



## Ileostomy: A Guide

Ileostomy surgery is done for many different diseases and problems. Some of the conditions that can lead to ileostomy surgery are ulcerative colitis, Crohn's disease, familial polyposis, and cancer.

For the thousands of people who have serious digestive diseases, an ileostomy can be the start of a new and healthier life. If you have had a chronic (long-term) problem or a life-threatening disease like cancer, you can look forward to feeling better after you recover from this surgery. You can also look forward to returning to most, if not all of the activities you enjoyed in the past.

This guide will help you better understand ileostomy – what it is, why it's needed, how it affects the normal digestive system, and what changes it brings to a person's life. Many of the terms you will hear from your health care team are used and defined here.

### What is an Ileostomy?

An ileostomy is an opening in the belly (abdominal wall) that is made during surgery. The end of the ileum (the lowest part of the small intestine) is brought through this opening to form a stoma, usually on the lower right side of the abdomen.

When you look at your stoma, you are actually looking at the lining (the *mucosa*) of your small intestine, which looks a lot like the lining of your cheek. The stoma will look pink to red. It is warm and moist and secretes small amounts of mucus. It will shrink over a short period of time after surgery. The shape will be round to oval. Some stomas may stick out a little, while others are flush with the skin.

Unlike the anus, the stoma has no valve or shut-off muscle. This means you will not be able to control of the passage of stool from the stoma. There are no nerve endings in the stoma, so the stoma itself is not a source of pain or discomfort.

As part of this surgery, the colon (large intestine) and rectum (the lowest portion of colon where formed stool is held until it is passed out of the body through the anus) are often removed (this is called a colectomy). This means that the normal colon and rectum

functions are no longer present. Sometimes, only part of the colon and rectum are removed.

## What does an ileostomy do?

After the colon and rectum are removed or bypassed, waste no longer comes out of the body through the rectum and anus. Digestive contents now leave the body through the stoma. The drainage is collected in a pouch that sticks to the skin around the stoma. The pouch is fitted to you personally. It is worn at all times and can be emptied as needed. The ileostomy output will be liquid to pasty, depending on what you eat, your medicines, and other factors. Because the output is constant, you will need to empty the pouch 5 to 8 times a day.

The major job of the small intestine is to absorb nutrients and water from what you eat and drink. Enzymes (chemicals made by the body to break down food) are released into the small intestine to break food into small particles so that proteins, carbohydrates, fats, vitamins, and minerals can be taken into the body. These enzymes are also in the ileostomy output and can irritate the skin. This is why the skin around your stoma must always be protected. (See "Protecting the skin around the stoma" in the "Helpful Hints" section.)

## Why have an ileostomy?

Ileostomy surgery is done for many different diseases and conditions. Ileostomy surgery is usually done when the bowel has disease or damage that cannot be treated by other methods. The most frequent reason for having surgery is inflammatory bowel disease (IBD) which includes Crohn's disease and ulcerative colitis. Ileostomies are also done because of birth defects, familial polyposis, injury, or cancer.

Certain bowel problems may be treated by giving part of the bowel a rest or with surgery to remove the damaged part. The bowel must be kept empty so it can heal. To keep stool from getting to the bowel, a short-term (temporary) ileostomy is created. Healing may take a few weeks, months, or even years. In time, the ileostomy will be surgically reversed (removed) and the bowel will work much like it did before. A temporary ileostomy can also be done as the first stage in forming an ileo-anal reservoir (or J-pouch), which we discuss in the section, "Types of ileostomies."

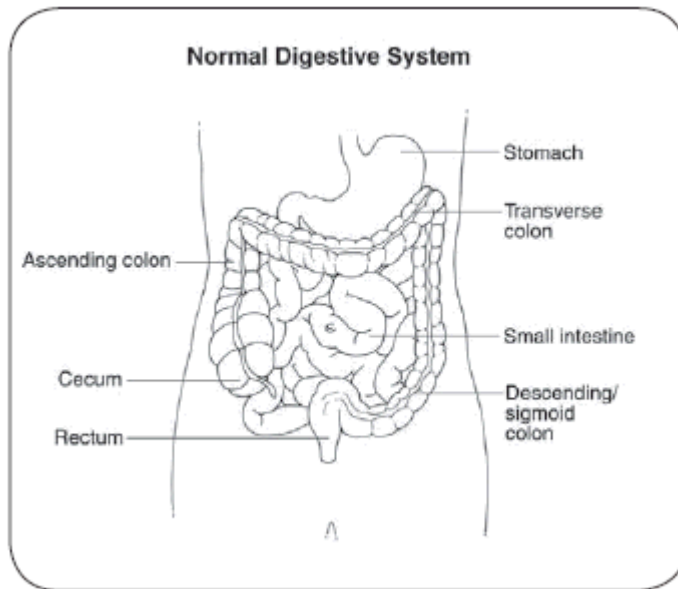
When part of the bowel becomes diseased, a long-term (permanent) ileostomy must be made. The diseased part of the bowel is removed or permanently rested. In this case, the ileostomy is not expected to be closed in the future.

## The normal digestive system

An ileostomy creates a major physical change for a patient, but it does not really change the digestion of food or body chemistry. To understand how an ileostomy works, it helps to know how the digestive tract normally works (see Figure 1).

After food is chewed and swallowed, it passes through the esophagus (swallowing tube) into the stomach. From there it goes into the small intestine. Hours can go by before it moves into the large intestine or colon. After hours or even days, it leaves the storage area called the rectum by way of the anus. For most of its passage, the food is liquid and loose. Water is absorbed in the colon, causing the stool to become a firm mass as it nears the rectum.

**Figure 1**



## The small intestine

The small intestine is the longest section of the digestive tract. Food nutrients are digested and absorbed here as food is moved through by peristalsis. (Peristalsis is the wave-like muscle contractions that move food through the digestive tract.)

The small intestine is about 20 feet long. It is made up of 3 sections:

- Duodenum (first part) – 10 to 12 inches beginning at the outlet of the stomach
- Jejunum (second part) – about 8 to 9 feet
- Ileum (third part) – about 12 feet, it connects to the colon at the cecum

The small intestine lies loosely curled in the belly (abdominal cavity).

## The large intestine or colon

The large intestine (also called the colon or large bowel) joins the small intestine where the ileum and cecum meet on the body's right side. It is about 5 to 6 feet long, and is made up of these sections:

- Cecum –the entry point for food that has been through the small intestine and is now a highly acidic liquid. It contains a valve that keeps food from going back into the ileum.
- Ascending colon – the contents are acidic liquid. This section goes up the right side of the body.
- Transverse colon – the contents are less acidic liquid. This section goes across the belly.
- Descending/sigmoid colon – the contents become more formed. This section goes down the left side of the body to the rectum.

