

EDUCATION

Living Well With Your Ileostomy



Allina Health



Ordering Information for Ileostomy Supplies

The following information will help you order the supplies you need to care for yourself at home. If you are receiving home care, your home care provider will help you get started with ordering your supplies.

Contact Information

- Outpatient ostomy nurse

Name: _____

Phone: _____

- Home care

Case manager: _____

Ostomy nurse: _____

Your Medical Supply Company

(See pages 34 to 35 for a list of suppliers.)

Company name: _____

Phone number: _____

Materials Needed

Product name: _____

Reference number: _____

Quantity: _____

Product name: _____

Reference number: _____

Quantity: _____

Product name: _____

Reference number: _____

Quantity: _____

Product name: _____

Reference number: _____

Quantity: _____

Product name: _____

Reference number: _____

Quantity: _____

Your Ileostomy

An ileostomy is a surgically made opening in your abdominal wall. You may have had this surgery to:

- **remove a diseased section of your intestine.**

This permanent (long-term) ileostomy changes the way your body works for the rest of your life.

- **disconnect an injured section of your intestine.**

This temporary (short-term) ileostomy changes the way your body works for a short time, giving your body time to heal until your intestine is reconnected.

To make the ileostomy, a surgeon removed all or parts of your digestive system and formed a stoma, which is usually about the size of a quarter. The stoma is a new opening in your abdomen where stool and gas pass through.

A pouch is worn over the stoma to collect waste. The size and shape of your stoma can change for up to 6 to 8 weeks after surgery. It may also change size if you gain or lose weight.

Types of Ileostomy

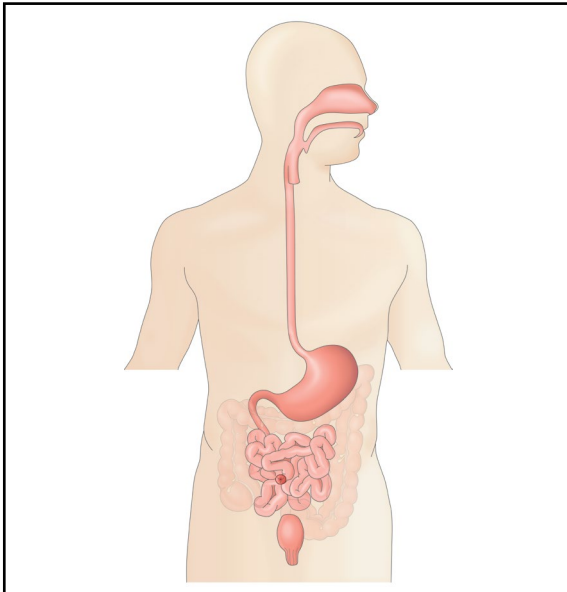
There are two main types of ileostomies. You and your surgeon will work together to decide the best option for you.

End ileostomy

This is the most common type of ileostomy. An end ileostomy can be permanent or temporary.

If you had an end ileostomy:

- The surgeon removed or disconnected your colon. He or she may also have removed or disconnected your rectum, anus, the muscle that controls when you pass stool and gas, and part of your small intestine (ileum).
- The surgeon created a stoma at the end of your ileum. The stoma is on the lower right side of your abdomen. Loose stool moves out of your body through the stoma and is stored in a pouch you wear. There is no muscle in the stoma. You cannot decide when to pass stool and gas.



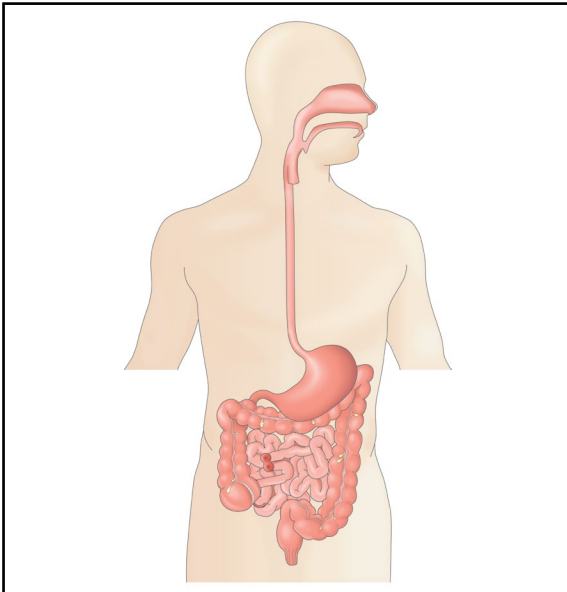
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Loop ileostomy

A loop ileostomy is temporary. It allows your intestine time to heal before being reconnected.

If you had a loop ileostomy:

- The surgeon pulled a “loop” of your small intestine through a small incision on the lower right side of your abdomen, opened it up and stitched it to your skin to form a stoma.
- Liquid stool moves out of your body through the stoma.



