

Support Resources and Contacts

Organizations

The United Ostomy Associations of America (UOAA) is a volunteer-based health organization dedicated to providing education, information, and support for people with an ostomy. The organization is a wonderful resource. If you join, you will receive *Phoenix* magazine to help keep you up to date on ostomy information. They have local and online support groups including ones for teens, over 30's, young adults and gay and lesbian ostomates. www.ostomy.org, or 1-800-826-0826.

The Crohn's and Colitis Foundation of America (CCFA) is a support and research funding organization. 800-932-2423 www.ccfa.org. The CCFA Northern California contact number is 415-356-2232.

American Cancer Society (San Francisco Area) 415-394-7100 www.cancer.org

Books

We recommend "The Ostomy Book: Living Comfortably with Colostomies, Ileostomies and Urostomies" by Barbara Dorr Mullen and Terry McGinn.

Pouch manufacturers

Many of pouch manufacturing companies have patient support programs, educational materials and provide samples. They also often provide an advice nurse to help you select a product appropriate for your needs.

Coloplast 800-533-0464
www.coloplast.com

Convatec 800-422-8811
www.convatec.com

Cymed 800-582-0707
www.cymedostomy.com

Hollister 888-740-8999
www.hollister.com

Marlen 216-292-7060
www.marlenmfa.com

Nu-Hope 800-899-5017
www.nu-hope.com

Mail order/distributors

Byram Medical Supplies 800-213-0890
www.Byramhealthcare.com

Shield Health Care 800-765-8775
www.shieldhealthcare.com

Sterling Medical 888-907-8775
www.sterlingmedical.com

American Ostomy Supply 800-858-5858
<http://aos.dirxion.com>

Bruce Medical 800-225-8446
www.brucemedical.com

Edgepark Medical 800-321-0591
www.edgepark.com

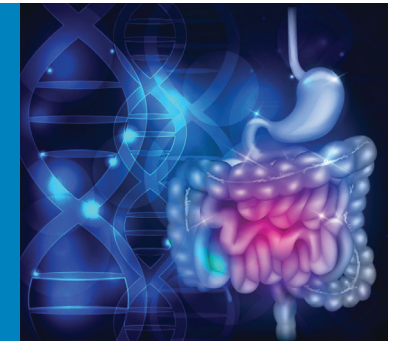
CCS Medical 800-260-8193
www.ccsmed.com

Liberator Medical 800-643-3953
www.liberatormedical.com

Ostomy accessories

There are a variety of products available to secure and disguise your pouch such as pouch covers, belts, tube tops, belly bands and underwear with a built in pocket for the pouch. Some web sites where you can find these items:
Ostomy Secrets.com
Stealth Belt.com
CSPouchCovers.com

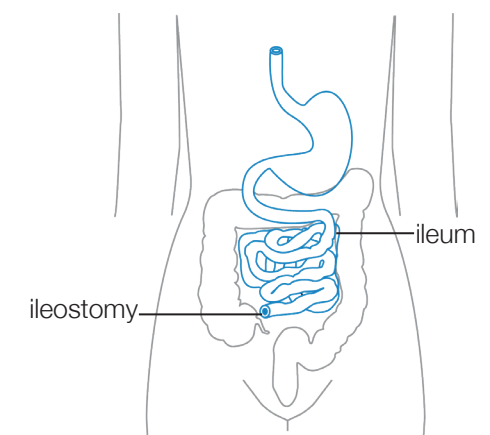
Living with an Ileostomy



Most people who have an ileostomy continue to have normal lives. They go to work, play sports, have babies and do the things that most people do. That is not to say that having an ileostomy is not a life-changing experience. It is a life-changing experience, but the changes can be incorporated into your lifestyle. This booklet provides information and addresses concerns about ileostomy. Please feel free to discuss any of these issues, or issues that aren't addressed here, with your health care provider.

An ileostomy is created when part of the small intestine (the ileum) is brought through the abdominal wall. This creates an opening, called a stoma. The stoma becomes the exit for all bowel movements and gas.

If you still have your rectum, you may feel like you need to have a BM, or have mucus or blood pass through the anus. This is normal. Some people will give themselves a Fleet enema or a very small tap water enema once a week to clean out the rectum. You need to get permission from your surgeon before doing this.



