



Colostomy: A Guide

Colostomy surgery is done for many different diseases and problems. Some colostomies are done because of cancer; others are not. For instance, a child may need one because of a birth defect. Sometimes a colostomy is only needed for a short time, but for some people it is life-long.

For the thousands of people who have serious digestive diseases, a colostomy 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 colon 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 colostomy – what it is, why it's needed, how it affects the normal digestive system, and what changes it can bring to a person's life. Many of the terms you will hear from your health care team are used and defined here.

What is a colostomy?

A colostomy is an opening in the belly (abdominal wall) that is made during surgery. The end of the colon (large intestine) is brought through this opening to form a stoma. Where the stoma will be on the abdomen depends on which part of the colon is used to make it. Some colostomies are large, some small; some are on the left side of the abdomen, some are on the right side, others may be in the middle. An enterostomal therapy (ET) nurse or the surgeon will figure out the best location for your stoma. (An ET nurse is a specially trained registered nurse who takes care of and teaches ostomy patients. This nurse may also be called a Wound, Ostomy and Continence nurse (WOC) or an ostomy nurse.)

When you look at a stoma, you are actually looking at the lining (the mucosa) of the 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.

The way the stoma looks depends on the type of colostomy the surgeon makes and on individual body differences. It may look quite large at first, but it will shrink to its final size about 6 to 8 weeks 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 the passage of stool from the stoma, but sometimes bowel movements can be managed in other ways. There are no nerve endings in the stoma, so the stoma itself is not a source of pain or discomfort.

A colostomy is not a disease, but a change in the way your body works. It surgically changes normal body function to allow stool to pass after a disease or injury. Although a colostomy is a big change for the patient, the operation itself is rather simple. Digestion and body chemistry are not changed by a colostomy.

What does a colostomy do?

After a colostomy has been created, the intestines will work just like they did before except:

- The colon and rectum beyond the colostomy is disconnected or removed.
- The anus is no longer the exit for stool.

Since nutrients are absorbed in the small intestine, a colostomy does not change how the body uses food. The main functions of the colon are to absorb water, move the stool toward the anus, and then store stool in the rectum until it is passed out of the body. When a colostomy changes the stool's route, the storage area is no longer available.

The higher up in the colon the colostomy is made, the shorter the colon is. The less time the colon has to absorb water, the softer or more liquid the stool is likely to be. A colostomy further down in the colon, near the rectum, will put out stool that has been in the intestine a longer time. Depending on the effects of illness, medicines, or other forms of treatment, the longer colon can put out a more solid or formed stool. Some people with colostomies find that they are able to pass this stool at certain times of the day with or without the help of irrigation. (Irrigation is discussed later.)

After surgery, some people still may feel urges and even have some discharge from the anus. This discharge is mucus, blood, and at times stool, left from the operation. If the rectum remains after surgery, it will keep putting out mucus that can be harmlessly passed whenever you have the urge.

Why have a colostomy?

Colostomy surgery is done for many different diseases and conditions.

Certain lower bowel problems are treated by giving part of the bowel a rest. It is kept empty by keeping stool from getting to that part of the bowel. To do this, a short-term (temporary) colostomy is created so that the bowel can heal. This may take a few weeks, months, or even years. In time, the colostomy will be reversed (removed) and the bowel will work like it did before.

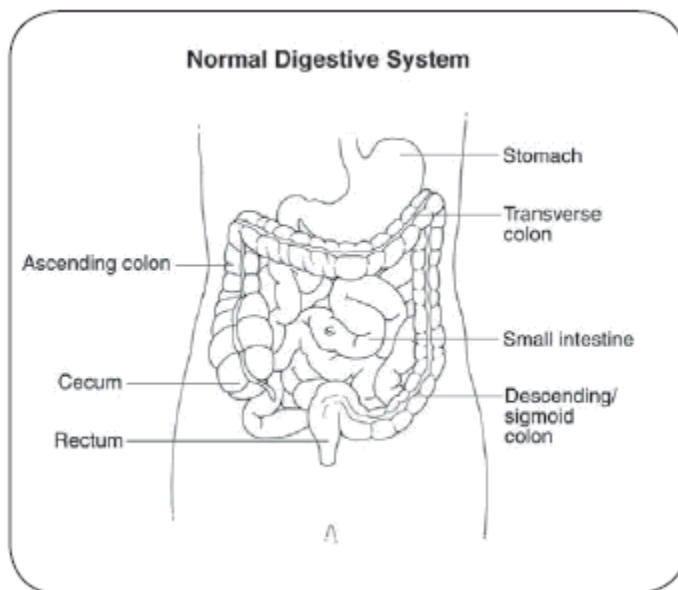
When part of the colon or the rectum becomes diseased, a long-term (permanent) colostomy must be made. The diseased part of the bowel is removed or permanently rested. In this case, the colostomy is not expected to be closed in the future.

The normal digestive system

A colostomy creates a major physical change for a patient, but it does not really change the digestion of food or body chemistry. To understand how a colostomy 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 long

- Ileum (third part) – about 12 feet long; 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 or sigmoid colon – the contents become more formed. This section does 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.

