

## Living with an Ostomy

It may be difficult to deal with the prospect of having an ostomy, but learning how this new and essential body opening is created and cared for can help you ask the right questions and progress toward a better quality of life. An ostomy has allowed many people to survive colorectal cancer and resume their lives, as the following woman describes:

*I'm an RN who had ulcerative colitis for years and knew my risk for colon cancer increased with each year. I swore I would never have a colostomy. I even had it written into my living will at one point. But when it came to the point of having it done or dying with a bowel obstruction, I chose the baggie.*

*And it really isn't all that bad. It hasn't stopped me from doing anything I really want to do. I swim, hike, go to social functions, whatever. No one outside my immediate family and a few close friends even knows it's there.*

### What is an ostomy?

Ostomy is the surgical creation of an opening through the abdominal wall to allow feces or urine to exit. During colorectal cancer surgery, part or all of the colon or rectum is removed in order to remove the cancer. If there is not enough intestine or rectum left to reconnect the remaining tissue, or if the anus is removed, an ostomy will be created in the abdominal wall so that waste can exit. The surgeon will make an opening and attach the end of the intestine to that opening. A person who has had an ostomy is called an ostomist or ostomate.

Technology has made caring for an ostomy much easier and more comfortable, and improvements continue. Here are a few insights from one ostomate:

*As far as how an ostomy under clothes looks to others, it looks—unless you know exactly what you're looking for—maybe just like somebody's shirt is bunched up wrong on one side. If someone is staring at your pants that much to start with, they've got other issues to deal with, so I wouldn't worry about it anyway!*

*When I went to a vacation spa, I questioned the*

*nurse there about restrictions. She suggested the only thing I shouldn't do was the thing where they use a hose to squirt you from a distance, a water massage. She didn't think it would be a good idea to pound the stoma with water. She also suggested I skip the seaweed wrap, which might dehydrate me—dehydration can be a problem for ileostomates. I did it anyway, but they kept the seaweed away from the stoma. I did the algae whirlpool baths, too. I just left my appliance on, just like I do when I'm swimming.*

### Extent of surgery

Most ostomies involve surgical creation of an open stoma. Waste passes out of the stoma and is collected in a pouch. However, in some cases a continent ostomy can be performed. For colorectal cancer, ostomies are further divided into colostomies and ileostomies, depending on how much of the colon must be removed.

During a partial colectomy, only part of the colon is removed and the remaining colon is reattached to the ostomy. Because part of the colon remains to remove moisture from waste after it passes through the small intestine, the waste will be more or less solid.

Removal of the entire colon (total colectomy) necessitates an ileostomy. The ileum, the portion of the small intestine nearest the colon, is what remains to create the ostomy.

Because the colon is not present to remove water from feces, the waste that passes out of an ileostomy will be more liquid.

### Types of ostomies:

- *Temporary ostomy.* When surgery for colorectal cancer does not require a colostomy or ileostomy, but the colon and rectum need to heal before they can safely process waste, a temporary ostomy is used. If you receive a temporary ostomy, you might have two closely positioned stomas instead of just one: one from the top portion of the intestine, which will remain active in the digestion of food and from which

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waste will exit. A second, for the temporarily inactive lower portion of intestine, is called the mucus fistula, from which only mucus will emerge. (A fistula is an abnormal tubelike tissue that connects two organs, or one organ and skin, usually developing as the result of disease. In this instance, it is manmade.)

- *J-pouch (ileoanal anastomosis with reservoir)*. In this surgical procedure, the small intestine is folded back onto itself to form a J shape, then stitched together to create a wider reserve. The sphincter muscle and the anus are left intact. The end of the constructed pouch is connected to the anus.
- *Continent ileostomy*. Certain patients who have had most or all colon tissue removed may be candidates for a type of ostomy called a continent ileostomy. This variation on ostomy surgery involves creation of an abdominal stoma implanted with a valve that remains closed until the patient opens it to drain the intestine.

