Your Personal Wellness Guide

NewYork-Presbyterian
Weill Cornell Medical Center

Center for
Advanced Digestive Care

TABLE OF CONTENTS

INTRODUCTION

CARING FOR YOUR ILEOSTOMY

DAILY CONSIDERATIONS & TROUBLESHOOTING

LIVING WITH AN ILEOSTOMY

INTRODUCTION

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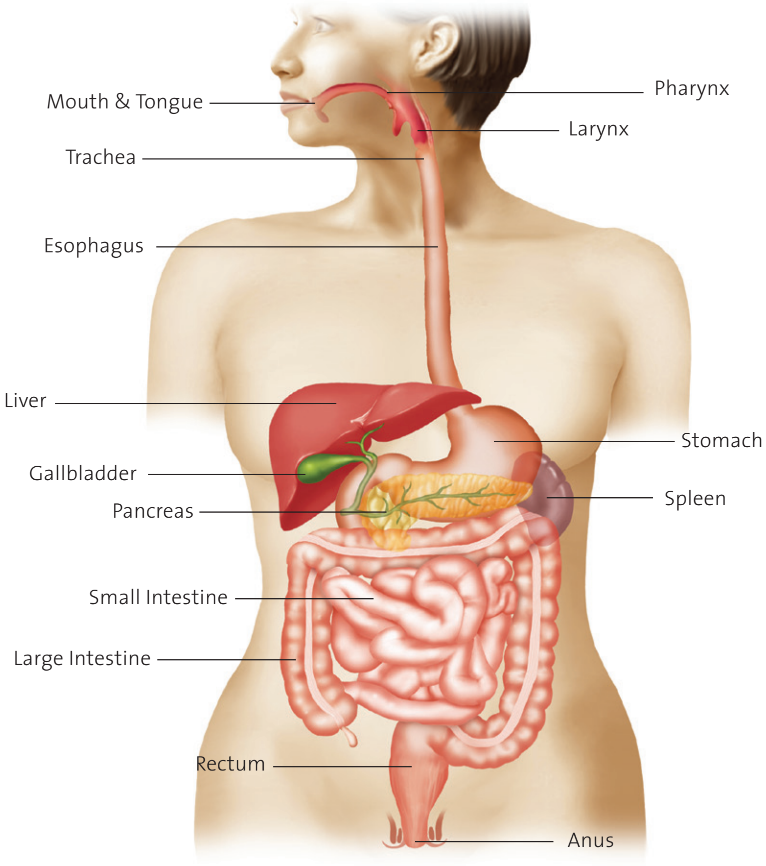
UNDERSTANDING YOUR DIGESTIVE TRACT

The human digestive tract is a series of organs designed to break down food, absorb nutrients and remove waste. It consists of the mouth, esophagus, stomach, small intestine, large intestine, rectum, and anus. When we swallow our food, it passes into the esophagus which connects the mouth and the stomach. Once food enters the stomach, it is broken down into liquid form before moving on to the small intestine.

By the time food enters into the small intestine, it is mostly liquid. The small intestine is a series of hollow loops measuring approximately 22 feet long. The small intestine's job is to absorb nutrients that will fuel our bodies. After leaving the small intestine, what remains enters the large intestine which is also known as the colon. In the colon, most of the liquid is absorbed, leaving human waste (also called stool) behind. The stool then moves into the rectum and is passed through the anus.



WHAT IS AN ILEOSTOMY?

An ileostomy is a surgically created opening where a piece of the small intestine is brought through the abdominal wall. You may also hear an ileostomy called simply an ostomy. This is a generic word for any surgically created opening. The piece of intestine that comes through the skin and is visible on the outside of the abdomen is called a stoma. People with ileostomies pass stool through their stomas. An ileostomy does not have a control muscle and therefore you will not be able to control when you pass stool and gas. The ileostomy is covered by an ostomy appliance that protects the stoma and surrounding skin, and collects waste.

Stoma

A healthy stoma is bright red and moist looking. Since there are many blood vessels that feed the stoma, it is normal to notice a small amount of blood when caring for your ostomy. Your stoma has no nerve endings so you will not have pain at your stoma. Initially after surgery, the stoma will look swollen. This swelling will gradually go away over a period of about 6 weeks.

Sometimes you may feel the urge to have a bowel movement. This feeling is probably related to a build up of mucus. This is nothing to worry about. If you feel this sensation, you should sit on the toilet and gently try to pass this mucus.

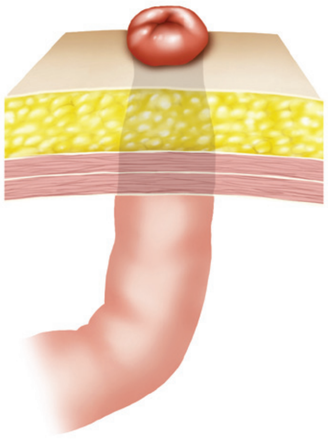
WHY DO I NEED AN ILEOSTOMY?

