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Ileostomy Guide

Ileostomy surgery is done for many different diseases and problems. Some conditions that can lead to ileostomy surgery include ulcerative colitis, Crohn's disease, familial polyposis, and cancer. Sometimes an ileostomy is only needed for a short time (temporary), or it may be needed for the rest of a person's life (permanent).

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

This guide will help you better understand ileostomy – what it is, why it's needed, how it affects the [normal digestive system](#)¹, and what changes it brings to a person's life.

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- [Types of Ileostomies and Pouching Systems](#)
- [Caring for an Ileostomy](#)

What Is an Ileostomy?

An ileostomy is an opening in the belly (abdominal wall) that's made during surgery. It's usually needed because a problem is causing the ileum to not work properly, or a disease is affecting that part of the colon and it needs to be removed. The end of the ileum (the lowest part of the small intestine) is brought through this opening to form a

stoma, usually on the lower right side of the abdomen. An ileostomy may only be needed for a short time (temporary), maybe for 3 to 6 months, because that part of the colon needs time to rest and heal from a problem or disease. But sometimes a disease, such as cancer, is more serious and an ileostomy may be needed for the rest of a person's life (permanent).

A Wound Ostomy Continence nurse (WOCN or WOC nurse) will probably work with the surgeon to figure out the best location and way to care for your stoma. (A WOC nurse is a specially trained registered nurse who takes care of and teaches ostomy patients. This nurse may also be called an *ostomy nurse*.)

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

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

As part of this surgery, the colon (the main part of large intestine) and rectum (the lowest part of large intestine where formed stool is held until it's passed out of the body through the anus) are often removed (this is called a *colectomy*). This means that colon and rectum no longer function as they used to. Sometimes, only part of the colon and rectum are removed.

What does an ileostomy do?

After the colon and rectum are removed or bypassed, waste no longer comes out of the body through the rectum and anus. Digestive contents now leave the body through the stoma. The drainage is collected in a pouch that sticks to the skin around the stoma. The pouch is fitted to you personally. It's worn at all times and can be emptied as needed.

Ileostomy output will be liquid to pasty, depending on what you eat, your medicines, and other factors. Because the output is constant, you'll need to empty the pouch 5 to 8 times a day.

References

In its original form this document was written by the United Ostomy Association of America (1962-2019). It has since been modified and updated by the American Cancer Society using the following sources.

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Types of Ileostomies and Pouching Systems

An ileostomy can be short-term (temporary) or life-long (permanent). The different types of ileostomies are described here.

Temporary ileostomies

Certain bowel problems may be treated by giving part of the bowel a rest or with surgery to remove the damaged part. The bowel must be kept empty so it can heal. To keep stool from getting to the bowel, a short-term (temporary) ileostomy is created. Healing usually takes a few weeks or months, but may take years. In time, the ileostomy will be surgically reversed (removed) and the bowel will work much like it did before. A

temporary ileostomy can also be done as the first stage in forming an ileo-anal reservoir (or J-pouch).

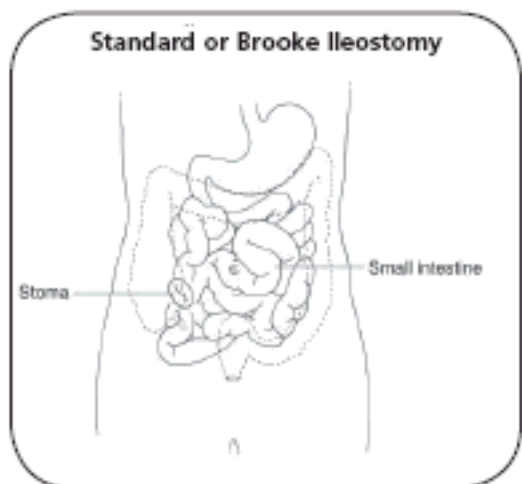
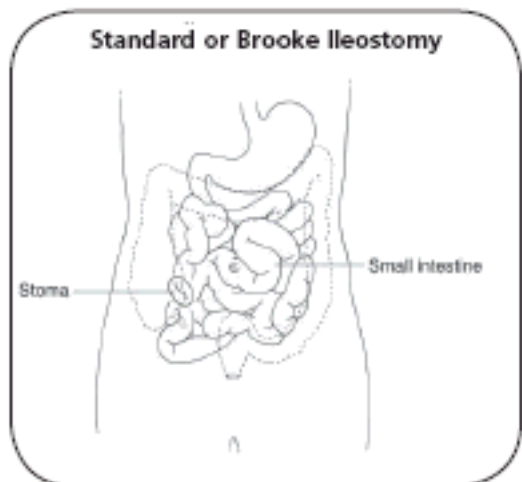
Permanent ileostomies

