening into the small intestine through the abdomen. With an ileostomy, a section of the small intestine and the large intestine (colon) have been removed or bypassed.

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.

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

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

Your stoma will probably be swollen after surgery. It may take several weeks or months for the stoma to shrink to its permanent size. While stomas come in a variety of sizes and shapes, a healthy stoma:

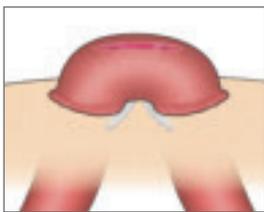
- Is pink or red in color and is slightly moist
- Is not painful
- Bleeds easily when rubbed or bumped (for example, when washing), but should resolve quickly. If the bleeding continues, contact your WOC/ET nurse or healthcare professional



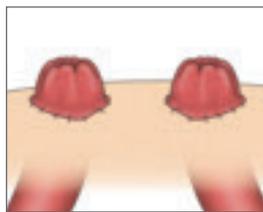
Whether your stoma is large or small, protrudes well, or is flush with the skin, drainage should empty into your pouch without leaking under the skin barrier. If the discharge (stool) from the stoma is bloody, you should contact your WOC/ET nurse or healthcare professional.

Temporary stomas

If you have a temporary stoma, it may be loop or double barrel. A loop ileostomy may have a supporting device (called a rod, or bridge) that is normally removed about two weeks after surgery — sometimes sooner. Be sure to remind your healthcare professional about this if it has not been removed after this time.



Loop Stoma



Double Barrel Stoma

Stool

Just after surgery, the stool from an ileostomy is generally a steady liquid type of drainage. 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. The pouch you wear must have a protective skin barrier that fits closely around your stoma. It may take several weeks or months for the stoma to shrink to its permanent size, so be sure to measure your stoma before every barrier application.



Pouching Systems

Explained

The pouching system selected for use in the hospital is often basic. After you are home, you may want to try some different pouching systems to find the one that works best for you.

The following general information about pouching systems can help you find the product that best meets your needs.

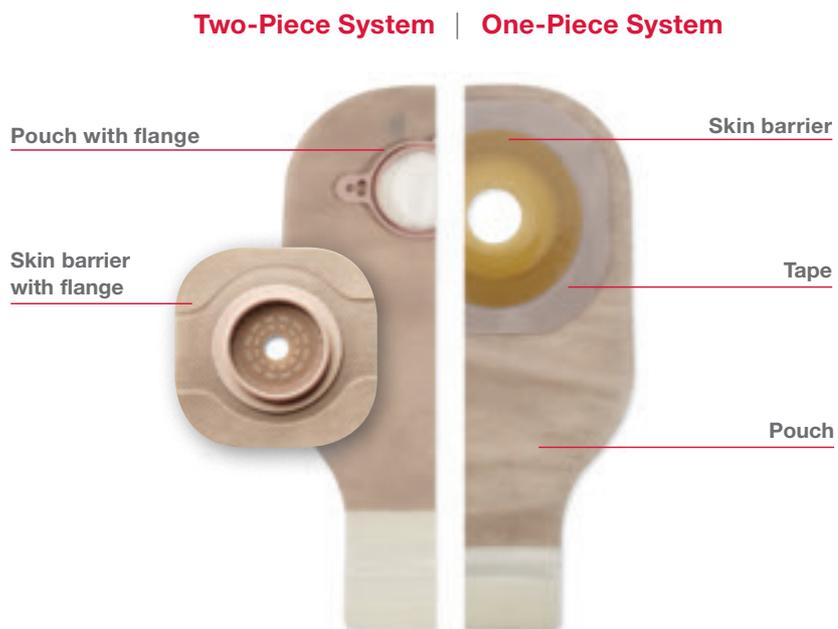
One-piece and two-piece pouching systems

There are two types of pouching systems: One-piece pouching systems and two-piece pouching systems. Each has different advantages and individuals tend to choose their pouching system based on what best meets their needs.

Both pouching system types include a skin barrier and pouch. The skin barrier is the adhesive portion of your pouching system that fits immediately around your stoma. It protects your skin and holds your pouching system in place, and is sometimes called a wafer. The pouch is the bag that collects output from the stoma.

In a one-piece pouching system, the skin barrier is attached to the pouch — so that it is in a single unit. When changing a one-piece pouching system, the pouch and skin barrier are removed together since they are connected.

