

# Having A Urostomy

*A Primer For The  
Urostomy Patient*

Cheryl Van Horn, B.S., M.T., C.E.T.N.



THE CLEVELAND CLINIC FOUNDATION

9500 Euclid Avenue  
Cleveland, Ohio 44195

***your questions***

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Urostomy Patient***

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***For further information, contact:***

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**United Ostomy Association, Inc.**

19772 Mac Arthur Boulevard  
Suite 200  
Irvine, CA 92612-2405

Phone: 949.660.8624 or 800.826.0826  
Fax: 949.660.9262  
Email: UOA@deltanet.com  
Internet www.uoa.org

**Wound, Ostomy & Continence  
Nurses Society (WOCN)**

1550 S. Coast Highway, Suite 201  
Laguna Beach, CA 92651

Phone: 888.224.WOCN  
Fax: 949.376.3456  
Email: Membership@wocn.org  
Internet: www.wocn.org

**Spina Bifida Association of America**

4590 MAC Arthur Blvd  
North West 250  
Washington D.C. 20007

Phone: 1.800.621.3141

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

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Pat Barrett, R.N., B.S.N., C.E.T.N.

Crina V. Floruta, R.N., B.S.P.A., C.E.T.N.

Nancy Heim, Medical Illustrator

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

Eric Klein, M.D.

Judy Landis-Erdman, R.N., B.S.N., C.E.T.N.

Drogo K. Montague, M.D.

Andrew C. Novick, M.D.

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

Leslie R. Schover, Ph.D.

John Sharp, L.I.S.W.

Marilyn Spencer, R.N., B.S.N., C.E.T.N.

Brenda Stenger, R.N., B.S.N., C.E.T.N.

Ralph A. Straffon, M.D.

Anthony J. Thomas, Jr., M.D.

Paula Erwin-Toth, R.N., M.S.N., C.E.T.N.

United Ostomy Association:

Sex and the Female Ostomate

Sex and the Male Ostomate

Sex, Courtship, and The Single Ostomate

Ostomy Quarterly (magazine)

Ostomy Brochure

## ***suggested reading***

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Jeter, K. ***These Special Children***, Bull Publishing Co., Palo Alto, CA, 1980.

Kushner, H.S. ***When Bad Things Happen to Good People***, Avon Publishers, New York, 1983.

Mullen, B., McGinn, K.A. ***The Ostomy Book: Living Comfortably With Colostomies, Ileostomies, and Urostomies***, Bull Publishing Co., Palo Alto, CA, 1980.

Philips, R.H. ***Coping With An Ostomy***, Avery Publishing Group Inc., Wayne, NJ, 1983.

Schover, Leslie ***For The Female Who Has Cancer And Her Partner***, American Cancer Society, 1988.

Schover, Leslie ***For The Male Who Has Cancer And His Partner***, American Cancer Society, 1988.

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***when to call your E.T. nurse***

1. If you have persistent leakage problems.
2. If you have skin irritation in the area of your urostomy pouch.
3. If you have difficulty locating retail sources for your urostomy supplies.
4. To help you locate the nearest U.O.A. support group.
5. If you are having difficulty resuming social and interpersonal relationships.

### ***when to call your urologist:***

1. If you notice extreme changes in the size or color of your stoma.
2. If you notice a marked decrease in your urine output that lasts for more than one day.
3. If you have persistent foul odor to the urine not explained by eating asparagus, onions, or garlic or by taking certain medications. Some antibiotics and some vitamins can produce unpleasant urine odor.
4. If you have a fever and/or pain in the kidney area.
5. If you have pain in or around the stoma.
6. If you have blood in the urine not explained by casual injury to the stoma.
7. For regular checkups.

## ***introduction***

Having a UROSTOMY can save your life; but having one also means changes. 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. Throughout 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 at the back of the booklet. Remember, there is no such thing as a silly question.

As you learn about your disease and urostomy surgery, it may help you to know that you are not alone. Each year thousands of people in the United States have this surgery—people of all ages (even newborn babies), and in all walks of life. Most are enjoying full, healthy, active lives years after their surgery.

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

19772 Macarthur Boulevard, Suite 200  
Irvine, CA 92612-2405  
**949.660.8624**  
**800.826.0826**  
**E-mail: UOA@deltanet.com**  
**Internet: 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.



## ***Who has urostomy surgery and why?***

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People who need urostomy surgery have a disease, defect, or injury to the urinary system serious enough that the bladder has to be removed or disconnected from the kidneys.

People of all ages may need this surgery, and approximately 25% of urostomy surgery is performed on children under nine years old. For them, birth defects account for most urostomy surgeries. The most common birth defects are:

1. **spina bifida** ( a defect in the spine that affects the nerves that allow a person to control bladder function and sometimes bowel function.)
2. **exstrophy of the bladder** ( meaning there is a failure of the abdominal wall to come together leaving the bladder open to the outside of the body.) This condition results in constant leakage of urine.

For adults, the most common reasons for urostomy surgery are:

1. **benign or malignant bladder disease**
2. **the effects of spinal cord injury.**

The reason for your urostomy surgery is \_\_\_\_\_

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## ***How will I know if I have a urinary tract infection?***

Along with the increased odor, the urine may change in color and become cloudy. If you experience fever, chills, and abdominal cramping or flank pain, call your urologist immediately.

## ***How much fluid is enough, and do coffee and tea count as a fluid?***

The recommended volume of **water** to be consumed daily is 8 to 10 glasses. Coffee and tea are not a substitute for water. Drinking plenty of fluids is an easy and effective method of preventing infections and helping the kidneys to function normally.

## ***When cleaning my reusable pouch, I notice a sandpaper-like crust on the inside of the pouch.***

### ***What is this?***

The “sandpaper crust” is probably crystals from strong alkaline urine that cling to the pouch wall. Sometimes they are sharp enough to scratch the stoma and cause bleeding. Soaking the pouch in vinegar will almost always dissolve them. It is a good idea to increase your fluid intake and to change the pouch more often if this happens.

## ***Why do I have to connect to bedside drainage at night?***

You don’t have to but while asleep, most persons produce more urine than the typical urostomy pouch can hold. You could train yourself to awaken at intervals during the night and empty the pouch in the bathroom. Most persons with urostomies find attaching the pouch to an overnight drain tube is far more convenient and restful.