There are 2 major types of activities in the colon, peristalsis and mass reflex. During peristalsis, the muscles of the colon are constantly contracting (squeezing) and relaxing. These movements happen in all the different parts of the colon, but cannot be felt. The purpose of peristalsis is to mix and knead the liquid from the small intestine and to remove water. This makes the end product, formed or solid stool. When stool collects in a part of the colon, muscles in that part relax and stretch to hold it. Pressure builds as the stretch limit is reached. At this point, a mass reflex, stronger than peristalsis, pushes the stool into the next part of the colon. Over time, the stool moves into the rectum. This reflex happens several times a day, usually after you eat or drink.

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 colostomies

A colostomy can be short-term (temporary) or life-long (permanent) and can be made in any part of the colon.

Transverse colostomies

The transverse colostomy is in the upper abdomen, either in the middle or toward the right side of the body. This type of colostomy allows the stool to leave the body before it reaches the descending colon. Some of the colon problems that can lead to a transverse colostomy include:

- Diverticulitis. This is inflammation of diverticula (little sacs along the colon). It can cause abscesses, scarring with stricture (abnormal narrowing), or rupture of the colon and infection in severe cases.
- Inflammatory bowel disease
- Cancer
- Obstruction (blockage)
- Injury
- Birth defects

If there are problems in the lower bowel, the affected part of the bowel might need time to rest and heal. A transverse colostomy may be used to keep stool out of the area of the colon that is inflamed, infected, diseased, or newly operated on – this allows healing to take place. This type of colostomy is usually temporary. Depending on the healing process, the colostomy may be needed for a few weeks, months, or even years. If you heal over time, the colostomy is likely to be surgically reversed (closed) and you will go back to having normal bowel function.

A permanent transverse colostomy is made when the lower portion of the colon must be removed or permanently rested, or if other health problems make the patient unable to have more surgery. The colostomy is then the permanent exit for stool and will not be closed in the future.

Types of transverse colostomies

There are 2 types of transverse colostomies: the loop transverse colostomy and the double-barrel transverse colostomy.

Loop transverse colostomy (Figures 2 and 3): The loop colostomy may look like one very large stoma, but it has 2 openings. One opening puts out stool, the other only puts out mucus. The colon normally makes small amounts of mucus to protect itself from the bowel contents. This mucus passes with the bowel movements and is usually not noticed. Despite the colostomy, the resting part of the colon keeps making mucus that will come out either through the stoma or through the rectum and anus. This is normal and expected.

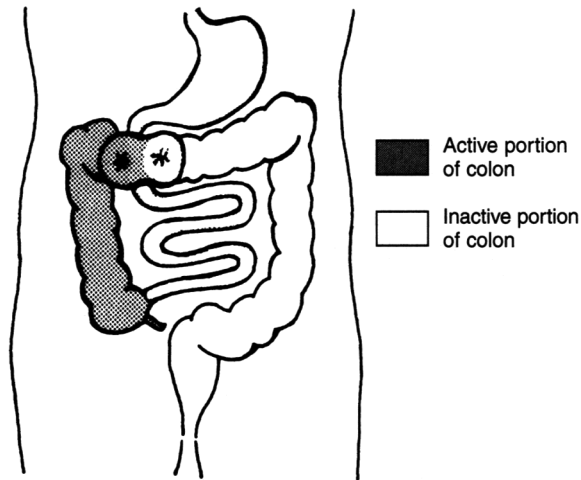


Figure 2
Loop Transverse Colostomy

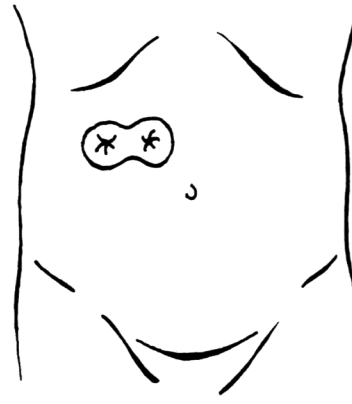


Figure 3
Loop Transverse Colostomy

Double-barrel transverse colostomy (Figures 4 and 5): When creating a double-barrel colostomy, the surgeon divides the bowel completely. Each opening is brought to the surface as a separate stoma. The 2 stomas may or may not be separated by skin. Here, too, one opening puts out stool and the other puts out only mucus (this smaller stoma is called a mucus fistula). Sometimes the end of the inactive part of the bowel is sewn closed and left inside the belly. Then there is only one stoma. The mucus from the resting portion of the bowel comes out through the rectum.