In a two-piece pouching system, the skin barrier and the pouch are two separate pieces. The plastic ring in a two-piece system that is used to connect the two parts together is called the flange. The two-piece pouching system allows you to change your pouch while the skin barrier stays in place on your body.



Drainable and closed pouches

There are two types of pouches — drainable pouches and closed pouches. However, the type of pouch most commonly used with an ileostomy is a drainable pouch. They either have a clamp or an integrated closure, and are meant to be emptied when they are about 1/3 to 1/2 full.



Drainable pouch with integrated closure



Drainable pouch with a clamp closure

Pouching system features

Ileostomy pouches are available with a variety of features that can help improve your quality of life. Some of the most common features found in an ileostomy pouch are:

Filters

Some pouches include filters that help to minimize gas from building up, so the pouch does not inflate like a balloon. The filter lets the gas out, but not the odor.

Panel material choices

Pouch panel options are available in ultra-clear, transparent and opaque. You can also select pouches that have a soft cover, to help increase your comfort and provide added discretion.

Viewing option

Viewing option (available on one-piece system) offers the discretion of a beige panel material and the confidence of a clear pouch all-in-one. When the beige flap is lifted, the stoma and output can be observed clearly and privately.

Closure systems

When using a drainable pouch, you have two options for containing stomal output. You can use a clamp, or a pouch that has an integrated closure system (a closure mechanism that is built into the pouch).

Skin barrier options

The skin barrier is the most important part of the pouching system because it protects your skin from stoma discharge and keeps your pouch in place. There are many skin barrier options designed to provide the most secure seal around your stoma to prevent leakage and protect your skin. Your WOC/ET nurse should be consulted to discuss which skin barrier is right for you.



Taking Care

of You

Skin care

The skin around the stoma is called the peristomal skin. Get into the habit of cleaning the peristomal skin each time you change your barrier. Less is better when caring for the skin around the stoma. For most people, water is sufficient for cleaning the skin.

The peristomal skin should be intact without irritation, rash, or redness. It should look similar to the skin anywhere else on your body. A properly fitting skin barrier and the right skin barrier formulation help protect the skin from being irritated by the stoma drainage.

If you discover red, broken, or moist skin around the stoma, seek the assistance of a WOC/ET nurse or healthcare professional. Be sure to assess your peristomal skin on a regular basis to ensure your skin is healthy and to help address any issues in a timely manner.

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 pouching system 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 free from all moisturizers, oils, and residue.

If you use a two-piece pouching system, you may find it convenient to switch to a different pouch for the shower so that the pouch you wear stays dry. If you choose to remove the pouch while showering or bathing, it's suggested to also remove the skin barrier to prevent exposing it to too much moisture.

Diet

Immediately after surgery, you may be on a restricted diet. To promote optimal healing and help you regain weight you may have lost either before or after your operation, it is vital to re-establish a healthy diet. After you recover from surgery, you should be able to go back to your usual diet unless you are otherwise instructed.

Odor

Odor is a concern for people who have ileostomy surgery. 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.

Empty your pouch when it is 1/3 to 1/2 full of discharge or gas. For many people with an ileostomy that means four to six times a day. The best time to change your pouching system is in the morning before you have had anything to eat or drink. 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 also affect the odor of the stool.

Foods that may increase odor:

- asparagus
- broccoli
- brussel sprouts
- cabbage
- cauliflower
- eggs
- fish
- garlic
- onions
- some spices

TIPS

- **Eat a balanced diet**
- **Eat slowly and chew your food well**
- **Drink plenty of water, juice, or other fluids each day**
- **Add different foods to your diet gradually, to see how those foods agree with your system**

Foods and beverages that may increase gas:

- **beans**
- **beer**
- **broccoli**
- **brussel sprouts**
- **cabbage**
- **carbonated beverages**
- **cucumber**
- **eggs**
- **fish**
- **garlic**
- **onions**
- **some spices**

Gas

As your bowel begins to function after surgery, you may notice gas in your pouch. The amount of gas varies. If you had excessive gas before your surgery, you will likely have similar experiences 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, but can be used with other output consistencies.

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 such as constipation or diarrhea. 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 healthcare professional or pharmacist

Food blockage

If the drainage from your ileostomy suddenly stops or consists only of watery fluid and you have abdominal pain and cramping, 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 or other causes so it is important to contact your healthcare professional or seek care at an emergency room.

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

Foods that may thicken your stool:

- applesauce
- bananas
- cheese
- creamy peanut butter – not chunky
- marshmallows
- noodles (cooked)
- pretzels
- white rice
- white toast
- yogurt

Diarrhea

With an ileostomy, you can still get diarrhea for a variety of reasons. It's normal for ileostomy output to be unformed. If your drainage changes to mostly fluid output and you experience a marked increase in the volume of 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.

