



# UROSTOMY GUIDE

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A publication of the United Ostomy Associations of America, Inc.

“SEIZE THE OPPORTUNITY...”

## *A Message To You...*

*Urostomy surgery is a lifesaving surgery that enables a person to enjoy a full range of activities, including traveling, sports, family life and work. Thousands of people annually undergo ostomy surgery for various reasons and return to a healthy, functioning lifestyle.*

*The United Ostomy Associations of America (UOAA) is a volunteer organization dedicated to helping those who have or will have ostomy or other diversionary surgery by providing one-on-one support, local support group meetings, conferences, and educational material through its web site, printed material and The Phoenix magazine.*

*You have many peers in the UOAA who are ready to answer your questions, provide support and reassure you that you can have a full, productive life after ostomy surgery.*

*We invite you to join us as we fulfill our mission in helping others.*

*From the United Ostomy Associations of America*

# **UROSTOMY GUIDE**

**Reviewed by Nancy Gutman, RN, CWOCN  
2011**

**Previously reviewed by: Jan Clark, RNET, CWOCN  
Helen DuBois, RNET**



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[www.ostomy.org](http://www.ostomy.org) • [info@ostomy.org](mailto:info@ostomy.org) • 800-826-0826

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# INTRODUCTION

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For the thousands of people every year suffering from bladder disease, urostomy (urinary diversion) surgery can be the beginning of a new and healthier life. If you have been burdened with a chronic or even life-threatening disease, after your initial recovery period you can look forward to feeling much better, and to resuming all the activities you have enjoyed in the past.

This booklet has been developed to help you better understand what is happening to you. Please read the following pages carefully. You will find a glossary in the back to help you with the technical terms. Many of the words will be used in your presence again and by doctors, your Wound Ostomy Continence Nurse (WOCN), hereinafter referred to as ostomy nurse, and in this booklet.

Urostomy is one of a number of surgical procedures that detour, or divert, urine away from a diseased or defective bladder. This booklet discusses only those operations which bring the urine to the outside of the body through an opening in the abdominal wall. The bladder is either bypassed or removed, and the urine is passed from the body through a surgically created opening called a stoma. You will not have voluntary control of the urine that comes out through the stoma, therefore a collection pouch will be fitted for your individual needs.

In addition to getting you ready for abdominal surgery, your doctor or your ostomy nurse will explain the surgery and examine your abdomen to determine the best location for the stoma. You may be asked to wear a sample pouch to make sure that the site chosen is on the flattest possible surface and that you are comfortable in all positions. If you have any hobbies or habits which might be affected by the location of the pouch, talk to the doctor or the ostomy nurse.

A special source of help is an ostomy visitor. The visitor is a person who, like you, has had urostomy surgery and has successfully adapted to the changes that occur with ostomy surgery. He or she can answer many of your questions about day-to-day life. You may also benefit from taking part in an ostomy support group. A support group allows you to share your feelings and ask questions as you make progress with your recovery. You can also share your story with others that may benefit from your experience. You can find a list of UOAA Affiliated Support Groups at [www.ostomy.org](http://www.ostomy.org) or by calling 800-826-0826.

## **FACTS ABOUT UROSTOMIES**

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A urinary diversion/urostomy is needed when the bladder is not functioning properly. There are four major reasons for performing a urinary diversion. The most common reason is for bladder cancer. Others include neurologic dysfunction of the bladder, birth defects and chronic inflammation of the bladder.

The urinary tract consists of two kidneys, two ureters, the bladder and the urethra. Urine is made in the kidneys, transported by squeezing movements called peristalsis through the ureters to the bladder for storage, and expelled through the urethra. One can live without a bladder, but must have a minimum amount of kidney function to grow and be healthy.

Should there be a malignancy (cancerous growth) in the bladder, the entire bladder may be removed or bypassed and the urine detoured through an abdominal stoma and patients may be cured of their disease.

Some patients find a urostomy easier to manage than a defective bladder that is caused by several reasons such as birth defect, surgery or spinal injury. With these bladder injuries, patients cannot control the flow of urine, causing them embarrassment and annoyance with skin problems that can occur with constant wetting. Some people have requested urostomy surgery over dealing with incontinence.

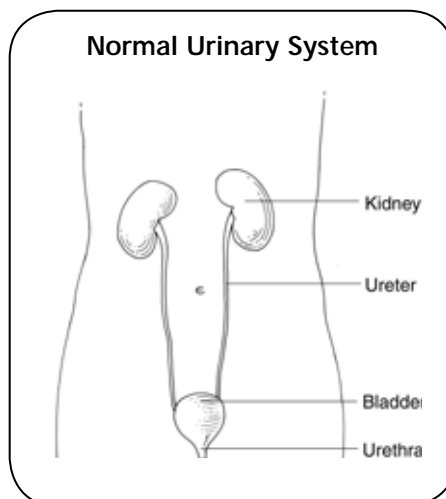
If a child is born with a defect in the urinary tract, causing the urine to back up into the kidneys resulting in chronic infection, a urostomy may be lifesaving. The surgical construction of a pathway through which the urine may travel rapidly, without interference, will allow the kidneys to function at their maximum efficiency.

There are two basic options for surgery: the conventional urostomy and the continent urinary reservoir. Not every person will be a candidate for the continent urostomy as there are factors that must be considered other than the person's preference. The surgeon, upon examination of a person's diagnosis, condition and surgical need, will present these considerations.

## **NORMAL URINARY SYSTEM**

**Kidneys:** The kidneys are paired organs lying behind the peritoneum, against the posterior abdominal wall, one on either side of the vertebral column. The kidneys serve a number of important body functions. They process and excrete urine, and maintain the fluid, electrolyte and acid/base balances of the body.

**Ureters:** The two ureters are tubes from the kidneys approximately 10-12 inches in length. They collect the urine as it is excreted from the kidneys. Peristaltic waves force the urine down the ureters into the bladder.



**Bladder:** The urinary bladder serves as a reservoir for urine. Periodically, the bladder expels urine from the body, via the urethra.

