

## *Having a Ileostomy*

– *A Primer for New Ostomates* –

Penelope Allen, B.A.  
and Cheryl Van Horn, B.S., M.T., E.T.



THE CLEVELAND CLINIC FOUNDATION

9500 Euclid Avenue  
Cleveland, Ohio 44195

Produced by the Department of Graphic Services / PWO 872 10/99





---

*for further information, contact*

**UNITED OSTOMY ASSOCIATION, INC.**

19772 MacArthur Blvd., Suite 200  
Irvine, CA 92612-2405  
(949)660-8624  
(800)826-0826  
E-mail: [uoa@deltanet.com](mailto:uoa@deltanet.com)  
Internet: [www.uoa.org](http://www.uoa.org)

**WOUND, OSTOMY & CONTINENCE NURSES SOCIETY**

1550 S. Coast Highway, Suite 201  
Laguna Beach, CA 92651  
Phone: (888) 224-WOCN  
Fax: (949) 376-3456  
E-mail: [membership@wocn.org](mailto:membership@wocn.org)  
Internet: [www.wocn.org](http://www.wocn.org)

**CROHN S & COLITIS FOUNDATION OF AMERICA**

386 Park Ave. South, 17<sup>th</sup> floor  
New York, NY 10016-8804  
(212) 685-3440

**AMERICAN CANCER SOCIETY**

(your county unit)

---

**This booklet is written in consultation with:**

*Victor W. Fazio, M.B., B.S., F.R.A.C.S., F.A.C.S.*

*Crina V. Floruta, R.N., E.T.*

*Nancy Heim, Medical Illustrator*

*Barbara J. Hocevar, R.N., B.S.N., E.T.*

*John Oakley, M.B., B.S., F.R.A.C.S.*

*Pamela J. Payne, R.N., B.S.N., E.T.*

*Olga Ramos-Wilson, R.N., E.T.*

*Leslie R. Schover, Ph.D.*

*John Sharp, L.I.S.W.*

*Marilyn Spencer, R.N., E.T.*

*Frances J. Tyus, R.D.*

*Joan Van Niel, R.N., M.A., E.T.*

*Frank L. Weakley, M.D., F.A.C.S.*

---

**Crohn s & Colitis Foundation of America**

Questions and Answers about Ileitis and Colitis

*(with glossary of inflammatory bowel disease terms)*

Questions and Answers about Diet and Nutrition in Ileitis and Colitis

Questions and Answers about Pregnancy in Ileitis and Colitis

Questions and Answers about complications of Ileitis and Colitis

Crohn s Disease and Ulcerative Colitis and Your Child

*(a booklet for children and teenagers)*

Questions and Answers about Emotional factors of Ileitis and Colitis

A Teacher s Guide to Crohn s Disease and Ulcerative Colitis

## suggested reading

---

- Jeter, K., **These Special Children**, Bull Publishing Co., Palo Alto CA, 1980.
- Kushner, H.S., **When Bad Things Happen to Good People**, Avon Publisher, New York, 1983.
- Mullen, B., and McGinn, K.A., **The Ostomy Book: Living Comfortably with Colostomies, Ileostomies, and Urostomies**, Bull Publishing Co., Palo Alto CA, 1980.
- Phillips, R.H., **Coping with an Ostomy**, Avery Publishing Group Inc., Wayne, New Jersey, 1986.
- Siegel, B.S., **Love, Medicine, and Miracles**, Harper & Row, New York, 1986.
- Simonton, O.C., and Matthews-Simonton, S., **Getting Well Again**, Bantam Books, New York, 1978.

## brochure publications

### **United Ostomy Association**, publications

- Sex and the Female Ostomate
- Sex and the Male Ostomate
- Sex, Courtship, and the Single Ostomate
- Ostomy Quarterly* (magazine)
- Ileostomy Brochure

## table of contents

---

Introduction .....	2
Who Has an Ileostomy and Why .....	3
The Digestive System .....	4
How a Ileostomy Changes Your Body .....	6
Wearing a Pouch .....	10
What to Expect After Surgery .....	12
Adjusting to an Ileostomy .....	13
Daily Living .....	15
Hygiene and Skin Care .....	15
Diet .....	16
Gas and Odor .....	18
Flood Blockage .....	18
Diarrhea .....	19
Dehydration .....	19
Medication and Medical Procedures .....	20
Physical Activity .....	21
Travel .....	22
Intimacy .....	23
Reimbursement for Supplies .....	25
Questions and Answers .....	28
Suggested Reading .....	32

## introduction

---

An ILEOSTOMY can save your life. But having one also means change. This booklet will help answer your questions about these changes, how to live with them, and how to cope with some of the feelings you may have about them.

Of course, this booklet cannot answer all your questions, so please ask questions of your own. At the back of the booklet, there are blank pages you can use to write down questions as you think of them and the answers when you hear them. Questions that other patients have asked are answered there, too. Remember, there is no such thing as a silly question.

As you learn about your disease and ileostomy surgery, it may help you to know that you are not alone. Each year about 200,000 people in the United States have this surgery—people of all ages (even newborn babies), in all walks of life. There are literally millions of healthy, active people who continue to enjoy full lives ten, twenty, even forty years after their surgery.

In addition to your doctor and enterostomal therapy nurse (ET), many other people are willing to help you with advice and emotional support. You can contact them through the:

**UNITED OSTOMY ASSOCIATION, INC.**  
19772 MacArthur Boulevard, Suite 200  
Irvine, CA 92612-2405  
(949)660-8624  
(800)826-0826  
E-mail: [uoa@deltanet.com](mailto:uoa@deltanet.com)  
Internet: [www.uoa.org](http://www.uoa.org)

If you would like to talk to a UOA visitor while you are still in the hospital, your ET nurse can arrange this for you.

---

### **Why should I take ostomy supplies if I go to the hospital?**

The hospital may not carry the exact type of supplies you need, or you may arrive when access to the ostomy supplies is limited. Always carry your own spare equipment.