Loop ileostomy

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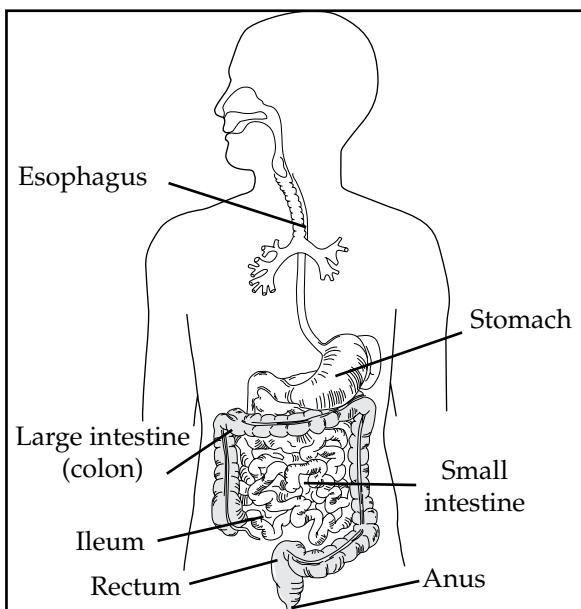
Your Digestive System

Your digestive system is a series of hollow organs joined in a long, twisting tube. The tube starts in the mouth and ends in the anus. Inside the tube is a lining called mucosa. The mucosa in the mouth, stomach and small intestine contains tiny glands that make juices to help digest foods.

Two solid digestive organs (liver and pancreas) produce juices that reach the intestine through small tubes. Through digestion, your body breaks down food and drink into the smallest parts so your body can use them to nourish cells and provide energy.

After you start to swallow, nerves take over the process. Food is pushed into your esophagus. This is the organ that leads to your stomach. Once food enters your stomach, four things happen:

- Your stomach stores the food and liquid you swallowed.
- The lower part of your stomach mixes the food, liquid and digestive juices.
- Your stomach empties the contents slowly into your small intestine. Your small intestine will absorb nutrients from the food and liquid you swallowed. As digestion progresses, the contents of your small intestine are pushed forward.
- All of the digested nutrients are absorbed through your intestinal walls. The waste products include fiber (undigested parts of food) and cells shed from the mucosa. The waste moves into the colon, where it usually stays for 1 to 2 days before being expelled in a bowel movement. If your colon has been removed or bypassed, the waste will pass out of your body through your stoma and collect in your ileostomy pouch.



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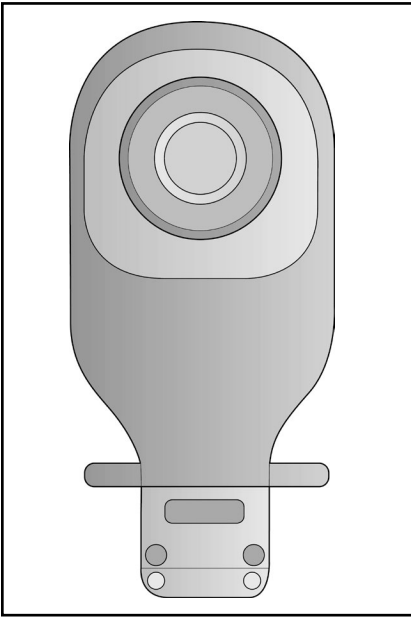
The parts of your digestive system.

- **Esophagus:** The food and liquid you swallow goes down the esophagus into your stomach.
- **Stomach:** The stomach stores swallowed food and liquid, mixing it up with digestive juices. After breaking up the food, your stomach empties its contents slowly into your small intestine.
- **Large intestine (colon):** This is a 5- to 6-foot tube that absorbs water and minerals back into your body. It also moves and stores stool.
- **Small intestine:** The small intestine finishes digesting food and liquid. It absorbs nutrients to nourish your body.
- **Ileum:** This is the last part of the small intestine that sends the digested food on to the large intestine (colon).
- **Rectum:** This is the place where stool and gas are stored until you pass them.
- **Anus:** This is the muscle at the bottom of the rectum. Stool and gas leave the body through this opening when you release them.

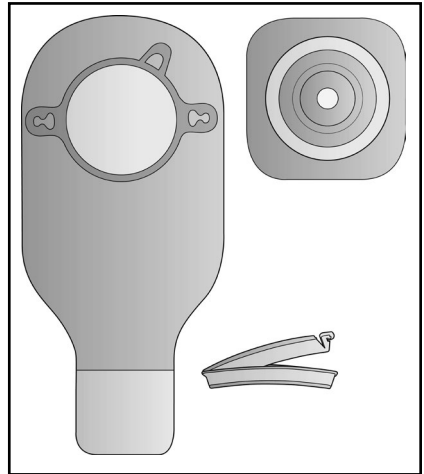
Types of Pouches

You will need to wear a pouch (also called a bag) over the stoma to collect waste. The pouch attaches to your body around the stoma. The adhesive skin barrier holds it in place.

There are many different types of pouches. Your ostomy nurse will help you choose the one that is right for you.



One-piece pouch with claspless closure



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Two-piece pouch with clamp closure

Sizing the Opening of Your Pouch

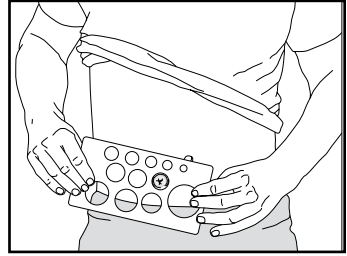
Some pouches will come with a presized opening and some you will need to size and cut yourself. You will use a measuring guide to find the right opening size for your stoma.