**Urethra:** The urethra is a tube from the bladder to the outside of the body.

## **CONVENTIONAL UROSTOMY**

### **Indications**

- cancer of bladder
- neurologic dysfunction
- birth defects
- chronic inflammation of bladder

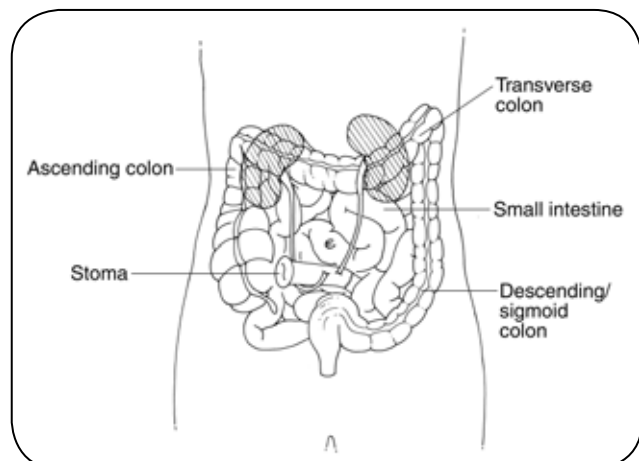
### **Discharge**

- urine
- some mucus

### **Management**

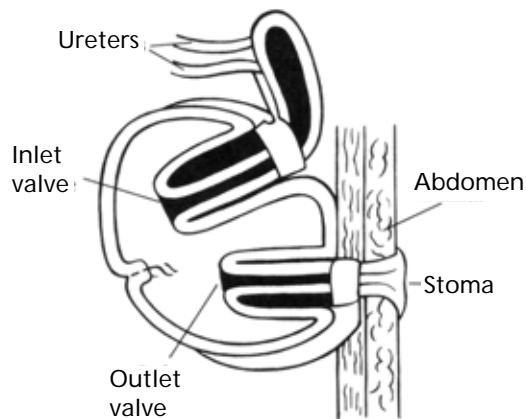
- skin protection
- drainable, valve-end pouch
- adaptable to night drainage

To create an ileal conduit, a segment of the small bowel (ileum) 6-8 inches long is excised near the entrance into the large bowel. The ileum is reconnected. The ureters are detached from the bladder and implanted into the ileal segment. The bladder may or may not be removed. The distal end of the ileal segment is brought through the abdominal wall and a stoma is formed on the abdomen, usually the right side. The proximal end of the ileal segment is sutured closed. This surgery is permanent. The urine is not controlled and will require wearing a collection pouch attached to the abdomen at all times.

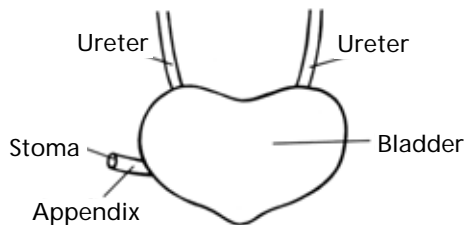


The small intestine produces mucous naturally. The segment of intestine that was used to form the ileal conduit will continue to produce mucous and will collect in the pouch.

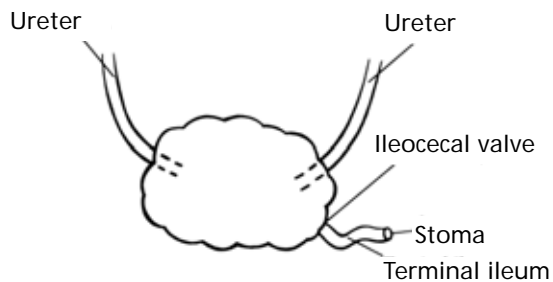
# CONTINENT UROSTOMIES



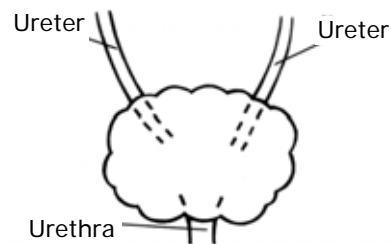
**Kock Pouch.** Pouch, valves and outlet are made from terminal ileum.



**Mitrofanoff Procedure (and variation).** Pouch is made from the bladder (large or small intestines or a combination of them). Outlet is made from the appendix (fallopian tube or ureter segment).



**Indiana Pouch.** Pouch is made from large intestine (ascending colon). Natural ileocecal valve is used for valve outlet made from terminal ileum.



**Ileal Neobladder.** Pouch is made from small intestine (ileum) and the outlet is the urethra (no stoma).

## UROSTOMY MANAGEMENT

Learning to care for your urostomy may seem like a complicated procedure at first, but with practice and your own adaptations, the entire process will become second nature, just like shaving or bathing.

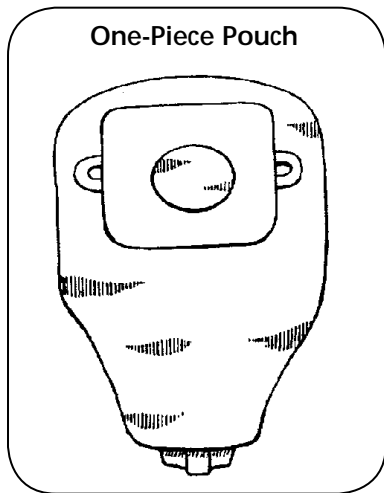
### Pouching Systems

A successful pouching system should provide the following:

- Security with a good leak-proof seal, lasting for 3-7 days
- Skin protection
- Be inconspicuous
- Easy to apply and to remove

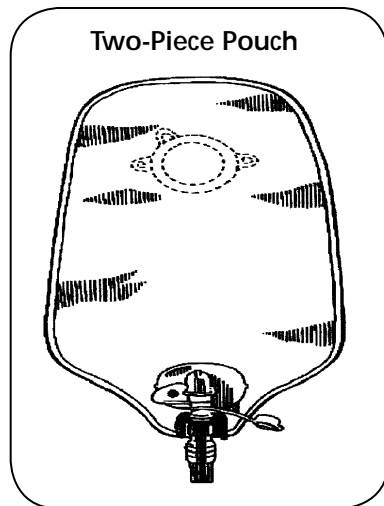


## UROSTOMY MANAGEMENT cont.



A pouching system is used to collect urine. There are two main types of systems available: one-piece pouches with attached skin barrier and two-piece systems composed of a skin barrier and detachable pouch. The skin barrier will require a hole to be cut for the stoma or may be purchased pre-cut to size.