### **How much equipment should I take when I go on a trip?**

Take twice the amount that you usually need for that period. Also, take a list of retailers in the community you are visiting. These lists are available from the manufacturers.

### **How often should I see a surgeon or ET nurse about my ileostomy if I am not having any problems?**

You will be advised about this in the course of your general follow-up. In general, a check on the stoma is recommended every two to three years.

### **Should I get a note from my doctor so I do not have to wear my seatbelt in the car?**

No. A seatbelt can be adjusted to accommodate the stoma and the pouch. Your safety far outweighs the minor inconvenience of a seatbelt.

### **Will medications be as effective with an ileostomy?**

Medications for the ileostomate should be prescribed in liquid or tablet form. Enteric coated pills often pass through the body unabsorbed. Discuss this with your physician and pharmacist.

---

### **Where should I change the pouch?**

The pouch should be changed in the bathroom. This a procedure for managing body waste, and the bathroom provides the proper environment for this.

### **What do I do about odor while I use a public restroom or the bathroom at a friend s home?**

Do not worry about it. That is what bathrooms are for. If you are concerned about odor, you can carry a pocket-sized room deodorizer spray. Flushing of the toilet is usually adequate.

### **When I empty the pouch, it splashes. How do I prevent soiling myself?**

Float a few sheets of toilet paper in the toilet before you empty the pouch. Another method is to flush the toilet while you are draining the pouch.

### **Can I get my supplies at the drug store?**

Ostomy supplies are available in surgical supply houses. Very few drugs stores carry these specialty items. Your ET nurse should give you information about local and mail order sources of supply when you are discharged from the hospital.

### **Where should I store my ostomy supplies?**

They should be stored in a cool, dry place.

### **What if the pouch leaks and I am away from home?**

ALWAYS carry a spare set of supplies in case a leak occurs.

---

## **who has an ileostomy and why**

People who need ileostomy surgery have a disease, defect or injury in the large intestine serious enough that the large intestine has to be removed or disconnected. The most common reasons are ULCERATIVE COLITIS and CROHN S DISEASE.

With ULCERATIVE COLITIS, the large intestine is inflamed and has ulcers (sores) on the inner lining. This may cause cramps, pain, diarrhea, and discharge of blood and mucus. The disease can affect all or part of the large intestine. Ulcerative colitis is cured when the diseased parts are removed.

Symptoms of CROHN S DISEASE are like those of ulcerative colitis and include cramps, loose stools, fever, weight loss, and a general feeling of ill health. Unlike ulcerative colitis, Crohn s disease is not always confined to the large intestine, but can also occur in the small intestine and, in rarer cases, elsewhere in the digestive system. Unlike ulcerative colitis, Crohn s disease affects all layers of the intestines, not just the inner lining. When this disease affects the lower small intestine (ileum), it is called CROHN S ILEITIS. CROHN S COLITIS affects only the colon. CROHN S ILEOCOLITIS affects both the ileum and colon. CROHN S PROCTITIS means the rectum is affected.

Some other reasons this surgery may need to be done are cancer, familial polyposis, birth defects, and injuries to the abdomen that puncture or bruise the intestine. Ask your doctor to write down your diagnosis and explain it for you and your family.

You diagnosis is: \_\_\_\_\_



## *the digestive system*

---

Knowing what your digestive system looks like and how it works will help you understand your surgery and how your digestive system will work afterward. The digestive system is a hollow tube that starts at the mouth, where you take food into the body, and ends at the anus, where waste passes out. In between are the esophagus, the stomach, the small intestine (small bowel), and the large intestine (large bowel, meaning colon and rectum). Figure 1 shows what the system looks like.

Digestion starts in the mouth where you break up the food by chewing, and chemicals in your saliva, called enzymes, start to break the food down into nutrients the body can use. When you swallow, the food mixture travels down the esophagus to the stomach. There the stomach's action and strong digestive juices and more enzymes break the food down into a soupy mixture. This mixture then passes to the small intestine.

In the small intestine, the mixture becomes even more liquid. Here, most of the nutrients your body needs are absorbed into the bloodstream to nourish all parts of the body, after further processing by the liver.

The small intestine is divided into three sections. The first part, called the duodenum, is only about 12 inches long. This is where more enzymes and digestive juices from the liver and pancreas are added. The second part, which is about eight feet long, is called the jejunum. This is where most of the nutrients are absorbed. The last portion, called the ileum, is about 10 to 12 feet long and is where more nutrients are absorbed. By the time the mixture has gone through these last two parts (the jejunum and ileum), almost all the nutrients and fluids your body can use have been absorbed into the blood.

---

### **If the stool is already liquid to pasty, how do I know if I have diarrhea?**

The stool will nearly always be a liquid to pasty consistency. When you have diarrhea, the volume will increase. Many times there will also be fever, cramping and nausea.

### **Should I shower or bathe with the pouch on or off?**

That is entirely up to you. There is no health reason why you cannot bathe with the pouch off. Remember that the ileostomy may function while you are washing. If that is distasteful to you, bathe or shower with the pouch on, or pick a time when your stoma is least likely to function—the first thing in the morning before you have anything to eat or drink.

### **What if water gets inside the stoma?**

This will not happen. The wave-like motions of the bowel (peristalsis) move the bowel content in one direction—out of the body. Water would not be harmful, though, if it did get inside the stoma.

### **How often should I empty the pouch?**

Empty the pouch when it is one-third full. This can be about five to seven times a day. This is about the number of times most people use the bathroom to urinate.

### **Should I rinse the pouch each time I empty it?**

No. It is not necessary to rinse the pouch every time you empty it, but you may rinse as often as you wish. For aesthetic reasons, some people with ileostomies like to rinse the pouch first thing in the morning and before going to bed. Be sure to wipe the spout clean with each emptying, because residual stool can be a source of offensive odor. Rinse the clamp from time to time as well.

