



UROSTOMY GUIDE

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

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

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2017**

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UOAA may be contacted at:
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INTRODUCTION

For the thousands of people every year suffering from bladder cancer or other bladder disease, urostomy (urinary diversion) surgery may be the treatment your physician recommends. This is a major surgery and causes changes to way your body functions, but after your initial recovery period, you can have a normal life and resum the activities you have enjoyed in the past. This booklet has been developed to help you better understand what is happening to you.

Urostomy is a general term that describes one of a number of surgical procedures that detour, or divert, urine away from a diseased or defective bladder. It is important to discuss with you physician what options you may have for surgery, but this booklet discusses only those operations which bring the urine to the outside of the body through an opening in the abdominal wall in a procedure called a vesicostomy or removed in a procedure called a cystectomy, 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, so you will need to wear an ostomy pouch over your stoma.

Your physician or your ostomy nurse will explain the surgery you will be having, and you should have a stoma site marking. A qualified health care professional will examine your abdomen to determine the best location for the stoma. It will most likely be located on the right side of your abdomen and should be on a flat surface. You may be able to see a sample pouch and get information on the care you will need to learn to take care of yourself after surgery. If you have any hobbies or habits which might be affected by the location of the pouch, talk with your physician or 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 who may benefit from your experience. You can find a list of UOAA Affiliated Support Groups at www.ostomy.org or by calling 800-826-0826.

FACTS ABOUT UROSTOMIES

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. You can live well without a bladder, but must have some 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.

A urostomy or urinary diversion is needed when the bladder is diseased or not functioning properly. The most common reason is for bladder cancer. Others include neurologic dysfunction of the bladder, birth defects and chronic infection of the bladder. Removal of the bladder is the only way to eradicate bladder cancer. If the cancer has spread outside the bladder, chemotherapy may also be necessary.

Some patients find a urostomy easier to manage than a defective bladder that could be caused by birth defects, previous radiation therapy or spinal cord injury. With these bladder injuries, you may have trouble controlling the flow of urine, causing embarrassment with frequent wetting. Often there are also odor and skin problems that can occur with chronic urine leakage. Some people have requested urostomy surgery rather than dealing with incontinence.

If a child is born with a defect in the urinary tract, causing the urine to back up or reflux into the kidneys resulting in chronic infection, a urostomy may be lifesaving. The surgical construction of a pathway through which the urine may travel, without interference or obstruction, 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.

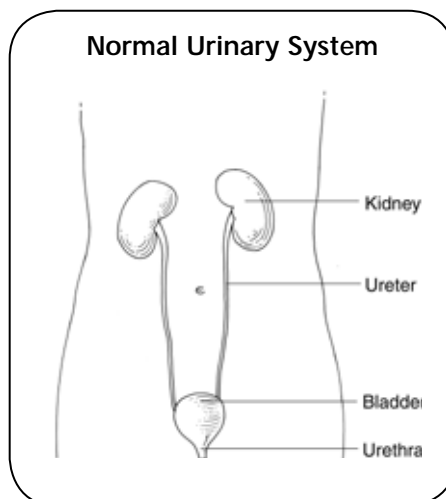
NORMAL URINARY SYSTEM

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

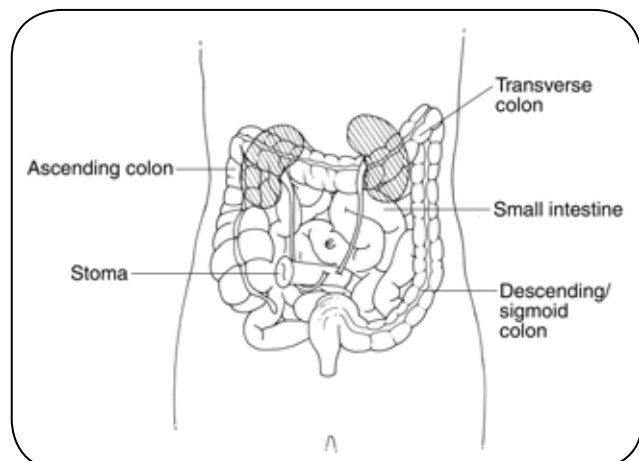
Discharge

- urine
- some mucus

Management

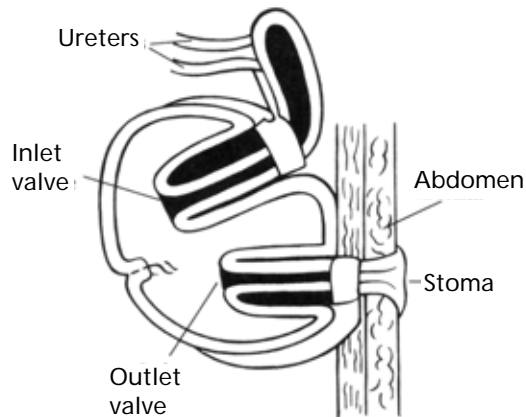
- skin protection
- drainable, valve-end pouch
- adaptable to night drainage

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.