The main jobs of the colon are absorbing water and electrolytes,(salts and minerals the body needs, like sodium, calcium, and potassium), moving stool, and storing waste until it is passed out of the body.

## The rectum and anus

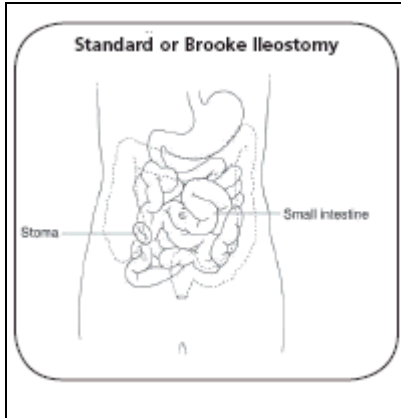
The 2 end portions of the digestive tract are the rectum and anus. Special nerve pathways to the brain make us aware when the stool reaches this section. As the stool enters the rectum, we feel the need to have a bowel movement. The anal sphincter muscle is like a valve that allows us to control this. Unlike the rest of the digestive tract, it closes (contracts) or opens (relaxes) at our will to allow stool to pass out of the body.

## Types of ileostomies

Three major types of ileostomies may be made when all of the colon must be removed. You and your surgeon should talk about your choices and together decide on the best surgery for you. Some of the things to think about when planning an ileostomy are the disease process, your age, your general health, and your preference.

### Standard or Brooke ileostomy

<b>Reasons for the surgery:</b>	<b>Output:</b>	<b>Management:</b>
Ulcerative colitis Crohn's disease Familial polyposis Cancer-related problems	Liquid or paste-like constant drainage that contains digestive enzymes	Skin protection is needed; use an open-ended pouch that can be emptied

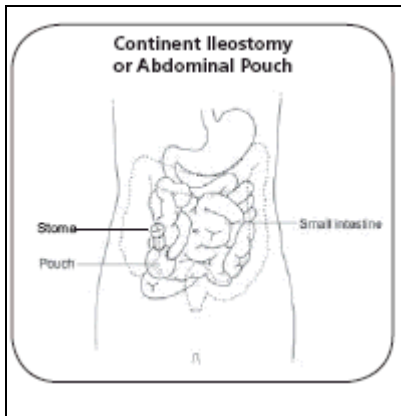


The standard ileostomy surgery is done most often. The end of the ileum is pulled through the abdominal wall and is turned back and sutured to the skin, leaving the smooth, rounded, inside-out ileum as the stoma.

The stoma is usually placed in the right lower part of the abdomen, on a flat surface of normal, smooth skin. The fecal output is not controlled. This means you will need to wear a collection pouch all the time, and empty it regularly.

### Continent ileostomy (abdominal pouch)

<p><b>Reasons for surgery:</b> Ulcerative colitis Familial polyposis Cancer-related problems</p>	<p><b>Output:</b> Liquid or paste-like drainage</p>	<p><b>Management:</b> Drain fairly often with a small tube (catheter) and use a stoma cover</p>
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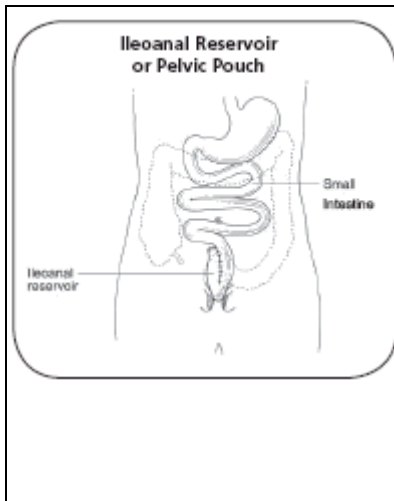


A continent ileostomy is a different type of standard ileostomy. You do not need to wear an external pouch with this kind of ileostomy.

It is made by looping part of the ileum back on itself so that a reservoir or pocket is formed inside the abdomen. A nipple valve is made from part of the ileum. A few times each day you put in a thin, soft tube called a catheter to drain the waste out of the reservoir.

### Ileo-anal reservoir (J-pouch or pelvic pouch)

<p><b>Reasons for surgery:</b> Ulcerative colitis Familial polyposis</p>	<p><b>Output:</b> Soft, formed stool</p>	<p><b>Management:</b> Natural bowel movements take place, but you need to protect the skin around the anus</p>
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The ileo-anal reservoir (or pelvic pouch) is a pouch made from the ileum and the rectum and placed inside the body in the pelvis. Other names for this include J-pouch, W-pouch, and S-pouch depending on the surgical procedure.

The pouch is connected to the anus. Waste passes into the pouch, where it is stored. When an "urge" is felt, the stool can be passed through the anus, out of the body. The sphincter muscle around the anal opening must be intact to keep the pouch from leaking. The consistency of the output of the pelvic pouch depends on what you eat and drink, and may be managed with medicines. In most cases at least 2 surgeries are done to make this type of ileostomy.

## Ileostomy management

Learning to care for your ileostomy may seem hard at first, but with practice and time it will become second nature, just like shaving or bathing.

There is no one way to take care of an ileostomy. This guide offers you tips and ideas for managing your ileostomy. Discuss these ideas with your doctor or ostomy nurse and adapt them to your needs. Give new things a fair trial, but do not keep doing them if they do not make you more comfortable. Use your recovery time to learn and try different things so that you can find what works best for you.

In our society, bathroom needs are kept private. Talking about stool and bowel movements can be awkward or uncomfortable. This is often true for a person with an ileostomy. But while you learn how to deal with the changes that have been made, you may need help and advice. A good sense of humor and common sense are needed when changes in body function take place. Be confident. You can learn the new system. Before long you again will be in control.

## Choosing a pouching system

Deciding what pouching system or appliance is best for you is a very personal matter. When you are trying out your first pouching system, it is best to talk with an ostomy nurse or someone who has experience in this area. There should be someone in the hospital who can get you started with equipment and instructions after surgery. As you are getting ready to leave the hospital, be sure you are referred to an ostomy nurse, a clinic, or a chapter of the United Ostomy Associations of America. Even if you must go out of town to get such help, it is worthwhile, as you want to get a good start and avoid mistakes. Even with help, you may have to try different types or brands of pouching systems to find the one that best suits you. (See the section "Getting help, information, and support.")

There are many things to think about when trying to find the pouching system that will work best for you. The length of the stoma, abdominal firmness and shape, the location of the stoma, scars and folds near the stoma, and your height and weight all must be considered. Special changes may have to be made for stomas near the hipbone, waistline, groin, or scars. Some companies have custom-made products to fit unusual situations.