## questions and answers

### Can I do the same things I used to do before I was sick?

Yes, and maybe a few more as your health improves after surgery. The few exceptions are heavy lifting (especially in the first three months after surgery) and contact sports that may result in a blow to your abdomen. If you have specific questions about this, ask your doctor.

### Will the stoma hurt when it is touched?

It will not hurt when it is touched. You will feel pressure, but not pain. For this reason the stoma must be protected from contact injury like blows or chronic rubbing or pressure. There are no pain nerve endings in the stoma.

### Why is the stoma red?

It is red because this is the color of the inner lining of the digestive system. When the stoma is surgically constructed, the ileum is folded back on itself to form a type of cuff.

### Will the stoma always stay red?

Yes, it will always stay red because the lining of the intestine has a rich blood supply.

### What color will the stool be?

When the ileostomy begins to pass stool, the color of the stool will be dark green to greenish brown. When one begins to resume eating, the stool color changes to brown. Sometimes food remnants can be identified in the stool. This is normal. Large quantities of highly colored foods such as licorice (black) or tomato sauce (red), change the color of the stool. Iron pills, for example, cause the stool to be black. Check with your physician for specific information about medication and the effect on stool color.

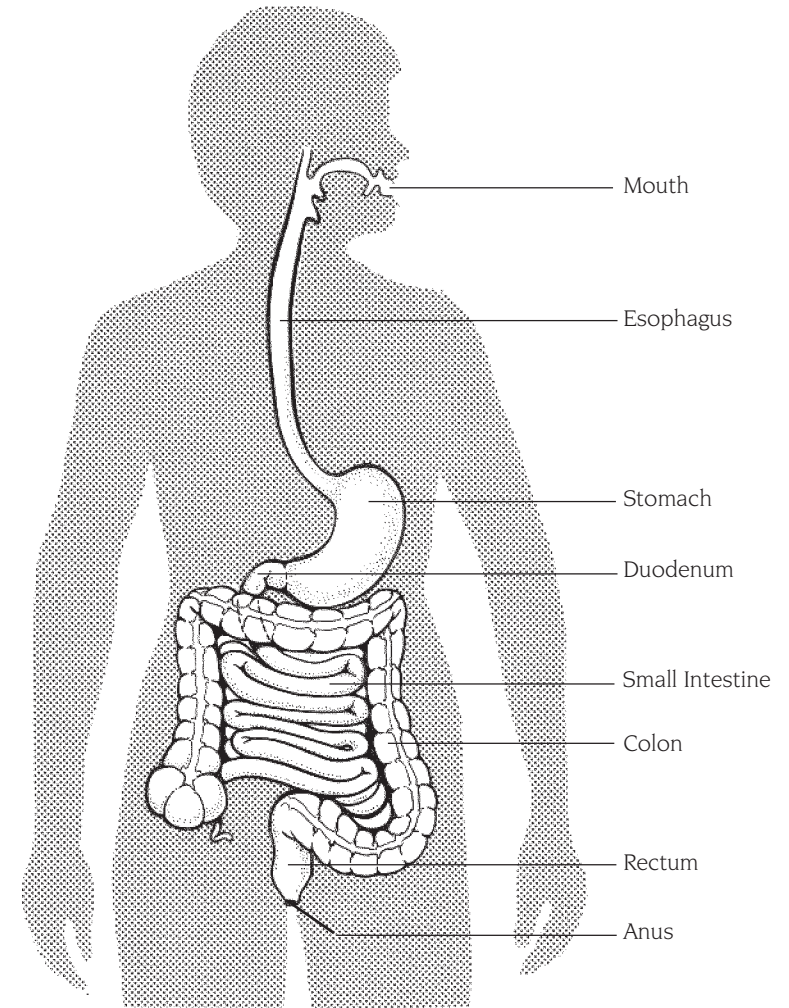


FIGURE 1: The Digestive System

---

The colon, rectum, and anus are the last sections of the digestive system. Although they are part of the system, they have little to do with digesting food or absorbing nutrients. You could think of the large intestine (which is the colon and rectum) as the body's trash compactor. As the colon and rectum absorb fluid, the left-over waste becomes more solid, forming stool. Stool is stored here until it is time for you to have a bowel movement. The strong muscles in the anus, called sphincter muscles, let you control the exit of stool from the body.

If your large intestine is so diseased that good medical treatment cannot keep you from being disabled, your large intestine must be removed or disconnected. Because the important job of absorbing nutrients and vitamins is taken care of in the small intestine, you can still maintain good health and nutrition without the large intestine.

## *how an ileostomy changes your body*

---

When your large intestine is removed or disconnected, a new opening must be made in the ileum where waste can leave your body. This opening is called an ILEOSTOMY. An ileostomy is permanent if the rectum and anus also have to be removed. If they do not have to be removed, the ileostomy may be temporary. To construct an ileostomy, the surgeon will bring one to two inches of healthy ileum through an opening on the lower right side (usually) of your abdomen, turn it back on itself like a small cuff, and stitch it just below your skin (see Figure 2). This is the ileal stoma, or ileostomy. (Stoma is the Greek word for "opening" or "mouth".)

---

## **veteran s administration:**

Veterans, depending on their eligibility and entitlement, may be able to obtain supplies from the pharmacy at the local VA medical center or outpatient clinic. Check with the local VA office.