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

The hospital may not carry the exact type of supplies you need. You may arrive when access to the ostomy supplies is limited. Every person with an ostomy should carry his or her own spare equipment.

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

Float a few sheets of toilet paper in the commode before emptying the pouch. Another method is to flush while draining the pouch.

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

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

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

Empty the pouch when it is one third full. This can be about five to seven times per day. This compares to the usual number of times most people without stomas use the bathroom to urinate.

***What causes the urine to have a strong odor?***

The most common reason is from not drinking enough fluids. Increase fluid intake. Some foods cause strong urine odor—especially asparagus and sometimes onions and garlic. An infection in the urinary tract is another source of odor. Certain drugs and vitamins may result in an offensive odor.

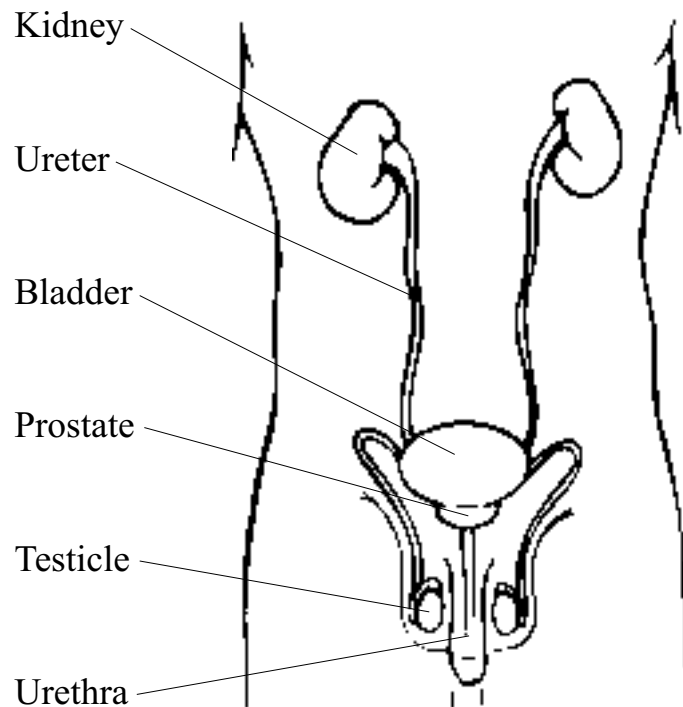
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***The Urinary System***

Knowing what your urinary system looks like and how it works will help you understand this surgery and how your urinary system will function after the operation. The system includes two kidneys, two ureters, one bladder, and one urethra. (See Figures 1A and 1B.) The two kidneys are lima bean-shaped and somewhat larger than your fist. They are located toward the back of the body on either side of the spine just above the hip bones. The kidneys filter blood through millions of tiny filters called nephrons, which flush out the body's waste products and return purified blood to the bloodstream. The kidneys maintain the balance of water and minerals in the body as well.

Each kidney empties the waste (now called urine) into a narrow muscular tube called a ureter. The muscular tube (ureter) squeezes the fluid through a one-way valve into the bladder for storage. Urine can then travel out of the body through a tube from the bladder called the urethra. Special nerves in the urethra allow a person to control the sphincter muscle that opens the urethra when it is a convenient time to urinate.

Kidney function and removal of urine from the body are essential for life. For this reason any condition that interferes with removing urine from the body can make urostomy surgery necessary.



**Figure 1A. The Genitourinary System (Male)**

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

Ostomy supplies are available from surgical supply houses. Very few drug stores carry these specialty items. You will be given local and mail order sources of supplies by your ET nurse when you are discharged from the hospital.

***What should I tell my small children/grandchildren has happened to me?***

When they ask, tell children the truth. It may be as simple a response as “I was sick, had an operation, and now I am well.” Or it may be more detailed. Listen to the question.

***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 the first three months after surgery,) and contact sports that may result in a blow to the abdomen. If you have specific questions about this, ask your physician or ET nurse.

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

The pouch should be changed in the bathroom. This is a procedure for management of body waste. The bathroom provides the proper environment for this.

***Should I get a note from my doctor so I don't have to wear my seat belt when traveling in the car?***

No. A seat belt can be adjusted to accommodate the stoma and pouch. The safety considerations outweigh the minor inconvenience of the seat belt.

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

ALWAYS carry a spare pouching system in the event a leak occurs.

## ***Frequently asked questions***

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### ***Will the urostomy hurt when touched?***

It will not hurt when it is touched. There are no sensory nerve endings in the stoma. You will feel pressure, but not pain.

### ***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,” exposing the inner lining.

### ***Will the stoma always stay red and moist?***

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

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

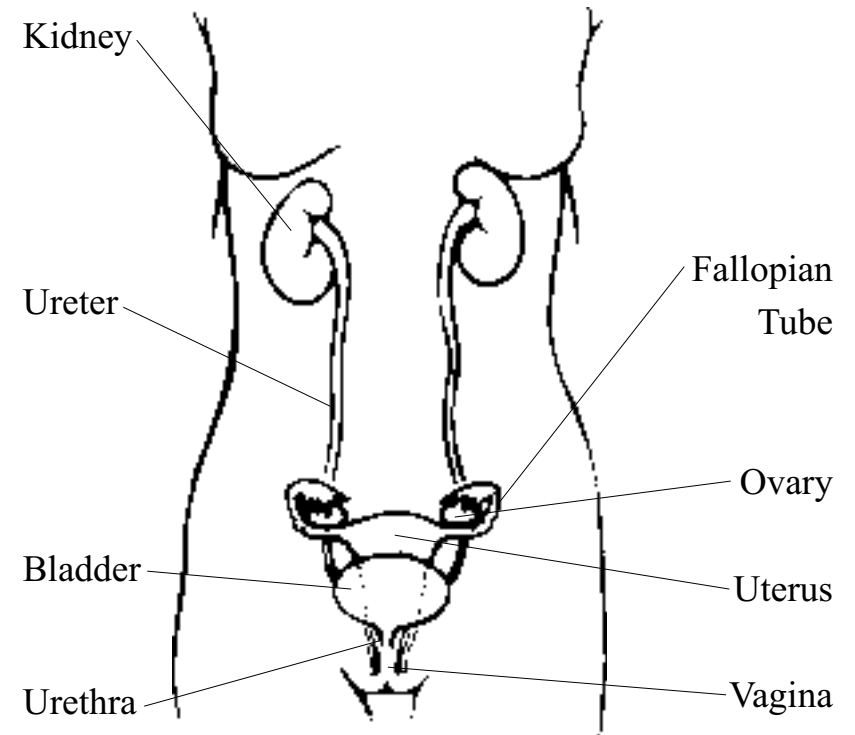
That is entirely up to you. There is no health reason why you cannot bathe with the pouch off. Remember that the urostomy may function while you are washing. If that is distasteful to you, bathe or shower with the pouch on, or pick a “quiet” time when your stoma is least likely to function- like first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

