Living with an Ileostomy

Most people who have ileostomies 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 isn't a life-changing experience. It is a life-changing experience, but the changes can be incorporated into your lifestyle. This booklet is aimed at answering the most common questions and concerns about ileostomy. Please feel free to discuss any of these issues, or issues that aren’t addressed here, with your nurse or doctor.

What you need to know before you leave the hospital

• Hospital nursing station: ________________________________
• Who can help with questions or problems: Ostomy Nurse Susan Barbour, RN (415) 353-1085 or Nurse Practitioner Lois Anne Indorf, (415) 885-3613, or ________________________________
• Name of your operation: ________________________________
• Ostomy supplies you are now using: ________________________________
• You can buy your supplies at (or they have been ordered from the following supply house): ________________________________

General information

An ileostomy is the creation of a passage that brings the end of your small intestine through an opening in your abdomen. The end of the intestine is sewn into place on your lower abdomen—usually your right side—with surgical stitches called sutures. You will have no control over the gas and stool coming out of the opening, which is called a stoma or ostomy. A bag or pouch worn over this opening (attached by adhesive) collects all the gas and stool. Usually people who have an ileostomy have had their colons (large intestines) removed because of Ulcerative Colitis or Crohn’s disease.

Sometime, an ileostomy is a temporary measure to keep the stool away from a leak lower down in the intestine or to protect an area while it heals. The stool in the small intestine is loose, varying from watery to the consistency of “refried beans.” Digestion and absorption of food and drugs takes place in your small bowel with the help of “active” enzymes. The large bowel or colon absorbs water and electrolytes (salt, potassium), stores the stool and inactivates the digestive enzymes. When the large bowel is removed, the stool coming through the ileostomy contains more water, salt, potassium and
the “active” enzymes. We will show you how to keep this loose stool off your skin so your skin stays healthy. If you still have your rectum, you can expect to have some mucus or blood through the anus. Some people will give themselves a Fleet enema once a week to clean out the rectum.

**Common Questions and Answers**

**How often do I change the pouch?**

Change the pouch regularly to avoid leaks. Most people change the pouch every three to seven days depending on their stoma, location and preferences. You will begin to notice when your ileostomy is “quiet,” or less active and you can schedule your pouch changes at that time.

**How do I change the pouch?**

The nursing staff will begin to teach you or your family how to change the pouch before you go home. Usually we can arrange for home health nurses to come to your house for continued teaching. Step by step directions on how to change the pouch are at the end of this booklet.

**How often do I need to empty the pouch?**

Empty the pouch when it is one third to one half full. Most people will empty their pouch about five to seven times a day. You may want to place toilet paper in the toilet bowl to prevent splashing when emptying. If the pouch gets very full, there is more chance for leakage, and it is more visible under your clothes.

**Where do I buy the pouches?**

You can buy the pouches at medical supply stores in your area or you can order them through the mail. See the end of this booklet for resources and numbers.
Does insurance pay for the supplies?

- Many insurance companies will pay 50 percent to 100 percent of the cost of pouches.
- If you belong to an HMO, they will tell you exactly where to get supplies they will cover.
- If you have MediCal your discharge coordinator will help determine the contracted supplier.
- MediCare pays 80 percent of the cost of most pouches. The monthly allowance includes 20 drainable pouches or 60 closed pouches, 20 skin barriers and one belt. If you have a secondary insurance plan to your MediCare, it will pick up the different between the actual cost and what MediCare covers.
- 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.

If I don’t have insurance, how much do supplies cost?

A typical colostomy pouch costs about $6. Extra supplies, like paste, powder, adhesive removers, wipes or a belt, add to the cost. It is hard to estimate a yearly cost as different people use different supplies and change pouches on different schedules. A minimum of $700 to $1000 per year would be a start.

What about odors?

Many years ago the pouches were not odor-proof, and people associated ostomies with odor. Today's modern pouches are odor proof and you shouldn’t smell anything unless there is stool on the outside of the pouch or on the clip or if the pouch is leaking. It is not unusual to be hypersensitive to odors after surgery. There are deodorants to put in the pouch or tablets you can take by mouth for the odor. If the odor bothers you when you are emptying your pouch in the bathroom, try using pouch deodorants.

What can I do about the gas and the noise it makes?