Ileostomy surgery is performed to bypass damaged or diseased intestine, or to protect a surgical site inside the intestine while it heals. Colon cancer, rectal cancer, familial adenomatous polyposis, Crohn's disease, Ulcerative Colitis, Hirschsprung's disease, diverticulitis, and trauma are some common reasons why someone may have an ileostomy. Sometimes people have ileostomy surgery because of weakness or damage to the anal sphincter muscle, which is the muscle that allows us to control when we pass gas and have bowel movements. An ileostomy may be temporary or permanent depending on the circumstances.

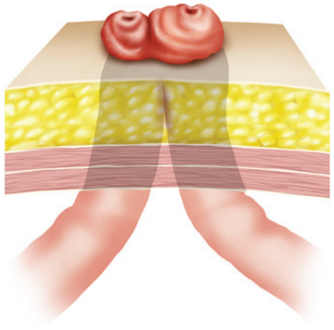
TYPES OF ILEOSTOMIES

End Ileostomy – An end ileostomy is created by taking the end of the small intestine through the abdominal wall and surgically attaching it to the skin.

Loop ileostomy – A loop ileostomy (also called a diverting ileostomy) is a procedure in which a loop of small intestine is brought through the abdominal wall and an opening is created for stool to pass. In the immediate post-operative period, you may notice a red catheter attached to the outside of your stoma. This temporary catheter holds the stoma in place during healing.



End Ileostomy



Loop Ileostomy

WHO WILL TEACH ME HOW TO CARE FOR MY ILEOSTOMY?

You will meet with a Wound, Ostomy, and Continence Nurse (WOC Nurse) in the hospital. A WOC Nurse is a registered nurse with specialty training and certification in the care of patients with ostomies. Registered nurses in the hospital are also able to provide basic ostomy care and education. Upon discharge you will be referred to a home nursing agency for follow up ostomy teaching. After a few visits, most people are comfortable caring for their ostomy. The goal is to become independent with all aspects of ostomy care.

There is also an outpatient WOC Nurse available to see you for additional teaching sessions, troubleshooting, and support. Remember to make a post-operative appointment with the outpatient WOC Nurse about two weeks after discharge from the hospital. Additionally, we recommend that you see an outpatient WOC Nurse at least once a year for as long as you have your ileostomy, even if you are not having any problems. Many people find that support organizations such as the United Ostomy Association of America (UOAA) can provide additional information about their ostomy.

CARING FOR YOUR ILEOSTOMY

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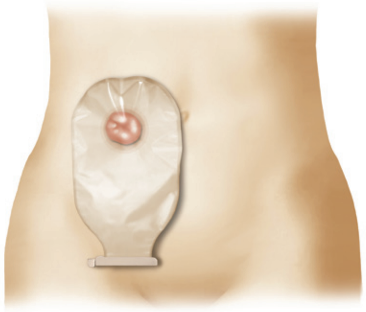
WEARING AN OSTOMY APPLIANCE

After surgery, you will need to wear an ostomy appliance to collect the stool that will drain from your ileostomy. Wearing an ostomy appliance takes some getting used to and it is normal to feel nervous at first. Everyone adjusts at their own pace, but most people are surprised by how quickly they get used to life with an ileostomy.



An ostomy appliance consists of an adhesive skin barrier (sometimes called a wafer) and a pouch. The adhesive skin barrier holds the appliance onto the abdomen and keeps the surrounding skin clean and protected. The pouch collects stool and gas, and prevents odor. These appliances are waterproof and can be worn in the shower or when swimming.

Ostomy appliances come in one and two piece systems. With two piece ostomy appliances, the pouch attaches to the skin barrier by snapping onto a circular piece of plastic known as the flange. This allows the pouch to be changed without having to remove the skin barrier. One piece ostomy appliances do not have a flange and the pouch does not disconnect from the skin barrier.

One piece appliances tend to be more flexible and comfortable. These may be the better option for people with decreased vision and/or decreased hand coordination.

One Piece Appliance

Two Piece Appliance

POUCH OPTIONS

Ostomy pouches are available in either transparent or opaque materials. Most people start out with transparent pouches until they get used to caring for their ileostomy. Once you are comfortable caring for your ileostomy you may wish to switch to an opaque pouch.

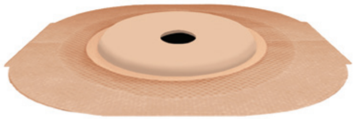
Ostomy pouches are either drainable or disposable. Drainable pouches open at the bottom so that stool can be emptied into the toilet. Disposable pouches (sometimes called closed-end pouches) do not open at the bottom. When a disposable pouch needs to be changed, it is disconnected from the skin barrier at the flange and a new disposable pouch is attached. Since the pouch will need to be emptied multiple times a day, most people with an ileostomy prefer to use a drainable pouch. This will be discussed in more detail in the section entitled "Draining your pouch". People with an ileostomy should not use one piece closed-end pouches because they cannot empty them without removing the entire appliance. Regardless of which system you choose, your pouch should be emptied or replaced when it is 1/3 of the way full or less.