To find the right size opening, choose the smallest hole on the guide that fits around your stoma without touching it. There should be $\frac{1}{16}$ inch to $\frac{1}{8}$ inch between your stoma and the guide.

If you cut the opening yourself, center the guide on the back of the skin barrier, trace the size that fits your stoma and then cut out the opening.

For presized openings, buy the pouches with the size opening that matches the size on the measuring guide.

Because your stoma will change in size during the first 6 to 8 weeks, you will use a cut-to-fit pouch right after surgery.



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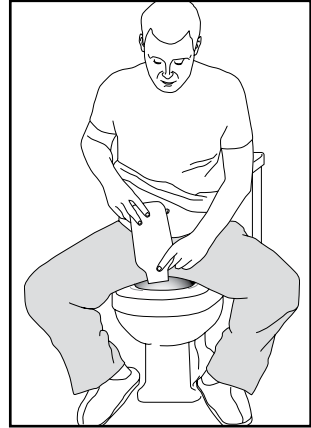
Using a measuring guide will help you find the right stoma opening size.

How to Empty Your Pouch

It is important to empty your pouch when it is one-third to one-half full of stool or gas. You do not want to let the pouch overfill. This can cause the pouch to leak. If you drain the pouch each time after you empty your bladder, it is unlikely the pouch will overfill.

To empty your pouch:

- Sit on the toilet* (if possible).
- Hold the tail of the pouch up and push the stool away from the clamp or clampless closure.
- Remove the clamp and save it (if present) or unroll the end of the tail.
- If your pouch has a clamp, put your thumbs into the corners of the pouch end and turn back a 1-inch to 1 ½-inch cuff.
- Empty the contents of the pouch
- Using toilet paper, clean the remaining stool from the cuff.
- If using a clamp, “uncuff” the tail of the pouch.
- Put on the clamp, if present, or roll the tail of the pouch up and press the two sides of the clampless closure together. Your ostomy nurse will show you how to do this.



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**To empty your pouch,
sit on the toilet
(if possible).**

***Note:** You can also stand in front of the toilet if it is difficult to sit after surgery or if your legs get in the way when you sit. If you choose to stand in front of the toilet, move in as close to the toilet bowl as possible. Lay toilet paper on top of the water to prevent the water from splashing.

How to Change Your Pouch

1. Assemble this equipment:

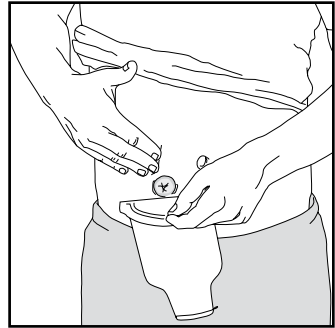
- pouch
- clamp (if needed)
- barrier ring or paste
- gauze (not sterile), paper towel or cotton balls
- warm water.

2. Prepare the pouch:

- If the opening is not presized, cut the opening of the pouch using the pattern or measuring guide your ostomy nurse gave you.
- Remove the paper backing from the skin barrier and tape.
- Stretch and apply the skin barrier ring or bead of paste to the edge of the opening.
- Set it aside.

3. Change the pouch:

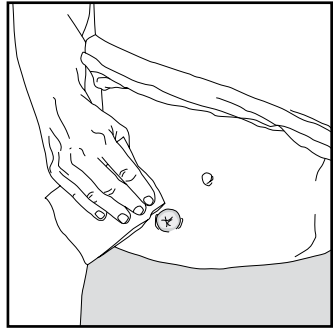
- Empty the pouch and close the bottom.
- Loosen the tape. Use one hand to gently push the skin away from the tape and skin barrier.
- Throw the pouch away. Save the clamp (if present).
- Control the discharge from the stoma with gauze or a paper towel.



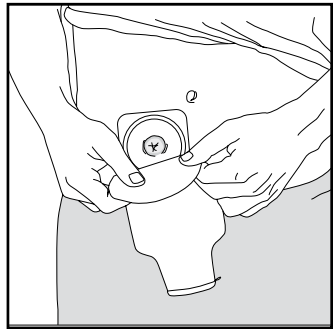
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Use one hand to gently push the skin away from the tape and skin barrier.

- Cleanse your skin around the stoma with warm water and gauze, paper towel or cotton balls. Dry your skin with gauze or a paper towel.
- If you use a one-piece pouch, center the stoma in the opening.
- If you use a two-piece pouch, apply the skin barrier centering the stoma in the opening. Attach the pouch to the skin barrier or apply as one piece.
- Close the tail of the pouch with a clamp, if present, or roll the tail of the pouch up and press the two sides of the clampless closure together.



Use warm water and gauze or a paper towel to cleanse your skin.



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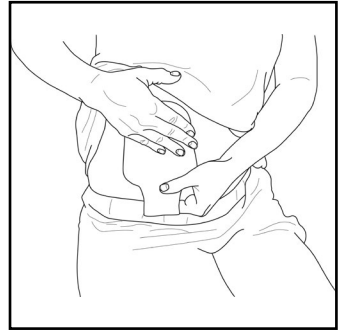
Apply the pouch over the skin barrier, centering the stoma in the opening.