Everyone worries about this. The amount of gas you have after the operation is usually more than you will have in a few weeks. The sound of the gas passing will lessen with time. Sometimes putting your arm/hand/handbag/book right over the stoma when it starts making noise will muffle the sound. If the gas continues and is a problem, avoid foods that cause gas or eat these foods when you don’t care about the noise. For example, don’t eat beans, broccoli or similar foods that often cause gas before you go out. Avoid carbonated drinks and drinking with straws.

Will everyone know I have an ileostomy?

Not 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. It will make noises that you will not be able to control. It makes the most noise in the first few weeks after surgery. Eventually, the noises usually diminish and they sound about the same as normal stomach rumbling.

What about sex?

Many people feel uncomfortable at first about being intimate when there are changes in their body. You may feel unattractive and 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 him or her to share their feelings. Keep your sense of humor.
and if you need more help, you can talk to an ostomy nurse for resources. Some operations may affect a man’s ability to have an erection and may cause pain with intercourse for a woman. Discuss this with your surgeon.

**Can I shower, take a bath or get in a hot tub?**

Yes. You can take a bath or shower with or without the pouch. The water does not hurt the stoma and will not 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. You may enjoy a hot tub/bathtub with a pouch on. If you shower with the pouch, be sure to cover gas filters to avoid getting them wet.

**Are there certain activities I can’t do?**

If you have had your rectum removed that area will be tender for a while and you may not be able to ride a bike or a horse until the pain is gone. All other activities are fine including swimming. Check with your surgeon if you have further questions.

**Do I have to follow a special diet?**

- For the first four to six weeks you must avoid a high fiber diet to prevent a blockage right behind the stoma. The abdominal muscle around the stoma is swollen after surgery making the opening narrower than it will be later. This shouldn’t be a problem once the swelling goes down. Occasionally a narrow area develops in the small intestine; in that case continued avoidance of these foods may be necessary. In general you can slowly resume eating a balanced diet, but you may wish to avoid certain foods that increase odor or gas, or disagree with you.
- Always watch your fluid intake and drink enough fluids so your urine is light yellow to clear in color to prevent possible formation of kidney stones. If you are exercising or live in a warm climate, you will need more fluids
- If you are lactose intolerant or are unsure, begin eating milk products slowly. Try changing to fermented milk forms (yogurt, cheese, buttermilk) if you experience bloating, cramping or gas after drinking milk. Soy products or goat’s milk may be substitutes.

**For the first four to six weeks (and as individually necessary) avoid the following foods:**

- Dried fruit
- Tough or large pieces of meat, meats with casings
- Coconut
- Raw vegetables including salad, celery, cole slaw
- Cooked corn
- Mushrooms
- Green beans
- Chinese vegetables
- Pickles
- Popcorn, nuts and seeds
- Some raw fruit, such as oranges, grapefruit, apples and strawberries
Foods which may increase odor
- Asparagus
- Broccoli
- Fish
- Cabbage
- Cauliflower
- Beans
- Eggs
- Brussels sprouts
- Onion
- Some spices

Foods that may increase gas
- Apple juice
- Beans
- Beer
- Peas
- Broccoli
- Brussels sprouts
- Cabbage
- Cauliflower
- Corn
- Cucumbers
- Mushrooms
- Carbonated soda
- Radishes
- Dairy products

Foods that usually thicken stool
- Apple sauce
- Bananas
- Cheese
- Boiled milk
- Yogurt
- Pasta
- Pretzels
- Rice
- Bread
- Tapioca
- Toast
- Marshmallows
- Bagels
- Creamy Peanut butter

Foods that may loosen stool
- Green beans
- Beer
- Broccoli
- Fresh fruits
- Grape juice
- Raw vegetables
- Prunes/juice
- Spicy foods
- Chocolate
- Spinach leafy green vegetables
- Aspartame/Nutrasweet
How do I find out about different types of pouches?

- Nurses who specialize in the care of people with ostomies can tell you about different pouches. These nurses may be referred to as stoma nurses, ostomy nurses, “ET” nurses (short for Enterostomal Therapist) or WOC nurses (Wound, Ostomy and Continence nurses).
- Your nurse practitioner or home care nurse can help.
- The United Ostomy Association of American is a good resource for information. www.uoaa.org
- Pouches are either “one-piece” or “two-piece” systems. In a one-piece pouch, the pouch and adhesive are in one piece. A two-piece pouch has a separate adhesive part. There are drainable pouches and closed pouches, short pouches and long pouches, transparent and opaque pouches, pouches with adhesive and those held on by a belt. Your nurses usually will choose the one that best suits your needs before you leave the hospital. You may need or want a different type of pouch later. You may contact the manufacturers of pouches for free samples.
- Some ostomy manufacturers and their toll-free telephone numbers are:

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<thead>
<tr>
<th>Company</th>
<th>Phone Number</th>
<th>Website</th>
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<tbody>
<tr>
<td>Convatec</td>
<td>(800) 422-8811</td>
<td><a href="http://www.convatec.com">www.convatec.com</a></td>
</tr>
<tr>
<td>Hollister</td>
<td>(888) 740-8999</td>
<td><a href="http://www.hollister.com">www.hollister.com</a></td>
</tr>
<tr>
<td>Coloplast</td>
<td>(800) 533-0464</td>
<td><a href="http://www.coloplast.com">www.coloplast.com</a></td>
</tr>
<tr>
<td>Nu-Hope</td>
<td>(800) 899-7711</td>
<td><a href="http://www.nu-hope.com">www.nu-hope.com</a></td>
</tr>
<tr>
<td>Cymed</td>
<td>(800) 582-0707</td>
<td><a href="http://www.cymedostomy.com">www.cymedostomy.com</a></td>
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These companies often provide an advice nurse to help you select a product appropriate for your needs.

What if my pouch leaks when I am out?

If you change the pouch on a regular schedule, it shouldn’t leak. However, it is always best to be prepared. Keep an extra pouch with you at all times. If your pouch leaks more than very rarely, you should see a specialist nurse for help.

What can I do if I feel I need more help in dealing with this?

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

What kind of problems can I have in the future?

- **Skin Irritation:** Skin irritation around your stoma may be due to an allergy to the adhesive, or from using soaps around the stoma, so cleanse with water only. Sometimes if the opening of the pouch is too large, this skin can be irritated by its exposure to stool. Measure the stoma and add 1/8 inch to the opening and you will usually not have skin irritation. Contact a specialist nurse if it persists.
- Make sure the pouch opening fits your stoma without actually touching the stoma with no skin showing.
- Expose the irritated skin to air for 20 to 30 minutes during changes.
- Do not use any solvents, sealants or medications on irritated skin unless your doctor or nurse has approved them.
- Call the stoma nurse if redness doesn’t go away.

**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 4–6 weeks. For 6 weeks following surgery avoid heavy lifting (more than 10 pounds), excessive coughing, vomiting or straining. Keep your weight in a healthy range.

**Helpful tips and information**

- Always change a leaky pouch (stool on the skin causes irritation).
- When traveling, carry your supplies with you in case your luggage is lost.
- Always carry an extra pouch in your purse or pocket.
- A small amount of bleeding from the stoma when you clean the area is normal. Do not be alarmed.
- 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 opening to prevent skin irritation if this occurs.
- Your stoma will shrink in size for awhile after surgery, mostly in the first month. If you notice skin irritation around the stoma later or notice that the pouch opening seems big, your skin barrier may need re-sizing.
- Carefully clip or shave the hairs under the pouch area if they interfere with the pouch sticking or if it is uncomfortable to take the pouch off because it pulls the hair.
- Medication or foods can change the color of the stool, making it look as if you are bleeding. Before becoming alarmed, try to remember what you might have eaten that could have caused the color to change.
- It is important that you change the pouch on a regular schedule, approximately every four days. Changing your pouch regularly should avoid unexpected leaks or skin irritation.
- 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.
- In case of leakage during the night, place a plastic sheet or plastic garbage bag under your mattress pad.
- Your clothes may seem snug at first because of some overall swelling but you should be back wearing the same clothes three to four weeks after surgery.
- Pre-cut pouches are available once your stoma has stopped shrinking.
Managing Diarrhea

• Don’t eat fibrous foods (like raw fruits and vegetables). Take small amounts of tea, boiled milk, 7-up or Gatorade.
• Eat bananas, applesauce, boiled rice, tapioca, or peanut butter, which help thicken the output.
• Drink fluids hourly and add salt to food.
• Notify your physician if diarrhea is severe or lasts longer than 24 hours.

Medications:

• Do not take laxatives, stool softeners or use enemas. You will never need a “bowel prep” as is sometimes needed for X-rays or surgery.
• Long-acting drugs or timed-release capsules are not well absorbed and should be avoided.
• Check the pouch after taking medication to be sure your medication has not passed through whole without being absorbed by your body.
• Medication that can be crushed, chewed or taken in liquid form may be easiest to absorb.