Drainable Pouch

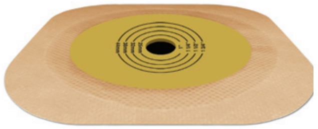
Closed Pouch

SKIN BARRIER OPTIONS

Skin barriers, also called wafers, are available with either standard wear or extended wear adhesive backing. Most individuals with an ileostomy need to use an extended wear skin barrier to protect their skin from the erosive nature of ileostomy drainage. Some people need a convex skin barrier. Convex skin barriers curve inwards towards the body, placing gentle pressure on the skin surrounding the stoma. This type of barrier is often used when people experience leakage or have soft abdominal folds.

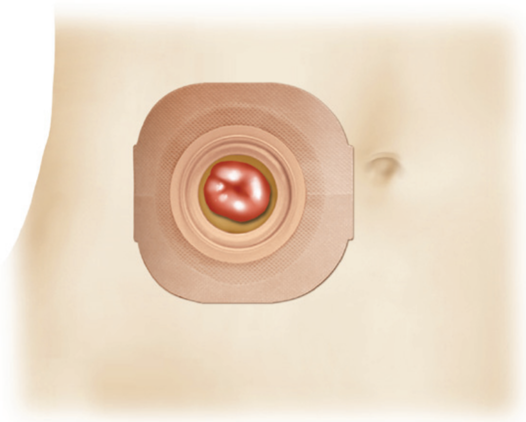


Convex Barrier



Flat Barrier

Regardless of which type of wafer you use, when it needs to be changed you will need to cut an opening in the center of the new skin barrier. The size of this opening will be based on the size of your stoma. The first six weeks following surgery, your stoma will gradually decrease in size and you will need to measure it frequently to know how large to cut this opening. Measuring your stoma and cutting your skin barrier will be discussed in more detail in the section entitled "Changing your ostomy appliance".



After six weeks, your stoma probably won't change in size and you can order pre-cut skin barriers. There are a variety of options available for your ostomy appliance. Your WOC Nurse will work with you after surgery to determine which appliance is best for you.

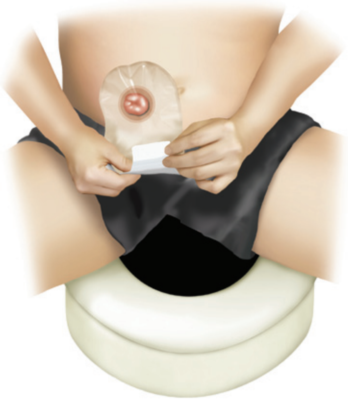
DRAINING YOUR POUCH

The number of times that an ostomy pouch needs to be emptied each day varies greatly from person to person. The important thing to remember is that your pouch should be emptied when it is 1/3 of the way full or less. Below are step by step instructions on how to empty your pouch:

Step # 1
Place toilet tissue into the toilet bowl to prevent splash.

Step # 2
Sit on the toilet seat as far back as possible and spread your legs.

Step # 3
Hold the bottom of your pouch upward and unroll or unclip the tail. If you use a pouch with a clip closure, turn the pouch tail inside out making a cuff (if you use a pouch that does not close with a clip you do not need to cuff the pouch tail).



Step # 4
Pinch the tail to keep it closed and bend forward, lowering the tail downward so that it hangs into the toilet.

Step # 5
Release the pouch tail allowing the contents to drain into the toilet bowel.

Step # 6
After all contents have drained wrap a finger with toilet paper and wipe the bottom 2-3 inches of your pouch tail on both the inside and outside. Remember to unroll the pouch tail if it is cuffed.

Step # 7
Seal or clip your pouch closed double checking to make sure that your pouch is closed securely.

RELEASING GAS FROM YOUR POUCH

From time to time your pouch may fill up with gas. If your pouch is 1/3 full or nearly 1/3 full you should empty your pouch following the steps listed above. If your pouch is not close to 1/3 full you may choose to just release the air and not drain the stool contents. You may want to do this in a restroom or private area as the gas released may produce an odor.

If you wear a two piece appliance, the gas can be released by separating the top of the flange. You should only make a small separation to prevent stool from escaping. Only a small crack is needed for the gas to escape. Once the gas has been released, reattach the pouch back to your skin barrier, double checking to make sure it is completely connected and secure.

If you wear a one piece appliance, the gas can be released by unclipping or unrolling the closure while holding the tail up so no stool contents can escape. Once the gas has emptied from the pouch you can seal or clip your pouch closed, double checking to make sure that it is closed securely.

You should never make a hole in your pouch to release gas. Doing so will allow odor and thin stool to leak from the pouch. If gas build up occurs frequently you should speak with your WOC Nurse about using a pouch with a built in filter. Pouch filters allow a small amount of air but not odor to be continuously released from the pouch.

ROUTINE SKIN CARE

Since the skin surrounding your stoma is usually covered by a skin barrier, it is important to thoroughly inspect this area when changing your appliance. You may notice a faint redness of the skin immediately after removing your appliance which quickly resolves. This is related to the action of removing the adhesive barrier and is nothing to be concerned about.

To clean your skin, all that is needed is warm water and a paper towel. This will be discussed in more detail in the section “Changing your ostomy appliance”. Soaps, lotions, ointments and creams contain ingredients that will interfere with the appliance adhering to your skin properly and should not be used. Using alcohol to clean the skin around your stoma can cause skin dryness and irritation and should also be avoided. Additionally, gauze is expensive and unnecessary and toilet tissue will fall apart and leave lint behind on your skin.