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

This won't happen. The wave like motions of the stoma (peristalsis) move the urine in one direction- out of the body.

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

They should be stored in a convenient, cool, dry place.



**Figure 1B. The Genitourinary System (Female)**

*notes or questions*

[illegible]

## *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 expenses are high, you may be eligible. Check with your county Department of Human Services.

## ***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.

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

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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.)
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 card 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.

### ***types of urostomy surgery***

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A urostomy is an opening in the body that allows the urine to bypass the bladder and urethra. The term urostomy comes from two Greek words, ouran meaning URINE, and stoma meaning OPENING or MOUTH. A urostomy can also be called a urinary diversion because it diverts the urine away from the disease, damage, or defect in the kidneys, ureter, bladder, or urethra. The diverted urine then flows out of the body through a surgically created opening on the abdomen called a stoma or ostomy.

There are different types of urinary diversions. The name of the diversion comes from the part of the body used to make the opening.

The most common type of urinary diversion is the ILEAL CONDUIT. About six to eight inches of small intestine (ileum) is separated from the digestive tract along with its own blood supply. (See Figure 2.) The intestine is then reconnected (See Figure 2A) so the digestive system remains intact and bowel function remains normal. The ureters are disconnected from the bladder and attached to the separated piece of ileum. The surgeon brings this piece of ileum through the abdomen and shapes a stoma or opening on the abdominal wall. The other end of the separated ileum (now called the conduit) is closed. The conduit does not store urine as the bladder once did. It serves as a passageway to direct the urine out of the body.

## *reimbursement for urostomy supplies*

Urostomy supplies can be costly. But almost everyone with a urostomy 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 urostomy supplies are considered prostheses just like artificial limbs, teeth, or eyeglasses they are deductible medical expenses on income tax.

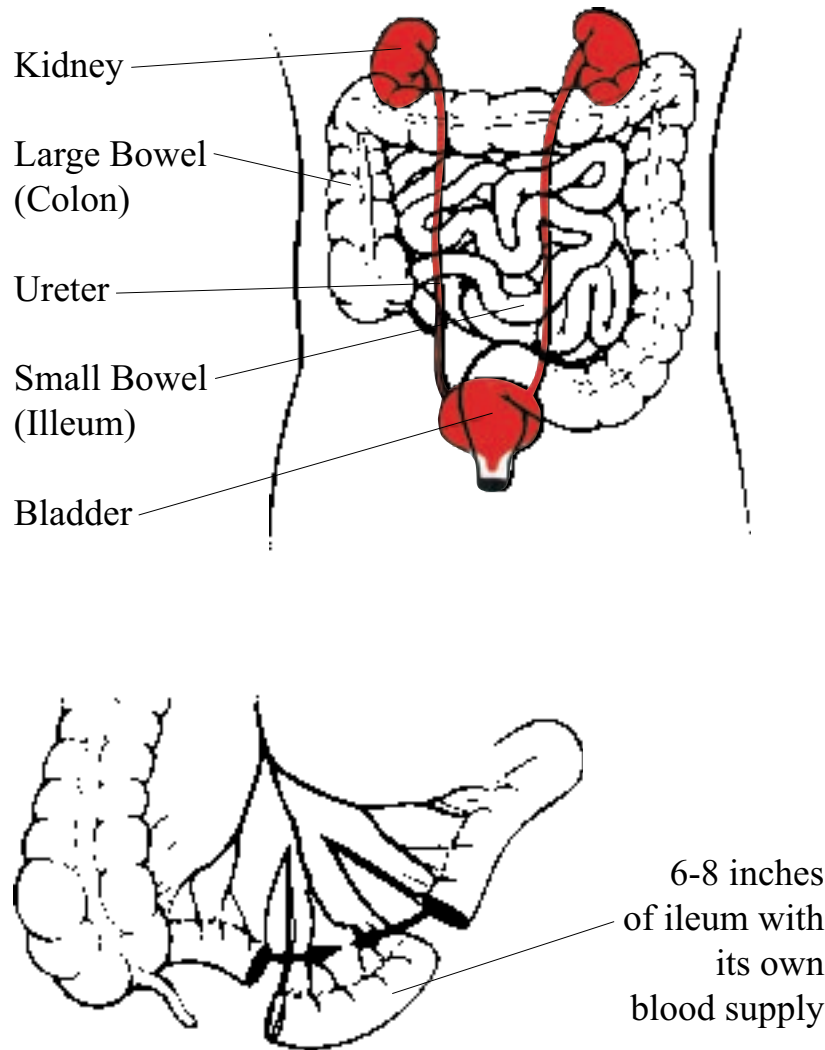
(Check yearly tax codes for specific guidelines.)

Be sure to keep careful, complete records of your medical expenses for a year so that you will know if you can deduct them.

Filling 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 you 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.