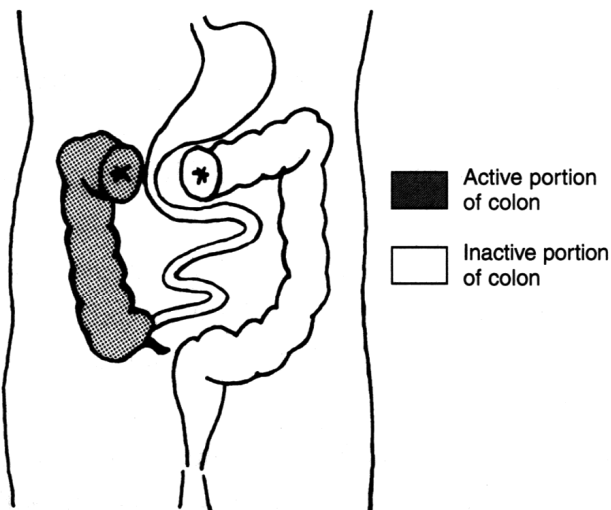


Figure 4
Double-Barrel Transverse Colostomy

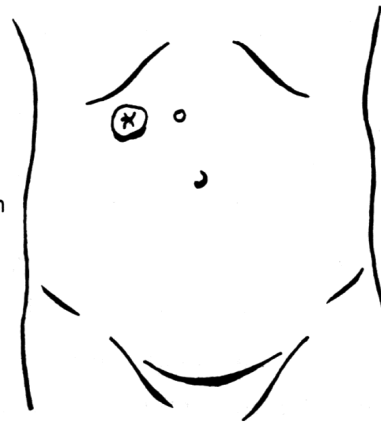


Figure 5
Double-Barrel Transverse Colostomy

The newly formed transverse colostomy

Right after surgery, your colostomy may be covered with bandages or it may have a clear pouch over it. The type of pouch used right after surgery is usually different from those you will use at home. Before you look at your colostomy for the first time, keep in mind that it may be quite swollen after surgery; there may also be bruises and stitches. While a stoma normally is moist and pink or red in color, it may be darker at first. Your stoma will change a lot as it heals. It will get smaller and any discoloration will go away, leaving a moist red or pink stoma. This may take several weeks.

You will soon notice that, but you can usually tell when your colostomy is going to pass stool or gas, you cannot control it. Your colostomy does not have a valve-like sphincter muscle like your anus does. Because of this, you will need to wear a pouch over your colostomy to collect the output. Your ostomy nurse or doctor will help you find a pouching system that is right for you. This is also discussed in more detail later in the section "Choosing a pouching system."

Characteristics of a transverse colostomy

When a colostomy is made in the right half of the colon, only a short portion of colon leading to it is active. The stool that comes out of a transverse colostomy varies from person to person and even from time to time. A few transverse colostomies put out firm stool at infrequent intervals, but most of them move fairly often and put out a soft or loose stool. It is important to know that the stool contains digestive enzymes (chemicals made by the body to break down food). These enzymes are very irritating, so the nearby skin must be protected. (See "Protecting the skin around the stoma" under "Helpful hints" for more information on this.)

Trying to control a transverse colostomy with special diets, medicines, enemas, or irrigations usually does not work and is seldom advised. In most cases, a pouching system is worn over a transverse colostomy at all times. A lightweight, drainable pouch holds the output and protects the skin from contact with the stool. The pouch does not usually bulge, and it's not easy to see under your clothes.

Closing a transverse colostomy

If you are to have your colostomy closed the surgeon may say that he plans to "take it down" or "reverse it" in a few weeks or months, but sometimes no plans are mentioned. Many things must be taken into account when thinking about closing a colostomy. Some of them are:

- The reason you needed the colostomy
- Whether you can handle more surgery
- Your health since the operation
- Other problems that may have come up during or after surgery

It is best to talk to your surgeon about these things before you leave the hospital so that you know what the plans are and when to see the surgeon again. If you are at home now and did not get instructions, call the doctor's office or clinic and find out what the doctor wants you to do. It is your job to stay in touch with the doctor.

Ascending colostomy

The ascending colostomy is placed on the right side of the belly. Only a short portion of colon remains active. This means that the output is liquid and it contains many digestive enzymes. A drainable pouch must be worn at all times, and the skin must be protected from the output. This type of colostomy is rare because an ileostomy is better if the discharge is liquid. (For more information, please contact us for a copy of *Ileostomy: A Guide*.)

Caring for an ascending colostomy is much like caring for a transverse colostomy (as discussed above).

Descending and sigmoid colostomies

Located at in the descending colon, the descending colostomy (Figure 6) is placed on the lower left side of the belly. Most often, the output is firm and can be controlled.

A sigmoid colostomy (Figure 7) is made in the sigmoid colon, and located just a few inches lower than a descending colostomy. Because there is more working colon, it may put out solid stool on a more regular schedule. The sigmoid colostomy is the most common type of colostomy.