Each urostomy pouch has a drain valve at the bottom of the pouch, so the pouch can be emptied as needed. Generally, it is a good idea to empty your pouch when it is about one-third full. During the day most people find it necessary to empty the pouch about as often as they did before urostomy surgery or any other bladder defects.



At nighttime a length of flexible tubing can be attached to the drain valve on your pouch. This allows the urine to flow into a bedside collector while you sleep. Many people find a bedside drainage unit preferable to getting up during the night and emptying the pouch.

In the hospital where there are ostomy nurses, your personal needs will be evaluated and your pouching system will be selected for you. For some, this pouch is the type worn for a lifetime. For others, weight gain, a child's normal growth and other factors may later on require a new or different type of pouching system. Do not continue using a recommended pouch if it is not satisfactory. Try different types until you find one that is both comfortable and convenient to use.

### Skin Protection

The constant flow of urine from the stoma can be very irritating to a person's skin, so most urostomy pouches have protective skin barriers. Pouching systems come with either a pre-cut opening or can be cut to fit the stoma size and shape. Immediately after surgery the stoma is swollen but will decrease in size in 6 to 8 weeks. During this postop period the stoma should be measured about once a week. A measuring card may be included in boxes of pouches or skin barriers or you may create your own template that matches your stoma shape. The opening should be no more than 1/8 inch larger than the stoma size to prevent urine drainage on the skin.

There are several other factors that can influence how long the pouch stays sealed. These include: proper fitting, weather, skin characteristics, scars, weight changes, diet, activity, and abdominal contours near the stoma:

- Perspiration during the summer months in warm, humid climates will shorten the number of days you can wear a pouch.
- Moist, oily skin may reduce adhesion time.
- Weight gain or loss will also affect the wearing time of a pouch. Weight gained or lost after urostomy surgery changes abdominal contours. You may need an entirely different pouching system.
- Physical activities will have some influence on your pouch wearing time. Very active sports or work that causes perspiration may cut down on pouch wearing time as well.

## **Changing the Pouching System**

Applying the pouch may be accomplished with greater ease if you change it in the morning before you eat or drink anything. If this is not convenient for you, try to wait at least one-to-two hours after you have had fluids so that urine is not dribbling on the skin.

You will be able to decide whether sitting, standing or lying down is the best position for putting on your pouch. This position should be the one that gives you the best view of your stoma and is the easiest when making a change. Some people stand facing the toilet so the urine, dripping from the stoma, may be caught in the toilet. When changing while sitting in a wheelchair, it is helpful to slide your buttocks toward the front of the chair and recline.

Using a mirror will help you center the pouch over the stoma. And some people find it helpful to use rolled gauze or paper towels to absorb dribbling urine from the stoma.

The first several times you change your pouch, you may find it takes thirty minutes or more. Once you gain confidence and experience, you may be able to change it in ten minutes or less. Remember that your pouch should be changed on a schedule that fits in with your routine. In other words, do not wait for it to leak to change it.

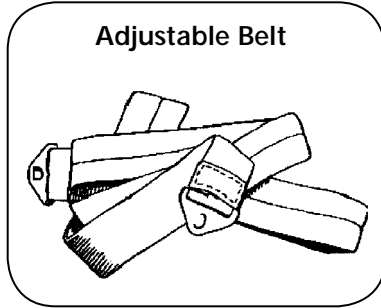
Clean pouches will decrease the chances of introducing bacteria into the urinary system. Bacteria will multiply rapidly even in the tiniest droplet of urine. These bacteria may travel up the ureters and cause a kidney infection. Furthermore, the bacteria can cause odor by acting on the urine. Keeping all items immaculately clean will save you time and money. Always have at least two complete pouches, one on your body and one ready for your next change.

## **Emptying the Pouch**

It is important to empty the pouch at regular intervals. During the day, you probably will find it necessary to empty the pouch every two-to-four hours and more often if you drink a lot of fluids. Children may have to empty more frequently because their pouch is smaller. The volume of urine could jeopardize the pouch seal.

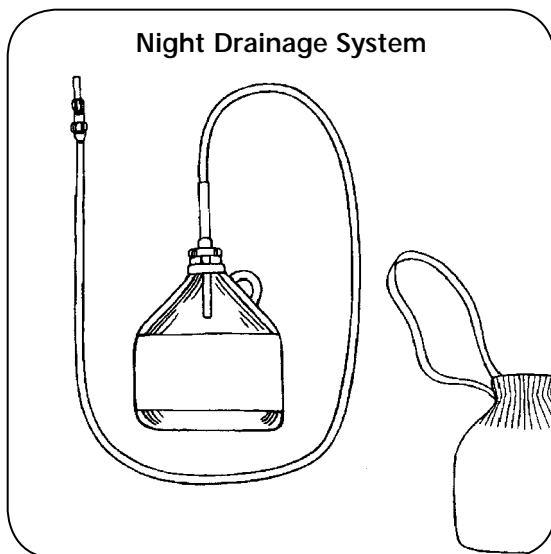
It is recommended to empty when the pouch is one-third to one-half full. Simply open the valve and drain into an appropriate receptacle usually directly into the toilet.