Skin rashes, open sores, pain, and redness that does not resolve within a few minutes after removing the appliance are not normal. Most of the time skin irritations are caused by contact with stool or are related to an irritation or allergy to one of the products you are using. Be sure to notify your WOC Nurse if you develop irritation of the skin surrounding your stoma. Usually a few minor adjustments are all that is needed to correct problems with skin irritation. It is important to be proactive with your skin assessment to prevent small issues from becoming bigger problems.

CHANGING YOUR OSTOMY APPLIANCE

Your ostomy appliance should be changed every 3-4 days. You should also change your appliance immediately at the first sign of leakage to prevent skin irritation. The best time to change your appliance is when your stoma is the least active. This is often as soon as you wake up before eating or drinking. Many people find it easiest to change their ostomy appliance in the bathroom while sitting or standing in front of a mirror. Below are step-by-step instructions on how to change your ostomy appliance:

Step # 1: Gather your supplies

Moist and dry paper towels, skin barrier & drainage bag, measuring guide, scissors, disposal bag, pen, and anything else you've been instructed to use.

Step # 2: Drain your pouch

If you use a drainable pouch you should drain your pouch prior to changing your appliance. Step-by-step instructions on how to empty your pouch are listed in the section entitled "Draining your pouch". If you use a disposable or closed end pouch you may ignore this step.

Step # 3: Remove your old appliance

Going from top to bottom, push down on your skin while gently peeling the barrier away from your skin. Once the appliance is off, place it in a disposal bag (these come packaged with ostomy pouches). Always be gentle when removing the skin barrier. Quickly ripping off the skin barrier may cause damage to your skin.

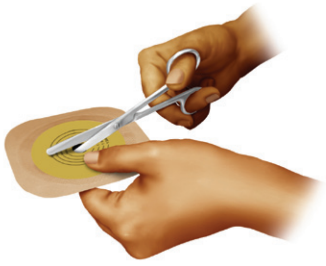
Step # 4: Clean your skin and stoma

Gently clean your stoma and skin with a water-moistened paper towel and thoroughly pat dry. It is normal for your stoma to bleed slightly during routine care. Do not use soap, lotions, or pre-moistened wipes for routine stoma care. These may interfere with skin barrier adhesion or cause skin irritation.

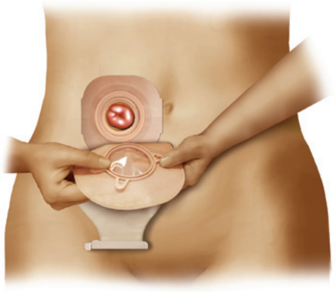
Step # 5: Measure your stoma

You will need to measure your stoma with each appliance change for about 6 weeks following surgery. Use the measuring guide that comes packaged with your skin barriers to measure the diameter of your stoma by finding the circle that fits closest to your stoma. There should not be skin visible between the stoma and measuring guide.

Step # 6: Trace and cut your skin barrier



Using the measuring guide, trace the correct size circle onto the back of your skin barrier. Using the starter hole, follow the tracing that you just made to cut an opening in your barrier that matches the size of your stoma.



Step # 7: Replace your appliance

Remove the backing from your skin barrier and apply it so that your stoma goes through the opening you have cut. If you wear a two piece appliance you may now attach the pouch onto the skin barrier. If you wear a transparent pouch, you may choose to attach the pouch onto the barrier first and apply them as one piece. Once your appliance is in place, you should take both hands and set them on top of the appliance applying gentle pressure for 1-2 minutes to activate the adhesive on your skin barrier.

Step # 8: Check and recheck

Once your ostomy appliance has been placed, you should check and recheck that the pouch is securely attached at the flange. If you use a drainable pouch you should also double check that the tail closure is secure.

DAILY CONSIDERATIONS & TROUBLESHOOTING

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Leakage and Skin Irritation

Frequent leakage of stool under your ostomy appliance is not normal and can cause skin irritation. If you experience leakage you should make sure that your skin barrier opening is cut to the correct size. If the opening is too large, stool can leak under the skin barrier and irritate the exposed skin. Remember that no skin should be visible between the stoma and skin barrier opening.

Frequent causes of leakage include:

- Allowing the pouch to become overfull with stool or gas
- Improperly sized barrier opening
- Inappropriate pouching appliance
- Weight gain or weight loss
- Wearing the same skin barrier for longer than the recommended 3-4 days

If you are having problems with leakage and/or skin irritation please notify your WOC Nurse. There are many products available to help correct problems with leakage and skin irritation. See the section entitled "Understanding and using ostomy accessory products" for more information.

Diet After Ileostomy Surgery

You will need to temporarily follow a restricted diet after ileostomy surgery. During your stay in the hospital, you will initially be started on oral liquids and will be advanced slowly from liquids to soft foods. Many patients receive additional fluids through an IV at first. By the time you are released from the hospital you will probably be on a low fiber diet that you will stay on for about 6 weeks unless instructed otherwise by your healthcare team. You will meet with a dietician to discuss your individual dietary needs and instructions prior to being discharged from the hospital.