TIPS

- **Diarrhea can cause dehydration, so you may need to increase the amount of fluids you drink**
- **If the diarrhea persists, call your healthcare professional**
- **Do not take laxatives unless prescribed by your healthcare professional**
- **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**



Caring for

Your Ileostomy

When your healthcare professional says it is appropriate, you can resume your normal activities. You will get used to your pouching system and develop a schedule that fits your lifestyle.

Sex and personal relationships

Because ileostomy surgery is a body-altering procedure, many people worry about how this procedure will affect sex, intimacy with and acceptance by their spouse or loved one. For people who are dating, a big concern is how and when to tell someone about their 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 is 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, although you never want to use the stoma for intercourse. If you have concerns about your emotional adjustment after surgery, be sure to talk to your healthcare professional or WOC/ET nurse.

If you are concerned about having children, you will be happy to know that after a satisfactory recovery, it is still usually 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 healthcare professional or your WOC/ET nurse.

TIPS

- Empty your pouch before having sexual relations
- Sexual activity will not hurt you or your stoma
- You may wear a small 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

Clothing

After ileostomy surgery, many people worry that the pouch will be visible under their clothing. Some people think they will not 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 are wearing a pouch unless you tell them.

The pouch can be worn inside or outside of your underwear. Select the option that is most comfortable for you.

Returning to work and traveling

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

Once you have recovered from the surgery, your ileostomy should not limit you. You should be able to return to work or travel just about anywhere. Your healthcare professional will guide and direct you accordingly. When you travel, take your ileostomy supplies with you. It’s a good idea to pack 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.

TIPS!

- **When flying, pack your ostomy products in your carry-on bag**
- **Check with your airline about restrictions on traveling with liquids, gels, scissors, and aerosols**
- **Explore carrying a travel card that has information about your ostomy — this can be helpful when communicating with airport security personnel**
- **Fasten the seat belt above or below your stoma**
- **Store your ostomy products in a cool, dry place**
- **Know where to contact a local WOC/ET nurse when traveling**



Activity, exercise, and sports

When your healthcare professional says it is appropriate, you may resume your normal activities. An ileostomy should not prevent you from exercising or 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. During warm months — and after activity, you should watch how your skin barrier performs. Also, you may want to add additional tape to the edges of your skin barrier before swimming.

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**

Caring for your Ileostomy guidelines

- Empty your pouch when it is 1/3 to 1/2 full of discharge or gas
- Change your skin barrier on a routine basis. You will get more comfortable with this after you learn what works best for you
- Wear time is based on personal preference and stoma characteristics, but three to four days is considered normal
- If you use soap, make sure it does not contain creams or lotions that may leave a residue. This can interfere with your skin barrier adhesive
- Make sure the peristomal skin is clean and dry before applying your skin barrier
- After you apply your skin barrier, apply gentle pressure for about a minute for best adhesion
- Verify that no skin is showing between the skin barrier and the stoma to help prevent leakage and skin irritation
- If you wear a two-piece pouching system, try placing the skin barrier on your body in 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
- Removing a pouch from a two-piece system before showering may affect the skin barrier adhesion — it's best to leave the pouch on or remove both the pouch and skin barrier
- If you discover red, broken or moist skin around the stoma, or your pouch is not staying in place, be sure to see your healthcare professional or WOC/ET nurse
- Be sure to assess your peristomal skin on a regular basis to ensure your skin is healthy and to help address any issues in a timely manner



Follow-Up

Care

Now that you are leaving the hospital, there are a few things you will need to know.

Below you can find a checklist of some basic ostomy skills for you to review with your WOC/ET nurse that will assist you with the transition from hospital to home.

LEARN HOW TO:

- Empty your pouch
- Remove your pouching system
- Assess and care for your stoma and the skin around your stoma
- Apply your pouching system
- Assess the signs of potential complications and when to contact a healthcare professional
- Manage gas and odor
- Follow dietary and fluid guidelines
- Follow instructions for home healthcare (if applicable)
- Enroll in Hollister Secure Start services — your WOC/ET nurse can facilitate your enrollment

Hollister Secure Start Services

You may have questions about your ostomy, how to care for your stoma, and how to keep living the life you want to live, but you don't have to figure it out on your own. Hollister Secure Start services offers FREE dedicated ostomy support for as long as you need it, regardless of the brand of products you use.