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

There are 3 major types of ileostomies. You and your surgeon will talk about your options and together decide on the best surgery for you. Sometimes an ostomy nurse will also help you learn more so you are making the best decision. Some of the things to think about when planning an ileostomy are the disease process, your age, your general health, and your preference.

Standard or Brooke ileostomy

<p>Reasons for the surgery:</p> <ul style="list-style-type: none"> Ulcerative colitis Crohn's disease Familial polyposis Cancer-related problems 	<p>Output:</p> <p>Liquid or paste-like constant drainage that contains digestive enzymes</p>	<p>Management:</p> <p>Skin protection is needed; use an open pouch that can be emptied</p>
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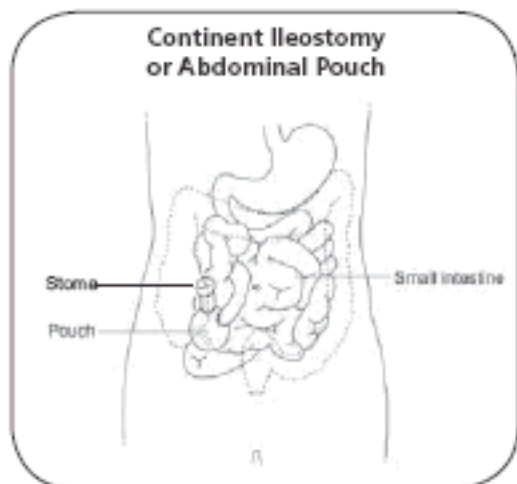
The standard or Brooke ileostomy surgery is the most common type. The end of the ileum is pulled through the abdominal wall and is turned back and sutured to the skin, leaving the smooth, rounded, inside-out ileum as the stoma.

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

Continent ileostomy (abdominal pouch)

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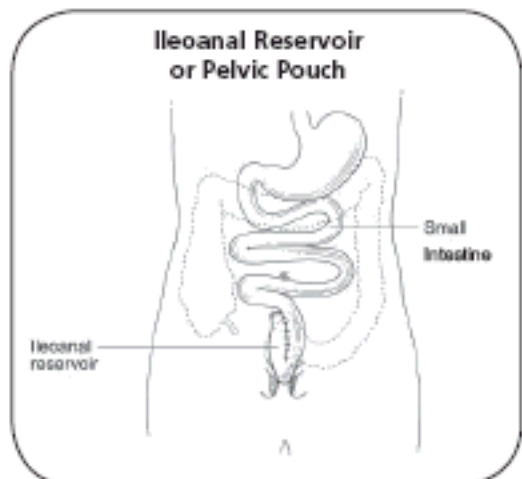


A continent ileostomy is a different type of standard ileostomy. You don't need to wear an external pouch with this kind of ileostomy.

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

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

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

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

Choosing a pouching system

Deciding what pouching system or appliance is best for you is a very personal matter. When you're trying out your first pouching system, it's 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're getting ready to leave the hospital, be sure you are referred to a Wound Ostomy Continence nurse (WOCN or WOC nurse, also called an ostomy nurse), a clinic, an ostomy manufacturer, or a chapter of the United Ostomy Associations of America. Even if you must go out of town to get such help, it's 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.