## UROSTOMY MANAGEMENT cont.



### Belts

Wearing a belt is a very individual matter. Some persons who have urostomies wear an ostomy belt because it makes them feel more secure or it gives support to the pouching system. Others find an ostomy belt cumbersome. If you choose to wear an ostomy belt, adjust it so that you can get two finger widths between the belt and your waist in order to avoid a deep groove or cut in the skin around the stoma. This could result in serious damage to the stoma and cause pressure ulcers on the surrounding skin. Belts should be worn so they do not ride above or below the level of the belt tabs on the pouching system. People who are in a wheelchair may need a special belt. Manufacturers carry special belts or you can make one from belting purchased at a fabric store.



### Night Drainage System

At night the bottom of the pouch is connected to a night drainage system which will carry the urine away from the stoma during the sleeping hours. This allows you to sleep undisturbed, with assurance that the urine has been transported to a bedside container by gravity. Your pouch will not get so full that it pulls away from the body.

When connecting the pouch to the bedside drainage receptacle (jar or bag) leave a small amount of urine in the pouch prior to attaching the tubing to prevent setting up a vacuum in the system. The bedside container should be vented and the tubing should be secured at the top of the bottle with no more than one inch of it extending down into a half-gallon bottle. Should urine rise above the end of the tubing, drainage ceases. The drainage container can be hung on the side of the bed, or placed in a receptacle on the floor. A decorative waste paper basket may be used for this purpose.

To clean the tubing and beside drainage collector insert two ounces of a vinegar/ water solution through the outlet valve of your emptied pouch and attach to bedside drainage collector. (1 part of white vinegar to 3 parts of water).

## **Ostomy Supplies**

For the sake of convenience keep all your supplies together on a shelf, in a drawer or in a small box in a cool dry area away from hot or cold temperatures. Reorder supplies several weeks before you expect to run out, to allow enough time for delivery. It is best to avoid stockpiling of supplies due to the fact that the products have a shelf life and are influenced by changes in temperatures. Supplies do not have to be sterile. The stoma and surrounding skin are not sterile and require only cleanliness.

To order additional pouches, skin barriers and other ostomy products, you will need the manufacturer's name and product numbers. Supplies may be ordered from a mail order company or from a medical supply or pharmacy in your town. For information and help in ordering, you may contact a local ostomy nurse, the product manufacturer, telephone directory business pages or the internet (search word: ostomy supplies).

## **HELPFUL HINTS**

### **Protecting the Skin Around the Stoma**

Urostomy output can be irritating to the skin area around the stoma. This skin area should appear the same as anywhere else on the abdomen. Using the following techniques will help keep your skin healthy.

- Use the correct size and type of pouch opening and skin barrier opening.
- Change the pouch regularly to avoid leakage and skin irritation. It is recommended to change the pouch if itching and/or burning occurs.
- Remove the skin barrier gently by pushing your skin from the pouch rather than pulling the pouch from the skin.
- Keep the skin clean with water. If necessary, use a mild soap and rinse very well. This can be done in the shower or tub. Pat skin dry before applying the skin barrier or pouch.
- Watch for sensitivities and allergies to adhesive, skin barrier, tape or pouch material. They can develop weeks, months or years after use of a product since the body can become gradually sensitized. If you have a skin irritation that is caused by the pouch material, you might try a pouch cover. These are available from several manufacturers, or you can make your own.

### **Spots of Blood on the Stoma**

Spots of blood are no cause for alarm. Brushing against your stoma as you are changing the pouch may cause pinpoint bleeding. The blood vessels in the tissues of the stoma are very delicate at the surface and are easily disturbed. The bleeding will usually stop as easily as it started.

## **HELPFUL HINTS cont.**

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### **Urine pH Balance**

Urine pH is defined as the fluid's degree of acidity or alkalinity. When the food you eat is burned in the body, it yields a mineral residue called "ash." This ash can be either acidic or basic (alkaline) depending on whether the food that is "burned" contains mostly acidic or basic ions.

Most fruits and vegetables actually give an alkalized ash and tend to alkaline the urine. Meats and cereals will usually produce an acidic ash residue.

Unless otherwise indicated the urine should be maintained in an acid state. To maintain an acid urine state, increase your daily fluid intake to eight to ten (8oz.) glasses of water. Drink cranberry juice in place of orange juice or other citrus juices that tend to make the urine more alkaline and take vitamin C daily (if approved by physician). Some of the acid ash foods include: most meats, breads and cereals, cheese, corn, cranberries, eggs, macaroni, nuts, pasta, prunes, fish and poultry.

### **Shaving Hair Under the Pouch**

Some men with excessive hair find it painful to remove their pouch because of hair pulling. Hair roots can also be injured and cause irritation. Shaving with an electric razor or trimming hairs with scissors is helpful. A straight edge or safety razor is not recommended.

### **Bathing**

Bathe or shower with or without your pouch. Soap cannot harm the stoma. Just rinse well. Do not use an oily soap around the stoma. If you bathe with your pouch off, hold a cool wash cloth over the area to close the pores of the skin. Then pat dry and apply the pouch. Sometimes the heat from a hot bath or shower will keep the skin warm and will generate moisture under the barrier and prevent a secure seal.

## **UROSTOMY COMPLICATIONS**

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### **Severe Skin Problems**

Large areas of skin irritation which are reddened, very sore and weeping (always wet) will prevent a good seal around the stoma. It is therefore important to combat minor irritations when they first occur. If you have an irritation that does not go away in a few days, or encrustation around the stoma, contact your physician or ostomy nurse. The severity of a problem depends on early intervention. Remember that with a properly fitted pouching system, adequate intake of fluids and good skin care, you can expect few difficulties.

### **Urinary Crystals**

Urinary crystals on the stoma or skin are associated with alkaline urine. The crystals appear as white, gritty particles and may lead to stomal irritation and/or

bleeding of the stoma. Proper cleaning, maintaining acidic urine and careful fitting of the opening in the pouch will help prevent urinary crystals. To help reduce urinary crystals, make a vinegar compress that can be applied to the stoma for a few minutes when the pouch is changed (mix equal parts of water and white vinegar).

