Living with a Colostomy

Most people who have colostomies 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 a colostomy is nota life-changing experience. It is a life-changing experience, but the changes can be incorporated into your lifestyle. This booklet is aimed at giving answers and information to the most common questions and concerns about colostomy. 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

A colostomy is creation of a passageway the brings the end of your colon, also called the large intestine, to an opening in the skin called a stoma or ostomy, usually on the left side of your lower abdomen,. People need to have a colostomy for many reasons including cancer, Crohn’s disease, perforations of the colon, accidents causing injury to the colon and congenital problems.

Some colostomies are temporary and some are permanent. Your pattern of having a bowel movement with a colostomy will depend on how much of your colon was removed and what your bowel pattern was like before surgery. If you still have your rectum, you can expect to have mucus or blood pass through the anus. Some people will give themselves a Fleet enema or a very small tap water enema once a week to clean out the rectum.
Common Questions and Answers

How often do I change the pouch?

Most people change the pouch once or twice a week. This also depends on the shape and location of your stoma and your personal preference. Change the pouch on a regular schedule to avoid leakage.

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. The 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?

You will empty the pouch when it is $\frac{1}{3}$ to $\frac{1}{2}$ full. Most people empty the pouch one to four times a day.

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 for 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 difference between the actual cost and the amount covered by MediCare.

- 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 is a reasonable estimate.

**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. You should not smell anything unless there is stool on the outside of the pouch, on the clip 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.

**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 in 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 may cause gas before you go out. Avoid carbonated drinks and drinking with straws. Will everyone know I have a colostomy?

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 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 him or her to share their feelings. If you continue to feel uncomfortable and 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 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. 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?

No. You can eat anything you ate before your operation. If certain foods cause you gas, and it is a problem for you, avoid those foods.

What is a colostomy irrigation and is it something I should learn?

A colostomy irrigation is like an enema given through the stoma. The purpose is to empty the colon once a day or every other day and not to have stool output the rest of the day. This doesn’t work for everyone and some people don’t want to do this. An irrigation takes about an hour a day to perform. Ask your nurse or enterostomal therapist nurse about how to perform a colostomy irrigation.

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 often 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 also may contact the manufacturers of pouches for free samples.
- Some ostomy manufacturers and their toll-free telephone numbers are:

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<tr>
<th>Manufacturer</th>
<th>Phone</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.
- It is important that you change the pouch on a regular schedule, approximately once or twice a week. 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.

**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>Supplier</th>
<th>Phone</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.bruceomedical.com">www.bruceomedical.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
How to change the pouch: One-piece pouch

Collect supplies:

- Pouch
- Plastic bag for disposing of used pouch
- Clamp closure
- Scissors
- Water and tissues
- 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 \( \frac{1}{8} \) 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 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 \( \frac{1}{2} \) 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.

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 $\frac{1}{8}$ 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.