General Information about Managing Your Ostomy



Emptying and changing your pouch

The nursing staff will teach you or your family how to empty and change your pouch before you go home.

To empty the pouch, sit on the toilet, place toilet paper on the water in the bowl to avoid splashing and empty contents into toilet. Clean the bottom of the pouch with toilet paper. The tail end must be absolutely clean or there may be an odor.

Once home you will change your pouch two times per week on a regular schedule. It's best to change your pouch first thing in the morning before eating or drinking, while the bowel is most quiet. After 4-6 weeks, you will change it 1-2 times per week. This depends on your

stoma output, the integrity of the flange and your personal preference.

Your stoma will shrink over 6 weeks. Until that time you will need to cut flanges to fit. Once the stoma stops shrinking, you can order pre-sized flanges from your ostomy supply company.

The stoma will change size and shape with weight loss or gain and with pregnancy. You will need to change the pattern or size of the flange opening to prevent skin irritation if this occurs.

You may need to clip or shave the hairs (carefully!) under the pouch area if they interfere with the pouch sticking or it is uncomfortable to take the pouch off because it pulls the hair.

Questions? Visit: <https://ostomy.ucsf.edu>

UCSF Health

General Information about Managing your Ostomy



Avoiding and fixing leaks

Empty the pouch when it is 1/3 to 1/2 full on a regular schedule.

Use only water to clean the area around your stoma and dry the area well to ensure a good seal when you apply a new pouch. Make sure the opening on your pouch fits around the stoma. Apply heat and pressure from your hand or a heating pad and hold for 2-5 minutes once you put on the pouch.

If your pouch leaks, change it. You will know it is leaking because it feels different, it itches under the flange or you notice a shadow on the flange. If your pouch leaks two times in a day, change it and add a belt or moldable ring/paste. If it leaks a third time, change it and use *both* a belt and moldable ring/paste. If it leaks again, it is likely you need a different type of pouch.

If you have a loop ileostomy use a moldable ring and/or belt right away as this type of stoma is most likely to have a leak.

An occasional leak is normal. Leaking frequently is not normal. Contact your ostomy nurse or clinic to assist you with finding a proper pouch.

Treating skin irritations and broken skin

Skin irritation around your stoma may be due to leaking pouches, an allergy to the adhesive, or from using soaps around the stoma. Cleanse this area with water only. Sometimes if the opening of the pouch is too large, the skin can be irritated by its exposure to stool. Be sure to measure the stoma and cut the flange opening so that the flange sits next to the stoma. This will prevent skin irritation. If your skin gets irritated:

- Expose the irritated skin to air for 20 to 30 minutes during changes.
- Use a skin barrier. Wash skin with water, dry well, put skin barrier on the skin where the flange will be placed, allow to dry, then put pouch on. Call the ostomy nurse if redness doesn't go away.

If your skin is broken, you will 'crust' with stoma powder and skin barrier.

- Wash skin with water, dry well.
- Sprinkle on stoma powder, brush off extra.
- Pat on skin barrier, let dry.
- Repeat applying powder and barrier for a total of three times. Allow to dry between each application. Apply pouch. Once skin is healed, stop using the powder and barrier.

Do not use any other products on your skin without speaking to the ostomy nurse.

If the plastic of the pouch causes discomfort or skin irritation, try using a pouch cover. You can make your own using your pouch as a pattern or you can buy them already made.



Minimizing gas

Everyone worries about gas and the noise it makes. Expect gas to be worse in the beginning of your recovery. Eventually the noises will diminish and sound about the same as normal stomach rumbling. Sometimes covering it with your arm, a piece of clothing, a handbag, etc. when it starts rumbling will muffle the sound.

If gas continues and is a problem, avoid foods that cause gas, or eat them when you don't care about the noise. For example, don't eat beans, broccoli or similar foods that may cause gas before you go out. Avoid carbonated drinks and drinking with straws. You can also try over the counter anti-gas medications like Gas-X or Beano.

A charcoal filter in your pouch allows gas to expel without odor. When stool is very liquid, the filter may clog. Burp the bag from top or bottom.