Special section for those of you with a temporary diverting ileostomy:

The temporary ileostomy is created by bringing a loop of bowel out to the skin. Most people do not notice that there are actually two stoma openings on the abdomen. One opening is where the stool comes out and the other goes down to the area of the bowel that needs time to heal. For the first five days after surgery, there may be a plastic rod under the loop of bowel while the ostomy is beginning to heal. This is slipped out painlessly before you go home. Some stool may get into this other hole and cause you to have stool out your anus. Don’t be alarmed but do contact the stoma nurse. You will have to change your pouch about every three days with a temporary ostomy. You may even need a CONVEX pouch. This is a special pouch that is curved on the back. You also may have diarrhea with these temporary stomas. If you are emptying the pouch more than seven times a day or if you are having trouble with the pouch not lasting more than 1–2 days, call the stoma nurse. When you return for the second operation, the ileostomy is “taken down” and the small intestine is reconnected. This is done through the stoma, usually without opening up the healed incision of the first operation. If you had your entire large intestine removed, the same loose stool that had been coming out of your ileostomy is now passed through the anus. If your large intestine is still in place and your rectum was removed, you will pass solid/semi solid stool through your anus. You will be in the hospital for about four to six days depending upon how long it takes you to be able to eat again. Because the second operation takes about one hour, you will be up and walking much sooner and you will need less pain medication than for the first operation. Except for your IV, you will have no tubes or drains. You will be allowed to drink fluids when your bowel function has returned, usually in two to five days. When you can tolerate fluids, your doctor will let you eat solid food.

How to get ostomy supplies after you go home:

• We will send you home with enough supplies for about five pouch changes.
• The Case Manager will order supplies to be delivered to your home after discharge, or will arrange with a home care agency for a visiting nurse to help with ongoing teaching and supplies.
Most often you will be set up with a medical supply distributor for ongoing supplies. The choice of distributor will depend on your insurance. All the distributors carry a wide range of products to meet your needs. Once you are discharged by the visiting nurse, you can arrange for supplies to be delivered monthly or every 3 months, depending on your preference and needs.

Some mail order/distributors:

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<tr>
<th>Distributor</th>
<th>Phone</th>
<th>Website</th>
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<tr>
<td>Byram Medical Supplies</td>
<td>(800) 213-0890</td>
<td><a href="http://www.Byramhealthcare.com">www.Byramhealthcare.com</a></td>
</tr>
<tr>
<td>Shield Health Care</td>
<td>(800) 765-8775</td>
<td><a href="http://www.shieldhealthcare.com">www.shieldhealthcare.com</a></td>
</tr>
<tr>
<td>Sterling Medical</td>
<td>(888) 907-8775</td>
<td><a href="http://www.sterlingmedical.com">www.sterlingmedical.com</a></td>
</tr>
<tr>
<td>American Ostomy Supply</td>
<td>(800) 858-5858</td>
<td><a href="http://aos.dirxion.com">http://aos.dirxion.com</a></td>
</tr>
<tr>
<td>Bruce Medical</td>
<td>(800) 225-8446</td>
<td><a href="http://www.brucemedical.com">www.brucemedical.com</a></td>
</tr>
<tr>
<td>Edgepark Medical</td>
<td>(800) 321-0591</td>
<td><a href="http://www.edgepark.com">www.edgepark.com</a></td>
</tr>
<tr>
<td>CCS Medical</td>
<td>(800) 260-8193</td>
<td><a href="http://www.ccsmed.com">www.ccsmed.com</a></td>
</tr>
<tr>
<td>Liberator Medical</td>
<td>(800) 643-3953</td>
<td><a href="http://www.liberatormedical.com">www.liberatormedical.com</a></td>
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Helpful contacts

- UCSF has an “ostomy nurse” also called an enterostomal therapist (ET) nurse or a wound, ostomy, continence (WOC) nurse to help you with this type of surgery. Ask your surgeon to put you in contact with her.

