

Continent Urostomy Guide

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

"Seize the Opportunity..."

CONTINENT UROSTOMY GUIDE

Ilene Fleischer, MSN, RN, CWOCN, Author
Patti Wise, BSN, RN, CWOCN, Author

Reviewed by: Authors and Victoria A.Weaver, RN, MSN, CETN
Revised 2009 by Barbara J. Hocevar, BSN,RN,CWOCN, Manager, ET/WOC Nursing, Cleveland Clinic

© 1985 Ilene Fleischer and Patti Wise

This guidebook is available for free, in electronic form, from
United Ostomy Associations of America (UOAA).

UOAA may be contacted at:
www.ostomy.org • info@ostomy.org • 800-826-0826



CONTENTS

INTRODUCTION 3

WHAT IS A CONTINENT UROSTOMY? 4

THE URINARY TRACT 4

BEFORE THE SURGERY 5

THE SURGERY 5

THE STOMA 7

AFTER THE SURGERY 7

- Irrigation of the catheter(s) 8
- Care of the drainage receptacles 9
- Care of the stoma 9
- Other important information 10

ROUTINE CARE AT HOME 10

- Catheterization schedule 11
- How to catheterize your pouch 11
- Special considerations when catheterizing 11
- Care of the catheter 12
- Other routine care 12

HELPFUL HINTS. 13

SUPPLIES FOR YOUR CONTINENT UROSTOMY 14

LIFE WITH YOUR CONTINENT UROSTOMY 15

- Clothing 15
- Diet 15
- Activity and exercise 15
- Work 16
- Travel 16
- Telling others 17
- Social relationships 17
- Sexual relations and intimacy 17

RESOURCES. 19

GLOSSARY OF TERMS 20

BIBLIOGRAPHY 21

INTRODUCTION

Many people have ostomies and lead full and active lives. Ostomy surgery is the main treatment for bypassing or replacing intestinal or urinary organs that have become diseased or dysfunctional. “Ostomy” means opening. It refers to a number of ways that bodily wastes are re-routed from your body. A urostomy specifically redirects urine. Continent refers to controlling the release of urine until an appropriate time. A continent urostomy gives you control of the urine flow from your body.

It can be frightening when you first hear that you are going to have an ostomy. You may experience denial, loss of control, anger, depression, hopelessness and isolation. These are perfectly normal responses that help you cope with the initial shock you experience when hearing that an ostomy will be your treatment. You are not alone. Support in both the hospital and the community is available to you to share your feelings and concerns.

A WOC(ET) nurse (also ostomy nurse) is an RN whose specialty includes the care of patients with ostomies. Your ostomy nurse provides you with information and instructions about your ostomy and living with it. This nurse is involved in your physical care and is a support for you not only in the hospital, but also after you are discharged. Be open, honest and ask questions. Your ostomy nurse, urologist, other physicians and health care personnel are concerned about you and want to help with your recovery and transition to self-care.

This booklet is for your information and guidance. It contains general information for all continent urostomies. Focus on the sections that apply to you and your situation. No two patients or hospitalizations are the same, so follow the advice of your doctor or ostomy nurse if it differs from what you read here. We hope this booklet answers your questions, calms your fears and helps you move toward a full and active life again.

WHAT IS A CONTINENT UROSTOMY?

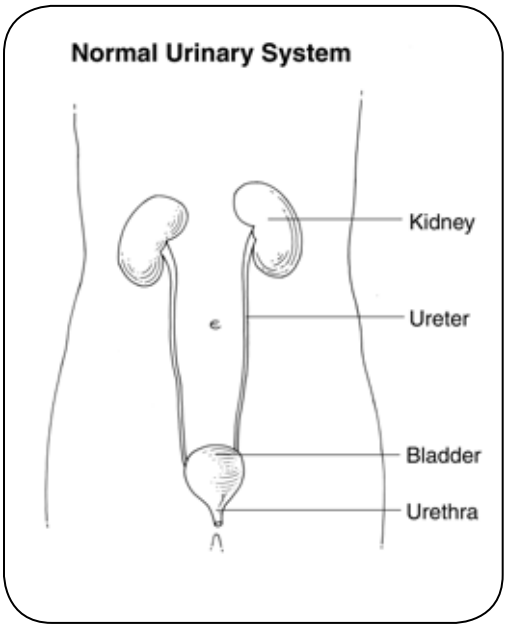
The continent urostomy is one of many surgical procedures that can be done when your bladder is removed because of disease (such as bladder cancer or interstitial cystitis) or because it is no longer functioning correctly (such as congenital conditions or neurogenic bladder). It is an internal reservoir (or pouch) created by your surgeon that acts as an artificial bladder to store your urine.

The urine is emptied from the pouch through a small opening (stoma) that is usually on your lower abdomen or in your navel. A small protective dressing is all that is needed to cover your stoma. Urine will not flow out until you insert a special flexible tube (catheter) into the stoma about four to six times a day to drain the pouch. In this manner, you will have control of your urine, or continence.

With some continent urostomies, the internal reservoir can be re-routed back to your own urethra (the passage through which your urine normally passes out of the body). Urine is then released by urinating or in some cases by inserting a small catheter into the urethra. This booklet deals with internal reservoirs that have a stoma that is catheterized.