## **Medical Emergencies**

You should call the doctor or WOCN when you have:

- A deep cut in the stoma
- Excessive bleeding from the stoma opening (or a moderate amount in the pouch at several emptyings)
- Continuous bleeding at the junction between stoma and skin
- Severe skin irritation or deep ulcers
- Unusual change in stoma size (prolapse or retraction) and appearance (color)
- Fever and strong odor that may indicate a kidney infection

## **Hospitalization**

Take your ostomy supplies with you as the hospital may not have your brand in supply. You may find that you are the expert on urostomies, especially if you are in a hospital where urostomy patients are rare or if you go for a condition not related to your ostomy. If you are in doubt about any procedure, ask to talk to your doctor. Ask to have the following information listed on your chart: 1) ileal conduit or continent diversion, 2) describe in detail your management routine and products used, 3) do not take a urine specimen from the urostomy pouch. Use a catheter inserted into the stoma.

## **LIVING WITH A UROSTOMY**

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After any major operation, you need time to regain your strength and to feel well again. After urostomy (ileal conduit) surgery you will wear an external collection device and learn new skills to manage it. The success of your surgery is based not only on its ability to cure or eliminate the disease or defect, but also on your ability to enjoy life and resume your work and your hobbies. Support and guidance can be found at [www.ostomy.org](http://www.ostomy.org) and through local, UOAA Affiliated Support Groups.

## **Telling Others**

You might be worried about how others will accept you and how your social role may be changed. It is natural to wonder how you will explain your surgery. Your friends and relatives may ask questions about your operation. You can tell them as much as you want them to know. You need not feel a need to explain your surgery to everyone who asks. A brief explanation would be that you had abdominal surgery or that you had your bladder removed or bypassed.

## **LIVING WITH A UROSTOMY cont.**

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If you have children, answer their questions simply and honestly. A simple explanation will be enough for them. Once you have explained what a urostomy is they may ask questions and want to see your stoma or pouch. Discussing your surgery and showing your stoma in a natural way will dispel any misunderstandings they may have. They will accept your urostomy much the same way you do.

If you are considering marriage, discussions with your future spouse about life with a urostomy and its affect on sex, children, and family acceptance will help to alleviate misconceptions and fear on the part of the spouse. Attending UOAA support group meetings together will also be helpful. Talking to other couples, in which one partner has had ostomy surgery, will provide an experienced viewpoint.

### **Returning to Work**

As your strength returns you may go back to your regular activities. People who have urostomies can do most jobs; however, heavy lifting may cause a stoma to herniate or prolapse and should not be resumed without physician approval. A sudden blow in the pouch area could cause the barrier or pouch to shift and cut the stoma. Still, persons who have urostomies do heavy lifting such as mechanics and truck drivers. There are athletes who have stomas. Check with your doctor about your type of work. As with all major surgery, it will take time for you to regain strength after your operation. A letter from your doctor to your employer may be helpful should the employer have doubts about your physical capabilities.

Employability and insurability are issues for some individuals. If these issues develop, seek help from healthcare professionals and/or talk with others who have found solutions to these issues. When you return to your job, you may wish to confide in your employer or a good friend. You may want to tell them you have a urostomy. Keeping it a complete secret may cause practical difficulties.

### **Psychosocial Issues**

There are times after surgery when you may feel discouraged. You may feel alone and isolated and unable to enjoy life again. These are common feelings. Serious illness, medication and the surgery itself may cause feelings of insecurity, dependence and discouragement. You may wonder if you will ever be the same and you may think that no one understands how you feel. Feeling discouraged is real and normal. Talking to a trusted friend, nurse or another person with an ostomy about your feelings can help you work through them.

Your social life can be as active as it was before surgery. You can enjoy all activities such as travel, sporting events, eating at restaurants or whatever you enjoyed before. The first time you go out of the house after surgery, you may feel as if everyone is staring at your pouch even though it is not visible under your clothing. You may feel your pouch on your body, but no one can see it. Did you know what a urostomy was or where the stoma was located before you had surgery?

## **Intimacy and Sexuality**

Sexual relationships and intimacy are important and fulfilling aspects of your life that should continue after ostomy surgery. Your attitude is a key factor in re-establishing sexual expression and intimacy. A period of adjustment after surgery is to be expected. Sexual function in women is usually not impaired, while sexual potency of men may be affected. This impairment can be temporary, but may be permanent. Consult your physician with continued issues or concerns.

Any sexuality concerns you have should be discussed openly between you and your partner. It is likely that your partner will have anxieties about sexual activities due to lack of information. An intimate relationship is one in which it matters how well two people can communicate.

The first time you become intimate after surgery things may not go perfectly. Men may have trouble getting and keeping an erection and women sometimes have pain during intercourse. These conditions can improve with time, consult your physician with continued issues or concerns. Your interest in sex will gradually return as your strength is regained and management issues are mastered. Body contact during sexual activities will usually not harm the stoma or loosen the pouch from the abdomen.

Women may consider wearing crotch-less panties, "teddies," or a short slip or nightie. Men may consider wearing a cummerbund around the midsection to secure the pouch. There are several types of pouch covers that can be purchased or you can make your own.

Ostomy surgery may present more concerns for single individuals. When to tell "that someone special" depends upon the relationship. Brief casual dates may not need to know. If the relationship grows and leads to intimacy, the partner needs to be told about the ostomy prior to a sexual experience.

Pregnancy in women who have had urostomy surgery is not uncommon. Before pregnancy is considered, it should be discussed with your doctor. The urostomy itself is not a reason to avoid pregnancy. If you are healthy, the risk during childbirth appears to be no greater than for other mothers. Of course other health problems that you may have must be taken into consideration and discussed with your physician.

For more information, the guidebook *Intimacy, Sexuality and an Ostomy* is available from UOAA or check out the sexuality fact sheets on the Web site under Ostomy Information.

## **Diet and Nutrition**

There are no eating restrictions as a result of urostomy surgery. If the kidneys have been severely impaired, your physician will monitor your protein and salt intake, but the functions of your kidneys are not affected by the surgery. The urinary tract and digestive tract are separate. A few foods and certain medications may cause urine odor or a change of urine color. Drink plenty of liquids each day following recommendations from your urologist or ostomy nurse.