- The United Ostomy Association of America (UOAA) is a volunteer-based health organization dedicated to providing education, information, and support for those having ostomy surgery. 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 for teens, over 30s, young adults and gay and lesbian ostomates. The website: www.uoaa.org

- The Crohn’s and Colitis Foundation of America (CCFA) is another support and research funding organization for people with Inflammatory Bowel Disease (ulcerative colitis and Crohn’s disease). They can be reached at (800) 932-2423 or on the Internet at www.ccfa.org. The CCFA Northern California contact number is (415) 356-2232

- American Cancer Society. San Francisco Area call (415) 394-7100, or visit online at www.cancer.org

- We recommend “The Ostomy Book: Living Comfortably with Colostomies, Ileostomies and Urostomies” by Barbara Dorr Mullen and Terry McGinn. It is available at your local library or can be ordered on-line or at your local bookstore

- Many of the manufacturers of ostomy products have educational materials on their websites. The websites are included in this booklet.

- Another website that is helpful is www.C3Life.com
How to change the pouch: One-piece pouch

Collect supplies:

- Pouch
- Clamp closure
- Water and tissues
- Plastic bag for disposing of used pouch
- Scissors
- Pattern or template

1. This is often done at your sink in the bathroom.

2. 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. Be sure to remove the clamp to use on your next pouch.

3. Cleanse the skin around your stoma with warm water. 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.

4. If you already have a pattern, check to make sure it is still the right size by placing it over the stoma and seeing if there is any skin exposed. Transfer the correctly sized pattern to the back of the pouch and trace the pattern onto the paper backing of the adhesive. Cut a hole in the skin barrier that matches the pattern. Check the cut opening to your stoma before taking the paper off to ensure a good fit.

5. Remove the paper covering on the back. If you use Stomahesive paste, squeeze it around the cut opening about 1/8 to 1/4 inch thick. If the paste is hard to squeeze out, put it in a glass of hot water for a few minutes to soften it. Once the pouch opening fits well, clean the skin again if there is some mucus or stool on the skin.

6. Pat the skin dry using tissues, a towel or a hair dryer. The skin must be absolutely dry or the adhesive will not stick to the skin.

7. Center the pouch opening over the stoma and press it against the skin. Press the tape against skin, working from stoma to the outside of the wafer.

8. The pouch must be emptied when 1/3 to 1/2 full or the weight will weaken the seal and the pouch might leak. To empty the pouch, sit on toilet, remove the clamp and empty contents into toilet.

9. Clean the bottom of the pouch with toilet paper. The tail end must be absolutely clean or there may be an odor.

10. Change the pouch one or two times a week, or as needed, to prevent leakage.
How to Change the Pouch: Two-Piece Pouch

Collect supplies:

- Pouch and skin barrier with flange
- Clamp closure
- Water and tissues
- Plastic bag for disposing of used pouch
- Scissors
- Pattern or template

1. This is often done at the sink in your bathroom.

2. 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. Be sure to remove the clamp to use on your next pouch.

3. Cleanse the skin around your stoma with warm water. 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.

4. Pat the skin dry using tissues, a towel or a hair dryer. The skin must be absolutely dry or the adhesive will not stick to the skin.

5. If you already have a pattern, check to make sure it is still the right size by placing it over the stoma and seeing if there is any skin exposed. Transfer the correctly sized pattern to the back of the skin barrier with flange and trace the pattern onto the paper backing of the adhesive. Cut a hole in the skin barrier that matches the pattern. Do not cut beyond the circular line indicated on the paper backing. Check the cut opening to your stoma before taking the paper off to ensure a good fit.

6. Remove the paper covering on the back. If you use Stomahesive paste, squeeze it around the cut opening about $\frac{1}{6}$ to $\frac{1}{4}$ inch thick. If the paste is hard to squeeze out, put it in a glass of hot water for a few minutes to soften it. Once the barrier opening fits well, clean the skin again if there is some mucus or stool on the skin.

7. Center the skin barrier opening over the stoma and press it against the skin. Press the tape against skin, working from stoma to the outside of the wafer.

8. Attach pouch to the flange on skin barrier. Place lower end of pouch gasket against lower portion of flange. Exerting pressure with your fingers and thumbs, press flange and gasket together. Then, work your way completely around flange, pressing gasket in place until it is securely sealed. Test by pulling outward on the pouch while holding the flange. Attach the clamp or turn the valve to the closed position, depending on type of ostomy.

9. The pouch must be emptied when $\frac{1}{3}$ to $\frac{1}{2}$ full or the weight will weaken the seal and the pouch might leak. To empty the pouch, sit on toilet, remove the clamp and empty contents into toilet.

10. Clean the bottom of the pouch with toilet paper. The tail end must be absolutely clean or there may be an odor.

11. Change the pouch one or two times a week, or as needed, to prevent leakage.