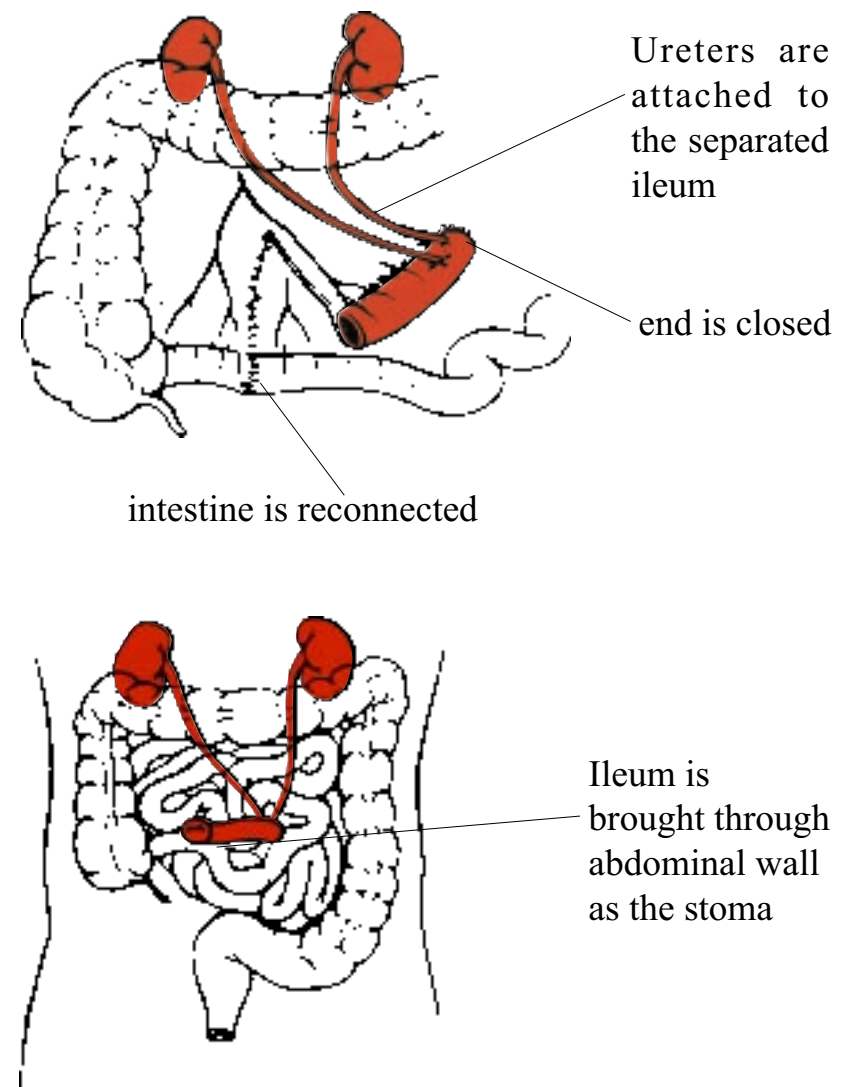


**Figure 2. Ileal Conduit Construction**

feel just as good as normal ones to most men, but he will not be fertile.

A woman's ability to achieve orgasm is rarely impaired by urostomy surgery. If a radical cystectomy is done, there is often reduced vaginal size and less vaginal moisture. A radical cystectomy in a woman means the bladder, uterus, ovaries, fallopian tubes, urethra, and front wall of the vagina are removed. Menopausal symptoms such as painful intercourse may be experienced. Using estrogen replacement, extra lubrication, or changing intercourse position can help. If a woman continues to have pain with sex, she should consult her doctor. If a radical cystectomy is performed, fertility is affected. If urostomy surgery is performed and a radical cystectomy is not necessary, a woman's ability to conceive and bear children is rarely affected.

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



**Figure 2A. Ileal Conduit Construction**



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To construct the END ILEAL CONDUIT stoma the surgeon will bring one to two inches of the intestine through an opening usually on the lower right side of your abdomen, turn it back on itself like a small cuff, and stitch it just below the skin. (See Figure 3.)

The stoma will usually measure about one to 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. There is no voluntary control of the flow of urine from the stoma because there is no muscle that opens and closes it like the sphincter that opened and closed the urethra (which will be removed or disconnected.) You will need to wear a pouch (ostomy collecting device) at all times to collect the urine flow. The section “Wearing a Pouch” later in this booklet will tell you more about it.

Often, the stoma is made to protrude above skin level like a small nipple. This will help maintain a better and longer seal between your skin and the pouch and will keep dampness away from your skin to prevent skin irritation.

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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 a urostomy should give a potential partner some time 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 urostomy 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, urostomy 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.

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.

In a man, if a radical cystectomy is done, the nerves controlling erection may be affected. A radical cystectomy means that the bladder, the prostate, upper urethra, and seminal vesicles are removed. The nerves that are affected by the surgery are not the same nerves that control the sensation on the penis, or the feeling of orgasm. A man can enjoy sexual activity and may reach orgasm without a full erection. Erection problems can be corrected with other treatment options. These options should be discussed with his urologist. After radical cystectomy men will experience dry orgasms - the feeling of climax without any seminal fluid. Dry orgasms