---

4. Keep a record of all your claims.

5. Keep track of the amount NOT covered, since you may be able to deduct it from your income tax.

6. If your claim is denied, ask why and resubmit it with a letter from your doctor if necessary.

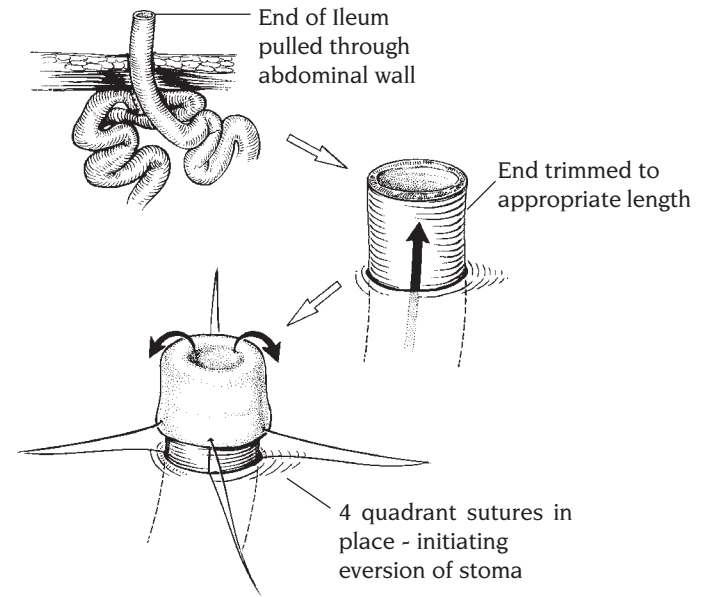
The following are some things to consider when you file for reimbursement with these specific agencies:

**medicare:**

If your Medicare care lists hospital insurance only, you do not have coverage for your supplies. You can elect to pay a monthly premium for additional coverage, and your card will then read, medical insurance coverage. In this case, Medicare covers a percentage of the ALLOWED cost of supplies after you pay the deductible. If you submit the Medicare claim yourself, attach your receipts or copies and a copy of your doctor's prescription to the form. Keep a set of receipts and the prescription as well as a copy of your claim.

**medicaid:**

If you are approved for coverage, show your identification card and your current month's validation card to your supplier. If your income and assets are low and/or your medical expense are high, you may be eligible. Some people who have Medicare and no other insurance are eligible. Check with your county Department of Human Services.



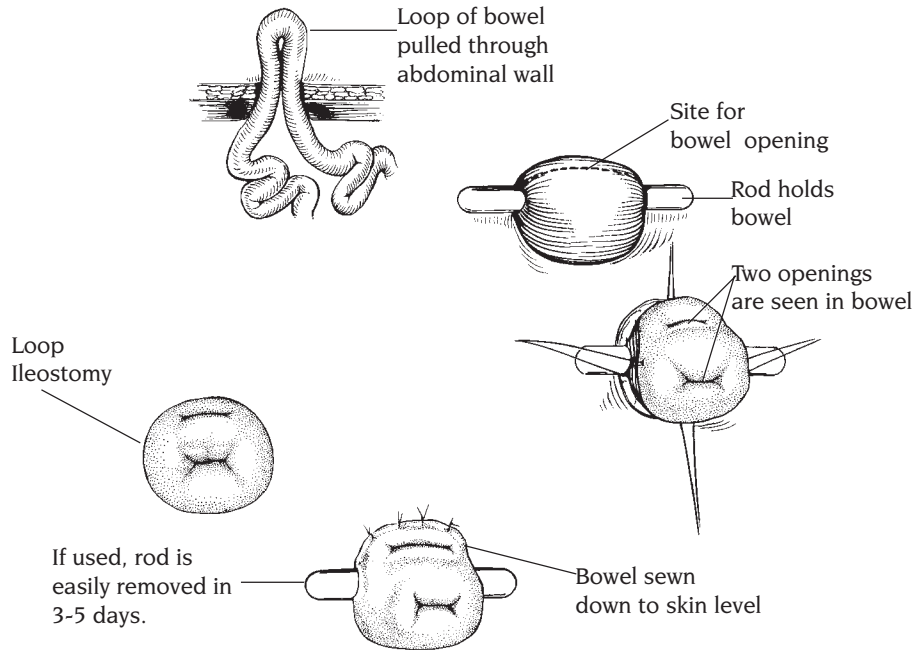
**FIGURE 2. End Ileostomy**

The stoma will usually measure about one and one half inches around and will be about one inch long. It will be moist and beefy red, much like the inside of your mouth. Because the blood supply is near the surface, the stoma stays red and bleeds easily with slight injury. This is not unusual. Unlike your anus, the stoma has no sphincter muscle, so you cannot control the exit of waste. You will need to wear a pouch (ostomy collecting device) at all times to collect the waste flow, much of which occurs soon after meals.

The stoma is made to protrude like a small faucet. This will help maintain a better and longer seal between your skin and the pouch. It will also help keep the digestive enzymes away from your skin to prevent skin irritation.

You can expect the new stoma to get smaller with time. In about six weeks to two months, it will shrink to its minimum size and will become softer.

## reimbursement for supplies



**FIGURE 3. Loop Ileostomy**

Not everyone will have a stoma like the END ILEOSTOMY we have just described. The surgeon may decide to construct a LOOP ILEOSTOMY. In this case, a small loop of intestine is brought through the abdomen. It is cut only half way through, leaving the intestine otherwise intact, but with two openings. Once again, the surgeon makes a "cuff" and stitches it to your body just below the skin (see figure 3).

The loop ileostomy is made for several reasons. Often it is used when the ileostomy is intended to be temporary. Sometimes it is done to ensure a good blood supply to the stoma or when the abdominal wall is thick. It is less complicated to close the loop ileostomy when the time comes. Not all loop ileostomies can be temporary.

Ileostomy supplies can be costly. But almost everyone with an ileostomy can be at least partly reimbursed by medical insurance, Medicare, Medicaid, the Veteran s Administration, the local Department of Human Services, or some social service agency.

Because ileostomy supplies are considered prostheses, just like artificial limbs, teeth or eyeglasses, they are deductible medical expenses on income tax returns. Check yearly tax codes for specific guidelines. Be sure to keep careful, complete records of your medical expenses for a year so that you will know whether you can deduct them.