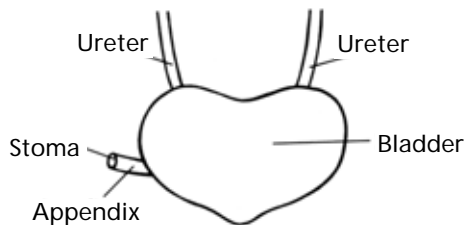


The small intestine produces mucous naturally. The segment of intestine that was used to form the ileal conduit will continue to produce mucous and will collect in the pouch.

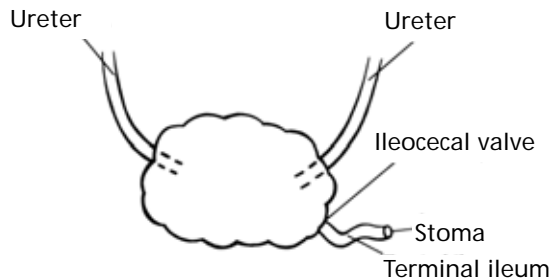
CONTINENT UROSTOMIES



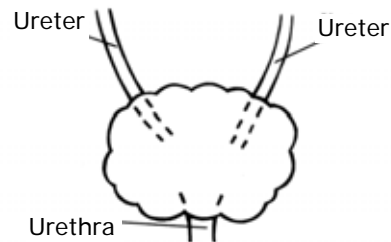
Kock Pouch. Pouch, valves and outlet are made from terminal ileum.



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

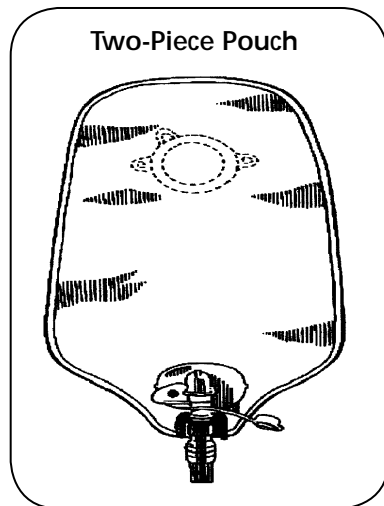
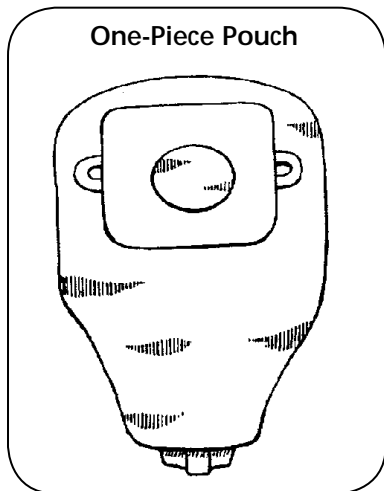
Learning to care for your urostomy may seem like a complicated procedure at first, but with practice and your own adaptations, the entire process will become second nature, just like shaving or bathing.

Pouching Systems

A successful pouching system should provide the following:

- Security with a good leak-proof seal, that lasts for 3-7 days
- Skin protection
- Discretion so that it is not visible under your clothing
- Ease of application and removal

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 already cut to the size of your stoma.

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 to one-half full. 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 you will be provided with urostomy pouches. However, as you recover from surgery, your stoma will likely become smaller in size and your abdominal contours may change. You may experience some leakage, and this means you will likely need a different pouching system. Contacting an ostomy nurse to assist you with this will be helpful. If an ostomy nurse is not available to you, the companies that make ostomy pouches have representatives who are able to help you over the phone. Once you have a pouching system that provides a reliable seal, you may never need to change the type that you use. However, if the pouch you wear is difficult for you in any way, there are many different types of pouches so try different ones 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.