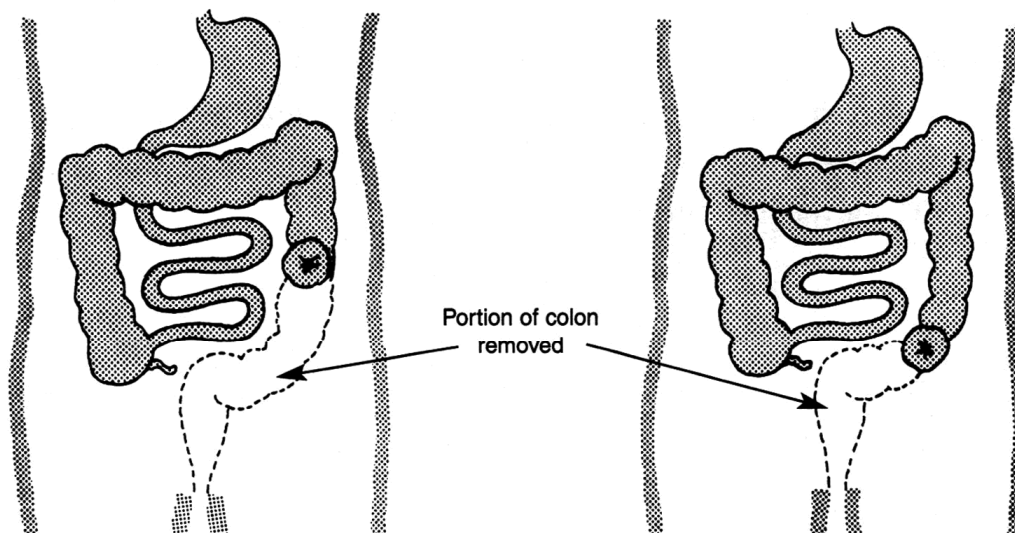


Figure 6
Descending colostomy

Figure 7
Sigmoid colostomy

Both the descending and the sigmoid colostomies can have a double-barrel or single-barrel opening. The single-barrel, or end colostomy, is more common. The stoma of the end colostomy is either sewn flush with the skin or it is turned back on itself (like the turned-down top of a sock).

The stool of a descending or sigmoid colostomy is firmer than the stool of the transverse colostomy. It does not have as much of the irritating digestive enzymes in it. Output from these types of colostomies may happen as a reflex at regular, expected times. The bowel movement will take place after a certain amount of stool has collected in the bowel above the colostomy. Two or 3 days may go between movements. Spilling may happen between movements because there is no muscle to hold the stool back. Many people use a lightweight, disposable pouch to prevent accidents. A reflex to empty the bowel will happen quite naturally in some people. Others may need mild stimulation, such as juice, coffee, a meal, a mild laxative, or irrigation. This is discussed later in the section called "Irrigation for descending and sigmoid colostomies only."

While many descending and sigmoid colostomies can be trained to move regularly, some cannot. Training, with or without stimulation, is likely to happen only in those people who had regular bowel movements before they became ill. If bowel movements were irregular in earlier years, it may be hard, or impossible, to have regular, predictable colostomy function. Spastic colon, irritable bowel, and some types of indigestion are some conditions that cause people with colostomies to continue to have bouts of constipation or loose stool.

Many people think that a person must have a bowel movement every day. In truth, this varies from person to person. Some people have 2 or 3 movements a day, while others have a bowel movement every 2 or 3 days or even less often. It may take some time to figure out what is normal for you.

Colostomy management

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

Think of your colostomy's function as you did your natural bowel movements. You still have the same bowel, just a little less of it. The real change is having the stool come out of an opening made on your belly (abdomen). Learning how to care for your colostomy will help you adjust.

There is no one way to take care of a colostomy. This guide offers you tips and ideas for managing your colostomy. Discuss the 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 a colostomy. 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.

At first, it will be hard to tell what your stools will be like or when they will come out. The doctor and ostomy nurse will work with you to find the best way to contain the stool so you will not be surprised or embarrassed. There are many ways that this can be done. The choice depends on your type of colostomy, your usual bowel function, and your personal preference.

Care of any colostomy is really not very hard to do, but getting to the point where you feel comfortable takes a lot of learning, a lot of practice, the right supplies, and a positive attitude.

Bowel movements with a transverse colostomy

A transverse colostomy will put out stool no matter what you do. Keep in mind these points:

- A pouching system (also called an appliance) that will keep you from soiling your clothing is the right one for you.
- The firmness of your stool is affected by what you eat and drink.
- Gas and odor are part of the digestive process and cannot be prevented. Still, they can be controlled so that you will not feel embarrassed.
- Empty the pouch often during the day to keep it from leaking or bulging under your clothes.
- Change the pouch system before there is a leak. It is best to change it no more than once a day and not less than once every 3 or 4 days.
- The ostomy output can irritate your skin. You can prevent skin problems by having a correctly fitted pouch system and by using special materials for ostomy care.

For more information on care, see the section called "Helpful hints."

Bowel movements with a descending or sigmoid colostomy

You can treat the bowel movement through a colostomy like a normal movement through the anus; just let it happen naturally. But, unlike the anal opening, the colostomy does not have a sphincter muscle that can stop the passage of stool. This means you must wear a pouch to collect anything that might come through, whether it is expected or not. There are many lightweight pouches you can buy that are hard to see under clothes. They stick to the skin around the colostomy and may be worn all the time, or only as needed.