Controlling odor

Pouches are odor-proof. You should not smell anything unless you are emptying or changing the pouch or if the pouch is leaking. It is not unusual to be very sensitive to odors after surgery. Deodorants are available to put in the pouch, or you can take tablets by mouth to prevent odor. If the odor bothers you when you are emptying your pouch in the bathroom, try using pouch deodorants or spraying the room with an odor eliminator spray before you empty the pouch.



Ostomy Output

Your output will thicken over time, becoming pasty. It is very easy to become dehydrated with an ileostomy, so it is important to monitor your output. You will measure your ostomy output, keeping a running total for 24 hours, every day until you return for your clinic visit. You will be taught how to measure and given supplies.

High output

If your stool is very watery and you empty your pouch more than 10 times per day or measure more than 1500ml in 24 hours; call the clinic.

Managing output

Follow instructions provided in your discharge paperwork to slow down your bowel, allowing you to absorb more fluid and decrease your output. You will take Benefiber, Lomotil or Imodium or a combination.

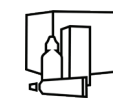
Foods suggested in the *Nutrition and Ileostomy* handout can be eaten to thicken up your output.

Blockage

If you notice an increase in the swelling of your stoma, swelling of your abdomen, abdominal pain and no ostomy output you may have a blocked stoma. Your abdomen will begin to swell and it is extremely painful. If this happens, do not eat. Walk as much as possible. Sip only on hot fluids, sometimes massaging the stoma may help. You may remove the pouch and stand in a warm water shower to help muscles relax. If it does not resolve or worsens, contact the clinic office for directions on what to do.

Urine Output

Goal urine output is more than 1000 mL in 24 hours. Stay hydrated by sipping on fluids throughout the day. Measure daily 24-hour urine output until your first follow up appointment with the clinic. Follow instructions provided by your nurse and the dietitian.



Getting supplies and accessories

You will receive 5 bags and necessary accessories when you are discharged from the hospital. Before you leave, your case manager will submit the initial order for supplies to be

delivered to your home with a medical supply company that contracts with your insurance. Thereafter, you call the company to arrange a delivery schedule for your ongoing supplies.

Most insurance companies cover 20 drainable pouches per month and needed accessories. You will know your supply company before discharge from the hospital.

If you have Medicare and a home health nurse, the nurse will bring supplies during the time they see you. When you know the date of the last home health visit, you will need to contact the supply company to start receiving supplies directly.

If you have a secondary insurance plan to your Medicare, it will often pay the difference between the actual cost and the amount covered by Medicare.

You can arrange for supplies to be delivered monthly or every three months depending on your preference, needs, and insurance. All the distributors carry a wide range of products to meet your needs.

An annual prescription for ostomy supplies is necessary. After the first year with a permanent ostomy your primary care provider will write the prescriptions you need for supplies.

Pouches are about \$5.00 - \$10.00 each. There are several web sites and some local medical supply stores and pharmacies where you can purchase extra supplies. Often the web sites will have the best prices.



Home Care

Your case manager will make every attempt to arrange home care nursing for you. They will come twice a week for two or three weeks to continue teaching you about caring for your ostomy. You will be given the information before you leave the hospital.

Resuming Daily Life

No one will know that you have an ostomy unless you tell them. At first, everyone feels that people can see the pouch under their clothes but after a while, you realize that they can't. Right after your surgery, you may feel more comfortable wearing loose fitting clothes, but eventually you will be able to wear your normal clothes. You should feel free to return to your normal life with this guidance:



Physical activity

Do not lift anything greater than 10 pounds for 6 weeks. Always use good body mechanics. Do not lift with your abdomen to avoid a hernia around the stoma.

If you enjoy activities that may potentially put pressure or damage the stoma you can purchase a stoma guard to protect the area.

If you have had your rectum removed, that area will be tender for a while and you will be given instructions on what activities you are allowed to do until the area is healed. Once your doctor gives you permission to take a bath/get in a body of water, you can enjoy all water sports. Check with your surgeon if you have further questions.



Diet

Follow a low residue diet for 6 weeks after surgery to prevent blockage from food at the swollen stoma. The dietitian will see you in the hospital and provide you with education and a handout for managing your diet. After 6 weeks, add fiber back slowly.