How to Close Your Pouch if Using a Clamp

- Hold the clamp open with the hinge facing your body.
- Lay the bar of the clamp flat on the tail of the pouch, about 1 inch from the bottom of the tail.
- Fold the tail up and over the bar.
- Make sure the entire width of the tail lies flat against the bar and is held by the bar.
- Close the clamp by pressing the hinge and bar together until they lock.

How to Release Gas if the Pouch Does Not Have a Gas Filter

- Hold the tail of the pouch slightly up.
- Remove the clamp or unfasten the clampless closure and unroll the pouch.
- Open the tail of the pouch.
- With one hand, hold the tail of the pouch.
- With your other hand, use your thumb and index finger to push the gas out from top to bottom of the pouch.
- Close the tail of the pouch.



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Push the gas out of the pouch from top to bottom.

What to Do if Your Pouch Leaks

If your pouch leaks, there is always a reason:

- A good seal was not made when the pouch was applied.
- The pouch is overfilled with stool, gas or urine.
- Your skin around the stoma is irritated.
- The area around the stoma may bulge and look uneven in places. There may also be deep creases in your abdomen, which can prevent the pouch from sticking properly.
- The pouch barrier is defective. (This is rare.)

What to do:

- Go over the procedure for pouch application to make sure you are following the steps correctly. Are you getting too close to the stoma or covering it with the barrier of the pouch? Use a hand-held mirror for a closer look to see if your placement is correct.
- Check your skin. If it is sore or irritated, see your ostomy nurse.
- Check the area around the stoma. It may be that your pouch does not fit properly, causing leakage. If this happens, call your ostomy nurse.
- Try a pouch from a different box of pouches.

One of your ostomy nurse's main goals is to prevent pouch leaks from happening. Follow any instructions he or she gives you.

Ostomy Accessories

There are a number of accessories that may be used with your ileostomy. Your ostomy nurse will recommend one or more of the following items:

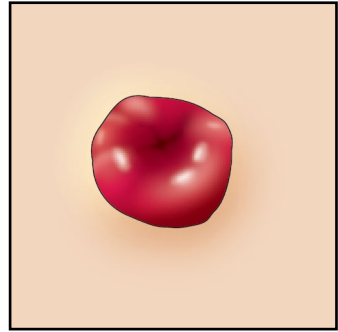
- **Paste** is used (like caulk) to create a seal around the stoma.
- **Barrier rings** are used (like caulk) to fill in creases around the stoma. They may be stretched to fit any shape and may be used as an alternative to paste.
- **Ostomy powder** is used to dry up moist skin. Brush off any extra powder before applying your pouch.
- **Ostomy belts** are used to help hold your pouch closer to your abdomen when the stoma is flat with your skin, you have abdominal creases or your pouch has been leaking.
- **Adhesive remover wipes** may be used to remove adhesive or adhesive residue from your skin. They are not usually needed each time you change your pouch. It is important to wash this product off of your skin thoroughly after use.
- **Pouch deodorant** helps to prevent odor when you empty or change your pouch.
- **Lubricating pouch deodorant** helps the stool slide to the bottom of the pouch easier. It also helps to prevent odor.

Caring For Your Stoma

Your stoma should be pink or red in color and moist.

When cleaning around your stoma, you may see some blood. Your stoma has many little blood vessels. It is common to see a small amount of bleeding when cleaning around your stoma. Using gauze, paper towels or cotton balls to gently clean around the stoma will prevent traumatizing the little blood vessels. Tell your doctor or ostomy nurse if you have any large amounts of bleeding.

It is also common to be able to see movement of the stoma. The bowel has a “wave-like” motion naturally that you may notice when your pouch is off.



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The size and shape of your stoma will change after surgery.

Caring For Your Skin

It is important to take care of your skin around the stoma. Keeping your skin clean and protecting it from contact with stool and moisture by wearing a properly fitted pouch will help prevent skin irritation.

Routine skin care

Skin barrier rings and paste become soft and moist under the pouch. Residue can be gently removed with warm water and dry wash cloth, gauze, or soft cotton squares or balls.

Do not use soap, isopropyl alcohol, disinfectants or baby wipes. These products can harm your skin (or leave residue that can harm your skin over time). Adhesive removers may also be used, but then the skin must be thoroughly rinsed in order to remove all chemicals from the skin.

If you want to take a shower without your pouch on, it is OK if some shampoo and soap applied above the stoma wash down over your skin. Do not apply soap directly on the skin around the stoma.

If your skin around the stoma is hairy, you will need to keep it trimmed to prevent skin irritation when the pouch is removed. Trim with electric razor and away from the stoma.

Possible skin conditions

There are three common skin conditions that may occur with an ileostomy:

- skin irritation
- yeast infection
- allergic reaction.

Learning how to identify a skin condition and knowing how to care for it can help keep the skin around your ileostomy healthy.

The following are guidelines on how to take care of your skin. If your skin does not heal or your condition becomes worse, see your ostomy nurse.