Some people with a descending or sigmoid colostomy find that by eating certain foods at certain times, they can make the bowel move at a time that works best for them. With time and practice, they may feel so certain of this schedule, they will wear a pouch only

when a movement is expected. Some people use only this method to keep bowel movements on a regular schedule, while others use it along with irrigation.

More information on diet and eating is covered later.

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.

You may not need to wear a pouch, but many people with colostomies do. For example, those who have a transverse colostomy, those who do not want to irrigate, and those who have some return between irrigations may wear pouches. (More information on irrigation is coming up.)

A good pouching system should be:

- Secure, with a good leak-proof seal that lasts for up to 3 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

Pouches come in many styles and sizes, but they all do the same job – they collect stool drainage that comes out of the stoma. Some can be opened at the bottom for easy emptying. Others are closed and taken off when they are full. Still others allow the adhesive skin barrier, also called the face plate or flange, to stay on the body while the pouch may be taken off, washed out, and reused.

Figures 8 through 15 show you some types of ostomy supplies. Along with the different kinds of pouches, other supplies that may be needed, such as flanges, clips, and belts are shown. Pouches are made from odor-resistant materials and vary in cost. Pouches are either clear or opaque and come in different lengths.

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.

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.

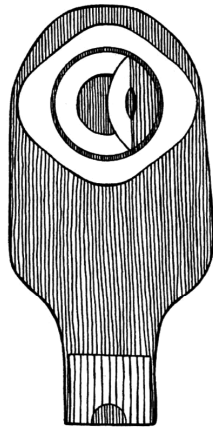


Figure 8
One-Piece Drainable Pouch with Skin Barrier

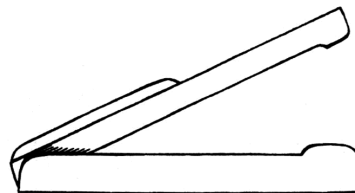


Figure 9
Tail Closure

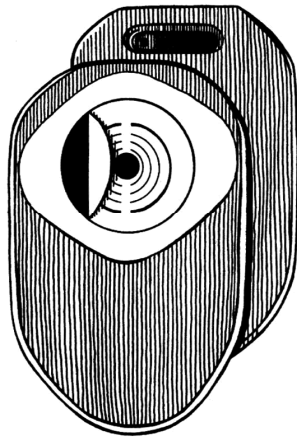


Figure 10
One-Piece Closed-End Pouch with Skin Barrier

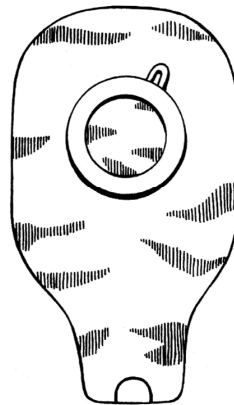


Figure 11
Two-Piece Drainable Pouch

Figure 12
*Flange for Two-Piece Drainable Pouch and for
Two-Piece Closed Pouch*

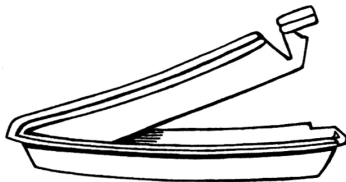
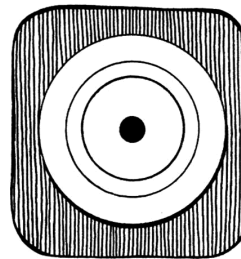


Figure 13
Drainable Pouch Clamp

Figure 14
Ostomy Belt

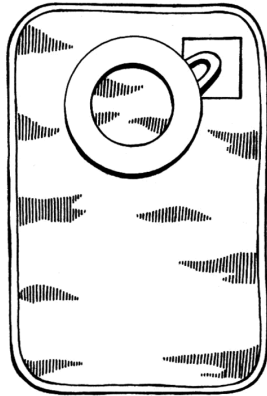
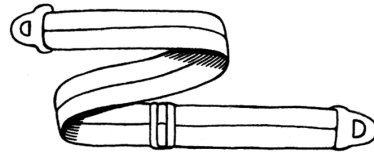


Figure 15
Two-Piece Closed Pouch

Stoma covers

A gauze or tissue can be folded neatly, dabbed with a small amount of water-soluble lubricant, placed over the stoma, and covered with a piece of plastic wrap. Such a dressing may be held on with medical tape, underclothing, or an elastic garment. Plastic, ready-made stoma caps (Figure 16) are also available. Stoma covers may be used for colostomies that put out stool at regular, expected times.

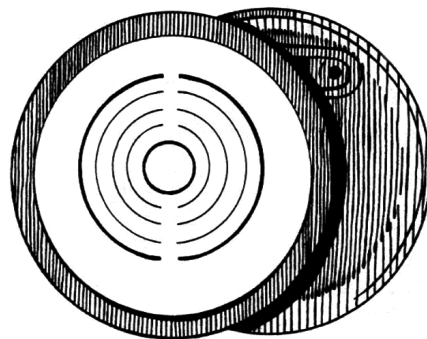


Figure 16
One-Piece Stoma Cap

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.