## **LIVING WITH A UROSTOMY cont.**

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### **Clothing**

You need no special clothing after urostomy surgery, but some minor adjustments may be necessary for personal comfort or preference. The gentle pressure of undergarments with elastic will not harm the stoma or prevent function of the urostomy. Avoid tight fitting pants that may cause some difficulty with the urine drainage.

Cotton knit or stretch underpants may give the support and security you need. Panty hose are also comfortable. A simple pouch cover adds comfort by absorbing perspiration and keeps the pouch from resting on the skin. Men can wear either boxer or jockey-type shorts.

### **Sports Activities**

A urostomy should not limit your participation in sports. Many physicians because of possible injury to the stoma from a severe blow discourage contact sports, but these problems can be overcome with special equipment. Weight lifting may result in a hernia at the stoma. Check with your doctor about such sports. There are many people who have had urostomy surgery who are distance runners, skiers, swimmers, and participants in many other types of athletics.

For swimming, remember these points:

- You can protect the barrier by taping the edges with waterproof or paper tape.
- You may want to choose a swimsuit that has a lining to provide a smoother profile.
- Women may wear stretch panties designed for swimsuits.
- Men may want to wear a support garment sold in men's underwear departments or athletic wear departments.
- Men may prefer to wear a tank top and trunks, if the stoma is above the belt line.
- Empty your pouch before going into the water.

### **Travel**

All methods of travel are open to you. Many people with urostomies travel extensively, including camping trips, cruises and plane excursions around the world. Since you should prepare for travel, here are some suggestions:

Take along enough supplies to last the entire trip plus some extras. Double what you think you may need, because they may not be easy to get where you are going. Even if you don't expect to change your pouch, take along everything you need to do so. Zip-Lock® bags may be used for pouch disposal. Leave home fully prepared. Find out if and where supplies are available before a long trip. A local UOAA support group may be helpful in locating ostomy supplies and local medical professionals. Contact the UOAA office or visit the Web site to find the nearest support group.

Seat belts will not harm the stoma when adjusted comfortably. You may place a clothes pin near the retraction slot to relieve tension on the belt. When traveling by car, keep your supplies in the coolest part. Avoid the trunk or back window ledge.

When traveling by plane, checked luggage sometimes gets lost. When you travel, carry an extra pouching system and other supplies on the plane with you. Small cosmetic bags with plastic linings or shaving kits work well. These should be placed in your carry-on luggage.

To avoid problems when going through customs or luggage inspection, have a note from your doctor stating that you need to carry ostomy supplies and medication by hand i.e., medically necessary ostomy supplies. Further problems might be avoided by having this information translated into the language or languages of the places you are visiting.

Before traveling abroad, get a copy of the current directory of English-speaking physicians in various foreign cities who charge a standard fee. The International Association for Medical Assistance to Travelers (IAMAT) publishes lists of English speaking physicians in over 2,500 cities around the world. Telephone number (716) 754-4883, [www.iamat.org](http://www.iamat.org).

In foreign countries, traveler's diarrhea is a common illness of tourists, whether you are a person with an ostomy or not. The most common cause of diarrhea is contaminated water and/or food. It may also be caused by mere changes in water, food or climate. It is wise to avoid unpeeled fruits and raw vegetables.

## **FOR PARENTS OF CHILDREN WITH UROSTOMIES**

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If you are a parent of a child with an urostomy, you probably have many questions and concerns. When the surgeon said your child needed this surgery, your first reaction may have been, "Is this the only choice?" Your doctor no doubt assured you that the urostomy was necessary to save your child's life. You may have felt shock. You may have asked yourself, "Why did this happen to us?"

Talking to a good friend, your doctor, clergy, ostomy nurse or the parents of a child who has an urostomy helps. Your local support group of the United Ostomy Associations of America can refer you to other parents. This will prepare you to help your child adjust to the urostomy. Deal with your own feelings first, then you may give your child the emotional support he or she needs.

If you are feeling guilty or responsible for your child's illness and surgery, this is a normal feeling for parents. You may think that your dreams have been shattered and may wonder if your child will be able to do the things that others do. Most parents worry about their child's life span, ability to work, adjustment to living with an urostomy and in later years, marriage and family. These are normal concerns of all parents facing major changes in their child's life.

When your child is in the hospital, be there as often as possible. Being in the hospital and having surgery are frightening at any age. At this time your child is especially vulnerable and needs to feel wanted and reassured about your love. You being there makes him/her feel secure.

Be prepared for how you will feel seeing an opening on your child's abdomen with urine running into a pouch. Your first reaction in your child's presence is vitally important and must be as positive and casual as possible. If your child has a fever or other symptoms, do not panic. He or she will have all the aches and pains that other children have. When in doubt, call your physician.

### **Psychosocial Issues**

As your child begins to recover from urostomy surgery, there are many ways you can be a source of strength and support:

Your son or daughter may be afraid that young friends and relatives will not want to be around them. Your acceptance is needed. Encourage your son or daughter to talk to you about these feelings. If you are open and natural about the urostomy, he or she will be, too.

Try to understand how your child feels. Your child needs to feel that you understand what it is like to have an urostomy. Too much sympathy, however, is not good and will take away a sense of independence. Listen, try to understand feelings, encourage and be tactful. It is difficult not to overprotect and pamper a child who is recovering from major surgery. Because it is so easy to give in to your feelings, be as firm as possible.

If your child is very young, they will probably accept the urostomy easier than you. The child will grow up with it and it will become a natural part of the self. For a teenager who is facing all the problems associated with puberty and adolescence, this surgery comes at an especially difficult time. The changes in body image caused by the urostomy may compound the stresses of adolescence. Your teenager may feel unattractive, rejected and different because of the urostomy.

You may notice temporary changes in behavior patterns. Your acceptance and support is especially needed now. Try to understand the feelings and listen to the complaints. Provide encouragement to find realistic solutions to these problems.