A good pouching system should be:

- Secure, with a good leak-proof seal that lasts for 3 to 7 days
- Odor resistant
- Protective of the skin around the stoma
- Nearly invisible when covered with clothing
- Easy to put on and take off

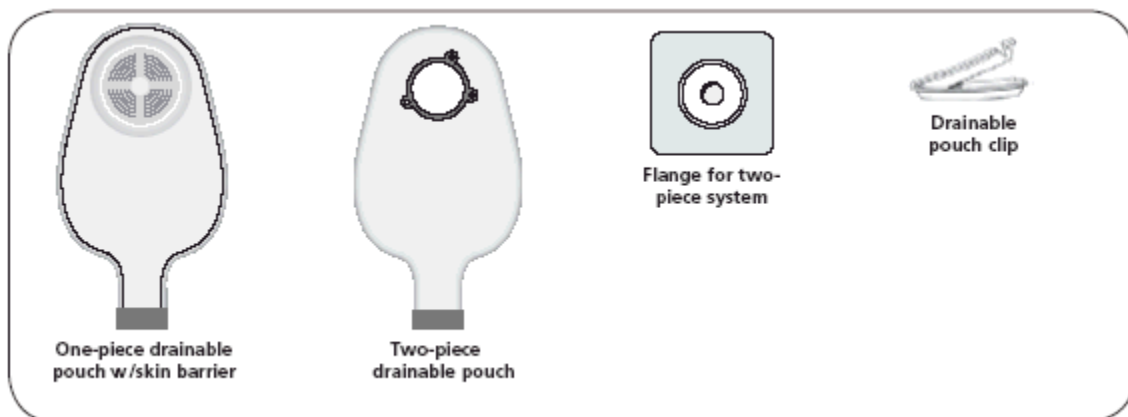
## Types of pouching systems

A pouching system is used to collect ileostomy output. There are 2 main types of systems available. Both kinds include an adhesive part that sticks to your skin (called a faceplate, flange, skin barrier, or wafer) and a collection pouch.

- One-piece pouches are attached to the skin barrier
- Two-piece systems are made up of a skin barrier and a pouch that can be taken off and put back on the barrier

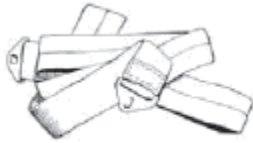
The skin barrier or faceplate of the pouch may need a hole cut out for the stoma, or it may be sized and pre-cut. It is designed to protect the skin from the stoma output and to be as gentle to the skin as possible.

Pouches for one- and two-piece systems are drained through an opening at the bottom. They are made from odor-resistant materials and vary in cost. Pouches are either clear or opaque and come in different lengths.



After surgery, the stoma may be swollen for about 6 to 8 weeks. During this time the stoma should be measured about once a week. A measuring card may be included in boxes of pouches, or you can make your own template to match your stoma shape. The opening on the skin barrier should be no more than 1/8 inch larger than the stoma.

## Belts and tape



Adjustable belt

Wearing a belt is a personal choice. Some people with ileostomies wear a belt because it makes them feel more secure and it supports the pouching system. Others find a belt awkward and use tape instead. Tape can be put around the outside edge of the skin barrier like a frame.

If you choose to wear a belt, adjust it so that you can get 2 fingers between the belt and your waist. This helps to keep you from getting a deep groove or cut in the skin around the stoma which can cause serious damage to the stoma and pressure ulcers on the nearby skin. Belts should be worn so they do not ride above or below the level of the belt tabs on the pouching system. People in wheelchairs may need a special belt. Supply companies often carry these special belts or an ostomy nurse can talk to you about making one yourself.

## Changing the pouching system

There may be less bowel activity at certain times in the day. It is easiest to change the pouching system during these times. You may find that early morning before you eat or drink is best. Or allow at least 1 hour after a meal, when digestive movement has slowed down. Right after surgery, ileostomy output may be thin and watery. As the output gets thicker, you will be better able to find the best time for changing your system.

## Sterility

You don't have to use sterile supplies. For instance, facial tissue or toilet paper can be used in place of gauze pads. The stoma and nearby skin are clean but not sterile.

## Factors that affect the pouching system seal

The length of time a pouch will stay sealed to the skin depends on many things, such as the weather, skin condition, scars, weight changes, diet, activity, body shape near the stoma, and the nature of the ileostomy output.

- Sweating during the summer months in warm humid climates will shorten the number of days you can wear the pouching system. Body heat, added to outside temperature, will cause skin barriers to loosen more quickly than usual.
- Moist, oily skin may reduce wearing time.
- Weight changes will also affect how long you can wear a pouch. Weight gained or lost after ileostomy surgery can change the shape of your abdomen. You may need an entirely different system.
- Diet may affect your seal. Foods that cause watery output may prevent a long-lasting seal.
- Physical activities may affect wearing time. Swimming, very strenuous sports, or anything that makes you sweat may shorten wearing time.

## Emptying the pouch

Empty the pouch when it is about 1/3 full to keep it from bulging and leaking. Follow these steps:

- Sit as far back on the toilet as you can or on a chair facing the toilet.
- Place a small strip of toilet paper in the toilet to decrease splashing.
- Hold the bottom of the pouch up and open the pouch at the tail.
- Slowly unroll the tail over the toilet.
- Gently empty the contents.
- Clean the outside and inside of the pouch tail with toilet paper.
- Roll up the end of the pouch and clip.

## Ordering and storing supplies

Keep all your supplies together on a shelf, in a drawer, or in a box in a dry area away from hot or cold temperatures.

Order supplies a few weeks before you expect to run out to allow enough time for delivery. But don't stockpile supplies -- they can be ruined by moisture and temperature changes.

To order pouches, skin barriers, and other ostomy products, you will need the manufacturer's name and product numbers. Supplies may be ordered from a mail order company, from a medical supply store, or from a local pharmacy. If you want to order supplies online, talk with your nurse about reputable dealers who can supply you with what you need. You will also want to check with your health insurance to be sure that they work with the company in question. You may want to compare prices when using

mail order and the Internet (remember to include shipping costs). For information and help ordering, you may contact a local ostomy nurse, the product manufacturer, you local phone book's business pages, or the Internet (try the search words "ostomy supplies").

## Helpful hints

As you learn more, you may have questions. There is no one right answer, only suggestions and ideas for you to try. This section has many tips that come from others. But remember, no two people are alike.