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

waistline, groin, or scars. Some companies have custom-made products to fit unusual situations.

A good pouching system should:

- Stay secure, with a good leak-proof seal that lasts for up to 3 days
- Be odor-resistant
- Protect the skin around the stoma
- Be nearly invisible under clothing
- Be easy to put on and take off
- Allow you to shower or bathe with the pouch on, if you wish to do so

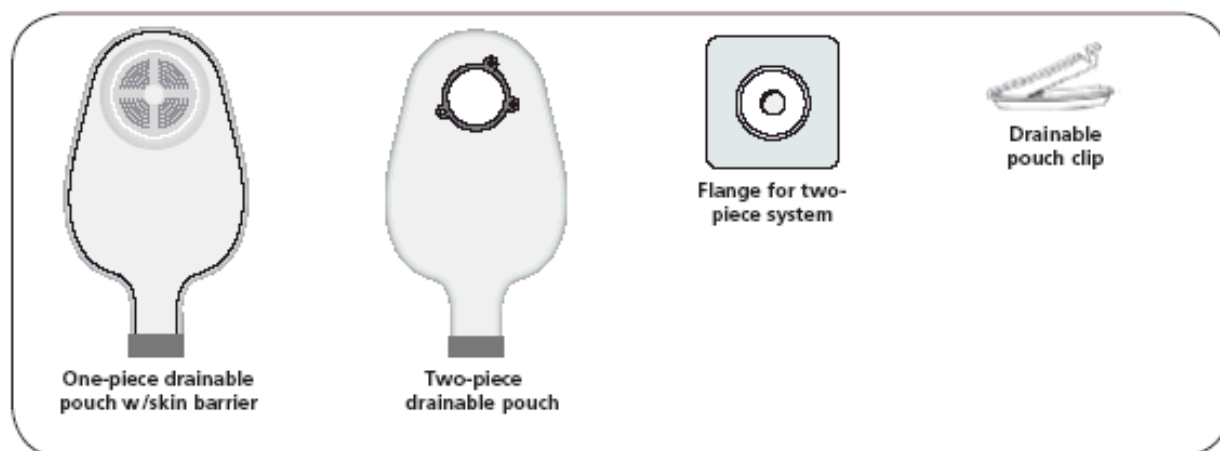
Types of pouching systems

Pouches come in many styles and sizes, and an ostomy nurse can help you choose the best one for your situation and lifestyle. They all have a collection pouch to collect stool drainage that comes out of the stoma and an adhesive barrier (called a flange, skin barrier, or wafer) that protects the surrounding skin. There are 2 main types of systems available:

- One-piece pouches have both a pouch and skin barrier attached together in the same unit. When the pouch is removed, the barrier also comes off.
- Two-piece systems have a pouch and a separate skin barrier.. When the pouch is taken off, the barrier stays in place.

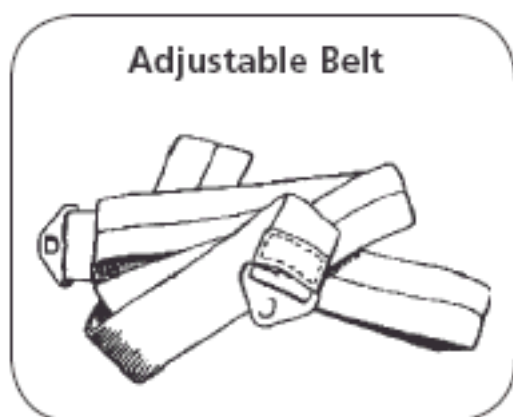
Depending on the design of your pouch's skin barrier, you may need to cut a hole out for your stoma, or it may be sized and pre-cut. It's designed to protect the skin from the stoma output and be as gentle to the skin as possible.