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## *travel*

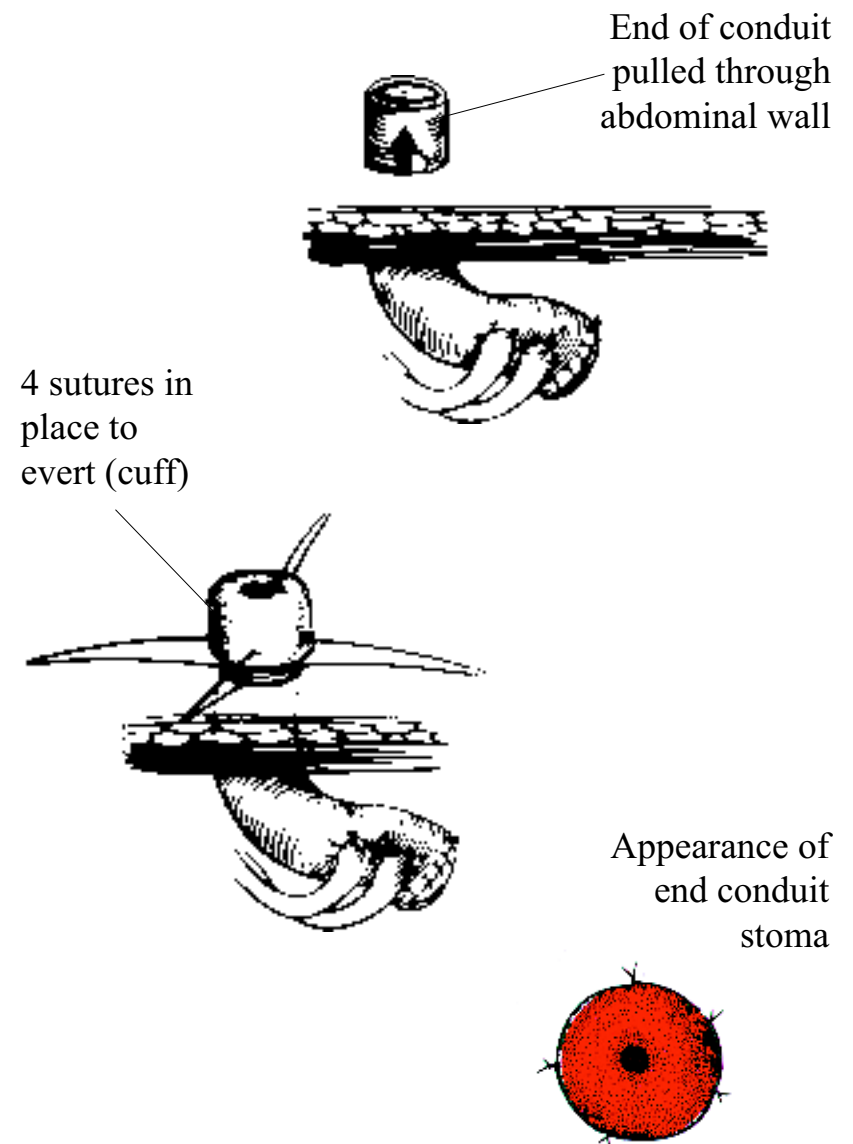
With a little planning, you can enjoy traveling as much as you like and wherever you like. Take plenty of pouching supplies and medications along - double what you might need. **Do not** pack these supplies in luggage that you are going to check through. Carry them with you. If you cannot pack all the 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. Check the Winter issue of the Ostomy Quarterly for a list of UOA chapters in the United States, Canada, and some other foreign countries.

## *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. Always empty your pouch before lovemaking and avoid foods that give a strong odor. If possible wear a smaller pouch for these occasions. Purchase or sew a pouch cover in 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.



**Figure 3. End Ileal or Colon Conduit**

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Not everyone will have a stoma like the END CONDUIT we have just described. The surgeon may decide to construct a LOOP CONDUIT. In this case, a small loop is made when the conduit is brought through the abdomen. (See Figure 4.) It is cut only halfway through, leaving the conduit otherwise intact, but with two openings.

Once again, the surgeon makes a “cuff” and stitches it to your body just below the skin. The loop conduit may be done to ensure a good blood supply to the conduit, especially when the abdominal wall is thick.

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It is comforting to know that the modern urostomy pouches are made from high-quality, odor resistant materials.

You may enjoy odor producing foods without fear of offending. Urine odor will be confined to the bathroom when you empty or change the pouch.

### *physical activity*

You will be able to resume physical activity gradually after surgery. The only limits you may have are 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 when and how much you can lift.

Keeping your pouch on securely during 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 or 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.

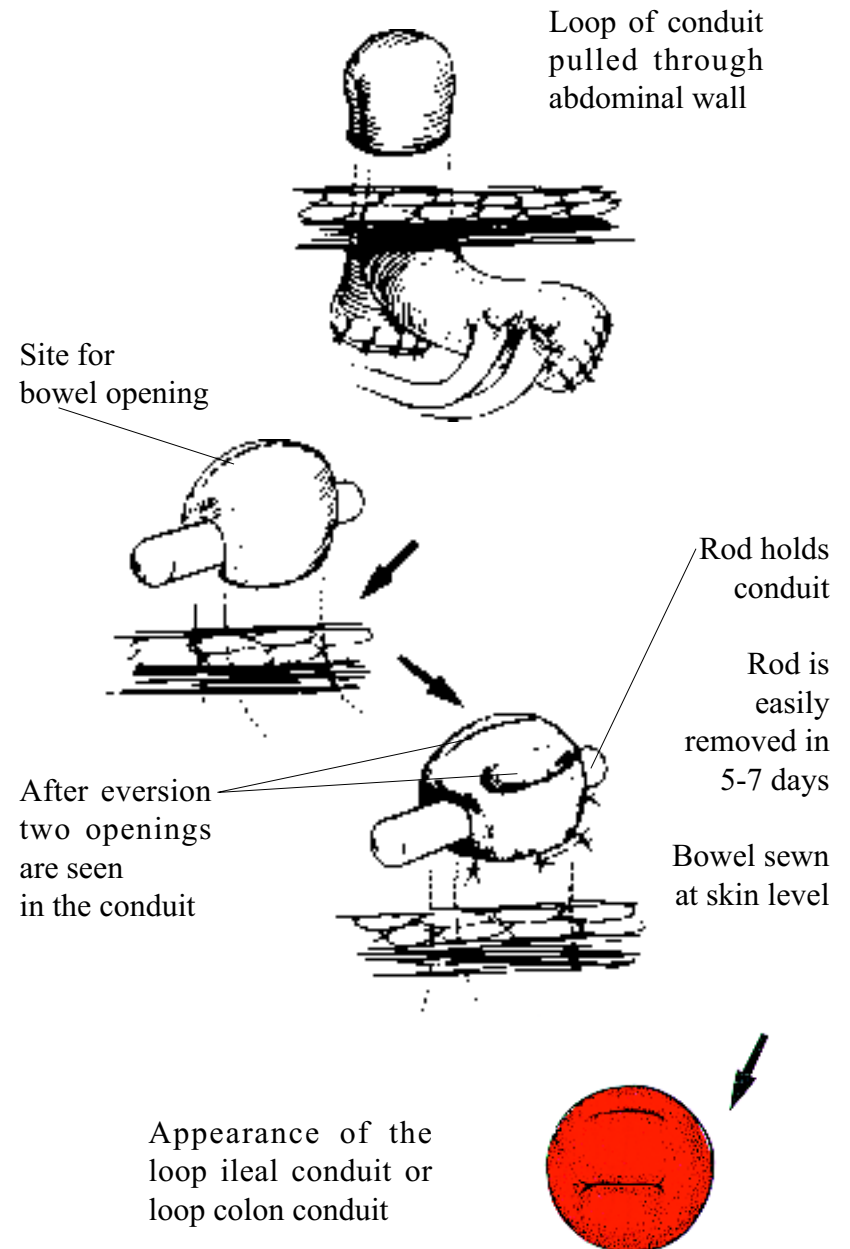
If the urine is alkaline, it will have a strong ammonia-like odor that could be a sign of infection. Alkaline, cloudy, discolored urine combined with chills, fever, and flank pain are signals to contact your urologist. If the physician thinks a urine culture for bacteria is necessary, there is a special way to collect the urine from the stoma by catheterization. This can be done by the physician or ET nurse, without discomfort for you. Urine from the pouch could give misleading information. If the test results show that you do have an infection, your physician will prescribe an antibiotic.