Skin irritation

If the skin is irritated, it will be red. This is due to leakage under your pouch seal or too large of an opening in your skin barrier.

Skin irritation may be slight (red skin) to severe (raw, painful and weepy).

If you have a problem with leakage, you may need to alter the way you change your pouch. The fit may no longer be the same due to changes in the size of the stoma or abdominal shape. If the opening in your skin barrier is too large, you will need to resize the opening.

To care for a skin irritation:

- Put stoma powder on your irritated skin.
- Brush off extra powder using a tissue or use a hair dryer (on cool setting) to blow off the extra powder.
- Apply your pouch, making sure it fits properly.

Yeast infection

Yeast infections show up in warm, moist areas such as your armpits, groin or under your pouch.

A yeast infection on the skin under your pouch will have small (the size of the head of a pin) red areas, white areas, or both. Your skin may itch. The yeast infection may spread past your skin barrier.

To care for a yeast infection:

- Clean and dry your affected skin.
- Spread an antifungal powder over the area and massage it into your skin. You may buy an over-the-counter miconazole nitrate 2 percent (Mitrazol[®]) or get a prescription for nystatin (Mycostatin[®]) from your health care provider.
- Brush off extra powder using a tissue or use a hair dryer (on cool setting) to blow off the extra powder.
- Apply your pouch, making sure it fits properly.
- Use the powder for one or two pouch changes after your skin is healed, and then stop using it.

Allergic reaction

You may become sensitive to any part of your pouch or other products you are putting on your skin.

An allergic reaction will affect your skin that comes in contact with the product to which you are allergic or sensitive. Your skin will be red and it may itch, sting or burn.

Put a small amount of the product on the other side of your abdomen and cover it with a piece of medical tape for 48 to 72 hours. If your skin reacts the same way, remove the product and call your health care provider or ostomy nurse.

There are other products you may use if you have an allergy to your current one. Make an appointment to see your health care provider or ostomy nurse for more information.

Blockage

It may be harder to digest foods that are high in fiber after having an ileostomy. These types of foods can clump together and cause a blockage close to where the small intestine comes up through the abdomen to the stoma.

Symptoms of a blockage include:

- constant spurting of watery stool
- strong odor to stool
- cramping or abdominal pain (sometimes in a “wave-like” motion)
- bloating
- nausea (upset stomach) or vomiting (throwing up)
- swollen stoma
- no stool output (sign of a complete blockage).

What to do at the first sign of a blockage (you may try more than one):

- Drink a glass of grape juice or a warm beverage if you’re not vomiting.
- Do not take laxatives.
- Avoid eating any solid food or taking laxatives.
- Massage your abdomen.
- Apply warm towels to your abdomen or take a hot bath.
- Lie on your back with your knees up. Rock from side to side.
- Apply a pouch with a larger opening if your stoma is swollen.

If the blockage lasts more than 2 to 3 hours, or if you start to vomit, call your health care provider or go to the nearest hospital emergency department.

Foods That Can Cause a Blockage

Eating large quantities of these foods are more likely to cause a blockage. Most people can eat these foods in small amounts.

- apples (unpeeled)
- bamboo shoots
- bean sprouts
- bran
- cabbage
- celery
- Chinese vegetables
- coconut
- coleslaw
- corn
- dried fruits
- granola
- grapefruit and oranges
- high-fiber grains with more than 2 grams of fiber per serving
- meat in casings
- mushrooms
- nuts and seeds
- pea pods
- pickles
- pineapple
- popcorn
- raw vegetables such as spinach
- seeds
- shrimp
- sweet peppers (all colors)
- wild rice

To help prevent a blockage, drink eight to 12 glasses of liquid a day unless your health care provider gives you other instructions. Try foods one at a time, *in small quantities*, and chew them well.

Diet

Your diet will begin with clear liquids only after surgery. A clear liquid diet consists of water, clear broth or bouillon, gelatin, frozen ice treat on a stick, coffee or tea, and clear fruit juices without pulp. As you recover, you may add full liquids (milk, custard, pudding, thin hot cereals) and then soft foods to your eating plan.

High-fiber foods (whole grains; legumes such as dried beans, peas and lentils; raw fruits and vegetables) are difficult to digest and should not be eaten until you have given your body time to heal. In the first few weeks after surgery, you should have less than 8 grams of fiber a day.

It may take several weeks for your appetite to return to normal. Slowly introduce foods back into your diet and see how they affect your ileostomy. Chew your food well and drink eight to 12 glasses of liquids a day.

Everyone reacts to food differently. If you are concerned about how you may react to a certain food, try eating a small amount to see how it makes you feel. If you have a bad reaction, avoid eating that food for now. You can try eating it again in a few weeks.

It is helpful to learn which types of foods can cause odor, gas, or thicken or loosen your stool. Here are lists of foods and the effects they can have on stool.