## Protecting the skin around the stoma

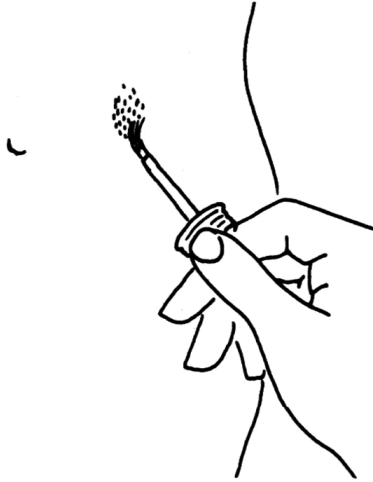
The skin around your stoma should always look the same as skin anywhere else on your abdomen. But ileostomy output can make this skin tender or sore. Use the following tips to help keep your skin healthy:

- Use the right size pouch and skin barrier opening. An opening that is too small can cut or injure the stoma and may cause it to swell. If the opening is too large, output could get to and irritate the skin. In both cases, change the pouch or skin barrier and replace it with one that fits well.
- Change the pouching system regularly to avoid leakage and skin irritation. Itching and burning are signs that the skin needs to be cleaned and the pouching system should be changed.
- Do not rip the pouching system away from the skin or remove it more than once a day unless there is a problem. Remove the face plate gently by pushing your skin away from the sticky barrier rather than pulling the barrier away from the skin.
- Clean the skin around the stoma with water. Use a mild soap and rinse well. Dry the skin completely before putting on the skin barrier or pouch.
- Watch for sensitivities and allergies to the adhesive, skin barrier, paste, tape, or pouch material. They can develop after weeks, months, or even years of using a product because you can become sensitized over time. If your skin is irritated only where the plastic pouch touches it, you might try a pouch cover. These are available from supply manufacturers, or you can make your own.
- You may have to test different products to see how your skin reacts to them. If you feel comfortable testing yourself, follow the directions under "Patch testing" that follow. If you are not comfortable doing this on your own and the problem continues, talk to your doctor or ostomy nurse.

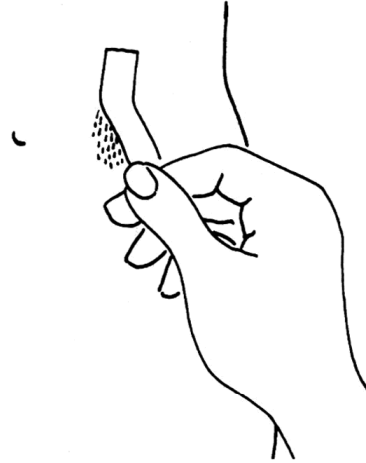
## Patch testing

Patch testing can be done to see if you are sensitive to or allergic to a product used as part of your ostomy care. Place a small piece of the material to be tested on the skin of your

belly, far away from the colostomy. If the material is not self-sticking attach it with an adhesive tape that you know you are not allergic to (Figures 21 and 22). Leave it on for 48 hours.



**Figure 21**  
*Patch Testing without Adhesive Tape*



**Figure 22**  
*Patch Testing with Adhesive Tape*



**Figure 23**  
*Reaction to the Tested Material*



**Figure 24**  
*Reaction to the Tape Only*

Gently remove the patch at the end of 48 hours and look for redness or spots under the patch. If there is no redness after 48 hours, it is generally safe to use the product. But, in a few cases, reactions that took longer than 48 hours to show up have been reported (Figure 23).

Itching or burning before 48 hours pass is a sign of sensitivity. Remove the material right away and wash your skin well with soap and water.

A reaction to the tape is also possible. If this is the case, the redness or other irritation will only be in the area outlined by the tape (Figure 24).

If you seem to be allergic to a certain product, try one made by another company and patch test it, too. It may take a few tries to find one that works for you. Keep in mind that allergies are not as common as is irritation caused by using a product the wrong way. For this reason, before using a product, always read the directions that come with it. When in doubt, check with your ostomy nurse or doctor.

## Spots of blood on the stoma

Spots of blood are not a cause for alarm. Cleaning around the stoma as you change the pouch or skin barrier may cause slight bleeding. The blood vessels in the tissues of the stoma are very delicate at the surface and are easily disturbed. The bleeding will usually stop quickly. If it does not, call your ostomy nurse or your doctor.

## Shaving hair under the pouch

Having a lot of hair around the stoma can make it hard to get the skin barrier to stick well and may cause pain when you remove it. Shaving with a razor or trimming hair with scissors is helpful. Extra care should always be taken when doing this. A mild soap or shaving cream may be used. Rinse well.

## Bathing

You may take a bath or shower with or without your pouch in place. If you do not wear the pouch, keep in mind that the output may keep coming out. Soap cannot harm the stoma. Just rinse it well. Do not use bath oil around the stoma – it can make it hard to get the pouch to stick well. If you bathe with your pouch off, be sure your skin is dry and cool before you replace the pouch. Otherwise the heat from a hot bath or shower can cause sweating under the barrier, which makes it hard to get a secure seal. Pat dry and apply the pouch.

## Gas (flatulence)

Right after surgery it may seem that you have a lot of gas almost all the time. Most abdominal surgery is followed by this uncomfortable, embarrassing, yet harmless symptom. As the tissue swelling goes down, you will have less gas. But certain foods may cause gas, such as eggs, cabbage, broccoli, onions, fish, beans, milk, cheese, and alcohol.

Eating regularly will help prevent gas. Skipping meals to avoid gas or output is not smart because it will make your small intestine more active and might cause more gas and watery output. Some people find it best to eat smaller amounts of food 4 to 5 times a day.

You may be worried about how others may respond to gassy noises. You will find that these noises sound louder to you than to others. They often only sound like stomach rumblings to those around you. If you are embarrassed by these rumblings when others are nearby, you can say, "Excuse me, my stomach's growling." If you feel as though you are about to release gas when you are with people, casually fold your arms across your belly so that your forearm rests over your stoma. This will muffle most sounds. Check with your ostomy nurse about products you can take to help lessen gas.

## Odor

Ileal output does not smell the same as normal stool. This is because the bacteria in the colon that break down food and cause odor are not found in the small intestine. Many factors, such as foods, normal bacteria in your intestine, illness, certain medicines, and vitamins can cause odor. Some foods can produce odor: eggs, cabbage, cheese, cucumber, onion, garlic, fish, dairy foods, and coffee are among them. If you find that certain foods bother you, avoid them. Learning by experience is the only solution to this problem. Here are some hints for odor control:

- Use an odor-resistant pouch.
- Check to see that the skin barrier is stuck securely to your skin.
- Empty the pouch often.
- Place special deodorant liquids and/or tablets in the pouch.
- There are some medicines you can take that may help. Check with your doctor or ostomy nurse about these products and how to use them. Some things that many people have found help with odor are chlorophyll tablets, bismuth subgallate, and bismuth subcarbonate.
- There are air deodorizers that control odor very well when you are emptying the pouch.

## Medicines

Be aware that coated tablets or time-released capsules may come out whole in the pouch. In most cases, this means you did not get the medicine. If you notice this, talk with your health care provider or pharmacist. There may be other medicines you can use to make sure you are getting what you need. Liquid or liquid gel medicines tend to absorb faster and may work better for you.