Intimacy

Many people feel uncomfortable at first about being intimate when there are changes in their body. You may feel unattractive and concerned that your partner may not want to get close to you anymore. Your partner may be afraid of hurting you, or afraid of your stoma. These are all common feelings. Talk to your partner about your feelings and encourage them to share their feelings. The stoma is never used for sex.

Some operations may affect a man's ability to have an erection. Women may have pain with intercourse. Discuss this with your surgeon.

Many people find it helpful to cover their pouch with a band or scarf or use a small ostomy pouch when they are intimate with their partner.

If you continue to feel uncomfortable and you need more help you can talk to an ostomy nurse for resources on this topic.

Emotional support



Talking to other people who have had the same operation either in support groups or one-on-one can be very helpful (see the Support Resources and Contacts on the last page of this booklet). Talk with your nurse, the specialist nurse and your friends and family. A referral to a therapist can be helpful in sorting out all the feelings you may have after your operation. It is perfectly normal to have these feelings and the need for help in dealing with them.

Possible associated problems

Hernias: Some people can get a hernia around their stoma. A hernia occurs when the opening in the muscle around the stoma stretches so much that the intestines slip into this hole and cause a bulge.

We don't know how to prevent this from happening but it seems sensible to avoid increasing the pressure behind the stoma for 6 weeks. For 6 weeks following surgery, avoid heavy lifting, excessive coughing, vomiting or straining. Keep your weight in a healthy range.

Prolapse: A prolapsed stoma is when the stoma becomes longer. While this may look alarming, it is usually not dangerous. Some reasons a prolapse may occur: poor abdominal muscle tone, weight gain/obesity, pregnancy, surgical technique, increased abdominal pressure from increased fluid in abdomen, excessive coughing, heavy lifting and straining.

If you have a prolapse, you may need a larger pouch and may need to wear a Prolapse belt.

The prolapse stoma can sometimes go back into the abdomen when lying down and/or when manipulated. Your Nurse Practitioner or stoma nurse can assist you with strategies to reduce the prolapse. There are times that a surgery is necessary to manage the prolapse.

If the stoma color changes, notify your surgeon right away.

Call your surgeon if you develop any of these:

1. Fever of greater than 101.5°F
2. Nausea or vomiting (especially if you are unable to keep liquids down)
3. Severe pain at the incision
4. Pus or foul smelling drainage from the incision
5. Severe cramping and no stoma output for 4 to 6 hours
6. Persistent diarrhea or emptying your pouch 10 times in 24 hours
7. During the period of time when you are measuring your output, more than 1500ml ileostomy output per day, or less than 1000ml urine output per day
8. Skin breakdown that is not healing
9. Bright red blood from the incision, rectum or ostomy (greater than 4 tablespoons). A small amount of bleeding may be normal, depending on your surgery
10. Dizziness, lightheadedness, or extreme fatigue



Showering and bathing

You can take a shower with or without the pouch. The water doesn't hurt the stoma and won't go inside. Stool will continue to come out of the stoma so if you want to shower with the pouch off choose a time when the stoma is inactive. If you shower with the pouch, you may need to cover the gas filters to avoid getting them wet and dry pouch with a towel or a blow dryer set on low.

You may also enjoy a hot tub/bathtub but with a pouch on. You will need permission from your surgeon.



Preparing for sleep

Empty the bag right before going to bed. For the first couple of weeks of being home check your pouch about every 4 hours during the night. Use a mattress protective pad under the sheet as a precaution for possible leaks.



On the go

When you leave the house, always carry extra supplies with you. Your kit should contain Peristomal wipes (for use as an adhesive remover and a wet cloth), a dry wash cloth, all the supplies you need to change your pouch, a small garbage bag and hand sanitizer. Some people carry extra clothing with them as well.

When you travel by air, carry your supplies in your carry on. Take twice as many as you think you will need. You can print a travel card from the United Ostomy Associations web site to show the TSA agent to make them aware that you have an ostomy. Check the website www.ostomy.org for travel tips.

Pouches

Pouches are either “one-piece” (pouch and flange are one piece) or “two-piece” systems (pouch and flange are separate and need to be assembled).