Some of the factors that may require changes in the type of pouch worn or cause a decrease in the wear time are:

- Perspiration
- Moist or oily skin
- Weight gain or loss
- Sports activities
- Normal growth in a child
- Sports activities
- Living in warm, humid climates

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.

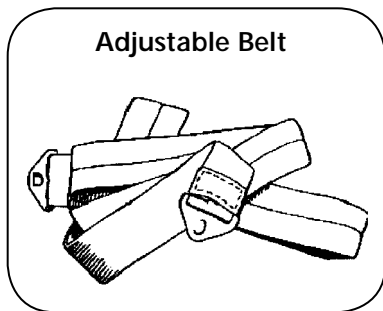
Make sure you or your caregiver always wash your hands before and after the pouch change. Keep your supplies in a clean dry place. Cleanliness will help to avoid the spread of bacteria that could lead to a urinary tract infection.

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. A large volume of urine in the pouch could jeopardize the pouch seal.

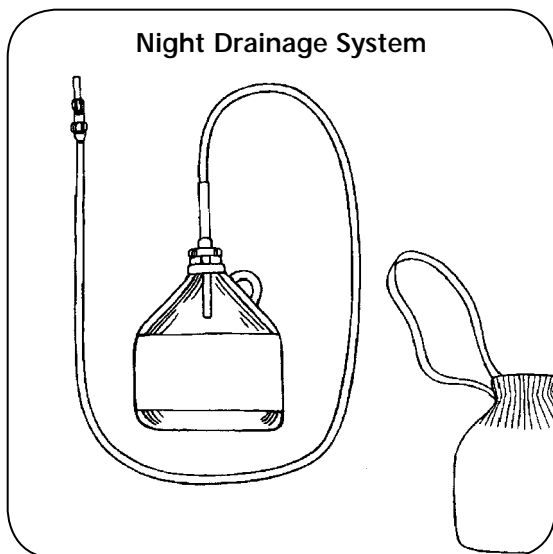
It is recommended to empty when the pouch is one-third to one-half full. Simply open the valve and drain into an appropriate receptacle usually directly into the toilet.

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.



Night Drainage System

At night the valve on the bottom of the pouch is connected to a night drainage system which will carry the urine out of the pouch during the sleeping hours. This allows you to sleep undisturbed, with assurance that the your pouch will not get so full that it pulls away from the body and leaks.

When connecting the pouch to the bedside drainage receptacle leave a small amount of urine in the pouch prior to attaching the tubing to prevent setting up a vacuum in the system.

Commercially produced systems are available in the form of bags or jugs that are designed for this use and are effective and reliable. 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 bedside drainage collector, rinse after each use with water. If you notice an odor from the drainage bag or jug, fill it with a solution of 1 part white vinegar to 3 parts water or 1 part bleach to 10 parts water through the tubing and let it sit for 15 minutes.

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 since the adhesive on the product may become less effective 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

Constant moisture from urine 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 without moisturizer 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.

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.

Urine pH Balance /Drinking adequate amount of liquids

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 alkalinized 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. Drinking at least 2 quarts of non-alcoholic liquids every day will keep your urine more acidic. Acidic urine is more resistant to bacterial contamination and decreases your risk of urinary tract infection. Mucus is secreted by the intestine that is used to make the stoma. You may see mucus in your urine which is normal, but it will be less noticeable and less likely to plug the valve on your pouch opening if you drink plenty of liquids.

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

You should contact your physician or ostomy nurse if you have:

- Large areas of peristomal skin irritation or deep ulceration which are reddened, sore and weeping (always wet) and will prevent a good seal around the stoma. It is therefore important to treat minor irritation when it first occurs. If you have skin irritation that does not go away in a few days, or raised, discolored bumps around the stoma called pseudoverrucus, contact your physician or ostomy nurse. Early intervention helps to prevent more serious problems from occurring.
- 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 treat 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).
- A deep cut in the stoma caused by injury.
- Excessive bleeding from the stoma opening, blood in the pouch or continuous bleeding at the junction between stoma and skin when you are changing your pouch.
- Unusual change in stoma size and appearance. This could be retraction or the stoma drawing below the skin surface. It could also be prolapse with the stoma protruding farther from the skin surface.
- Fever and strong odor of the urine that may indicate a kidney infection.
- Remember that with a properly fitted pouching system, adequate intake of fluids and good skin care, you can expect few difficulties.