Examples of easily digestible foods that you can incorporate into your diet after surgery include:

- **Dairy:** low fat milk, buttermilk, yogurt, most cheeses
- **Proteins:** poultry, fish, eggs, ham, lean beef
- **Vegetables:** vegetable juice without pulp and seeds, cooked seedless vegetables
- **Fruits:** juices without pulp, bananas, canned fruit (except pineapple), seedless melons
- **Grains:** white breads, white rice, white pasta, rice and corn based cereals
- **Fats/oils:** smooth peanut butter, butter, margarine, olive oil
- **Miscellaneous:** salt, pepper, mild seasonings, sugar, honey, jelly, decaffeinated coffee, and tea

There are certain foods you should avoid for the first 6 weeks after undergoing ileostomy surgery. After 6 weeks many people are able to eat almost everything. The key is to try one new food at a time, start with a small portion, chew well, eat slowly, and listen to your body. If you develop nausea, vomiting, bloating, or decreased drainage from your ileostomy you may have a food blockage and should call your physician's office immediately. If your symptoms are severe, you should go to the emergency room. Food blockages are discussed in more detail in the "Bowel obstruction and food blockages" section of this book.

Below are some foods that should be avoided for the first 6 weeks following ileostomy surgery:

- **Proteins:** fried fatty meats, tough meat and gristle, beans, legumes, lentils
- **Vegetables:** all raw vegetables, corn, peas, lima beans, cauliflower, broccoli, cabbage, coleslaw
- **Fruits:** raw fruit except seedless melons, dried fruit, prune juice
- **Grains:** whole wheat, bran, breads with seeds, brown rice and pasta, grits, oat bran, oatmeal
- **Fats/oils:** nuts, seeds, crunchy peanut butter, coconut
- **Miscellaneous:** popcorn, caffeinated beverages

Stool that comes from an ileostomy does not pass through the colon so it is watery and contains a lot of fluid, making it easy to become dehydrated. For this reason, staying properly hydrated is extremely important for anyone with an ileostomy. In order to do this you should drink 8-10, 8 ounce glasses of non-caffeinated beverages a day. Please note that caffeinated beverages can be dehydrating. Therefore, you should drink one extra non-caffeinated beverage for every caffeinated beverage you consume throughout the day.

Selecting foods and beverages that are high in sodium, potassium, and electrolytes can help to prevent and correct dehydration. See the below examples:

- **High in sodium:** chicken and beef bouillon, sports drinks, oral electrolyte drinks, rice water, pretzels, crackers, soy sauce, and tomato juice
- **High in potassium:** sports drinks, orange juice, bananas, potatoes, bullion, tomato juice, watermelon

There are certain foods that will help thicken your stool. Adding the foods listed below can help thicken your stool and may help to prevent dehydration:

- **Stool thickening foods:** applesauce, boiled milk, peanut butter, tapioca, bananas, rice, cream of rice, toast, mashed potatoes, pasta, cheese

There are also certain foods that tend to loosen stool. If you have large amounts of watery stool from your ileostomy you may want to consider limiting the following foods:

- **Stool loosening foods:** beer, hot beverages, caffeine, broccoli, cabbage, figs, prunes, fried foods, fruit juice, onions, spicy foods, leafy vegetables

In addition to the consistency of your stool, food also affects gas production and the odor of your stool. See below for examples of gas producing and inhibiting, and odor producing and inhibiting foods:

- **Gas producing foods:** apple juice, melon, vegetable juice, broccoli, asparagus, mushrooms, onions, spinach, brussels sprouts, cabbage, beans, beer, eggs, fish, carbonation, chewing gum
- **Gas inhibiting foods:** buttermilk, cranberry juice, yogurt
- **Odor producing foods:** beer, wine, asparagus, beans, broccoli, garlic, mushrooms, onions, cabbage, pears, cheese, nuts, fish, eggs, vitamins
- **Odor inhibiting foods:** buttermilk, cranberry juice, tomato juice, lettuce, parsley, spinach, yogurt

DEHYDRATION

People with an ileostomy are at an increased risk for dehydration because of the increased fluid lost in ileostomy drainage. As discussed previously in the "Diet after ileostomy surgery" section, it is important to drink 8-10 glasses of non-caffeinated fluid each day to prevent dehydration. Below are some of the signs and symptoms of dehydration:

- Dry mouth and tongue
- Dark colored urine
- Dizziness when going from a sitting to standing position
- Weakness
- Leg cramps
- Confusion
- Tingling feeling in your hands and feet
- Nausea

If you develop any of these symptoms, you should try to drink sodium and potassium containing beverages and notify your doctor's office. If your symptoms are severe, you should go to the emergency room. Suggestions for beverages high in sodium and potassium can be found in the "Diet after ileostomy surgery" section of this book.

If you or your doctor are concerned that your ileostomy is putting out too much, you may want to consider measuring your ileostomy drainage. This can be done by emptying your ileostomy drainage into a urinal or other container with volume measurements. The hospital, your doctor, or a surgical supply store should be able to supply you with an appropriate container. If your ileostomy drains more than one liter (1000 cc/1000 ml) in twenty four hours, you should notify your health care team.