Filing for reimbursement and following up your claims can sometimes be difficult and frustrating. Fortunately, most surgical supply companies will file your claims and follow them up for you, saving a lot of headaches.

### **Whether you file claims yourself or have a supplier do it for you:**

1. Have your doctor write a prescription for your supplies and have it renewed every year. Most insurance companies, Medicare, and other agencies require this evidence of your need for the supplies.

2. Keep good records. Save all your statements and receipts so you will have good tax records or evidence to follow up claims.

### **If you purchase supplies and file claims yourself:**

1. Check your policy or with the agency to find out whether you are covered for supplies. This may be under the category of durable medical equipment.

2. Be sure to use the right claim form.

3. Get a receipt for every purchase. Save copies of the receipts and attach the originals to your claim form. (Medical insurance companies often require the **originals**, not copies.)

---

In a man, if the rectum is removed, the nerves controlling erection may be affected. These are NOT the same nerves that control the sensation on the penis or the feeling of orgasm. For some men, erections recover with time. If not, a man should discuss the treatment options with his doctor. A few men may also experience dry orgasms - the feeling of climax without any seminal fluid. Dry orgasms feel just as good as normal ones to most men but may be a problem for fertility. A urologist may help with treatment for fertility.

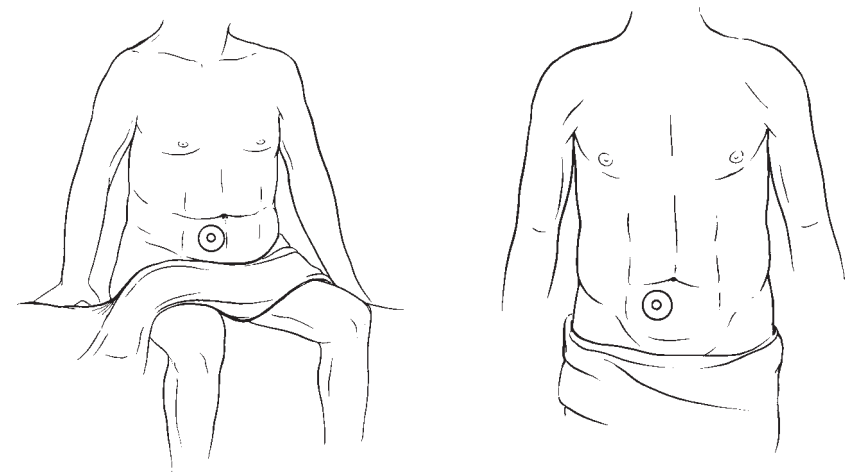
A woman's sexual response is not medically impaired by this surgery, but some women may experience pain with intercourse. Using extra lubrication or changing positions can help. If that is not enough, she should consult her doctor. A woman's ability to conceive and bear children is rarely affected.

Lovemaking itself does not have to change much. Empty the pouch beforehand. You and your partner may need to make some minor adjustments in positioning to avoid too much friction on your pouch, but contact during lovemaking cannot hurt your stoma.

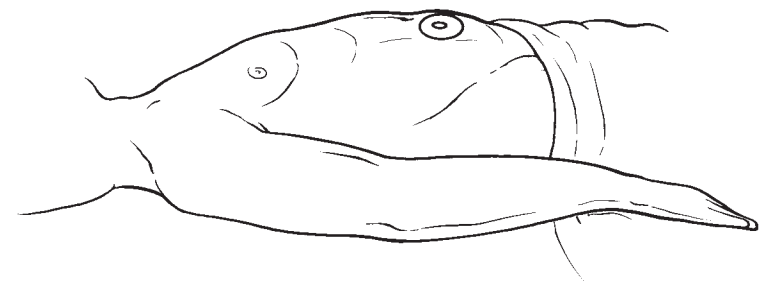
If you have any questions or concerns about sex and intimacy, do not hesitate to seek advice from your ET nurse, a sex counselor, or a trusted friend in the UOA.

---

The ET nurse and the surgeon will make every effort to place and construct the stoma so you can see it easily, take care of it yourself, and allow the pouch to fit well. Before you go to surgery, your doctor or ET nurse will find the best location for the stoma on your body. Because the shape of your abdomen changes as you move, they need to see you lying flat, sitting up, and standing (Figure 4).



**FIGURE 4. Stoma sitting in sitting, standing, and lying positions**





## wearing a pouch

---

Wearing a pouch (ostomy collecting device) is one of the biggest changes you will face after surgery. It takes getting used to, but it is not as difficult as you might imagine.

The basic piece of equipment is a pouch (made of odor-resistant plastic or vinyl) that collects the semiliquid waste. The pouches attach to your body with adhesive skin barriers that are custom-fitted by your ET nurse and do not irritate your skin. A closure at the bottom of the pouch allows you to empty it without removing it from your body (see Figures 5 & 6).

You should find it reassuring that the pouch will not be conspicuous. It is small and stays flat, so you do not have to wear baggy clothes. The pouch for adults measures only about 6 inches by 8 to 10 inches. It stays flat because you empty it about four to six times per day, about the number of times you use the bathroom to urinate.

Opaque pouches and fabric pouch covers keep the waste from being visible when you are undressed. The use of a fabric pouch cover also makes wearing the pouch more comfortable by reducing heat build-up between the plastic pouch and your skin.

Offensive odor does not have to be a worry either. Modern pouches are made of materials that confine odor to the inside of the pouch. The only time you should notice any odor is the time when you change or empty your pouch. Deodorants placed in the pouch, certain medications, and attention to food intake can control these odors. (You will find these discussed in the Daily Living section of this booklet, under "Diet".)

## intimacy

---

As you recover from your surgery and begin to resume or develop an intimate relationship, give yourself **and your partner** time. Try to resume or begin your sexual activity in a gradual, non-pressured way. After all, your partner needs to get used to and overcome any negative reactions to the way your stoma and pouch look, just as you do.