Sterility

You don't have to use sterile supplies. For instance, facial tissue or cotton balls 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 colostomy 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 colostomy 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 are more likely to break a seal than a thicker discharge.
- Physical activities may affect wearing time. Swimming, very strenuous sports, or anything that makes you sweat may shorten wearing time.

Irrigation (for descending and sigmoid colostomies only)

Irrigating to have regular, controlled bowel movements is up to each person, but you should fully discuss it with your doctor or ostomy nurse before a decision is made. Your doctor or nurse will teach you how to irrigate your colostomy. The procedure may be a little different than what we describe here, depending on the experience of the person teaching you.

Needed equipment (Figures 17 to 20) includes a plastic irrigating container with a long tube and a cone or tip. (The plastic cone-shaped piece at end of the tubing fits snugly against the stoma to run water into the colostomy.) An irrigation sleeve is worn to take

the irrigation output into the toilet. You can use a tail closure clip and a belt for extra irrigation sleeve support, too.

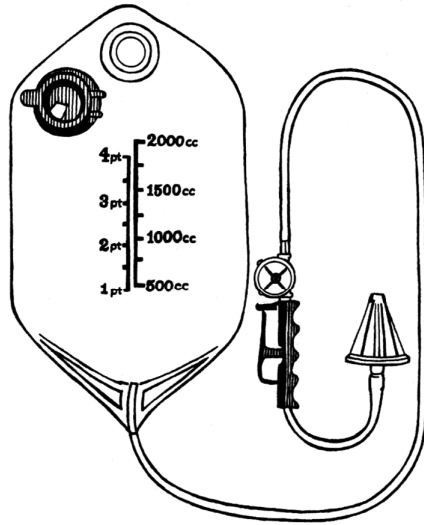


Figure 17
Irrigation System

Figure 18
Irrigation Sleeve

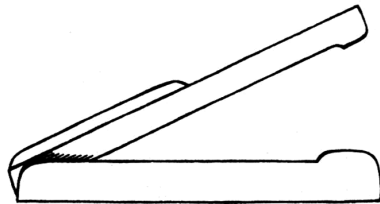
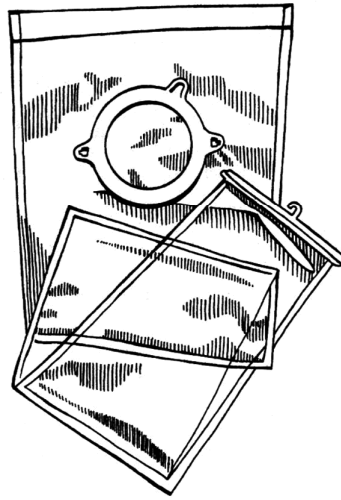
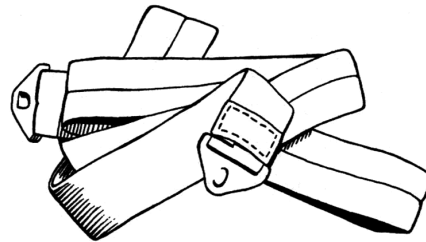


Figure 19
Tail Closure

Figure 20
Adjustable Belt



Basic irrigation tips

- Choose a time in the day when you know you will have the bathroom to yourself.
- Irrigation may work better if it is done after a meal or a hot or warm drink. Also, consider irrigating at about the same time of day you usually moved your bowels before you had the colostomy.
- Clamp the tubing and put 1000 cc (about 1 quart) of lukewarm (not hot) water in your irrigating container. You may need a little less. NEVER connect the tube directly to the faucet.
- Hang the container at a height that makes the bottom of it level with your shoulder when you are seated.
- Sit on the toilet or on a chair next to it. Sit up straight.
- Seal the plastic irrigation sleeve onto your faceplate and place the bottom end of the sleeve in the toilet bowl.
- Wet or lubricate the end of the cone with water-soluble lubricant.
- To remove air bubbles from the tubing, open the clamp on the tubing and let a small amount of water run into the sleeve. Re-clamp the tubing and put the cone into the stoma as far as it will go, but not beyond its widest point. Slowly open the clamp on the tubing and allow the water to gently flow into your bowel.
- The water must go in slowly. You may shut the clamp or squeeze the tube to slow or stop the water flow. It takes about 5 minutes to drip in 1000 cc (about 1 quart) of water. Hold the cone in place for 10 seconds after all the water has gone in.
 - The amount of water you need depends on your own body. You may need less, but do not use more than 1000 cc (1 quart). The purpose of irrigating is to remove stool, not to be strict about the amount of water used.
 - You should not have cramps or nausea while the water flows in. These are signs that the water is running in too fast, you are using too much water, or the water is too cold. After the water has been put in, a bowel movement-type cramp may happen as the stool comes out.
- After the water has run in, remove the cone. Output or "returns" will come in spurts over the next 45 minutes or so. As soon as most of it has come out, you may clip the bottom of the irrigating sleeve to the top with a tail closure clip. This allows you to move around, bathe, or do anything you wish to pass the time.
- Over time you will know when all the water and stool have all come out. A squirt of gas may be a sign that the process is done, or the stoma may look quiet or inactive.
- If the complete irrigation process always takes much more than an hour, talk to your doctor or ostomy nurse.