# Ileostomy problems

## Severe skin problems

Large areas of skin that are red, sore, and weeping (always wet) will keep you from getting a good seal around your stoma. It is important to treat minor irritations right away. If you have a large irritated area, contact your doctor or ostomy nurse. They may prescribe medicine to help dry out and heal your skin.

For deep pressure ulcers caused by a very tight ostomy belt, loosen or remove the belt and call your doctor or ostomy nurse right away. You will need treatment.

## Blockage (obstruction)

There will be times when your ileostomy does not have output for short periods of time. This is normal. But, if your stoma is not active for 4 to 6 hours and you have cramps and/or nausea, the intestine could be blocked (the medical word is obstructed). Call your doctor or ostomy nurse right away if this happens.

There are some things you can do to help move things through your ileostomy.

- Watch for swelling of the stoma and adjust the opening of the pouch as needed until the swelling goes down.
- Take a warm bath to relax your abdominal muscles.
- Sometimes changing your position, such as drawing your knees up to your chest, may help move along the food in your gut.
- Do **NOT** take a laxative.

High-residue foods (foods high in fiber) such as Chinese vegetables, pineapple, nuts, coconut, and corn can cause obstruction. Obstruction can also be caused by internal changes such as adhesions (scar tissue that forms inside your abdomen after surgery).

## Diarrhea

Diarrhea is usually a warning that something is not right. Diarrhea is defined as frequent loose, or watery bowel movements in greater amounts than usual. It happens when food passes through the small intestine too quickly for fluids and electrolytes to be absorbed. It can come on suddenly and may cause cramps. It can cause your body to lose a lot of fluids and electrolytes. You must quickly replace these electrolytes to avoid getting sick from dehydration and mineral deficiency.

Loose stool can also come from eating certain foods, but it usually only lasts a short time. Raw fruits and vegetables, milk, fruit juice, prune juice, or impure drinking water are examples of things that may change your stoma output. Loose stool may also be caused by emotional stress. Some people with ileostomies may always have "watery discharge" and this is normal for them.

Several things can cause diarrhea:

- Intestinal flu or food poisoning, which may also often cause fever and vomiting
- Antibiotics and other prescription medicines
- Partial blockage, which also causes smelly discharge, cramps, forceful liquid output, and a lot of noises from the stoma. It can be caused by food or other factors. Get medical help if this happens to you.

Talk with your doctor or ostomy nurse if you have ongoing diarrhea or constipation. Discuss the foods and liquids you take in, your eating schedule, how much you usually eat, and any medicines you might be taking. You may be given medicine to help slow things down or to stimulate the bowel. Remember, no matter what, you need a well-balanced diet and good fluid intake to have a good output.

## Electrolyte balance

Electrolytes are salts and minerals in the blood, like potassium, magnesium, and sodium. Keeping them balanced is important. When the colon (large intestine) is removed, you are at a greater risk for electrolyte imbalance. Diarrhea, vomiting, and a lot of sweating can increase this risk.

Dehydration is also a serious concern. Symptoms include increased thirst, dry mouth, decreased urine output, feeling light-headed, and feeling tired. If you get dehydrated, you will need to drink more fluids. To avoid dehydration, you should try to drink 8 to 10 eight-ounce glasses of fluid a day. If you have diarrhea, you may need more. Drinks such as Gatorade<sup>®</sup>, PowerAde<sup>®</sup>, or Pedialyte<sup>®</sup> contain potassium and sodium. But any liquid containing water (soda, milk, juice, tea, etc.) helps to meet your daily need for fluid.

Loss of appetite, drowsiness, and leg cramps may be signs of sodium loss. Fatigue, muscle weakness, and shortness of breath may be signs of potassium loss. Dehydration, low sodium, and low potassium can all be dangerous and should be treated right away. Keep in mind that some of these symptoms can be caused by other problems which may be emergencies. Call your doctor or 911 right away if you are dizzy, weak, or having other serious symptoms.

## Phantom rectum

Phantom rectum is much like the "phantom limb" of amputees who feel as if their removed limb is still there. It is normal for you to have the urge to move your bowels the way you did before surgery. This can happen for years after surgery. If the rectum has not been removed, you may have this feeling and also may pass mucus when sitting on the toilet. Some people who have had their rectum removed say that the feeling is helped by sitting on the toilet and acting as if a bowel movement is taking place.

## Short bowel syndrome

This condition happens when surgery is done to remove a large part of the small intestine. Short bowel syndrome needs special attention because there is not enough intestine available to absorb nutrients the body needs.

People with short bowel syndrome must be under a doctor's care. They must be closely watched to make sure they are taking in enough calories, carbohydrates, proteins, fats, vitamins, and minerals. They can live a normal life, but must be careful to avoid diarrhea, and be within quick reach of medical care. The shorter the small intestine, the more watery the discharge will be. This may reduce the time a pouch can be worn because the skin barrier breaks down more rapidly. Special pouching systems are available for people with very liquid ileostomy output.

## When you should call the doctor

You should call the doctor or ostomy nurse if you have:

- Cramps lasting more than 2 or 3 hours
- Continuous nausea and vomiting
- No ileostomy output for 4 to 6 hours with cramping and nausea
- Severe watery discharge lasting more than 5 or 6 hours
- Bad odor lasting more than a week (This may be a sign of infection.)
- A deep cut in or injury to the stoma
- Bad skin irritation or deep ulcers (sores)
- A lot of bleeding from the stoma opening (or a moderate amount in the pouch that you notice several times when emptying it) (NOTE: Eating beets will cause some red discoloration.)
- Continuous bleeding where the stoma meets the skin
- Unusual change in your stoma size and color
- Anything unusual going on with your ostomy

## Hospitalization

Take your ostomy supplies with you if you have to be in the hospital. The hospital may not have the same type you use. Be ready to do some explaining and teaching, especially if you go into a hospital where ileostomy patients are rare, or if you go for a problem not related to your ostomy.

Do not assume that all hospital staff know a lot about ileostomies. Do not let the hospital staff do anything you think may be harmful, such as give you laxatives, give an enema through your stoma or rectum, or use a rectal thermometer. If you are in doubt about any procedure, ask to talk to your doctor first.

Also ask to have the following information listed on your chart:

- Type of ostomy you have
- Whether your rectum has been removed or is intact
- Details of your management routine and the products used
- Procedures to be avoided (see above)

## Living with an ileostomy

Learning to live with an ileostomy may seem like a big project. It is a lot like any other major change in your life. Starting a new job, moving to a new city, marriage, and having children are all examples of life changes that get easier over time. At first, you have to get used to the new aspects of these experiences and be open to the changes that are taking place. Having a positive outlook, patience, and a sense of humor are keys to adjusting to any life changes.