When you are intimate with your partner, there are a number of things you can do to feel attractive. Wear a smaller pouch for these occasions. Cover the pouch with a pleasing fabric. Wear a sexy undergarment that leaves the genital area free. Or wear a sash or cummerbund over the pouch. In addition, it may help to remind yourself that your stoma and pouch cover only a few square inches of your body, and the rest of you looks as good as ever.

Your attractiveness and sexual self esteem are a part of you and cannot be "removed" in an operation. If you already have a warm, satisfying relationship, remember that it cannot easily be destroyed.

A single person with an ileostomy should give a potential partner some time to come to value him or her enough as a person to overlook a physical imperfection. You do not have to tell a new friend about the ileostomy on the first date, but do not let it become a long-term secret. Someone who genuinely cares for you will accept you as you are. Even if you are single, you have a right to discuss your sexual concerns with your health care team. Single patients often need the most support in this area.

From a medical standpoint, ileostomy surgery does not impair the desire for sex or the nerves that control the orgasmic response. That means that touching in the genital area should feel normal and still lead to orgasm.

---

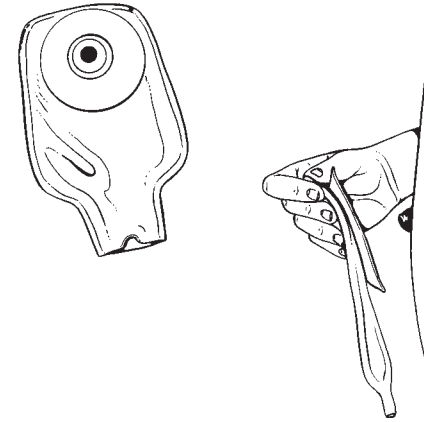
## travel

With a little planning, you can enjoy traveling as much as you like and where you like. Take plenty of supplies and medications along - double what you think you might need. Do not pack these supplies in luggage that you are going to check through. Carry them with you. If you cannot pack all the supplies you need for an extended trip, find out ahead of time where you can purchase them. You can get a list of equipment dealers from manufacturers, or check the Winter issue of the *Ostomy Quarterly* for a list of UOA chapters in the United States and Canada.

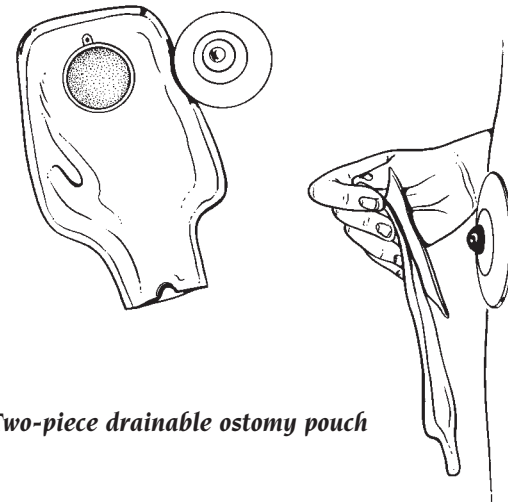
You also need to guard carefully against intestinal diseases, such as dysentery or traveler's diarrhea and giardiasis when you travel or camp where the water may not be pure. If the water is not pure enough to drink, do not use it for stoma care - for bathing with your pouch off, cleaning the skin around your stoma, or rinsing your pouch. Even pure-looking mountain streams in remote areas of the United States (in the East as well as the West) may have the *Giardia* parasite. Fortunately, there are water filters that remove it and most bacteria. These devices, which are available in most camping stores, are a good investment for travelers or campers who cannot carry bottled water.

---

The pouch should be changed about every three to seven days. After surgery, the ET nurse will teach you how to do this using the equipment that has been selected to fit your needs. Step-by-step instructions will be enclosed with your discharge folder. The ET nurse will also help you learn how to deal with other aspects of daily living, which are discussed in more detail in this booklet.



**FIGURE 5. One-piece drainable ostomy pouch**



**FIGURE 6. Two-piece drainable ostomy pouch**



## *what to expect after surgery*

---

Hospital stays after ileostomy surgery average from one to two weeks. Abdominal surgery is stressful for the body, and it takes some time to recover, so do not make a judgement about the results right away. Although you can expect to feel better soon, the first few days after surgery will be uncomfortable, and pain medication will be available if you need it.

When you return to your hospital room, you will be wearing a pouch that was put on after surgery. Your digestive system will not be active for a few days. When it does start to function, you will begin to drink liquids. As you improve, you can gradually begin eating solid food.

On the first days after surgery, the ET nurse will change your pouch for you. After a few days, you will begin to participate actively in your ileostomy care. You will start learning how to change the pouch by observing the ET nurse. Notice that she will have all the things she will need before she begins. You should do the same when you do it yourself. Among the items required are wipes or soapy wet clothes to clean the skin around the stoma, the pouch with its closure, the skin barrier (which fits against your skin around your stoma and attaches to the pouch), hypoallergenic or paper tape, and deodorant. The ET nurse should give you a sheet of step-by-step instructions for the equipment that has been selected to fit your needs. The next step will be to try changing the pouch yourself with the ET nurse standing by. The ET nurse will coach you through the process until you can confidently change the pouch on your own.

The ET nurse's support continues after you leave the hospital. You will see your ET nurse when you see your surgeon at four to six weeks, six months, and one year after you leave the hospital.

Vitamins can sometimes cause odor and are usually not necessary if you eat a balanced diet. If you had part of your ileum removed, your doctor may prescribe vitamin B<sub>12</sub>. Antibiotics may cause odor and may also cause diarrhea when they kill some helpful intestinal bacteria. Be sure your doctor has determined you have or must be protected against a bacterial infection before he or she prescribes an antibiotic. If you take one and have odor or diarrhea, refer to the previous section of this booklet for what to do. Although there has been some concern that women with ileostomies who use birth control pills may pass the pills intact, unwanted pregnancy is a very uncommon problem for these women. Other medications not discussed here, such as influenza shots and vaccines, may pose questions for you, so it is a good idea to discuss **ANY** medication you plan to take, even over-the-counter ones, with your doctor or pharmacist.