Foods That Thicken Stool:

- applesauce
- bananas
- cheese
- creamy peanut butter
- marshmallows
- oatmeal or barley
(when it's OK to have fiber)
- pasta (no sauce)
- potatoes (no skin)
- pretzels
- saltines
- tapioca
- white bread or rice
- yogurt

Foods That Loosen Stool:

- alcohol
- beverages with caffeine
- chocolate
- dried beans or string beans
- fried foods
- fruit juice
- greasy, high-fat or
high-sugar foods
- impure drinking water
- leafy green vegetables
(spinach, broccoli)
- milk or dairy foods
- prunes or prune juice
- raw fruits
- raw vegetables
- spiced foods
- sugar-free foods
containing mannitol
or sorbitol

Foods That Cause Stool Odor:

- alcohol
- asparagus
- cabbage-family vegetables*
- dairy foods
- dried beans
- eggs
- fish
- garlic
- some spices**
- strong cheeses
- turnips

Foods That Help Prevent Odor:

- buttermilk
- cranberry juice
- parsley
- yogurt

Foods That Cause Gas:

- beer
- beverages with carbonation
- cabbage-family vegetables*
- corn
- cucumbers
- dairy foods
- dried and string beans
- garlic
- green peppers
- mushrooms
- peas
- spinach

*onions, cabbage, Brussels sprouts, broccoli, cauliflower, kohlrabi, sauerkraut, kale, radishes and rutabagas

**coriander, cumin, curry, caraway, turmeric, dill, fennel

Gas

There are many reasons for gas. It is a product of the digestive system and is mostly formed in the colon or large intestine. The most common source of gas is from swallowing air, especially when eating rapidly, chewing gum or drinking from a straw. Poorly fitted dentures may also cause an increase in the amount of air swallowed.

Certain foods and liquids such as cabbage, Brussels sprouts, cauliflower, baked beans, eggs, carbonated beverages, and beer may cause gas. Some people are sensitive to dairy products, too.

What to do:

- Eat meals slowly, and chew foods well.
- Check to make sure dentures fit well.
- Avoid chewing gum and using straws.
- Drink limited amounts of carbonated beverages.
- Check with your health care provider for the possibility of “lactose intolerance” (sensitivity to dairy products).
- Try over-the-counter “anti-gas” products such as Gas-X® or Beano®. Your ostomy nurse may suggest other products.
- Adding a “gas filter” to your pouching system may be helpful. Ask your ostomy nurse about this kind of product.

Preventing Dehydration

Your small intestine does not absorb as much liquid as the colon. Ileostomy output is usually between 800 to 1,200 cc (about 1 quart) each day. The output should be the thickness of applesauce or oatmeal but will vary depending on what you've eaten throughout the day. It is normal to empty your pouch six to eight times each day when it is half full (about as many times as you urinate).

It is important to drink enough liquids every day to prevent dehydration (not enough fluids in your body).

Symptoms of dehydration

Symptoms of dehydration include:

- weakness
- fatigue
- thirst
- chills
- excessive perspiration
- rapid heartbeat
- dizziness
- shortness of breath
- muscle cramping (abdomen or legs)
- decreased urine volume
- urine that is dark amber in color

- nausea (upset stomach)
- abdominal bloating
- rapid weight loss (more than 2 pounds in 24 hours)
- dry mouth or cracked lips
- tingling or cramping in hands and feet.

Call your health care provider if your symptoms don't go away after 12 hours.

Here are some tips to help prevent dehydration:

- Drink eight to 12 glasses of liquid a day unless your health care provider gives you other instructions. You may need more. If you are thirsty, drink.
- Drink liquids by sipping them throughout the day instead of drinking them all at once.
- Eat six to eight small meals throughout the day (one small meal every 2 to 4 hours).
- Eat solid foods first, then drink liquids after your meal.
- Chew your food well to a mashed-potato consistency.
- Avoid sugary or diet beverages, alcohol and caffeinated beverages. These can increase the amount of water in the bowel, causing more stool output.
- Avoid dairy (milk products) if you do not tolerate them well.

Replacing electrolytes in your body

If you become dehydrated, your health care provider may recommend you consume foods and beverages high in sodium and potassium, which help replace electrolytes often lost during dehydration.

Some examples of these foods and beverages include:

- sports beverages with less than 15 grams of sugar
- beverages for rehydration such as Pedialyte[®], Ceralyte[®], Glucerna[®] or PediSure[®]
- homemade solution (see next page for recipe)
- creamy peanut butter
- cheese of all kinds (including cottage cheese) and crackers
- fish
- fruit (especially those high in potassium such as bananas or strawberries)
- nuts
- potatoes without skin
- orange juice without pulp
- tomato or vegetable juice, if tolerated well
- yogurt.

What to drink if you have high stool output

- sports beverages with less than 15 grams of sugar
 - For best absorption, add $\frac{1}{8}$ teaspoon salt to every 8 ounces of liquid.
- beverages for rehydration such as Pedialyte[®], Ceralyte[®], Glucerna[®] or PediSure[®], which can help replace electrolytes often lost in stool
- homemade solution:
 - Mix together:
 - 4 cups water
 - $\frac{2}{3}$ teaspoon salt
 - 2 tablespoons sugar
 - sugar-free, low-calorie powdered beverage mix (Crystal Light[®], Kool Aid[®]), to taste.
 - Sip between meals. Do not add ice or more water to the solution.

Medicines

Because your large intestine (colon) was removed or disconnected with the ileostomy, some medicines cannot be absorbed. Talk with your health care provider or pharmacist about your medicines to make sure they are working properly.

