

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. 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 young 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.

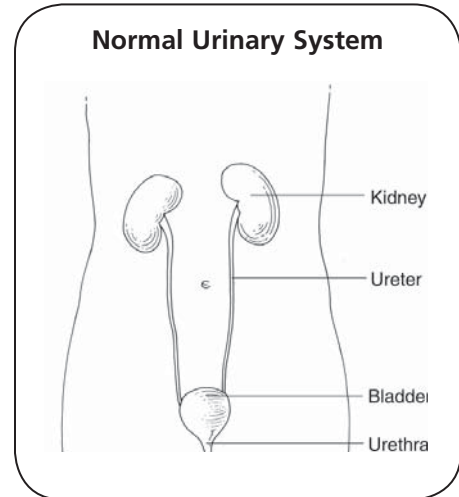
NORMAL URINARY SYSTEM

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

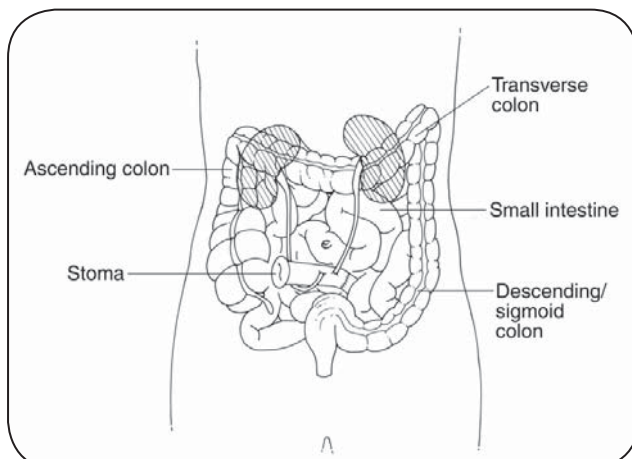
Discharge

Urine
Some mucus
Continuous drainage

Management

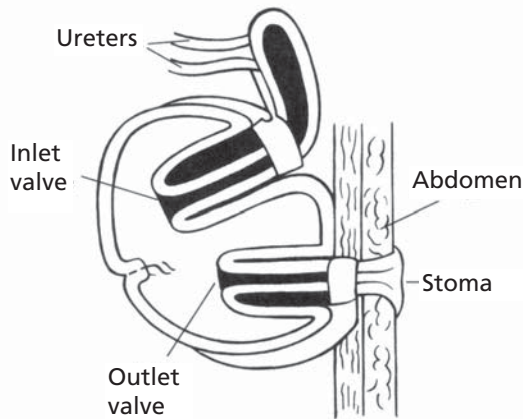
Skin protection
Drainable, valve-end pouch
Adaptable to night drainage

To create an ileal conduit, a segment of the small bowel 6 to 8 inches, is excised near the entrance into the large bowel. (ileum). 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. 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.

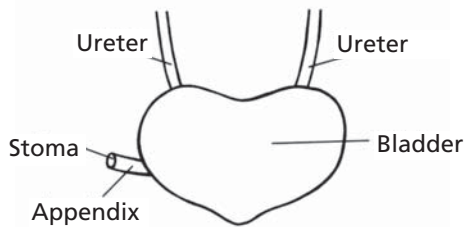


The small intestine produces mucous naturally. The segment of intestine that was used to form the ileal conduit will continue to produce mucous and will collect in the pouch.

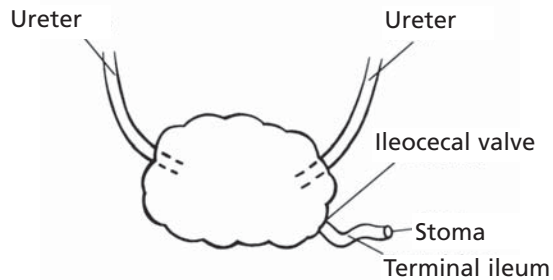
CONTINENT UROSTOMIES



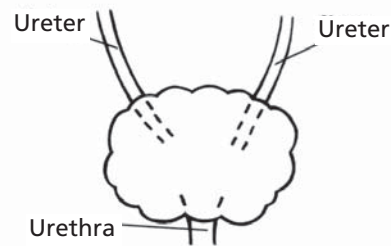
Kock Pouch. Pouch, valves and outlet are made from terminal ileum.