There are many pouch styles (drainable, closed, short, long, transparent, opaque, pouches with adhesive and those held on by a belt). Your nurses will work with you to choose the one that best suits your needs before you leave the hospital. You may need or want a different type of pouch later.

Pouch liners are disposable bags that fit inside a two-piece pouch and can be removed and discarded. These are an option some people like to use because they feel it keeps their pouch cleaner. If you are interested in trying liners you can obtain samples and order from Colomajic (www.colomajic.com).

Changing a one-piece pouch

Collect supplies

- New pouch
- Peristomal wipes and one dry wash cloth
- Scissors
- Measuring guide/marker
- Plastic bag for used pouch
- Other supplies you are using such as a moldable ring

This is often done in front of a mirror in the bathroom. You can either sit or stand.

- 1 Gently remove the pouch you are now wearing by using both hands, one hand pulling off the pouch while the other is pushing the skin away from the pouch.
- 2 Cleanse the skin around your stoma with warm water only. Soap can leave an oily residue on the skin and keep the pouch from sticking. Some soap also may cause skin sensitivity from the chemicals in the soap.
- 3 Using the template, place it over the stoma. The opening should sit around the stoma, not on it or leaving skin exposed. Trace the pattern onto the paper/ plastic backing of the adhesive. Cut a hole in the flange that matches the pattern. Check the cut opening to your stoma before taking the backing off to ensure a good fit.
- 4 Prepare the flange and pouch to put on. Remove the paper/plastic covering on the back. If you use stoma paste, squeeze it around the opening about 1/8 inch thick.
- 5 Clean the skin again if there is some mucus or stool on the skin. Pat the skin dry using a towel or a hair dryer. The skin must be absolutely dry or the adhesive will not stick to the skin.
- 6 Center the pouch opening over the stoma and press it against the skin. Press the flange against skin, working from stoma to the outside of the flange. Close the bottom of the pouch.
- 7 Once the pouch is on, adding heat and pressure will help you get a good seal. Apply a heating pad and then slight pressure with your hand for 2-5 minutes. Another option is to heat the flange before putting it on. Place the flange between your arm and chest or use a hair dryer on the back of the flange after removing the backing.

If the paste is hard to squeeze out, put the tube in a glass of hot water for a few minutes to soften it.

If you use a moldable ring, place it around the opening of the flange or directly on your skin around the stoma after washing and drying the skin.

Changing a two-piece pouch

Collect supplies

- New pouch and flange
- Peristomal wipes and one dry wash cloth
- Scissors
- Measuring guide/marker
- Plastic bag for used pouch
- Other supplies you are using such as a moldable ring

This is often done at your sink in the bathroom. You may either sit or stand.

- 1 Follow steps 1-5 for changing a one-piece pouch.
- 2 Center the skin barrier opening over the stoma and press it against the skin. Press the flange against skin, working from stoma to the outside of the flange.
- 3 Attach the pouch to the flange. Exerting pressure with your fingers and thumbs, press flange and pouch together. Then, work your way completely around the connection, pressing in place until it is securely sealed. Test by pulling outward on the pouch while holding the flange. Close the bottom of the pouch.
- 4 Once the pouch is on, adding heat and pressure will help you get a good seal. Apply a heating pad and then slight pressure with your hand for 2-5 minutes or, heat the flange before putting it on. After cutting the opening for the stoma, put the flange between your arm and chest for a few minutes or use a hair dryer on the flange after the backing is off.

Donating Ostomy Supplies

Please consider donating your extra supplies. This will save landfill and help others. Some choices are listed below.

Re-CARES (Collecting Redistributing and encouraging Reuse)

Three Bay Area sites collect and redistribute donations of clean, gently used medical equipment and unused home health care supplies each week. These are provided free of charge to those in need who visit our sites. For more information or to leave a message call the numbers below:

Oakland 510-251-2273

San Francisco 415-487-5405

Marin County 415-388-8198

You can mail surplus supplies to the following organizations:

Friends of Ostomates Worldwide-USA

Osto Group

Ostomy 2-1-1

Organizations that may accept donations:

UOAA's Affiliated Support Group(s)

Home Health Agencies

Wound Clinic

Ostomy Outpatient Clinic

Goodwill Industries

Nursing Schools

Homeless Shelters