## **Management Issues**

Take an interest in your child's care and management. If he or she is old enough, you will want to encourage independence in their ostomy care. Your child may require some help and support at first, due to insecurity about the new supplies, physical weakness and tiring easily. A very young child can be taught to empty the pouch. An older child can get supplies together and learn steps of changing the pouch, until the whole process can be done alone. You may want to use a teaching process that begins with your son or daughter assisting you. Later on you can help, standing by to help only when it is needed.

A very important person to help with care of your child is the ostomy nurse. This is a person who has received special training in ostomy management. To find an ostomy nurse, check with your hospital or contact the United Ostomy Associations of America and its support groups who can refer you to an WOC(ET) nurse in your area.

Be prepared for trial and error in managing, or helping to manage, your child's urostomy. There are some changes that will occur in the beginning that will not happen later. There may be skin or pouching problems. The important thing to remember is that anything new needs experimentation and adaptation. A sense of humor and a positive attitude will be helpful.

## **Everyday Living**

Be flexible in dealing with your child's adaptation to school and everyday living situations. If at first, the pouch should happen to leak at school, your child can go to the school nurse. You might pick up your child for a pouching change at home, then he or she can return to school. One youngster tells this story: he noticed that his pouch was leaking and had wet his trousers. Instead of rushing out of the class as everyone else did, he calmly waited until everyone had left the room. In this way, he very wisely avoided embarrassment and then called home so that his mother could pick him up. You may want to visit the principal, the classroom teacher, the physical education teacher and the nurse to explain your child's needs.

You will find that your child can participate in sports, can go on overnight trips, to camp and do all activities enjoyed before. At first, it will be difficult to let your child go away on his or her own. Discuss what can be done if any problems come up while your child is away from home. Treat them as you treat your other children.

## **FOR PARENTS OF CHILDREN WITH UROSTOMIES cont.**

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Talk with your child about how they will explain the surgery to others. He or she may want to tell close friends, relatives and acquaintances. Naturally, people will be curious. Once the surgery is explained, chances are your child will be accepted as before. Your child will likely duplicate your explanation. If you discuss it in a natural way with others, he or she will discuss it the same way. Most people will want to know what to expect and how they can help. Encourage others to empathize, not sympathize.

Remind your child to be considerate of others. Cleaning up the bathroom after urostomy care is important to maintaining family harmony. You and your child are facing a new situation in your lives. If it is approached with openness, perseverance and a sense of humor, you will find that an urostomy will not stop your son or daughter from engaging in the everyday activities of living. Parents find that a healthy child with an urostomy can once again be a happy child.

Each summer, there is a Youth Rally for ages 11 through 17. This is a camp for young people with ostomies, alternate procedures and other related conditions. Planned educational sessions on self esteem, body image, hygiene and ostomy update, plus discussion sessions, craft projects, tours and sports are offered. For further information, contact the Youth Rally Committee (address is located at the end of this booklet under "Resources").

Join the local UOAA support group and keep abreast of the newest products and medical progress and share experiences with other parents. Additional information for support of the children and their families can be obtained by contacting the UOAA at 800-826-0826 or by visiting [www.ostomy.org](http://www.ostomy.org)

## **RESOURCES**

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If your problem is medical, you should seek help from your physician, surgeon or clinic. If you are in a place where you cannot make contact with them, try to find a doctor or clinic specializing in ostomy care. If that fails, contact the UOAA at 800-826-0826 or ostomy nurse to ask for advice in finding a physician.

### **United Ostomy Associations of America**

UOAA is a volunteer-managed non-profit organization whose vision is the creation of a society where people with bowel and urinary diversions are universally accepted socially, in the work place, medically and psychologically. UOAA has a comprehensive website, [www.ostomy.org](http://www.ostomy.org), that includes ostomy information, support group locations and discussion boards so people can connect, ask questions and share advice.

UOAA staffs a national Help Line at 800-826-0826. Call to find the affiliated support group in your area or to talk to an ostomy nurse. Another free service offered by UOAA is provided by our advocacy legal specialist. If you experience some form of discrimination as a result of your surgery, call our Help Line and they will put you in touch with our specialist.

The official publication of the UOAA, The Phoenix magazine, is America's leading source for ostomy information, education and inspiration. Subscriptions to the magazine are a major source of funding for the UOAA and are available by calling 800-826-0826 or going online: [www.phoenixuoaa.org](http://www.phoenixuoaa.org).

### **Wound, Ostomy and Continence Nurses Society (WOCN)**

The WOCN professional is an expert in the care of patients with wound, ostomy and continence problems. The UOAA can refer you to an ostomy nurse in your area. You can also contact the WOCN national office for information and local referrals: 1-888-224-9626 or visit [www.wocn.org](http://www.wocn.org).

### **International Ostomy Association (IOA)**

The International Ostomy Association provides information regarding ostomy associations worldwide. For information about support groups in foreign nations, visit [www.ostomyinternational.org](http://www.ostomyinternational.org).

### **Youth Rally Committee, Inc.**

For information on this one-week "camp," visit [www.rally4youth.org](http://www.rally4youth.org)

### **Agencies That May Be Helpful**

- American Dietetic Association, 1-800-877-1600, [www.eatright.org](http://www.eatright.org)
- American Cancer Society, 1-800-ACS-2345 or [www.cancer.org](http://www.cancer.org).
- American Pharmaceutical Association. [www.pharmacyandyou.org](http://www.pharmacyandyou.org)
- National Institutes of Health. [www.nih.gov](http://www.nih.gov)
- Visiting Nurse Association (VNA), 202-384-1420, [www.vnaa.org](http://www.vnaa.org)

### **Medicare, Medicaid and Social Security in the United States**

Colostomy care and supplies are covered under part B of Medicare. These same supplies and care may be covered under Medicaid (state regulated). Check with an ostomy nurse about which health department or other agency in your state administers this program. Social Security disability benefits are available to those who qualify. For more information, visit [www.medicare.gov](http://www.medicare.gov).