There may be times after surgery when you may feel discouraged. You may feel alone and isolated. Because the whole experience is so new to you, you may feel awkward, frustrated and uncertain. Feeling discouraged is real and normal. You might cry, be angry, and react in ways that are unusual for you. Talking to a trusted friend, nurse, clergy, and certainly another person with an ostomy may help you work through those feelings.

Your social life can be as active as it was before surgery. You can enjoy all the things you did before, such as travel, sporting events, and eating at restaurants. The first time you go out of the house after surgery, you may feel as if everyone is staring at your pouch even though it cannot be seen under your clothes. Remember, you may feel your pouch on your body, but no one can see it.

You may also worry about your pouch filling with gas and bulging under your clothes. A quick trip to the rest room can take care of this problem. If you are worried about your pouch filling up right after eating at a social event, remember that people without ileostomies often need to go to the rest room after eating. Nobody will think it unusual if you do the same. You will likely find that you need to empty your pouch less often than you need to urinate.

## Telling others

You might be worried about how others will accept you and how your social role may change. It is natural to wonder how you will explain your surgery. Your friends and

relatives may ask questions about your operation. Tell them only as much as you want them to know. Do not feel as if you have to explain your surgery to everyone who asks. A clear, brief answer would be that you had abdominal surgery, or that you had all or part of your intestine removed.

If you have children, answer their questions simply and truthfully. A simple explanation is often enough for them. Once you have explained what an ileostomy is they may ask questions about it and want to see your stoma or the pouch. Talking about your surgery in a natural way will help get rid of any wrong ideas that they may have. They will accept your ileostomy much the same way you do.

If you are single and dating, you can pick your time to tell a partner, but it might be better to do so early in a relationship. Stress the fact that this surgery was necessary and managing your ileostomy does not affect with your activities and enjoyment of life. This not only lessens your anxiety, but if there is an issue that cannot be overcome, the letdown is not as harsh as it might be later. Do not wait until intimate sexual contact leads to discovery.

If you are considering marriage, talking with your future spouse about life with an ileostomy and its effect on sex, children, and family acceptance will help correct any of your partner's wrong ideas. Going to an ostomy support group meeting together may also be helpful. Talking to other couples in which one partner has an ileostomy will give you both an experienced point of view. See the section called "Intimacy and sexuality" for more information.

## Clothing and appearance

You will not need special clothes. Ileostomy pouches are fairly flat and hard to see under most clothing. The pressure of undergarments with elastic will not harm the stoma or prevent bowel function.

If you were sick before surgery, you may find you can now eat normally for the first time in years. As your appetite returns, you may gain weight. This can affect the clothes you choose more than the pouching system itself.

Cotton knit or stretch underpants may give you extra support and security. A simple pouch cover adds comfort by absorbing body sweat and also keeps the plastic pouch from resting against your skin. Men can wear either boxer or jockey-type shorts.

## Eating and digestion

After healing is complete and the ostomy is working normally, most people with ileostomies can return to foods they normally eat. If you have a special diet because of heart disease, diabetes, or other health problems, you should ask your doctor about a diet that will work for you. Here are a few simple guidelines about your diet:

- Doctors often have their patients follow a low-residue diet the first weeks after any abdominal surgery. This includes only foods that are easily digested and don't leave

much waste behind, which means no raw fruits and vegetables. Be sure to find out when you can start eating regular foods. Eat foods that you like unless they are restricted by your doctor.

- When going back to foods you have not eaten since surgery, try one of these foods a day. Eat small amounts at first, then slowly increase the amount. If a small serving gives you cramps or diarrhea, cut out that food for now, but try it again in a few weeks. Chew well and see how each food affects your ileostomy.
- Drink plenty of liquids. At least 8 to 10 eight-ounce glasses of water per day are recommended. Dehydration and loss of electrolytes (salts and minerals) are possible if you don't take in enough fluids each day. Drink even more fluids if you are sweating or in a hot climate.

A warning: Beets turn ileostomy output a reddish color much like blood, but this is not harmful. Tomato juice and food dyes may change the usual color of ileostomy output, too.

## Returning to work

As your strength returns, you can go back to your regular activities. If you go back to work, you may want to tell your employer or a good friend about your ileostomy. Being open about it will help educate others. Keeping it a complete secret may cause practical problems.

People with ileostomies can do most jobs. But heavy lifting may cause a stoma to herniate (the whole thing bulges outward) or prolapse (the inside falls outward). A sudden blow in the pouch area could cause the face plate to shift and cut the stoma. Still, people with ileostomies do heavy lifting when they work as fire fighters, mechanics, and truck drivers. There are athletes who have stomas, too. Check with your doctor about your type of work. As with all major surgery, it will take time for you to regain strength after your operation. A letter from your doctor to your employer may be helpful should the employer have doubts about your physical abilities.

Being able to find work and get insurance are issues for some people with ostomies. If you have these issues get help from health care professionals and/or talk with others who have found solutions to these problems. You should know that your right to work may be protected by parts of the US Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1992, and sometimes by sections of your state and local laws. If you feel you are being treated unfairly because of your ileostomy, check with the United Ostomy Associations of America or with a local legal resource about protecting your rights.

## Intimacy and sexuality

Sexual relationships and intimacy are important and fulfilling aspects of your life that should continue after ostomy surgery. But there is a period of adjustment after surgery. Your attitude is a key factor in re-establishing sexual expression and intimacy. Sexual

function in women is usually not changed, but sexual potency of men may sometimes be affected. (If so, this is usually only for a short time.) Talk to your doctor and/or ostomy nurse about any problems or concerns you or your partner might have.

Any sexuality concerns you have are best discussed openly between you and your partner. A stoma on your belly is quite a change in how you look and can make you feel anxious and self-conscious. It is likely that your partner will be anxious about sex, too, and may be afraid of hurting your stoma or dislodging the pouch. Talk to your partner about the fact that sex is not likely to harm the stoma. Try to be warm, tender, and patient with each other.

The first time you become intimate after surgery things may not go perfectly. Men may have trouble getting and keeping an erection and women sometimes have pain during sex. These problems usually get better with time. Your interest in sex is likely to return as your strength returns and you get better at managing your pouch system. Body contact during sex will usually not hurt the stoma or loosen the pouch. If the pouch or stoma covering seems to be in the way during sex, try different positions or use small pillows to take pressure off the stoma.

If possible, empty the pouch beforehand. Women may consider wearing crotchless panties, "teddies," or a short slip or nightie. Men may consider wearing a cummerbund around the midsection to secure the pouch. There are many types of pouch covers that can be purchased or you can make your own.