Whether you will irrigate your colostomy and how you will do it depends on many factors, such as:

- The amount of active bowel you have left.
- Your lifelong bowel habits.
- Your skill and comfort level with irrigation.
- Your personal feelings about the colostomy.
- Your talks with your doctor or your ostomy nurse.

Try to find a method, or combination of methods, that most closely matches your body's normal bowel habit or pattern. At first, you may need to try different things under a doctor or nurse's guidance. Just remember, it will take time to set up a new system. Having regular daily habits will help. If you find certain foods or irrigation procedures let you regulate your bowel movements, keep doing those things at the same time every day. Regular habits will promote regular bowel functions, but occasional changes in routine will not harm you.

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 them 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, your 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. A colostomy that puts out firm stool usually causes few, if any skin problems. If the stool is loose, as is often the case with transverse colostomies, it can make the nearby skin tender and sore. As you get stronger and get better at handling your equipment, skin irritation will become less of a problem. Here are some ways to 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 from the skin.
- Clean the skin around the stoma with water. Use a mild soap and rinse well. Pat dry before putting on the cover or pouch. You can clean your stoma in the shower or tub.
- 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 will react 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.

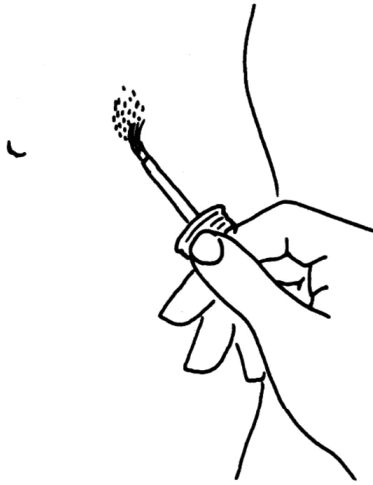


Figure 21
Patch Testing without Adhesive Tape

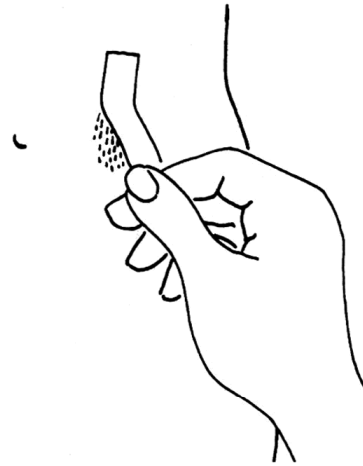


Figure 22
Patch Testing with Adhesive Tape



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. Extreme care should always be taken when doing this. A mild soap or shaving cream may be used. Rinse well.

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. Some people find it best to eat smaller amounts of food 4 to 5 times a day.

You may be worried about how others will respond to the 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

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. Odors may be worse with transverse colostomies. 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 to 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.

Care of the posterior wound

In some patients the rectum and anus are removed. This will leave a surgical wound in that area called a posterior wound. Care of the posterior wound is based on good hygiene and the use of dressings or pads to collect and contain any drainage. Infections or drainage that lasts may be treated by antibiotics, irrigations, or sitz baths (sitting in a tub or pan of warm water). Your doctor or nurse should tell you how to care for this wound and what problems need to be reported right away.

Colostomy problems

Hernia

The most common problem after colostomy surgery (other than skin irritation) is herniation around the colostomy. A hernia is the bulging of a loop of organ or tissue through the belly (abdominal) muscles (called an abdominal hernia). This bulging can happen around a stoma.

Signs of a hernia may be a bulge in the skin around the stoma, problems irrigating, partial obstruction (blockage, discussed further on), and sometimes prolapse of the colon (the bowel pushes itself out through the stoma). These changes tend to happen slowly over time. But let your doctor know about any changes you see or feel. There are things you can do to better support the area around the stoma and keep the hernia from getting worse. If the hernia is bad, you may need to have it repaired with surgery.

Many of these problems can be avoided if the stoma site is marked before surgery at a place that lies within the rectus abdominus muscle (the "6-pack muscle") near the middle of the abdomen. The ostomy nurse can be of great help with this.

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.

Constipation, loose stools, and diarrhea

In a normal state of health, the form of stool that the bowel puts out is related to what is put in. Timing and frequency of meals, emotional states, medicines, and sickness also play a role.

Constipation is often the result of an unbalanced diet or not drinking enough liquids. Certain medicines may also be the cause. Fear may be at the root of it, or problems with the irrigation process. These are matters to talk over with your ostomy nurse or doctor. If you have had constipation problems in the past, before surgery, remember how you solved them and try the same things now. But **DO NOT** use laxatives without talking to your doctor first.

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. Diarrhea is different from loose bowel movements. Loose stools are common in transverse and ascending colostomies. This is because of the shortened length of the colon and is not a sign of sickness or disease. Certain foods or drinks may cause diarrhea. If this happens, and you should try to figure out what these foods are and avoid them.