# **GLOSSARY**

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**Appliance:** see pouch

**Colonic Conduit:** one type of urinary diversion. A short section of colon is cut away, with blood and nerve supply intact. The section is closed at one end, ureters are attached to it, and the open end is brought through abdominal wall to form stoma. This section thus becomes conduit, or passageway, for urine to outside of body. The remaining ends of intestine are reconnected and resume function of moving feces out of the body.

**Congenital:** present or existing at the time of birth.

**Continent Urostomy:** surgical variation on ileal conduit urinary diversion. Surgeon constructs internal reservoir and nipple valve/stoma from segment of ileum. With continent urostomy, segment is severed from rest of intestine; remaining ends of intestine are reconnected and resume function of moving feces out of body. Additional nipple valve is constructed where ureters are connected to reservoir; this prevents backup of urine into kidneys. Urine is drained from the reservoir a few times a day with a catheter introduced through the stoma/nipple valve.

**Cystectomy:** removal of the bladder. If the bladder is removed, some kind of urinary diversion is necessary.

**Cystoscope:** "cysto" pertaining to the bladder, and "scope" an instrument to look through. An examination of the inside of the bladder.

**Encrustation:** gray, raised area sometimes appearing on skin around urinary stomas; caused by alkaline urine bathing skin. Prevented by correctly fitted skin barrier which covers all the skin around the stoma.

**Enterostomal Therapy Nurse:** See Wound, Ostomy, Continence Nurse

**Exstrophy of the Bladder:** birth defect which may require urinary diversion surgery. The bladder is "turned wrong-side-out" and exposed outside the body.

**Face Plate/Flange:** molded rubber or plastic component of a two-piece reusable pouch system. The face plate fits around the stoma next to the skin.

**Fistula:** an abnormal passage between two internal organs or from an internal organ to the surface of the body.

**Hernia (abdominal):** the protrusion of an internal organ through the abdominal musculature; can occur around stomas.

**Ileal Conduit (Bricker loop, ileal loop):** Urinary diversion operation which allows urine to pass from kidneys and ureters through passageway made of short segment of small intestine to outside of body. Similar to colonic conduit except that ileum is used instead of colon. Stoma usually on lower right abdomen.

**Incontinence:** the inability of the bladder to hold urine, causing uncontrollable dribbling or wetting.

**Malignancy:** a cancerous growth.

**Mucus:** fluid secreted from glands or cells. It lubricates membranes, including digestive tract.

**Nephrostomy:** surgical opening into kidney. In this urinary diversion, a catheter (nephrostomy tube) is sutured into place to drain urine.

**Night Drainage System:** large container with tubing which can be connected to the valve bottom of urostomy pouch while ostomate sleeps or is on bed rest. These commercially available or homemade systems provide additional storage capacity; they keep pouches from becoming too full and pulling loose from skin and they keep urine draining away from stoma. It is essential that the tube remain above the level of urine in the container at all times so that urine continues to drain.

**Obstruction:** a blockage in the urinary tract which causes the urine to be held up in its normal course to the outside of the body.

**Ostomate:** one name for the person who has a colostomy, ileostomy, or urostomy.

**Ostomy:** surgically created opening in the body. Refers to ileostomies, colostomies, and urostomies. Also referred to as a stoma.

**Ostomy Visitor:** person with an ostomy, member of United Ostomy Associations of America, with special training to visit people before or shortly after ostomy surgery. The visitor offers support and educational advice rather than medical information.

**Peristalsis:** the squeezing motion in the ureters and ileal segment which pushes the urine down from the kidneys.

**Peristomal Skin:** the outlying skin immediately around/touches the stoma.

**Pouch:** collecting device for waste eliminated from your urostomy.

**Prolapse:** a "falling out" in which the stoma becomes longer.

**Prosthesis:** an artificial substitute for a missing body part, such as an arm or leg, eye or tooth, used for functional or cosmetic reasons or both.

**Reflux:** a flowing back. This means urine is flowing back from the bladder into the kidneys.

**Resection:** surgical removal or excision.

**Retraction:** the act of drawing back. In reference to ostomy, the stoma draws back into the body.



## **GLOSSARY cont.**

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**Revision:** construction of a new stoma when the original one does not function well.

**Skin Barrier:** any one of several substances used to cover peristomal skin to protect it from urine. Can be pliable sheets, pastes, etc.

**Stenosis:** narrowing or tightness of the stoma which may cause obstruction.

**Stoma (opening):** an end of the ileum or colon which is brought through the skin as a site for stool or urine to exit the body. (Note that even urinary stomas are built from a segment of ileum or colon.) The stoma often protrudes like a nipple and may be around 3/4" to 1-3/4" in diameter. It is usually pink to red in color. Stomas do not include nerves sensitive to pain, so it is possible to cut or burn a stoma without feeling anything. Stomas do, however, include nerves sensitive to other stimuli such as stretching.

**Stricture:** an abnormal narrowing of a body passage.

**Urinary Diversion:** any one of several surgical procedures to divert urine away from diseased or defective kidneys, ureters, bladder, or urethra. In many diversions, a new passageway for urine is formed through the abdominal wall to outside the body; this involves constructing a stoma or suturing a tube in place for drainage of urine. If a stoma is made, a pouch is usually worn.

**Urinary Tract:** the system in the body composed of the kidneys, ureters, bladder and urethra. Urine is made in the kidneys, passes down the ureters, accumulates in the bladder and passes to the outside through the urethra.

**Urinary Crystals:** sharp, gritty crystals which can form on a urinary diversion stoma or unprotected peristomal skin. Dissolved with soaks using white vinegar and water.

**Urostomy:** see urinary diversion.

**Vesicostomy:** urinary diversion in which bladder opens directly to stoma, located about midway between umbilicus and pubic bone. Some are continent, drained at regular intervals with a catheter. The conventional vesicostomy needs a pouch. A vesicostomy is usually temporary.

**Wound, Ostomy and Continence Nurse:** also known as WOC(ET) nurse or ostomy nurse. A person who takes care of and teaches ostomy patients. A special training course for registered nurses is required for certification.