Ostomy surgery may present more concerns for single people. When you choose to tell that someone special depends on the relationship. Brief casual dates may not need to know. If the relationship grows and is leading to physical intimacy, your partner needs to be told about the ostomy before a sexual experience.

For more information, see our documents *Sexuality for the Man With Cancer*, or *Sexuality for the Woman With Cancer*.

## **Pregnancy**

Pregnancy is possible for women who have had ileostomy surgery. But before you plan to get pregnant you should talk about it with your doctor. The ileostomy itself is not a reason to avoid pregnancy. If you are healthy, the risk during childbirth appears to be no greater than for other mothers. Of course, any other health problems must be considered and discussed with your doctor.

## **Exercise, play, and sports**

Everyone needs daily exercise to keep good health and body function. An ostomy should not keep you from exercising and playing sports. But there are a few safety measures you should think about. Many doctors do not recommend contact sports because of possible injury to the stoma from a severe blow, or because the pouching system may slip. But special protection can prevent these problems. Weight lifting could cause a hernia at the stoma. Check with your doctor about such sports. Indeed, people with ostomies are

distance runners, weight lifters, skiers, swimmers, and take part in most other types of athletics.

## Bathing and swimming

Water will not hurt your ileostomy. You can take a bath or shower with or without a pouching system in place. Normal exposure to air or contact with soap and water will not harm the stoma. Soap will not irritate it and water will not flow in.

You can swim with your pouching system in place. Remember these points:

- If you use a support ostomy belt, you can leave it on if you want to.
- You may want to protect the barrier by taping the edges with waterproof tape.
- You may want to choose a swim suit that has a lining for a smoother profile. Dark colors or busy patterns can also help hide the pouching system. Women may want to choose a suit with a well-placed skirt or ruffle. Men may want to try a suit with a higher waist band or longer leg.
- Women may wear stretch panties made especially for swim suits.
- Men may want to wear bike shorts or a support garment sold in men's underwear departments or athletic wear departments under their bathing suits.
- Men may prefer to wear a tank top and trunks, if the stoma is above the belt line.
- Before swimming, empty your pouch and remember to eat lightly.

## Travel

All methods of travel are open to you. Many people with ileostomies travel just like everyone else, this includes camping trips, cruises, and air travel. Here are some travel tips:

- Take along enough supplies to last the entire trip plus some extras. Double what you think you may need, because supplies may not be easy to get where you are going. Even if you don't expect to change your pouch take along everything you need to do so. Plastic bags with sealable tops may be used for pouch disposal. Leave home fully prepared. Find out if and where you can get supplies before a long trip. A local ostomy support group may be able to help you find ostomy supplies and local medical professionals.
- Seat belts will not harm the stoma when adjusted comfortably.
- When traveling by car, keep your supplies in the coolest part of the car. Avoid the trunk or back window ledge.
- When traveling by plane, remember that checked-in luggage sometimes gets lost. Carry an extra pouching system and other supplies on the plane with you. Small

cosmetic bags with plastic linings or shaving kits work well. These should be kept in your carry-on luggage. Air travel security will generally let you take on all medical supplies. You may want to review the Transportation Security Administration's information at: [www.tsa.dhs.gov/travelers/airtravel/specialneeds/index.shtm](http://www.tsa.dhs.gov/travelers/airtravel/specialneeds/index.shtm)

- To avoid problems with customs or luggage inspection, have a note from your doctor stating that you need to carry ostomy supplies and medicine by hand. Further problems might be avoided by having this information translated into the languages of the countries you are visiting.
- Before traveling abroad, get a current list of English-speaking doctors in the areas you will be visiting. The International Association for Medical Assistance to Travelers (IAMAT) at 716-754-4883 or [www.iamat.org](http://www.iamat.org) publishes lists of English speaking doctors who were trained in North America or Europe and are available in over 90 countries around the world.
- Traveler's diarrhea is a common problem for tourists in foreign countries, whether you have an ostomy or not. The most common cause of diarrhea is impure water and/or food. It may also be caused by changes in water, food, or climate. It is best to avoid unpeeled fruits and raw vegetables. Be sure drinking water is safe. If the water is not safe, do not use the ice either. Bottled water or boiled water is recommended, even for brushing your teeth. People with ileostomies lose water and minerals quickly when they have diarrhea. (See "Electrolyte balance" in the section "Ileostomy problems.") For this reason you may need medicine to stop the fluid and electrolyte loss. Your doctor can give you a prescription to control diarrhea. Get it filled before you leave so that you can take the medicine with you just in case you need it.

## **For parents of children with ileostomies**

If your child has an ileostomy, you probably have many questions and concerns. When the surgeon said your child needed this surgery, your first reaction may have been, "Is this the only choice?" Your doctor no doubt assured you that the ileostomy was needed to save your child's life. You may have felt shock. You may have asked yourself, "Why did this happen to us?"

It helps to talk to a good friend, the doctor, clergy, an ostomy nurse, or the parents of a child who has an ileostomy. This will prepare you to help your child adjust to the ileostomy. Deal with your own feelings first, then you will be better able to give your child the emotional support he or she needs.

You may feel guilty or responsible for your child's illness and surgery. These feelings are normal. You may think that your dreams have been shattered and may wonder if your child will be able to do the things that other children do. Most parents worry about their child's life span, ability to work, adjustment to living with an ileostomy, and in later years, marriage and family. These are normal concerns for all parents facing major changes in their child's life.

When your child is in the hospital, be there as often as possible. Being in the hospital and having surgery are frightening at any age. Your child may feel very helpless and scared at this time and needs the love and comfort you can give. You being there makes him or her feel safe.

Be prepared for how you will feel when you see an opening on your child's abdomen with bowel contents running into a pouch. The first reaction your child sees from you is vitally important and must be as positive and casual as possible.

If your child has a fever or other symptoms, don't panic. He or she will have all the aches and pains that other children have. When in doubt, call the doctor.

## Psychosocial issues

As your child begins to recover from ileostomy surgery, there are many ways you can be a source of strength and support.

Your son or daughter may be afraid that young friends and relatives will not want to be around them. Your acceptance is key. Encourage your child to talk to you about these feelings. If you are open and natural about the ileostomy, he or she will be, too.

Try to understand how your child feels. Your child needs to feel that you understand what it is like to have an ileostomy. Still, too much sympathy is not good and can take away a sense of independence. Listen, try to understand feelings, be encouraging, and be tactful. It is hard not to overprotect and pamper a child who is recovering from major surgery.

If your child is very young, they will probably accept the ileostomy more easily than you. The child will grow up with it and it will become a natural part of them. For a teenager who is facing all the problems that come with puberty and adolescence, this surgery comes at an especially difficult time. The changes in body image caused by the ileostomy may make the stresses of adolescence worse. Your teenager may feel unattractive, rejected, and different because of the ileostomy.