Enrolling is simple and provides lifetime access to Hollister Secure Start services. Ask your clinician for help enrolling, or you can speak to a member of our team by calling 1.888.808.7456.

Here's how it works:

After you enroll, you will receive an introductory kit that includes a travel bag, stoma measuring guide, mirror, scissors, and educational booklets. You will be matched with a dedicated Consumer Service Advisor who can walk you through the introductory kit and work with you to ensure you get the care you need, including help with:

- Finding the right products
- Helping you sort out insurance coverage
- Identifying product supplier options
- Accessing an ostomy nurse over the phone to find answers to clinical product questions
- Providing product information and condition-specific education
- Finding local resources

Your Consumer Service Advisor will check in periodically to see how you are doing and to answer any questions. You should expect your first phone call within 72 hours of enrolling.

To learn more about taking care of your ostomy or how Hollister Secure Start services can support you, please call us at 1.888.808.7456 or visit www.securestartservices.com.

Ostomy product supplies

Once you have established a product fit that is right for you, it is time to find a supplier that can provide you with an ongoing supply of ostomy products. There are several considerations when choosing a supplier:

- Do you want to work with a national or regional durable medical equipment (DME) supplier who can mail your supplies, or do you prefer to pick up supplies at a local pharmacy or DME supplier?
- Can the supplier bill your insurance in-network to minimize your out-of-pocket expense?
- Do you already have a DME supplier that serves your other medical device needs?

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.

Many 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.

How much to order

Your monthly quantity of ostomy supplies is determined primarily by the type of ostomy, its location on the body, and the condition of the skin surface surrounding the stoma. It really depends on your specific situation. Medicare has established monthly “usual maximum quantities” that provide guidance on the maximum amount of various products to accommodate most individuals. Private insurers are not required to follow the Medicare usual maximum quantities but many of them do — or at least use Medicare’s quantities as a guide to establishing their own.

When to call your WOC/ET nurse

Call your WOC/ET 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
- Diarrhea with pain and/or vomiting

Resources

Your healthcare professional and your WOC/ET nurse will be very important resources for you in the days ahead. You also have ongoing access to online information, or printed educational materials, at www.hollister.com/ostomycareresources such as:

- **The “Living with an Ostomy” Booklet Series** — provides information on lifestyle-related topics such as diet, travel, sports, and fitness
- **“Caring for Your Loved One with an Ostomy” Booklet** — provides information and support for your loved one(s), in helping you live life to the fullest after ostomy surgery
- **“Routine Care of Your Ostomy” Care Tip** — provides information on how to care for an ostomy
- **“Ostomy Educational Theatre” Video Modules** — provides an overview of ostomy products, helping you to choose the products that are right for you and learn how to use them
- **“Living with a Stoma” Video Modules** — provides insights from other people who have been through stoma surgery on how to lead full and productive lives

Ostomy support groups are also available to individuals who have had ostomy surgery. Here, you are able to interact with people who are facing many of the same challenges that you are. The ability to discuss issues with someone who understands what you are experiencing can be very beneficial.

Hollister Secure Start Services

1.888.808.7456

www.securestartservices.com

United Ostomy Associations of America, Inc. (UOAA)

1.800.826.0826

info@uoaa.org

www.ostomy.org

Crohn’s & Colitis Foundation of America, Inc. (CCFA)

1.800.932.2423

www.ccfa.org

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.

Enzymes

Digestive proteins that break down the food we eat so it can be used as a source of nutrition.

Ileostomy

An ostomy (surgical opening) created in the small intestine.

Large Intestine

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

One-Piece Pouching System

The skin barrier and pouch are a single unit.

Peristomal Skin

The area around the stoma starting at the skin/stoma junction and extending outward to the area covered by the pouching system.

Pouch

The bag that collects output from the stoma.

Rectum

The lower end of the large intestine leading to the anus.

Skin Barrier

The portion of your pouching system that fits immediately around your stoma. It protects your skin and holds the pouching system in place. Sometimes called a wafer.

Small Intestine

The portion of the gastrointestinal system that first receives food from the stomach. It absorbs important nutrients and fluids.

Sphincter

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

Stoma

A surgically created opening in the gastrointestinal or urinary tract. Also known as an ostomy.

Stool

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

Two-Piece Pouching System

The skin barrier and pouch are two separate pieces.

Wear Time

The length of time a pouching system can be worn before it fails. Wear times can vary but should be fairly consistent for each person.

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