Important: Make sure your health care provider(s), including pharmacist(s) know you have an ileostomy before being prescribed any new medicine.

Medicine Side Effects

Medicines can have different effects on people with an ileostomy. The following information may be helpful.

Medicines that can cause diarrhea:

- antibiotics
- oral diabetic medicines
- antacids containing magnesium, such as Maalox[®]

Medicines that can help treat diarrhea:

- Kaopectate[®]
- Imodium[®]
- bulk forming preparations, such as Metamucil[®], Citrucel[®] or Benefiber[®] (taken under the direction of your health care provider).

Note: Always check with your health care provider about medicines that you are thinking of taking for diarrhea.

Medicines that can cause constipation:

- antacids that contain aluminum
(Read the labels carefully or ask the pharmacist.)
- certain pain medicines, such as oxycodone and acetaminophen (Percocet[®]), or hydrocodone bitartrate and acetaminophen (Norco[®], Vicodin[®])
- antidepressant medicines
- medicines to treat Parkinson's disease.

Note: Constipation may be a sign of a blockage. Check with your health care provider if you have any combination of the following (these may indicate a blockage — see page 18):

- severe cramping or vomiting
- no output or unusually high liquid output from the stoma
- excessive protrusion of the stoma.

Adjusting to Your Ileostomy

Having an ileostomy is a major surgery. Give your body time to adjust. Once you begin feeling better physically, you will be better able to cope emotionally.

Your body looks and works different, and your emotions will be affected. Some people feel sad or disgusted while others are glad to no longer have the symptoms they once did. As you get used to how your stoma works, caring for your ileostomy will become part of your daily routine.

No one will be able to tell you have had an ileostomy unless you decide to tell them. It's your choice. It may also be helpful to talk with someone else who has had an ileostomy. Ask your ostomy nurse about local support groups.

Everyday activities

Your everyday activities should not be limited by your ileostomy. You should be able to continue doing all of the things you enjoy. Talk with your ostomy nurse if you have questions regarding certain sports activities. An ostomy belt may help stabilize the pouch if you will be doing activities that require twisting or bending.

It is important that you carry ostomy supplies with you at all times. Keeping a stock of extra pouches in your car (in the coolest spot), briefcase, purse, travel bag or desk is an easy way to make sure you are always prepared.

Hints for summertime

When warm weather arrives and brings vacations, picnics, gardening, swimming and other summer fun, there are ways to maintain a trouble-free ileostomy:

- Sprinkle a small amount of stoma powder over skin. Brush away all extra powder. A small amount will remain on the skin and help decrease a “melt down” of the barrier.
- Change your pouch more often.
- Wear an ostomy belt to help stabilize the pouch if you are active with sports or if you do activities that require twisting or bending.
- Sitting in a hot tub or sauna may soften the barrier. Plan to change your pouch after those activities.
- Have any sign of a “rash” checked. It could be “heat rash” or it could be a yeast infection. Talk with your ostomy nurse.
- Keep your extra pouch “cool” during hot days by placing it in the cooler; or taking a small insulated lunch bag and put a small ice pack inside.

- Use a waterproof tape to secure the edges of the pouch for watersport activities.
- Always drink extra liquids during hot days to prevent dehydration. Certain foods help with liquid intake, such as gelatin, sherbets, ice cream and various melons.

Sexual activity

Sexual activity is a common concern among people who have had an ileostomy. Most people can enjoy sexual activity again with some minor changes. You and your partner can continue to share physical closeness and emotional intimacy

Experiment with new ways of being together as you recover from surgery. You may find pleasure in giving foot or back massages, caressing and cuddling.

To make intimacy more comfortable, try positions that are comfortable for you and keep your weight off the stoma. Keep the pouch clean and empty. Some people switch to a smaller pouch or wear a pouch cover, ostomy belt or shirt over the pouch.

The United Ostomy Association of America (UOAA) has a helpful publication available — “Intimacy, Sexuality and an Ostomy,” which you can find at ostomy.org.

Travel

Having an ileostomy does not mean you have to stop traveling. You will just need to take all of your supplies with you. Here are some tips to help make traveling easier:

- Bring your pouches with you in your carry-on luggage when flying and always have an extra pouch in your purse or pocket.
- Carry more pouches than you think you'll need when traveling to unfamiliar places. You can buy pouches from medical supply stores in the area. Plan ahead.
- Keep pouches in the coolest place possible in warm weather locations. For example, when driving do not put your supplies in the trunk or glove compartment because they could melt.
- Fasten the car seat belt above or below your stoma to avoid irritation and rubbing.
- Empty your pouch often. You may not have the opportunity to empty it at a certain time.
- Follow the advice of the State Department regarding food and liquids when traveling out of the country. You may want to avoid eating fresh vegetables and fruits that cannot be peeled. Talk with your health care provider ahead of time. He or she may wish to give you an "anti-diarrheal" medicine to take with you.
- Drink bottled water unless you are sure the water will not cause you problems.