Alkaline urine does not always mean infection, but it can produce strong odor, skin irritation, and urine crystal formation. The crystals make the inside of the pouch feel “sandy” and can cause the stoma to bleed by having an abrasive effect. Again, drinking fluids is recommended to dissolve the crystals and promote urine acidity. Drinking cranberry juice also helps.

Many people report offensive odor in the urine after eating asparagus, garlic, onions, and certain spices. There is no health reason to eliminate these foods. Simply be aware that they can produce strong-smelling urine that may be a social concern.

Some people with urinary stomas may be using a two-piece pouching system and reuse the pouch for economy or for special fitting considerations. It is important that if the pouch is to be reused, it should be properly cleaned. Soaking the pouch in vinegar helps to reduce urine pouch odor and dissolve crystal deposits. Be sure the pouch passes the “sniff” test before you use it again.

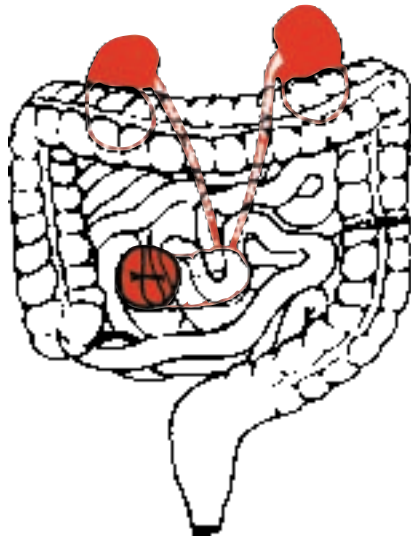
Some medications and some vitamins are responsible for strong urine odor. If you suspect this is the case and the odor is bothersome, consult your physician. He or she may be able to change the prescription.



**Figure 4. Loop Ileal or Colon Conduit**

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A COLON CONDUIT is made in a similar way using a piece of the colon (large intestine) rather than ileum (small intestine) for the conduit. (See Figure 5.) The one your surgeon selects to make the conduit depends on the condition of your intestinal tract.



**Figure 5. Colon Conduit**

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## ***Diet***

The person with a urostomy can resume a completely normal diet soon after surgery if there is no medical reason for a special diet, for example, diabetes, heart disease, kidney disease, or food allergy. If a colon or ileal conduit was performed, the digestive system is shortened by only a few inches. This is not a significant change in a healthy intestinal tract, so normal digestion returns quickly. It may, however, take several weeks for bowel movements to return completely to normal.

As always, and especially while convalescing, your daily meals should include a sensible amount from the four food groups- dairy products, meat and other protein sources, fruits and vegetables, and bread and cereals.

It is especially important to drink plenty of fluids. A person with a urostomy is more susceptible to infections of the kidneys and urinary tract. The easiest and most effective preventive measure is to drink 8 to 10 glasses of water daily. Diluted urine will have less mucus accumulation as well.

A weight gain or loss following urostomy surgery may result in improper fit of the pouching system. For this reason it is important for the ET nurse to remeasure the stoma from time to time.

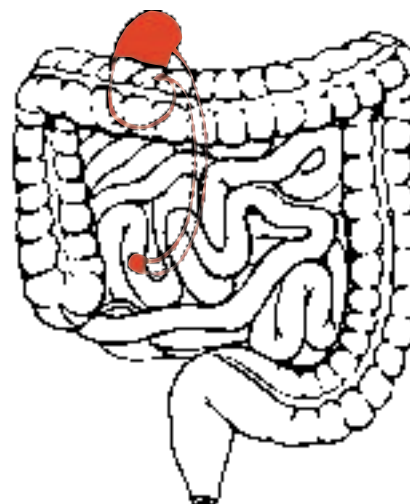
## ***Odor***

Fresh normal urine is usually acidic and has a characteristic but not offensive odor. The more dilute it is, the less likely it is to be offensive. This is another good reason for following the rule of drinking 8 to 10 glasses of water daily.

<b>Cause of irritation</b>	<b>How to avoid it</b>
Not cleaning well enough.	Clean the skin 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 urine under the appliance.	<p>If this happens because your stoma has shrunk, see your ET nurse to have your pouching system re-evaluated. Refitting may be necessary because of weight gain, weight loss, or stoma changes.</p> <p>Do not try to fix a leak. Remove the pouching system, clean your skin, and try again.</p>
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 pouching system against your skin. If you have an allergy to a pouching material, you can be refitted with a different brand.

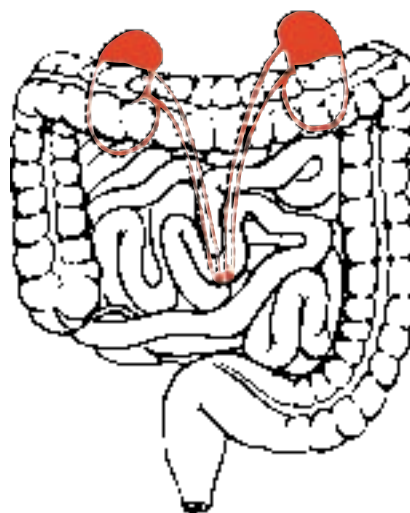
Prevention is best, but if irritation develops, your ET nurse can advise you about products to use and how to use them.