## *physical activity*

You will be able to resume physical activity gradually after surgery. The only limits you may have to place on yourself are on very heavy lifting and contact sports, such as football, wrestling, or karate where you could receive a direct blow to your abdomen. Heavy lifting, especially in the first three months or so after surgery, could cause a hernia. But after you recover, you should have no problems lifting and holding lighter weights, like small children or bags of groceries. Talk to your doctor about how much you can lift and when.

Keeping your pouch on securely for sports is easy to do. For active sports involving running or jumping, a sport brief or close-fitting underpants will hold your pouch snugly against your body. For times when you will get wet, either from perspiring heavily from exercise, the sauna, or from being in a pool or jacuzzi, you can temporarily use water-proof tape to hold the edges of the pouch to your skin. Your ET nurse can show you how to do this.

---

## medication and medical procedures

Tell your doctor and your pharmacist that you have an ileostomy; they can prescribe or dispense the right kinds of medications for you. You should not take enteric-coated pills and time-released or spansule medications. They have coatings that dissolve only after passing through the stomach or part of the small intestine and may not be released at all before they pass into your pouch. Soft pills, liquids, and injections are the best forms for your medication.

Laxatives are medications you should **NEVER** take unless prescribed by your doctor. They can cause cramps, diarrhea, and dehydration. Taking laxatives is **NOT** the way to solve a blockage problem. In the hospital, laxatives are often given before surgery or x-ray procedures to clear air and waste matter from the colon. Obviously, this is not necessary for you. A clear liquid diet (broth, tea, ginger ale, and jello) for 24 to 48 hours is all the preparation you need.

Enemas can damage your rectum if it has been left in place, and any probing of the anal area can damage tissues if your rectum has been removed. In the future, you may need to remind doctors or hospital personnel about laxatives and these medical procedures. Ask your doctor to write on your file or hospital chart: no laxatives, no enemas, no rectal temperatures at any time.

There are other medications you should use carefully, although you can usually take them. Diuretics (used to control high blood pressure, heart disease, water retention during menstrual periods, and other conditions) can be dehydrating. You may need to avoid these medications or take a diuretic that minimizes potassium loss and make adjustments in your salt and fluid intake.

---

When you come to the outpatient clinic, bring your ileostomy supplies with you. Meanwhile, of course, your ET nurse is available by phone if you have a problem. **Do not hesitate to call.**

Your ET nurse: \_\_\_\_\_

Phone: \_\_\_\_\_

Alternate ET nurse: \_\_\_\_\_

Phone: \_\_\_\_\_

---

## adjusting to an ileostomy

Living with an ileostomy takes some psychological adjustment in addition to the physical adjustment in daily living. It is not unusual to feel depressed after the body is surgically changed. There is a kind of grief for the old habits of daily life and the parts of the body that are gone. Remember that the old YOU is not gone. You are the same person you were before surgery.

Give yourself time. It takes about three months to recover just physically from major surgery. If you feel blue or frustrated with your progress, it helps to talk to someone who understands what you are going through. Call your ET nurse or a member of the United Ostomy Association (UOA).

A good way to chase the blues is to set small goals for yourself - goals you know you can reach. Then you can feel like you are accomplishing something. Did the mail pile up while you were in the hospital? Try answering one letter today, then another or two tomorrow. You could begin to exercise by walking a short, easy distance and going a little farther each day. Putting in a little time every day on a craft or a hobby helps give you a sense of achievement, too, because you can see the progress you are making. If the blues do not go away - if you have crying spells and trouble sleeping, especially in the very early morning, and for more than a few weeks - seek professional help through your ET nurse or doctor.

---

Feeling in control is an important key to well-being. Bowel habits are one of the first things we, as children, learn to control, thereby increasing our sense of independence, dignity, and well being. Naturally, it is disturbing to feel that you have lost that control. That is why it is so important to learn to change and empty the pouch yourself. The first few times may seem difficult, but it gets easier with practice. Knowing how puts you back in the driver's seat.

Feeling attractive is also important to a sense of well-being. It gives us confidence in social situations and sparks our intimate relationships. You may have negative feelings about the way your body looks with an ileostomy. These feelings may undermine your positive feelings about your appearance and your self-confidence.

One key to overcoming the negative feelings is to make some adjustments that help you continue to feel attractive. After surgery, you can gradually resume exercise to keep fit. Also, because the ileostomy pouch is not bulky and does not show under your clothes, you can continue to wear and build an attractive wardrobe. No one else, except your intimate partner, needs to know you have a stoma and wear a pouch unless you want to tell them.

---

**What to do:** The blockage may resolve on its own if you get into a knee-chest position by lying on your back and pulling your knees up to your chest, or by leaning far forward while you are in a sitting position. Warm compresses or a heating pad on your abdomen may help. Do not eat or drink anything for three to four hours. If the problem does not resolve in that time, call your doctor. **Do not take laxatives.**

**DIARRHEA:** Fibrous foods like raw fruit, broccoli, and green beans as well as beer, milk, and some spices may cause diarrhea. It may also be caused by the flu or food poisoning.

**What to do:** Eating mashed, ripe bananas, tapioca, boiled white rice, baked potato without skin, applesauce and increasing water intake may help. Since diarrhea makes you lose fluids and electrolytes (potassium and sodium), it is very important to prevent dehydration, too. Consult your doctor if diarrhea is prolonged.

**DEHYDRATION:** A person with an ileostomy is susceptible to dehydration. It can result from prolonged diarrhea, vomiting, or excessive sweating from fever, hot weather, or exercise. Signs of dehydration include warm skin, excessive thirst, abdominal cramps, low urine output, shortness of breath, and headache.