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.

Blockage (obstruction)

If you have cramps, vomiting and/or nausea, belly swelling, stoma swelling, little to no output, or gas from your stoma 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 colostomy.

- Drink enough fluids. Talk to your doctor or nurse about how much is enough for you.
- 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).

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 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.

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 or vomiting
- Bad or unusual odor lasting more than a week (This may be a sign of infection.)
- Unusual change in your stoma size or color
- Blockage at the stoma (obstruction) and/or the inner part of the stoma coming out (prolapse)
- 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.)
- Injury to the stoma
- A cut in the stoma
- Continuous bleeding where the stoma meets the skin
- Bad skin irritation or deep ulcers (sores)
- Watery output lasting more than 5 or 6 hours
- Anything unusual going on with your ostomy

A stoma can become narrowed with time, usually over many years. This narrowing or tightness of the stoma is called stenosis and it may cause obstruction (blockage). Stenosis may also be caused by injury from irrigation or a short-term poor blood supply right after surgery. It can usually be corrected with a minor operation if it becomes a problem.

Rupture or perforation of the colon is also possible. This is when the colon wall breaks and stool leaks into the abdomen. Now that we use irrigation cones, rupture or perforation of the colon is rarely seen. They can still happen, though, if the irrigation cone is not carefully put into the stoma.

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 to a hospital where colostomy 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 colostomies. 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 a colostomy

Learning to live with a colostomy 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 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 clothing. 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 colostomies 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 part of your colon removed.

If you have children, answer their questions simply and truthfully. A simple explanation is often enough for them. Once you have explained what a colostomy 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 colostomy 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 colostomy does not affect 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 a colostomy and its effect on sex, children, and family acceptance will help correct any wrong ideas your partner may have. Going to an ostomy support group meeting together may also be helpful. Talking to other couples in which one partner has a colostomy 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. Colostomy 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

Everything we eat and drink serves as building blocks for the body. To stay in good health, the body needs carbohydrates, proteins, fats, minerals, and vitamins. Water is also a key part of good health. At least 8 to 10 8-ounce glasses of water a day is usually recommended. Having a balanced diet helps maintain good nutrition and keep the bowel's activity normal.

There is no such thing as a colostomy diet. After healing is complete and the ostomy is working normally, most people with colostomies can return to foods they normally eat. Chew well and see how each food affects your colostomy. Those foods that have disagreed with you most of your life may still do so. If you are on 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.

If you wear an appliance all the time, you will suffer no embarrassment if something you have eaten produces an unexpected discharge. You will soon learn which foods produce gas or odor, which cause diarrhea, and which lead to constipation. As you learn these things you can regulate the bowel's behavior to a large extent.

Note: You cannot prevent the intestine from moving by not eating. An empty intestine produces gas and mucus. No matter what your plans for the day might be, eat regularly, several times a day. Your colostomy will work better for it.

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 colostomy. Being open about it will help educate others. Keeping it a complete secret may cause practical problems.

People with colostomies (sometimes called colostomates) 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, there are colostomates who do heavy lifting, such 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 your employer have doubts about what you will be able to do.

Sometimes people with a colostomy find that their employer thinks the colostomy will keep them from doing their job. This also happens to some colostomates who are applying for new jobs. 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 colostomy, 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 may 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 harm 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 special someone 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 colostomy surgery. But before you plan to get pregnant you should talk about it with your doctor. The colostomy 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 help prevent these problems. Weight lifting could cause a hernia at the stoma. Check with your doctor about such sports. Indeed, people with colostomies are distance runners, weight lifters, skiers, swimmers, and take part in most other types of athletics.

Bathing and swimming

Water will not hurt your colostomy. 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. For sanitary reasons, you should use a stick-on pouch when you go swimming in fresh water or in the ocean. 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 with 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 colostomies 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
- 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 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. Don't eat 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. Your doctor can give you a prescription for medicine 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 colostomies

If your child has a colostomy, 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 colostomy 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 a colostomy. This will prepare you to help your child adjust to the colostomy. 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 be feeling guilty or responsible for your child's illness and surgery. These are normal feelings. 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 a colostomy, and in later years, marriage and family. These are normal concerns of 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 colostomy 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 colostomy, 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 a colostomy. 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 colostomy 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 colostomy may make the stresses of adolescence worse. Your teenager may feel unattractive, rejected, and different because of the colostomy.

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 colostomy care

Take an interest in your child's colostomy 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.

Be prepared for trial and error in caring for, or helping to care for, your child's colostomy. 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 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 to best 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 tell 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 colostomy 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 a colostomy will not stop your son or daughter from taking part in life's everyday activities. Parents find that a healthy child with a colostomy 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 for more information.

Getting help, information, and support

There are many ways to better understand your life with a colostomy. 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

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

International Ostomy Association (IOA)

Web site: 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

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

Ostomy 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 other 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.

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

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For additional assistance please contact your American Cancer Society
1 · 800 · ACS-2345 or www.cancer.org