### Appearance and location

The ostomy's exit through the skin of the abdomen is called the stoma, a Greek word meaning mouth. The most visible portion of the stoma is actually a portion of the inner lining of the intestine. When healthy, the stoma is pliant, painless, red, and moist. It has these characteristics because centuries of surgery and research—colostomies have been performed since ancient Egyptian times—have shown that the most workable, infection-free ostomies are made by pulling intestinal tissue through the abdominal opening and rolling it outward to form a ridge.

Although directly after surgery the stoma may appear large and swollen, in time the healthy stoma will shrink, protruding a bit past the skin of the abdomen and developing a puckered appearance. Ileostomies protrude farther than colostomies because ileostomy must accommodate more liquid waste than colostomy, as the removal of the entire colon changes the ability of the body to remove water from the stool. This liquid waste is more likely to “travel” and irritate nearby skin than solid waste; the protruding stoma is intended to be a larger barrier between waste and skin.

Where the ostomy is positioned on the abdomen is determined by several factors:

- The location of the tumor
- The extent of disease
- The kind of surgery performed—that is, how much of the colon is removed
- Certain physical characteristics of the patient, including weight, posture, and skin folding
- The typical stoma location for an ileostomy is a little below and to the right of the navel. For a colostomy, there is more variety in location, but often it is on the lower left side of the abdomen.

If time permits before surgery, you should discuss with your surgeon any preferences or concerns you might have regarding the proposed position of the stoma, such as your desire to remain active in a certain sport and the subsequent possibility that the position of the stoma might interfere with this activity. Most surgeons will do their best to accommodate their patients' concerns, but the overriding consideration must be the positioning of the stoma to facilitate proper functioning of the intestine after removal of all cancer.

### Caring for an ostomy

While you are still in the hospital, the nurses, and especially a nurse trained as an enterostomal therapy (ET) nurse, will help you learn to care for your stoma, the skin around it, and the health of your altered digestive tract. If your hospital does not have an ET nurse, contact your surgeon or medical oncologist for a referral or contact one of the ostomy associations, such as the United Ostomy Associates, and ask a volunteer to visit you to discuss up-to-date tips and techniques. Often the regular nursing staff haven't time to keep abreast of new advances in ostomy appliances and care. You'll save time, money, and peace of mind by learning the best ideas as soon as possible.

Issues with which these professionals can help you include:

- How to clean and care for the skin around the stoma.

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The stoma itself is relatively tough tissue compared to the skin nearest it, which must be protected from intestinal enzymes, bacteria, and potentially irritating ostomy products.

- How to choose, empty, and clean appliances that attach to the stoma to collect waste.
- How to select clothing that will not injure the stoma or interfere with its emptying.
- How to eat to avoid constipation and diarrhea and how to choose foods to cause bowels to move at your convenience.
- How to irrigate your bowel through the stoma, if you have a sigmoid colostomy and choose to irrigate instead of using a collection pouch. Irrigation, which is similar to an enema, is a means to remove waste from the remaining colon on a schedule that's convenient for you.

### Ostomy appliances and supplies

An ostomy appliance consists of two parts: a collection pouch and a positioning plate that surrounds but does not touch or enter the stoma. If you've had an ostomy for years, you may remember how few products used to be available in the past, and you may note happily how many are available now. The era of the leaky rubber pouch that smelled odd even when clean and didn't accommodate gas episodes is over. Today's options include:

- Disposable pouches.
- Reusable pouches that empty from the bottom, or from the top, while still attached. These are the most practical choice for ostomies that produce liquid waste.
- Pouches with filters to control odor.
- Pouches that hang sideways instead of down for use when jogging or playing tennis. This might be a more suitable option for sigmoid colostomates who will manage solid waste rather than other colostomates and ileostomates.
- Small patches similar to Band-Aids to cover and protect the stoma during swimming. These are suitable only for sigmoid colostomies or those with continent ileostomies. An ileostomate with a traditional stoma and many colostomates with liquid waste would have the patch pushed away from the body by the constant flow of diarrhea from the small intestine.
- Ornamental stoma covers for romantic interludes.
- Pouches that glue in place.
- Pouches that are held in place with a belt for those who are allergic to some adhesives.
- Hypoallergenic gluing and skin-sealing products made from vegetable matter.
- Neoprene pouch belts for use during sports activities.
- Irrigation tubes (catheters) for those who prefer to empty the bowel by irrigation (enema) instead of collecting waste in a pouch. This applies only to sigmoid colostomates; many other colostomies as well as ileostomies produce continuous liquid waste.
- Catheters for opening and draining the continent ileostomy.
- Skin barrier creams to protect the skin nearest the stoma, which must be shielded from bacteria and digestive enzymes (to which the stoma itself is impervious).
- Appliances geared either to the continual liquid waste of ileostomy or the more solid and periodic waste of sigmoid colostomy.
- One-piece appliances, or two-piece appliances with a stoma-surrounding attachment that stays glued in place but a bag that's detachable.
- Appliances in different sizes to accommodate individual stomas and more copious flow overnight or during travel.

Many of these products are preferred by some people but disliked by others. Some people say, for instance, that certain pouches with built-in filters that are intended to allow gas to escape without odor don't work as advertised. The best way to find what works for you is

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to contact a local branch of one of the ostomy associations and talk to a volunteer (many of whom have ostomies), to join a support group for colon cancer survivors or ostomates, and to try various products. Products can be purchased by mail until you feel comfortable talking about your needs with your pharmacist.

### Cleaning the stoma and skin

The stoma will clean itself by producing and shedding intestinal mucus, but the skin near the stoma, called peristomal skin, must be kept gently and scrupulously clean. There are several reasons for this. Its juxtaposition to both feces and digestive enzymes makes it very likely to become infected, as digestive enzymes are capable of breaking down skin, which is then very likely to be infected by fecal bacteria. Fecal bacteria are common, abundant, and necessary for digestion but not at all healthy for skin. The peristomal skin is more likely to be scratched or scraped owing to the amount of activity it sees in its new role: pouch attachment, cleaning, removing adhesives, and so on. These scratches and scrapes make it more likely to become infected or to develop allergic reactions.

Most people find it easiest to clean the stoma and its surrounding skin when the digestive tract is least active. For many, this is in the morning before breakfast.

The stoma can be rinsed with water and patted dry, if you wish, although it is not necessary to clean it: as mucus-shedding intestinal tissue, it will clean itself. Exposing the stoma to the spray from a shower will not hurt it. A stoma should never be scrubbed.

Peristomal skin should be cleaned gently with very mild soap and patted dry—never rubbed. If you use a skin barrier or a skin sealant, cleaning is done every few days to once a week, dictated by your skin's tolerance for the barrier substance. If a bit of skin sealant or barrier remains after washing and rinsing, leave it until the next cleaning, provided the skin beneath looks healthy. Rubbing away residual barrier or sealant is more likely to harm your skin than leaving the residue in place.

If your stoma was placed amidst body hair, trim it regularly so that removing the pouch or adhesive will not

pull hair, causing pain and opening the skin to infection.

Peristomal skin should look just like the skin anywhere else on your abdomen: not red, wrinkled, grey, or chapped. Changes in peristomal skin should be discussed with an ET nurse and reported to your oncologist.

### Skin barriers and seals

A skin barrier or seal is a liquid, powder, paste, or membrane that rests between your skin and the stoma attachment in order to protect the skin from bacteria, moisture, and the irritants in adhesives. These are excellent products that truly save the skin; many varieties are available and should be used no matter what model appliance you prefer. Each comes with its own instructions and precautions for use.

As one ostomate notes:

*People normally gain weight after surgery, especially if they've had ulcerative colitis, because they feel better. They warn you not to gain too much weight because then the stoma can pull inside, it doesn't protrude like it's supposed to, and it makes life interesting. But they have appliances that will work around that. The barrier spray goes on to protect the skin from any irritation.*

*I had trouble with yeast infections under the wafer. I got little blisters and it was irritated all the time. I had to change the wafer every couple of days because it got itchy, and I had to spray cortisone on it. Basically, once I got the rhythm down for the combination of products I use, I haven't had any trouble like that for a year or longer. How much you sweat and what kind of food you eat can also come into how well the appliance stays on.*

Even if you've never had a skin allergy before, you should assume that these products might cause an allergic reaction because:

- Humans develop more allergies as they age.