Some pouching systems can be opened at the bottom for easy emptying. Others are closed and are taken off when they are full. Still others allow the adhesive skin barrier to stay on the body while the pouch may be taken off, washed out, and reused. Pouches are made from odor-resistant materials and vary in cost. They can be either clear or opaque and come in different lengths.



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

Belts and tape



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

If you choose to wear a belt, adjust it so that you can get 2 fingers between the belt and your waist. This helps to keep you from getting a deep groove or cut in the skin around the stoma which can cause serious damage to the stoma and sores (pressure ulcers) on the nearby skin. If a belt is used, it shouldn't ride above or below the level of the belt tabs on the pouching system. People in wheelchairs may need special belts. Supply companies often carry these special belts or an ostomy nurse can talk to you about

making one yourself.

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Caring for an Ileostomy

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

There's no one way to take care of an ileostomy. This guide offers you tips and ideas that you can discuss with your doctor or ostomy nurse and adapt to your needs. Give new things a fair trial, but don't keep doing them if they don't make you more

comfortable. Use your recovery time to learn and try different things so that you can find what works best for you.

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

Protecting the skin around the stoma

The skin around your stoma should always look the same as skin anywhere else on your abdomen. But ostomy output can make this skin tender or sore. Here are some ways to help keep your skin healthy:

Use the right size pouch and skin barrier opening. An opening that's 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 leaks and skin irritation. It's important to have a regular schedule for changing your pouch. Don't wait for leaks or other signs of problems, such as itching and burning.

Be careful when pulling the pouching system away from the skin and don't remove it more than once a day unless there's a problem. Remove the skin barrier gently by pushing your skin away from the sticky barrier rather than pulling the barrier away from the skin.

Clean the skin around the stoma with water. Dry the skin completely before putting on the skin barrier or pouch.

Watch for sensitivities and allergies to the adhesive, skin barrier, paste, tape, or pouch material. They can develop after weeks, months, or even years of using a product because you can become sensitized over time. If your skin is irritated only where the plastic pouch touches it, you might try a pouch cover or a different brand of pouch. A stoma nurse can offer ideas if needed. Pouch covers are available from supply manufacturers, or you can make your own. You may have to test different products to see how your skin reacts to them.

Emptying and changing the pouching system

You'll be taught how to change and empty your pouching system before you leave the hospital. You don't have to use sterile supplies. For instance, facial tissue, toilet paper, or paper towels can be used to clean around the stoma instead of sterile gauze pads.

How to empty the pouch

Empty the ostomy pouch when it is about 1/3 to 1/2 full to keep it from bulging and leaking. Follow these steps:

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

When to change the pouching system

It's best to have a regular changing schedule so problems don't develop. Different pouching systems are made to last different lengths of time. Some are changed every day, some every 3 days or so, and some just once a week. It depends on the type of pouch you use.

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

Factors that affect the pouching system seal

The pouching system must stick to your skin. It's important to change it before it loosens or leaks. 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 ostomy output. Here are some other things that may affect how long a pouch sticks:

- Sweating 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 affect how long you can wear a pouch. Weight gained or lost after ostomy 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 wear time.

Bathing

Water will not hurt your ostomy. Normal exposure to air or contact with soap and water won't harm the stoma. Water will not flow into the stoma. Soap will not irritate it, but soap may interfere with the skin barrier sticking to the skin. It's best to only use water while cleaning the skin around your stoma. If you do use soap, be sure to rinse your skin well.

If you shower, you can remove your pouch, but it's not necessary and not usually recommended. If you take a bath, it's recommended to leave the pouch in place. One big reason not to remove your pouch when you shower or bathe is to avoid the risk of fecal output happening, which of course you cannot control.

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 doesn't, call your ostomy nurse or your doctor.