MANAGING GAS AND ODOR

Ostomy appliances are specifically designed to be odor proof. The only time you should notice an odor is when you are draining stool or releasing gas from your pouch. If you notice an odor at any other time, you should make sure that your pouch is completely secure at both the flange and tail closure. You should also check to make sure that stool has not leaked behind your wafer. To decrease odor when draining your pouch, there are pouch deodorizers that can be placed inside the pouch.

If your pouch frequently fills up with gas, you may want to consider a pouch with a built in filter. This allows a small continuous amount of air, but not odor, to be released from the pouch. If you do use a pouch with an air filter and start to notice an odor not related to leakage you may want to change your pouch. Occasionally these filters can become clogged by liquid stool which decreases their effectiveness. This is especially true if the same filtered pouch is used for more than 3 days.

As discussed in the section "Diet after ileostomy surgery", it is possible to decrease the amount of gas and odor you experience by limiting and adding certain foods. Often, the gas from an ileostomy is related to swallowed air. You can reduce this by eliminating things such as smoking, chewing gum, drinking through a straw, carbonated beverages, and eating quickly.

BOWEL OBSTRUCTION AND FOOD BLOCKAGE

A bowel obstruction is a blockage inside the intestine that prevents waste from exiting the body. The most common cause of a bowel obstruction for individuals with ileostomies is a food blockage. This is especially true during the first 6 weeks after surgery.

If you have large amounts of clear watery drainage or very little ileostomy drainage for several hours, especially when accompanied with nausea, vomiting, bloating, abdominal pain, or hiccups, you may have a bowel obstruction. If you develop these symptoms, it is important that you call your doctor's office immediately. If your symptoms are severe, you should go directly to the emergency room.

To decrease the chance of a food blockage, you should follow a low fiber diet after surgery. After the initial 6 weeks, many people are able to eat whatever they want, while other people learn to avoid certain foods because they have a tendency to develop food blockages. This is very individualized. After the first six weeks from surgery, and with your doctor's permission, you should experiment eating a variety of foods to see how your body reacts. See below for tips on preventing food blockages and a list of foods that are most likely to cause a food blockage (keep in mind that not everyone who eats these foods will develop a food blockage).

- **Tips to prevent a food blockage:** eat slowly, chew every bite thoroughly, add one new food at a time, drink fluids with meals, eat small frequent meals
- **Foods most likely to cause a food blockage:** fruit and vegetable skins, coconut, popcorn, nuts, pineapple, cabbage, broccoli, corn, dried fruits, celery, raw carrots, grapes

MEDICATION

You should avoid taking extended release and enteric coated medications when possible. These types of medications are designed to be absorbed slowly and will most likely drain into your pouch before they are completely absorbed. This can decrease the effectiveness of your medication. If you are taking an extended release or enteric coated medication, you should speak to the physician that prescribes this medication about an alternative. Uncoated tablets, gel capsules, and liquids are easily absorbed and make better options for people with ileostomies.

In general, people with ileostomies are rarely prescribed stool softeners or laxatives. If you are told to take either of these medicines, please remind your health care team that you have an ileostomy and confirm that these medications are appropriate. Other medications may also affect the amount that drains from your ileostomy. Please be mindful of this when starting new medications and notify your health care team if you notice any significant changes.

ORDERING SUPPLIES

You will be discharged from the hospital with a list of supplies that you will need to order and a list of distributors that accept insurance. In most cases, your home care nurse will be happy to help you start the ordering process. Eventually, you will need to start ordering your supplies on a monthly basis. The "Resources" section of this book lists many of the ostomy supply distributors. You can choose to order your supplies from one of these companies or any other company that accepts your insurance.

Most insurance companies do provide coverage for ostomy supplies. If you do not have insurance or if your insurance company does not cover ostomy supplies, you should contact your WOC Nurse. There are resources available for patients without insurance through the various ostomy manufacturing companies.

UNDERSTANDING AND USING OSTOMY ACCESSORY PRODUCTS

There are many ostomy accessory products available to make caring for your ostomy and the skin surrounding your ostomy easier. These products can be very helpful when used appropriately. It is important to note that not every person with an ostomy will need to use these extra products. Remember that less is more when caring for your ostomy and you should only use accessory products if the need arises.