**What to do:** Replace fluids as well as sodium and potassium by drinking broth or athlete's beverages, like Gatorade. Eating bananas and using extra salt on your food can also help.

---

It takes a long time for your digestive system to fully recover. Eating regularly and at a leisurely pace, chewing well, and drinking plenty of liquids will help avoid problems with gas and odor, stoma blockage, diarrhea, and dehydration. You cannot thicken the waste or keep your stoma from functioning by fasting, skipping meals, or by not drinking fluids, nor can you make the waste more watery simply by drinking lots of water.

**GAS AND ODOR:** Foods that may cause gas are dried beans, onions, cabbage, eggs, fish, asparagus, melons, beer, carbonated drinks, and very fatty foods. Swallowing too much air or missing meals may also cause gas. Odor should not be a problem except when you change or empty the pouch. If you experience offensive odor at other times, your pouch may need to be changed or refitted.

**What to do:** Stir some of the carbonation out of the problem beverages before you drink them, avoid chewing gum and avoid gulping down food too fast. Also, avoid skipping meals. Odor can be controlled with deodorants, medications you take by mouth, and some foods. In addition to commercial pouch deodorants, vanilla or mouth-wash in the pouch works well. Bismuth subgallate, chlorophyll products, and charcoal products are useful odor-controlling medications you can buy over the counter. Foods that minimize odor include parsley, spearmint, yogurt, and buttermilk.

**FOOD BLOCKAGE:** The flow of waste may stop completely, or you may have thin, watery output, or a combination of lack of flow and abdominal cramps. In addition, there may be bad odor, vomiting or a swelled abdomen. Foods that may cause blockage are popcorn, corn, nuts, very fibrous fruits and vegetables, dried fruits, mushrooms, bean sprouts, and any food not well chewed.

---

## *daily living*

This section of the booklet will outline some adjustments you need to make in daily living with an ileostomy - how to practice good hygiene and skin care, how to manage your diet and medications, and how to prepare for physical activity and for travel. Once you learn these techniques, you will find that life with an ileostomy is not very different from life without one.

### *hygiene and skin care*

You can bathe or shower with your pouch on. As a matter of fact, you will be doing that most of the time, since you should remove your pouch only every three to five days. It is also OK to bathe or shower with the equipment off. Be aware that your stoma may function while your pouch is off, so plan a bath or shower before meals or first thing in the morning before eating or drinking.

Keeping the skin around your stoma clean is an important part of your ileostomy care. The waste that comes through your stoma contains digestive enzymes that can be very irritating when they contact your skin. If your skin does become irritated, your skin barrier will not stick as well, forcing you to change the pouch more often and permitting more irritation. When you wash around the stoma, be gentle. Use a clean, soft cloth and a small amount of non-oily soap. Do not be concerned if you see a little blood. Some bleeding is normal because the stoma has such a rich blood supply. Rinse and dry the skin well because soap or bath oil residue can keep the skin barrier from sticking. Use a hair dryer set on COOL or use an electric fan as gentle ways to dry your skin. A number of things can irritate skin, but you can avoid them. Here is how:

Cause of irritation	How to avoid it
Not cleaning well enough.	Clean the skin carefully every time you change the pouch.
Cleaning too roughly.	Wash gently.
Pulling out hair (you will see red dots around the follicles).	Shave the hair around the stoma very carefully with an electric razor or clip with round ended scissors.
Leaking waste under the appliance.	If this happens because your stoma has shrunk, see your ET nurse to have your skin barrier refitted. Refitting may be necessary because of weight gain, weight loss, or stoma changes. Do not try to fix a leak. Remove the pouch and skin barrier, clean your skin, and try again.
Chemical irritation or allergy.	Follow the directions carefully for using solvents, pastes, or cements. For example, you may need to let alcohol in the paste evaporate before you put the barrier against your skin. If you have an allergy to a pouching material, you can be refitted with a non-irritating brand.

Prevention is best, but if irritation develops, your ET nurse can advise you about what products to use and how to use them.

## diet

Except for the first **six weeks** after surgery, you can eat almost any food you want. As always, your meals should include a sensible amount of food from the four groups every day - dairy products, meat, and other protein sources, fruits and vegetables, breads and cereals. **Drink plenty of liquids. You must chew all food thoroughly.** If you had Crohn's disease or ulcerative colitis and could not eat normally before your surgery, you may develop a huge appetite now that you can eat whatever you want.

Take care to maintain your normal weight because excessive weight gain can affect the fit and wearing time of your pouch. If you remain underweight after you resume a normal diet, you may need calorie and protein supplements. Be sure to consult your dietitian and doctor about it.

During the first six weeks after surgery, you need to eat soft foods low in fiber to give your intestines a rest. A dietitian will give you detailed nutritional guidelines you can take home in your discharge folder. Here are some general guidelines for those first six weeks:

Include in your diet	Avoid the following
Cooked cereals without bran (like Cream of Wheat), white or part whole wheat bread, white rice, cornflakes, or puffed cereal.	Coarse-grained bread or bread containing fruit, nuts, and seeds.
Cooked, canned fruit (like applesauce); canned peaches and pears; fruit juices; soft fresh fruit without peels.	Fruit like coconut, dried fruit, pineapple, orange, apple.
Vegetable soups, creamed soups with rice or potato, soft-cooked vegetables, and vegetable juices.	Vegetables like corn, bean sprouts, celery, Chinese or stir-fry vegetables, cabbage-family vegetables, sauerkraut.
Eggs, most meats, poultry, and fish.	Shellfish, e.g. lobster, scallops, shrimp, crab.
Baked, steamed, boiled, or stewed foods.	French-fried foods.

The key to resuming a normal diet after six weeks is to experiment. Although the foods that may cause problems have been listed above, they may not cause problems for YOU. Add new foods to your diet one at a time. Then you can be sure which food bothers you. Just to be certain, try that food again after a week or so.