Less common types of urostomies do not use a conduit. Infrequently and for special circumstances, the ureters may be brought to the abdominal surface and used to create one, or in some cases, two stomas.



A **UNILATERAL URETEROSTOMY** involves one kidney and one ureter. The other kidney and ureter may be in place and functioning, or they may have been removed. (See Figure 6.)

**Figure 6.**  
**Unilateral**  
**Ureterostomy**

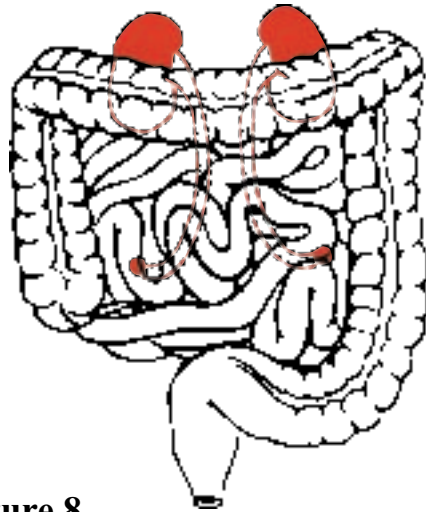


When both ureters are brought out side-by-side, they are called **DOUBLE-BARRELED URETEROSTOMIES** (See Figure 7.)

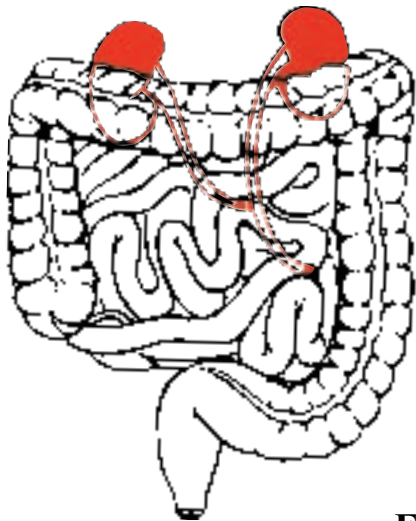
**Figure 7.**  
**Double-Barreled**  
**Ureterostomies**



**BILATERAL URETEROSTOMIES** mean there are two separate stomas. Each ureter is brought to the abdominal surface, one on each side of the body. This would require two separate pouches to collect the urine. (See Figure 8.)



**Figure 8.**  
**Bilateral**  
**Ureterostomy**



**Figure 9.**  
**Transuretero-ureterostomy**

**TRANSURETEROURETEROSTOMY** means that the ureters are joined inside the body and then one ureter is brought through an opening in the abdominal wall, forming one stoma and requiring one pouch. (See Figure 9.)

This section of the booklet will outline some adjustments you need to make in daily living with a urostomy, 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 a urostomy 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.

Keeping the skin clean around your stoma is an important part of urostomy care. If the urine, which flows constantly, comes in contact with your skin, it can be very irritating. Properly fitted equipment is a must to prevent this irritation. If your skin does become irritated, your pouching system will not hold as well, forcing you to change the pouch more often.

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 a rich blood supply. Rinse and dry the skin well because soap or bath oil residue can keep the pouching system from holding. Use a hair dryer set on COOL or an electric fan as gentle ways to dry your skin quickly. A number of things can irritate skin, but you can avoid them. Here is how:

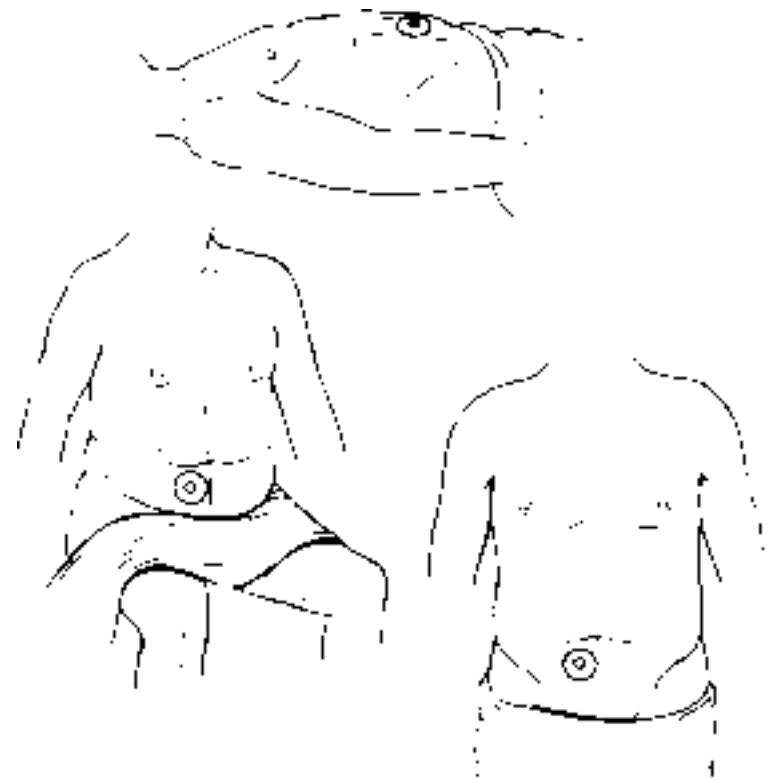
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Feeling attractive is also important to a sense of well-being. It gives us confidence in social situations and sparks our intimate relationships. You may have negative feelings about the way your body looks with a urostomy. These feelings can undermine 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 urostomy pouch is not bulky and does not show under clothes, you can continue to wear and build an attractive wardrobe. No one, except your intimate partner, need know you have a stoma and wear a pouch unless you want to tell them.

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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 (See Figure 10.)