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

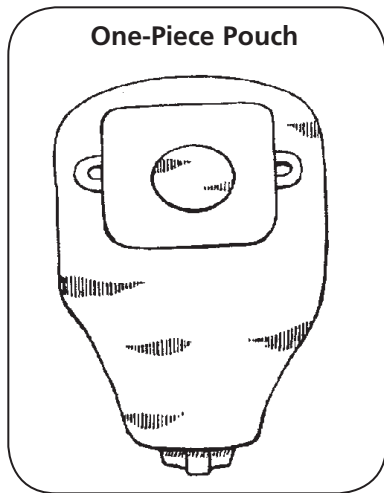
Learning to care for your urostomy may seem like a complicated procedure at first, but with practice and your own adaptations, the entire process will become second nature, just like shaving or bathing.

Pouching Systems

A successful pouching system should provide the following:

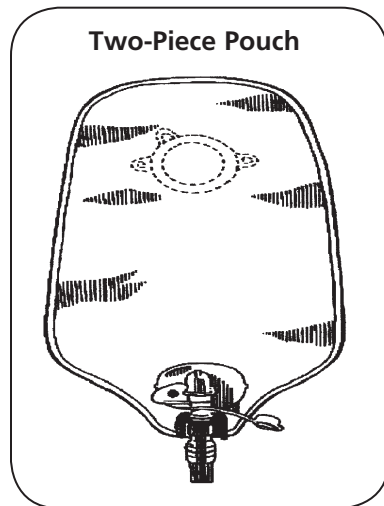
- Security with a good leak-proof seal, lasting for 3-7 days
- Skin protection
- Be inconspicuous
- Easy to apply and to remove

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 or base of the pouch 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 remeasured 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 up to thirty minutes. 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.

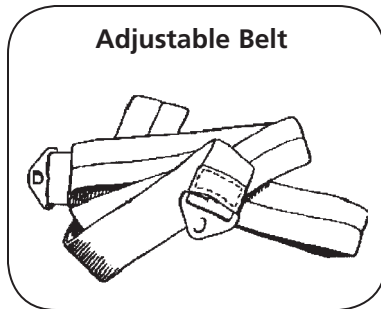
Emptying the Pouch

Since bacteria multiply rapidly in urine, 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.

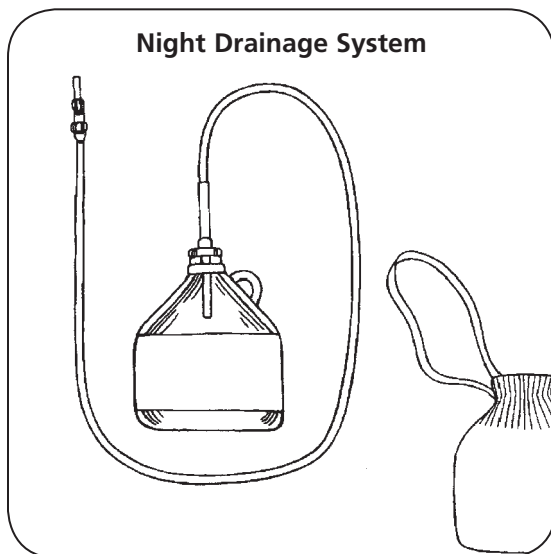
UROSTOMY MANAGEMENT cont.

Belts and Tape



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 and use tape. Tape can be applied around the outside edge of the skin barrier in a picture frame method. 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 and your stoma will be protected against the accumulation of "strong" urine.

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 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.

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

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 ostomy nurse 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

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.

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.

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 an ostomy support group meeting 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. 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 sometimes be affected, usually only temporarily. Discuss any problems with your physician and/or ostomy nurse.

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 will usually improve with time. 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.

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.

Clothing

You need no special clothing because urostomy pouches are fairly flat and inconspicuous. 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 ostomy support group may be helpful in locating ostomy supplies and local medical professionals.

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.

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.