PRODUCT:	WHEN TO USE:	HOW TO USE:	THINGS TO KEEP IN MIND
Stoma powder	For skin redness and irritation	Sprinkle a small amount on the skin surrounding the stoma, and brush off all excess powder. There should only be a light dusting of powder left on the skin	Using too much powder can interfere with the adhesion of your ostomy appliance
Barrier film	Used as a skin protectant	Available as a wipe, swab, or spray. Often applied over stoma powder to protect and treat irritated skin	Barrier film contains chemicals that may irritate the skin and should only be used if necessary
Adhesive remover	Used to help remove adhesive products and adhesive residue	Usually comes as a wipe. Applied over an adhesive or adhesive residue to assist in removal	Adhesive remover leaves a residue that will interfere with pouch adhesion and must be carefully washed away from the skin before applying a new appliance. It also contains chemicals that may irritate the skin and should only be used if necessary
Stoma paste	Used to fill creases and uneven areas around your stoma or as caulking to prevent leakage	Apply a small amount directly to the skin to fill creases or apply around the opening of your skin barrier to use as caulking	Stoma paste should be used as a filler, not glue. Paste can be irritating to the skin and difficult to remove, and should only be used if necessary
Barrier ring	Used to create a more even surface around your stoma and prevent stool from draining under the skin barrier	Stretch to the size of your stoma and apply directly around your stoma or on the back of your skin barrier	Barrier rings can be broken into pieces and used as filler instead of paste
Stoma belt	Holds your ostomy appliance close to your body creating a feeling of security. Belts are also used to help prevent leakage	Adjust the belt to fit your waste and connect the belt at the belt tabs found on the sides of your pouch	Belts are usually avoided immediately after surgery. Most one piece flexible ostomy appliances do not have belt tabs
Pouch deodorizer	Decrease odor when emptying your pouch	Place into your pouch prior to applying	If you have trouble emptying your pouch completely, consider a lubricating deodorizer

WHEN TO CALL MY DOCTOR OR WOC NURSE

You should notify your health care team if you experience any of the following symptoms:

- Large amount of bleeding from your stoma
- Your stoma turns a dark purple or black color
- Visible trauma or swelling of your stoma
- Your stoma sinks below the level of your skin
- Nausea and vomiting
- Severe abdominal pain
- Signs of dehydration
- Fever
- Decreased or absent ileostomy drainage that lasts for several hours.
- Skin irritation, redness or discomfort
- Frequent problems with leakage

You should also call your WOC Nurse if you have questions about your ostomy, supplies, or diet.

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Weill Cornell Medical Center

Center for
Advanced Digestive Care

It is important to know that having an ileostomy should not limit you from having an active lifestyle. With the proper guidance and support most people are able to thrive after ostomy surgery, living very active and fulfilled lives. In fact, many people feel their quality of life actually improves after ileostomy surgery. You will have to make some minor adjustments in your daily life; however, being proactive and planning ahead will allow you to do most if not all of your usual activities.

TIPS FOR DAILY LIVING

People with an ostomy should learn to expect the best, but plan for the worst. See the below list for tips on managing day-to-day life with an ostomy:

- Keep a change of clothes and an extra set of supplies at work and in your car
- Make sure you order your supplies well before you expect to run out
- Keep an updated record of the exact supplies you use including product numbers
- Do not store your supplies in excessively hot or cold places
- Take your supplies with you to the hospital in case they don't carry the products that you use
- Wear your seat belt. Having an ostomy should not prevent you from wearing your seat belt

EXERCISE

Fitness and exercise is an important part of living a healthy lifestyle and having an ostomy should not prevent you from exercising. When you have recovered from surgery, you may resume your exercise routine. Remember to begin any program slowly and only after you have spoken with your doctor.

Walking, biking and running are unrestricted. Remember to empty your ostomy pouch before you start. You may be more comfortable if you wear an ostomy support belt while doing these activities. Please check with your doctor before playing sports or lifting heavy weights.

Keep in mind that heat and sweat can make your ostomy appliance less adhesive so you may want to reinforce your appliance with tape and have extra supplies on hand. It is important to make sure that you drink plenty of water while exercising to avoid dehydration.

You may also swim with your ostomy. Many people feel more comfortable with closed end pouches when swimming because they tend to be easier to hide. As with other sports, empty your pouch before you go swimming and reinforce your skin barrier with waterproof tape. Men may want to wear a swim shirt or tank top if their pouch is not completely covered by their swimming suit alone. Women often find that lined bathing suits with "tummy support" panels make the ostomy less noticeable. Ruffles, ruching and patterns also help conceal ostomy appliances.

TRAVEL

Travel by any means (car, air, rail) is unlimited if you are healthy enough to do so. Again, it is important to plan ahead to ensure that you have enough supplies for the length of your trip. If you are going on an extended vacation, you may want to bring your doctor's contact information and research the local UOAA branches in case you need support. When traveling to a foreign country, you may consider carrying copies of pages from the suppliers' catalog that show the supplies that you use. This may help bridge any language barrier.

If you are traveling by air, it is important to inform the security screening agent that you have an ostomy so they can use discretion during the screening process. Please see the Screening Notification Card in the back of this book. You should carry this card with you when you travel by air. This card will alert the Transportation Security Administration personnel to be mindful when you go through security. You may not be allowed to board an airplane with scissors so make sure that you pre-cut your skin barrier appliances and bring plenty of extra supplies in your carry-on luggage on the plane. You can pack scissors and extra ostomy supplies in your checked luggage.

Make sure that you empty your pouch before boarding and as needed during your flight. If you are traveling to a warm climate, it is important to drink plenty of extra fluids to avoid dehydration.

INTIMACY

People with a new ostomy are often concerned about how it will affect the most intimate areas of their lives. It is important to know that having an ileostomy does not prohibit you from having a meaningful sex life. Furthermore, you should know that many people with ostomies have children and families after they have their ostomy surgery.

As with all relationships, communication is crucial for promoting closeness and intimacy. You should have an open discussion with your partner before you become intimate and allow time for any questions that may arise. This will further enhance both parties' comfort level and confidence.