LIVING WITH A UROSTOMY

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 and through local, UOAA Affiliated Support Groups.

Hospitalization after initial surgery

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 physician. Ask to have the following information listed on your chart: 1) ileal conduit or colonic conduit 2) management routine and products used 3) if a urine specimen is ordered, obtain with a catheter inserted into the stoma.

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. 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.

LIVING WITH A UROSTOMY cont.

If you are in a relationship discussions with your partner 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 partner. 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 can go back to your regular activities. People who have urostomies can do most jobs; however, heavy lifting may cause a stoma to herniate (abdomen protrudes) or prolapse (stoma protrudes farther) and should not be resumed without physician approval. A sudden blow in the pouch area could cause the stoma to be injured or disrupt the pouch seal. 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 that 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, therapist 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 both men and women may be changed with men often experiencing erectile dysfunction and women having painful intercourse. . 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," ostomy bands, or a short slip or nightie. Men may consider wearing a ostomy band 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 at www.ostomy.org 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 a change of urine color or odor. Drink plenty of liquids each day following recommendations from your urologist or ostomy nurse.

LIVING WITH A UROSTOMY cont.

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. There are devices to wear over your stoma if you are engaging in contact sports such as football. 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 tape using barrier strips made for this purpose.
- You may want to choose a swimsuit that has a lining to provide a smoother profile. Bathing suits made of a print fabric rather than a solid color may be more discrete.
- 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. Some of the information below may be helpful to consider when planning your trip.

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 at 800-826-0826 or visit www.ostomy.org to find the nearest support group.

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 drink bottled water and avoid unpeeled fruits and raw vegetables.

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.

Request Passenger Support from the TSA. Travelers with medical conditions such as an ostomy and who have concerns about airport screening should contact TSA Cares at least 72 hours before travel: (855) 787-2227 or email TSA-ContactCenter@tsa.dhs.gov. They will coordinate assistance available from a Passenger Support Specialist (PSS) and/or customer service manager at the airport.

Download a printable travel notification card from www.ostomy.org. This is NOT a special security pass but it is a way to communicate discreetly to agents that you have an ostomy. You can also show a note from your physician explaining any of your medical conditions.

Understand security. You should expect to be screened without having to empty or expose the ostomy through the advanced imaging technology, metal detector, or a pat-down. If your ostomy pouch is subject to additional screening may be required to conduct a self pat-down of the ostomy pouch outside of your clothing, followed by a test of your hands for any trace of explosives. If an incident occurs outside of protocol, report it to the TSA and follow-up with UOAA.

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) 54-4883, www.iamat.org.

FOR PARENTS OF CHILDREN WITH UROSTOMIES

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.

It is not unusual for you, as parents, to feel guilty or responsible for your child's illness and surgery. 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.

Prepare yourself as much as possible 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. Encourage your child to have a sense of independence while providing emotional support.

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. Then you can be 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/Ostomy nurse/OMS 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.

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 at www.rally4youth.org

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

RESOURCES

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, that includes ostomy information, support group locations and discussion boards so people can connect, ask questions and share advice.

Call UOAA at 800-826-0826 to find the affiliated support group in your area.

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.

Wound, Ostomy and Continence Nurses Society (WOCN)

This is the professional organization for WOC nurses. 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.

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.

Youth Rally Committee, Inc.

For information on this one-week "camp," visit www.rally4youth.org

Agencies That May Be Helpful

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

Medicare

Medicare (Federal regulated) covers 80% of the cost of ostomy supplies under Part B. Ostomy supplies may be covered under Medicaid (state regulated). Check with your case worker or 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.

Definitions

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: : A section of ileum or lower portion of the small intestine is removed from the intestinal tract, with blood and nerve supply intact. The section or conduit 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 a conduit, or passageway, for urine to leave the body. The remaining ends of intestine are reconnected and resume function of moving fecal matter out of the body.

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 Management Specialist (OMS): a healthcare professional who is certified in all aspects of ostomy care & management. A special training course is required for certification.

Ostomy Visitor: person with an ostomy, member 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 and protrudes farther from the skin surface.

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

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 back²¹ into the body.

Definitions cont.

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: A surgical procedure in which a section of intestine is brought out onto the abdomen and formed into a stoma that will allow urine to pass from the body.

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 to contain the urine.

Wound, Ostomy and Continence Nurse: also known as WOC nurse or ostomy nurse. A registered nurse with specialized training in ostomy care.