Shaving hair under the pouch

Having a lot of hair around the stoma can make it hard to get the skin barrier to stick well and may cause pain when you remove it. Shaving with a razor or trimming hair with scissors is helpful. Extra care should always be taken when doing this. It's recommended that you dry shave the skin around your stoma with stoma powder, since

soap and shaving creams have lotions and oils that may cause the skin barrier not to stick. After shaving, rinse well and dry the skin well before applying your pouch.

What to wear when you have a ileostomy

You will not need special clothes for everyday wear. Ostomy pouches are fairly flat and hard to see under most clothing. The pressure of elastic undergarments won't 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.

Snug undergarments such as cotton stretch underpants, t-shirts, or camisoles may give you extra support, security, and help conceal pouches. A simple pouch cover adds comfort by absorbing body sweat and keeps the plastic pouch from resting against your skin. Men can wear either boxer or jockey-type shorts.

Managing ostomy problems

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. Gassy noises or stomach rumblings may be a concern. If you are concerned about others nearby hearing this, you can say, "Excuse me, my stomach's growling." If you feel as though you are about to release gas when you're 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. Certain foods may cause gas, such as eggs, cabbage, broccoli, onions, fish, beans, milk, cheese, carbonated drinks, and alcohol.

- Eating regularly will help prevent gas.
- Eat smaller amounts of food 4 to 5 times a day.
- **DO NOT** skip meals to avoid gas or output.

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

Finding medicine capsules in your pouch

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

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's important to treat minor irritations right away. If you have a large irritated area, or one that's getting larger despite special care, contact your doctor or ostomy nurse. They may prescribe medicine to take by mouth or to put around your ostomy to help dry out and heal your skin.

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

Blockage (obstruction)

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

Call your doctor or ostomy nurse right away if this happens.

These are some things you can do to help move things through your ostomy:

- Watch for swelling of the stoma and adjust the opening of the skin barrier as needed until the swelling goes down.
- Take a warm bath to relax your abdominal muscles.
- Fluids can be taken if there is some stool output: avoid solid foods
- 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.

Foods high in fiber such as cabbage, greens, celery, 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).

If you keep having pain and cramping with no output from your stoma for more than 2 hours, and you can't reach your doctor or ostomy nurse, go to the emergency room. Take all your ostomy supplies with you.

Diarrhea

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

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

Several things can cause diarrhea:

- Intestinal infection or food poisoning, which may also cause fever and/or vomiting
- Antibiotics and other prescription medicines
- Partial blockage, which also causes smelly discharge, cramps, forceful liquid

output, and a lot of noises from the stoma. It can be caused by food or other factors. Get medical help if this happens to you.

Talk with your doctor or ostomy nurse if you have ongoing diarrhea. 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. Remember, no matter what, you need a well-balanced diet and good fluid intake to have a good output.

Electrolyte imbalance

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

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

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

Phantom rectum

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

Short bowel syndrome

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

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

When you should call the doctor

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

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

Ordering and storing ostomy supplies

Supplies may be ordered from a mail order company, from a medical supply store, a local pharmacy, or online. For additional help ordering, try contacting the product manufacturer, check your local phone book's business pages, or check the Internet (try searching for "ostomy supplies").

- To order pouches, skin barriers, and other ostomy products, you'll need both the: **manufacturer's name** and **product numbers**
- Talk with your ostomy nurse about reputable dealers who can supply you with what you need
- Before ordering your supplies, check with your health insurance to be sure that they work with the company in question
- Compare prices when using mail order and the Internet (remember to include shipping costs)
- Keep all your supplies together on a shelf, in a drawer, or in a box in a dry area away from moisture and hot or cold temperatures.
- Order supplies a few weeks before you expect them to run out to allow enough time for delivery. **DO NOT** stockpile supplies – they can be ruined by moisture and temperature changes.

References

In its original form this document was written by the United Ostomy Association of America (1962-2019). It has since been modified and updated by the American Cancer Society using the following sources.

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