Remember to empty your pouch before you engage in intercourse. You may also consider using a pouch cover or stoma undergarments for increased comfort for both parties.

CLOTHING

One of the biggest concerns for living with an ostomy is how to conceal the ostomy appliance under clothing. You do not need to buy special clothing but certain styles may conceal your appliance better than others. Avoid thin materials and body-hugging clothes. Thicker materials, empire waists, patterns and loose-fitting styles provide more coverage. Texture, ruffles, pleats, and ruching can also help conceal your ostomy appliance. Undergarments such as panty hose, camisoles, tank tops, and slips help keep the pouch smooth and less visible under your clothing. It is important to remember that these undergarments must be loose enough for stool to drain into your pouch.

There are also special accessories (pouch covers, underwear, support belts) that can provide support, reduce noise, and smooth any bulges or wrinkles. These products are optional and may not be covered by your insurance. You should speak with your WOC Nurse if you would like more information about these specialty products.

TALKING ABOUT YOUR OSTOMY

You will probably want to discuss your ostomy with those closest to you, especially people in your household. The best way to discuss your ostomy with children is by being open and explaining things in a simple and direct way. Curious children may benefit from actually looking at the ileostomy.

You should also discuss your ostomy with your partner before having intimate relations. Wait until you feel comfortable enough to have an open and honest conversation. Again, the best way to discuss this is by explaining things in a simple and direct way. For more information, see the section entitled "Intimacy."

Some people find it helpful to disclose that they have an ostomy to their work colleagues and supervisors. Although having an ostomy should not impact your work performance, you may need more time and privacy in the restroom until you become comfortable with your new ostomy.

You may or may not choose to discuss your ostomy with more casual acquaintances. Some people feel that from a practical stand point it is helpful to discuss their ostomy with their immediate supervisor at work, while others feel more comfortable keeping this to themselves. Telling someone you have an ostomy is a personal decision and there are no right or wrong answers in regards to discussing your ostomy.

It is important to know that everyone adjusts to having an ileostomy at their own pace. There is no emotional formula; each person comes to accept their ileostomy in their own way. Remember that you are not alone; there are many resources and support groups available.

RESOURCES, GLOSSARY & NOTES

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RESOURCES

Ostomy Supplies – distributors

See below for companies that sell and distribute ostomy supplies:

Edgepark:	1-800-321-0591, extension 3833
Byram:	1-866-839-1342
Better Living Now:	1-800-854-5729
Sterling:	1-888-907-8775
Liberty:	1-866-486-2379

Ostomy Supplies – Manufacturers

See below for companies that manufacture ostomy supplies:

Hollister:	1-888-740-8999
Convatec:	1-800-422-8811
Coloplast:	1-888-726-7872
Nu-Hope:	1-800-899-5017
Cymed:	1-800-582-0707
Marlen:	216-292-7060

Additional Resources and Support

- **NewYork-Presbyterian/Weill Cornell Medical Center**
  Center for Advanced Digestive Care
  Ostomy Care Center
  212-746-6030
  nyp.org/cadc
- **United Ostomy Association of America**
  1-800-826-0826
  ostomy.org
- **The Crohn's and Colitis Foundation**
  1-800-932-2423
  ccfa.org
- **The J-Pouch Group**
  j-pouch.org
- **The Wound, Ostomy, and Continence Nurses Society**
  wocn.org
- **The American Society of Colon and Rectal Surgeons**
  fascrs.org

GLOSSARY

Barrier Ring	Stretchable ring that creates a seal around the stoma
Convexity	Type of skin barrier that curves inwards towards the body, placing gentle pressure around the stoma
Filter	Device built into some pouches that allows a small continuous amount of air, but not odor, to be released from the pouch
Ileum	Last part of the small intestine. This is the part of intestine used to make an ileostomy
Ileostomy	Surgically created opening in the small intestine that is brought to the skin for stool to drain
Large Intestine	Often called the colon this is the portion of intestine responsible for absorbing fluids
Obstruction	When something blocks the passage of stool in the intestines, often caused by fibrous foods
Ostomy	Generic term for a surgically created opening that drains waste. Frequently used when talking about ileostomies, colostomies, and urostomies
Ostomy Appliance	Equipment used to protect the skin and stoma and collect stool. This includes the skin barrier and pouch
Ostomy Belt	Belt that holds your ostomy appliance close to your body
Pouch Deodorant	Placed into the pouch prior to application, to reduce odor while draining the pouch
Skin Barrier	Adhesive part of the ostomy appliance that protects the skin and attaches to the ostomy pouch
Small Intestine	Part of the intestine responsible for absorbing vitamins and nutrients
Stoma	A surgically created opening
Stoma Powder	Protective powder used to protect and treat irritated skin next to the stoma
Stoma Paste	Use as filler to create an even surface on which to place the ostomy appliance or as caulking to prevent leakage
Stool	Human waste that comes from the bowel, also called feces
Wound, Ostomy, and Continence Nurse (WOC Nurse)	Nurse with special training in how to teach and care for individuals with ostomies

NOTES

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www.nyp.org/cadc