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- Skin that is repeatedly injured is more likely to develop sensitivity.
- Chemotherapy and radiation therapy are known to cause skin to become more sensitive to a variety of substances.
- When trying a new product, it's wise always to do a patch test first on a part of the abdomen well away from the stoma. The instructions packaged with the barrier or seal will explain how to do a patch test.

### Emptying the pouch

The pouch should be changed when it's about one-third full. Accumulating excessive material increases the pouch's weight and may cause it to pull away from the skin. Leakage, odor, and infection of nearby skin may result.

One pouch user says:

*Many pouches are what is termed "drainable," or open ended. The "open" end hangs down. There is a plastic clip that folds the pouch end back and keeps it closed. The seal created by the clip is water/liquid- and gas-proof. I couldn't change the appliance every time it starts to fill. It would cost a fortune and take a lot of time. Drainable pouches come in one- and two-piece models. Most appliances are designed to be left on for up to two weeks.*

At times, the pouch should be emptied before it's one-third full:

- If you're traveling and won't be able to empty it easily en route, it should be emptied first. Some ostomates report that air travel in particular may cause the pouch to expand as the cabin is unevenly pressurized during takeoff and landing.
- If you're having a spell of diarrhea.
- If you've prepped for a colonoscopy.
- If you're about to engage in sports or any physical activity.

Gently remove all pouch models, but especially the

one-piece models, to avoid damaging the skin beneath the attachment plate.

### Discarding waste

If you are using disposable pouches, you can empty the pouch into the toilet first, then wrap it and put it in the trash, or you can dispose of it, well wrapped, while it's still full. What you choose to do depends on how well you're feeling, what trash collection facilities are available, and the sensibilities of those you live with.

If you have a reusable pouch, you can empty it while sitting on or standing in front of the toilet. Put some toilet tissue into the toilet bowl first to act as a cushion for the material you're discarding—this helps prevent splashback. For emptying, some reusable pouches open from the top, some from the bottom. All come supplied with directions for emptying.

A reusable pouch must be carefully cleaned and deodorized. Fortunately, this is easy today, as many very good products are available for these purposes. A few points to remember are to avoid hot water, as this will cause the pouch material to expand and hold odors, and to dry the pouch thoroughly. Empty the pouch into the toilet (you might need to squeeze the outside of the pouch to get all material out); give it a good rinse; soak it for a spell; then scrub the inside gently with a bottle brush. Add a few drops of mineral oil to the bottom of the bottom-opening type to make the next emptying easier. It might be useful to purchase three reusable pouches at once: one for wearing, one for washing, and one for emergencies.

If you share a bathroom with others, take an extra minute to clean splashes and stow away supplies and trash.

### Attaching or reattaching the pouch

How the pouch is attached or reattached depends on which model you're using. Most people find it easiest to reattach any pouch while seated.

For either the two-piece or one-piece pouch, you may need to adjust the stoma opening in the skin plate to match the size and shape of your stoma—they differ

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among people and may change as age and weight change. Some appliances come with a template that you can match to your stoma to choose the correct size opening. The skin plate then can be cut carefully to match your needs.

### Two-piece pouch

If you're using a two-piece pouch, you can simply continue to reattach fresh pouches to the skin plate for several days or a week until it's time to change the skin attachment.

Your own body will dictate the schedule for changing the skin plate, based on your skin's sensitivity. In general, the skin should be left undisturbed by plate changes for as long as possible in order to avoid irritation by too-frequent changes.

### One-piece pouch or pouch plate

The skin plate of a one-part pouch that's glued in place must be changed whenever the pouch is changed. A skin barrier is a must in this instance; otherwise, skin layers are stripped away whenever the adhesive is removed, leaving exposed newer, more tender skin that's increasingly likely to become irritated or infected.