You may notice short-term changes in your child's behavior. Your acceptance and support are very important. Try to understand the feelings and listen to the complaints. Give encouragement and try to help your child find realistic solutions to his or her problems.

## Your child's ileostomy care

Take an interest in your child's ileostomy care. If he or she is old enough, you will need to help your child learn to take care of the ostomy and pouching system on his or her own. Your child may need some help and support at first. He or she may be unsure about how to use the new supplies, feel physically weak, and tire easily.

A very young child can be taught to empty the pouch. An older child can get supplies together and learn the steps of changing the pouch, until the whole process can be done alone. You may want to use a teaching process that begins with your child helping you. Later on you can help them, then over time, stand by to help only if you are needed.

It is very important that your child have an ostomy nurse to help out at this time. This is a person who has special training in ostomy management and the emotional needs that may come at this time of change. To find an ostomy nurse in your area, call the Wound, Ostomy and Continence Nurses Society at 1-888-224-9626 or visit their Web site at [www.wocn.org](http://www.wocn.org).

Be prepared for trial and error in caring for, or helping to care for, your child's ileostomy. There are some changes that will happen in the beginning that will not happen later. There may be diet adjustments, skin problems, pouching problems, and more. The important thing to remember is that all of these new changes will become more comfortable over time. A sense of humor and a positive attitude will help you and your family through this time.

## Going back to school and everyday living

Be flexible as your child adjusts to school and everyday living. Have a plan in place in case there are problems. Maybe the pouch will leak at school. If that happens, your child can go to the school nurse. Or, you might pick up your child for a pouching system change at home, then he or she can return to school. One youngster tells this story: he noticed that his pouch was leaking and had stained his pants. Instead of rushing out of the class as everyone else did, he calmly waited until everyone had left the room. In this way, he very wisely avoided embarrassment and then called home so that his mother could pick him up. You may want to visit the principal, the classroom teacher, the physical education teacher, and the nurse to explain your child's needs.

You will find that your child can take part in most sports, go on overnight trips, camp, and, in fact, enjoy the same activities as before. At first, it may be hard to let your child go away on his or her own. Talk about what can be done if any problems come up while your child is away from home. If you can help your child know how best to handle any problems that may come up, he or she will not need any "special" treatment or seem different from any other children.

Talk with your child about how they will talk to others about the surgery. He or she may want to tell close friends and loved ones. Naturally, people will be curious. Once the surgery is explained, chances are your child will be accepted as before. Your child is likely to repeat what you say. If you talk about the surgery in a natural way with others, your child will too.

Remind your child to think about others, too. For example, cleaning up the bathroom after ileostomy care is important. You and your child are facing a new situation in your lives. If it is approached with openness, firmness, and a sense of humor, you will find that an ileostomy will not stop your son or daughter from taking part in life's everyday activities. Parents find that a healthy child with an ileostomy can once again be a happy child.

Being around other kids with ostomies can also be a great help. Each summer a camp for young people ages 11 to 17 with ostomies or any other bowel or bladder changes is held at a college campus. The camp is called The Youth Rally. Planned learning sessions on

self-esteem, body image, hygiene, and ostomy issues, plus discussion sessions, craft projects, tours, and sports are offered. Visit [www.rally4youth.org](http://www.rally4youth.org) for more information.

## **Getting help, information, and support**

There are many ways to better understand your life with an ileostomy. Your doctor and ostomy nurse are important sources of information and support. A lot of information can also be found at various Web sites, such as those listed in the "To learn more" section.

A special source of help with your adjustment is an ostomy visitor. The visitor is a person who, like you, has had colostomy surgery. They can answer many of your questions about day-to-day life. Your ostomy visitor has successfully adapted to the changes that ostomy surgery makes, and can help you adjust, too. Taking part in an ostomy support group can also be very helpful. It allows you to share your feelings and ask questions as you learn to live with your colostomy. It also lets you share your successes with others who may need the benefit of your experience. Most ostomy visitor programs and support groups are sponsored by local chapters of the United Ostomy Associations of America (UOAA).

A number of cancer centers have ostomy rehabilitation programs which include all types of ostomies, whether or not they are caused by cancer. Ask about services that may be available, such as educational pamphlets, ostomy supplies for people without insurance coverage, or assistance in contacting the local UOAA chapter. You can also contact the American Cancer Society (1-800-227-2345) for information on ostomy support groups.

## **To learn more**

### **More information from your American Cancer Society**

We have selected some related information that may also be helpful to you. These materials may be ordered from our toll-free number.

After Diagnosis: A Guide for Patients and Families (also available in Spanish)

Americans With Disabilities Act: Information for People Facing Cancer

Caring for the Patient With Cancer At Home: A Guide for Patients and Families (also available in Spanish)

Sexuality for the Man With Cancer (also available in Spanish)

Sexuality for the Woman With Cancer (also available in Spanish)

Colorectal Cancer: Detailed Guide (also available in Spanish)

Colorectal Cancer Overview (also available in Spanish)

## National organizations and Web sites\*

### **United Ostomy Associations of America, Inc. (UOAA)**

Toll-free number: 1-800-826-0826

Web site: [www.uoaa.org](http://www.uoaa.org)

For local support group information; the interactive Web site includes discussion boards

### **International Ostomy Association (IOA)**

Web site: [www.ostomyinternational.org](http://www.ostomyinternational.org)

Advocates for and outlines the rights of ostomates

### **Wound, Ostomy and Continence Nurses Society (WOCN)**

Toll-free number: 1-888-224-9626

Web site: [www.wocn.org](http://www.wocn.org)

The WOC nurse is a specialist in ostomy care and rehabilitation. These nurses care for and teach people with ostomies, coordinate patient care, teach nursing staff in hospitals and clinics, and work closely with the nursing and medical professions to improve the quality of ostomy rehabilitation programs. The WOCN Society can help you find a WOC nurse in your area.

### **Centers for Medicare & Medicaid Services**

Toll-free number: 1-800-633-4227

Web site: [www.cms.hhs.gov](http://www.cms.hhs.gov)

Ileostomy care and supplies are covered under part B of Medicare. These same supplies and care may be covered under Medicaid (this is state regulated and varies). Check with an ostomy nurse about which health department or agency in your state may be able to help you.

*\*Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit [www.cancer.org](http://www.cancer.org).

*In its original form this document was written by the United Ostomy Association, Inc. (1962-2005) and reviewed by Jan Clark, RNET, CWOCN. It has since been modified and updated by the American Cancer Society.*

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Last Medical Review: 3/17/2011

Last Revised: 3/17/2011

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1 - 800 - ACS-2345 or [www.cancer.org](http://www.cancer.org)