- Try to avoid changing eating schedules or eating foods that cause diarrhea, since these can cause temporary loose stools when traveling. If you need to take an anti-diarrheal medicine, try eating foods that thicken stools naturally, such as cheese, applesauce, rice, pasta products, breads or peanut butter, before you take the medicine. Take care when using these medicines so you don't become constipated.
- Make sure to drink enough liquids to prevent dehydration.

When to Call Your Health Care Provider

Call your health care provider if:

- you have black or bloody stools
- you have severe cramping for more than 2 hours
- you have nausea and vomiting that won't stop
- your stoma swells, changes color or will not stop bleeding
- you have cramping, nausea and have not had any output for 4 to 6 hours
- you have severe watery output for more than 5 to 6 hours
- you have severe skin irritation or sores around your stoma.

Sources for Ileostomy Products

For insurance plans other than Medicare, please call your insurance provider for a list of preferred medical equipment suppliers.

Local suppliers that **do** accept Medicare assignment:

- Handi Medical Supply,
2505 University Ave. W.
St. Paul, MN 55114
651-644-9770
1-800-514-9979
- Handi Medical Supply,
3960 Coon Rapids Blvd.
Coon Rapids, MN 55433
651-789-5858
- Midwest Medical Services, Inc.
8400 Coral Sea St. N.E.
Suite 200, Blaine, MN 55449
763-780-0100 or 1-800-780-8553

Mail order suppliers that **do** accept Medicare assignment:

- AARP (American Association of Retired Persons)
5050 East Belknap, Box 14899
Fort Worth, Texas 76117-0899
1-800-284-4788 (catalog)
- Edgepark Surgical, Inc.
1810 Summit Commerce Park
Twinsberg, Ohio 44087
1-800-321-0591

Mail order suppliers that **do not** accept Medicare but will prepare and submit Form 1500 for you. Payment must be made “up front.”

- AOS (American Ostomy Supply), 1-800-858-5858
- Bruce Medical Supply, 1-800-225-8446
- Parthenon, 1-800-453-8898
- US Med Express, 1-877-409-1234

Resources

Ostomy product manufacturers

- Coloplast
1-800-533-0464
us.coloplast.com
- ConvaTec
1-800-422-8811
convatec.com
- Cymed
1-800-582-0707
cymed-ostomy.com
- Hollister
1-888-740-8999
hollister.com
- Marlen
216-292-7060
marlenmfg.com
- Nu-Hope
1-800-899-5017
nu-hope.com
- Ostomy Secrets
1-877-613-6246
ostomysecrets.com

Organizations

- Allina Health
allinahealth.org
- American Cancer Society
1-800-ACS-2345
cancer.org
- C3Life.com
c3life.com
- Cancer Care
1-800-813-4673
- Caregiver Action Network
202-454-3970
caregiveraction.org
- Colon Cancer Alliance (CCA)
877-422-2030 (toll free)
ccalliance.org
- Crohn's & Colitis Foundation of America
1-800-932-2423
ccfa.org
- International Ostomy Association (IOA)
ostomyinternational.org
- Ovarian Cancer National Alliance (OCNA)
866-399-6262 (toll free)
ovariancancer.org
- United Ostomy Association of America
1-800-826-0826
ostomy.org

- Women's Cancer Network
312-578-1439
wcn.org
- Wound, Ostomy & Continence Nurses Society
1-888-224-9626
wocn.org

Books

- "100 Questions & Answers about Colorectal Cancer"
by David Bub
- "Alive and Kicking" by Rolf Benirschke
- "A Patient's Guide to Managing a Short Bowel"
by Carol Rees Parrish
- "Bag Lady" by Sandra Benitez
- "Bedpan Banter" by Brenda Elsagher
- "Be Prepared: The Complete Financial, Legal, and
Practical Guide to Living with Cancer, HIV, and other
Life-Challenging Conditions" by David Landay
- "Betty Crocker's Living with Cancer Cookbook"
by Kris Ghosh, Linda Carson and Elyse Cohen
- "Dear Dr. Humor" by Stuart Robertshaw
- "Great Comebacks from Ostomy Surgery"
by Rolf Benirschke
- "I'd Like to Buy a Bowel Please" by Brenda Elsagher
- "If the Battle is Over, Why am I Still in Uniform?"
by Brenda Elsagher
- "It's OK to Have an Ostomy" (poems) by Ann Favreau
- "Lifelines: Keeping Your Head Above Water"
by Carol Larson
- "Positive Options for Colorectal Cancer" by Carol Larson

- “Positive Options for Living with Your Ostomy: Self-Help and Treatment” by Craig A. White
- “The Human Side of Cancer: Living With Hope, Coping with Uncertainty” by Jimmie Holland and Sheldon Lewis
- “The Ostomy Book: Living Comfortably with Colostomies, Ileostomies, and Urostomies” by Barbara Dorr Mullen and Kerry Anne McGinn
- “When the Trip Changes: A Traveler’s Advisory to Colorectal Cancer” by Carol Larson
- “Weathering the Storm: Stories of Hope and Healing” by Carol Larson
- “Yes We Can: Advice on Traveling with an Ostomy and Tips for Everyday Living” by Barbara Kupfer, Kathy Foley-Bolch, Michelle Fallon Kasouf with Brian Sweeney



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