Most people find that placing the bottom of the skin plate under the stoma and "rolling" the plate upward provides a better fit around the stoma, because visibility is better using this method.

### Odor

The improved pouches available today hardly ever emit odors. When odors exist, they are identical to the odor of gas and feces of those who have an intact colon.

There are steps you can take to be very certain that odors will not become a problem:

- Use deodorant tablets or liquids in the bottom of the pouch, as recommended by the manufacturer.
- Clean and dry reusable pouches carefully.
- Pretest pouches that contain charcoal filters to be sure they work as advertised.

- Ask a sensitive, helpful, honest person if he or she notices any odors.
- Eat yogurt, parsley, and other foods known to ameliorate odors in the gastrointestinal tract.
- Avoid foods such as cabbage that increase gas if you'll be with people who object to tummy rumbles and possibly an aroma.
- Ensure that the skin attachment fits well and is firmly attached. Most people don't have the ideal flat tummy that allows no gas to escape; firm attachment can remedy this.
- If your pouch has a "burp" valve, engage it in the bathroom or use a room deodorizer.

This pouch user offers some advice:

*I've never had a problem with gas in my bag when on an airplane, as some ostomates report. It depends more on what you eat first: you'll only have gas in your bag if you've eaten something that causes gas to form... and you can take care of releasing it from the bag in the bathroom.*

### Noises

Passage of waste material and gas through the stoma can create wheezes, sighs, rumbles, or gas-like noises. Do try to be gentle with yourself when assessing these: are they really any worse than the stomach noises your body made when you had an intact colon?

But suppose one of the "healthy unaware" notices and is rude enough to comment? You might explain that it's just your intestine, that your digestive tract has been noisy all your life, which is a true statement for many of us. As Miss Manners says, those who ask nosy questions deserve to be lied to.

If your stoma regularly makes noise as gas passes, you may be able to anticipate it. If the setting is less than ideal for such noise, you can suppress it temporarily by subtly moving your forearm over the stoma and holding it there.

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### Other sensations

You will undoubtedly have other observations or will note other sensations:

- You may see the pouch expand as material, especially gas, passes into it. It's unlikely anyone else will notice this unless you point it out to them.
- You may feel warmth against your skin as waste material collects in the pouch. At first, you may think this is a leak.
- Your remaining gastrointestinal tract will continue to behave as before, with sensations of movement or mild gas pains. Any pronounced pain should be reported at once to your oncologist, even if it's transient.

### Resuming activities

Everything you enjoyed doing before surgery can continue to be done after ostomy. Sunbathing, swimming, dancing, sexual activity—all of these are still possible; all have appliances and techniques developed to allow the gastrointestinal tract to go about its healthy business while you have fun.

Here's what one ostomate takes along when away from the house:

*I carry an emergency kit with me, which includes a towel, a fresh bag, a new wafer, scissors, remover pads, skin prep pads, and a roll of paper towels. I am very open about my "emergency kit" and take it anytime I'm going anywhere that is too distant from my house to get back quickly. No need to worry about odor. The modern appliances are tighter than crazy glue, and no odor escapes unless the wafer is broken.*

For activities that require lots of skin to be bared, a sigmoid colostomate might consider a stoma plug and a patch that can be used. For ileostomates who have a continent ileostomy, this might also be an option; for other ileostomates and for colostomates with liquid waste, however, the constant flow of diarrhea from the small intestine would push the patch away from the body. For strenuous physical activities, pouches with special capacity and belts that wick away sweat have been developed.

For the best tips and news of advances in ostomy care, join a local support group. In addition to learning of new products, you'll likely find it an immense relief being able to share feelings with others who know exactly what you're going through.

This fact sheet was adapted from *Colon and Rectal Cancer: A Comprehensive Guide for Patients and Families*, by Lorraine Johnston, © 2000 by Patient-Centered Guides. For more information, call **(800) 998-9938** or see [www.patientcenters.com](http://www.patientcenters.com).