**Figure 10.**  
**Stoma in lying,**  
**sitting and standing positions.**



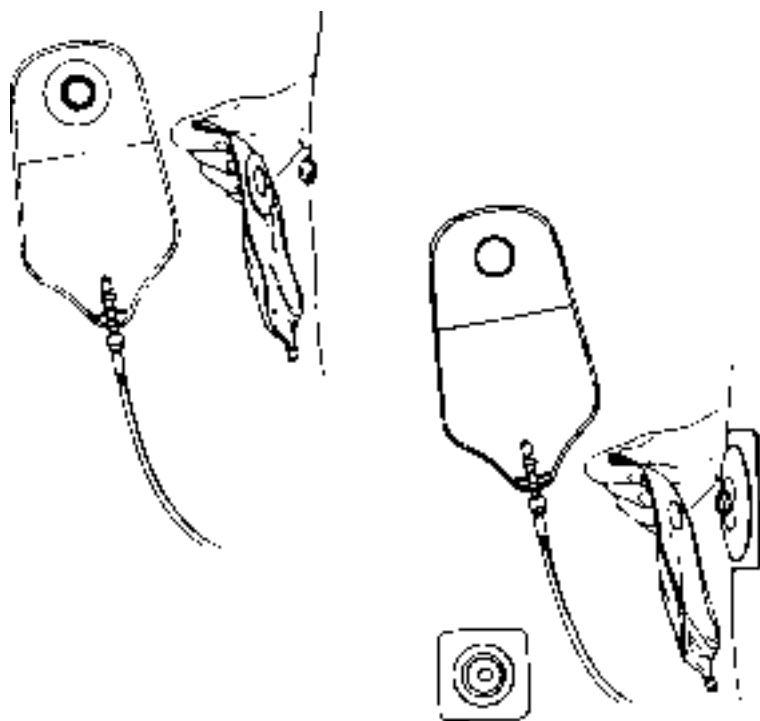
## ***Wearing a pouch***

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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 urine. The pouch, which is custom fitted by your E.T. nurse, attaches to your body with adhesives that do not irritate your skin. A spout at the bottom of the pouch allows you to drain the pouch without removing it from your body.

**Figure 11.**  
**One piece urinary pouching system.**



**Figure 12.**  
**Two piece urinary pouch system.**

## ***Adjusting to a urostomy***

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Living with a urostomy 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 part of the body that is 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 down 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 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 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. Urinary habits are one of the first things we, as children, learned to control, thereby increasing our sense of independence, dignity, and well-being. Naturally it is disturbing to feel 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.

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The ET nurse's support continues after you leave the hospital. You will see your ET nurse and your surgeon at four to six weeks, three to six months, and one year after you leave the hospital. When you come to the outpatient clinic, bring your urostomy supplies with you. Meanwhile, of course, your ET nurse is available by phone if you have a problem.

**DO NOT HESITATE TO CALL!**

**Your E.T. Nurse** \_\_\_\_\_

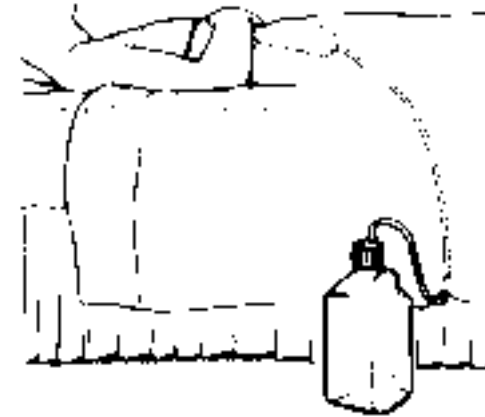
**Phone** \_\_\_\_\_

**Alternate E.T. Nurse** \_\_\_\_\_

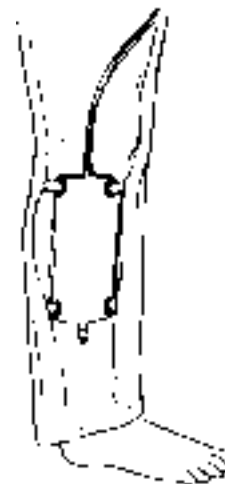
**Phone** \_\_\_\_\_

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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 six to eight times a day, or when it is one third full.



**Figure 13. Bedside drainage system.**



Using a special adapter, the spout can be connected to a bedside drainage bag or bottle (Figure 13) or leg bag (Figure 14) when a larger volume output is expected. This is often done at night so you don't have to disturb your sleep to empty the pouch.

**Figure 14. Leg Bag.**

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It is not unusual to see threads of mucus in the urine in the pouch, especially if the urostomy is an ileal conduit or colon conduit. Mucus is secreted by the glands in the intestine used to construct the conduit. The urine rinses the mucus from the conduit to the pouch. If you notice this mucus, do not be alarmed.

Opaque pouches and fabric pouch covers keep the urine from being visible when you are undressed. A fabric pouch cover makes wearing the pouch more comfortable by reducing heat buildup between the plastic pouch and your skin.

Offensive odor does not have to be a worry either. Fresh urine should not have an offensive odor. Odor can be caused by not drinking enough fluids, from certain medications, from a urinary infection, or from certain foods. (You will find these discussed in the “Daily Living” section of this booklet.) But usually, the materials used to make modern pouches confine odor to the inside of the pouch.

The pouch should be changed about every three to five days. A few persons can wear one for seven days. It is not recommended that you wear a pouch longer than this, even though it may be maintaining a good seal. To ensure good hygiene, the stoma and the skin underneath the pouched area should be thoroughly cleaned. This will prevent skin irritation, urine crystal buildup, urinary infection, and unpleasant odor.

About one week after your surgery, the ET nurse will teach you how to change the pouch that has been selected to fit your needs. The ET nurse will also guide you as you learn to deal with other aspects of daily living, which are discussed in more detail in this booklet.

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## *what to expect after urostomy surgery*

Hospital stays after urostomy surgery average from one to two weeks. Abdominal surgery is stressful for the body, and it takes 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. The urine will be flowing right away. The pouch you are wearing will be connected to a bedside drainage bag so the volume of urine can be measured easily. 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 foods.

The first day after surgery, the ET nurse will change your pouch. After about a week, you will begin to participate actively in your urostomy care. You will start learning how to change the pouch by observing the ET nurse. Notice that she will have ready all the things she needs before beginning. You should do the same when you change the pouch yourself. Among the items required are plain wipes or soapy wet cloths to clean the skin around the stoma, the pouch, the skin barrier (which protects the skin around your stoma), and hypoallergenic or paper tape. The ET nurse will give you a step-by-step instruction sheet for the equipment that has been selected to fit your needs. The next step will be to change the pouch yourself with the ET nurse standing by. The ET nurse will assist you through the process until you can confidently change the pouch on your own.