THE URINARY TRACT

The kidneys, ureters, bladder and urethra make up the urinary tract. The kidneys form urine by filtering your blood of water and waste products. Urine flows from the kidneys down through two small tubes, called ureters, into the bladder. The bladder stores urine until you are ready to urinate or void through the urethra (see illustration). When your bladder is removed, a new "bladder", also known as a pouch or reservoir, is surgically created to store your urine, and a new pathway is made to redirect the urine out of your body.



BEFORE THE SURGERY

The preparation for your continent urostomy surgery is much like that for any major abdominal operation. In conjunction with routine preparations such as blood work, E.K.G., and chest x-ray, your intestines (bowels) must be thoroughly cleansed because a portion of them will be used to create your continent urostomy. This intestinal cleansing is called a bowel prep. It can include oral medications, laxatives and/or enemas.

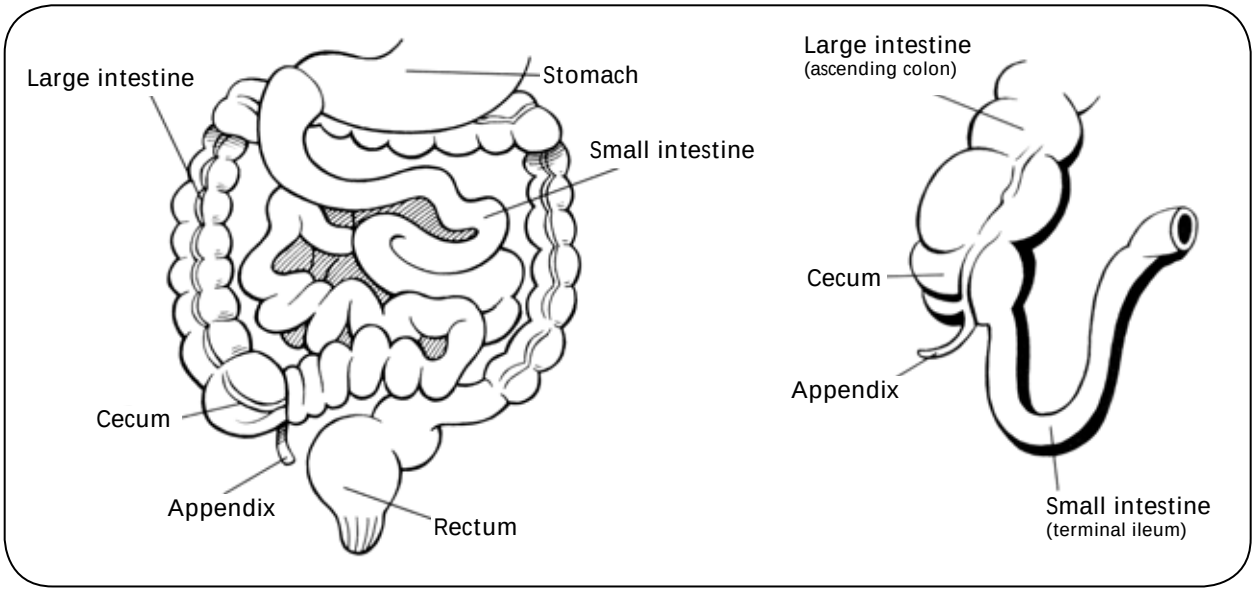
During this pre-operative time, the ostomy nurse will meet with you to examine your abdomen and choose the best site for your stoma. The ostomy nurse will select a site on your lower abdomen that is easy to locate, easily accessible for care and concealed. The site is also chosen so the stoma doesn't interfere with clothing or activities. Sometimes the navel is used for the stoma site.

Your ostomy nurse will also provide you with information about your surgery and its effect on your lifestyle. Feel free to ask questions and clarify any uncertainties you have.

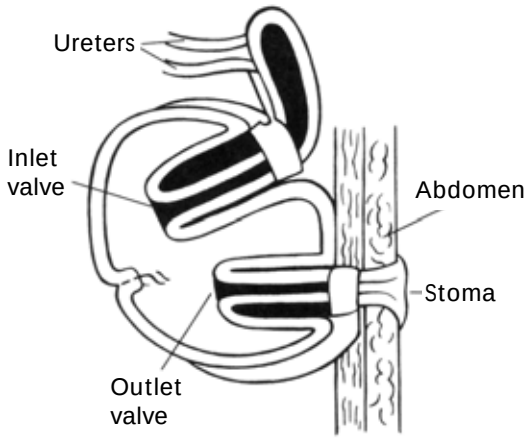
THE SURGERY

Continent urostomies were first described in 1950, but it was not until the extensive work of Dr. Nils Kock in 1975 that they became a viable alternative to urinary diversions that required external pouches. This initial pouch was named after Dr. Kock. The Kock Pouch, as well as the Indiana Pouch, Mitrofanoff Procedure, Mainz Pouch, Camey Procedure, Miami Pouch, Ileal Neobladder and other variations. Continent Urostomy surgery options are now offered by many surgeons. Your surgeon can give you details about the exact method planned for you. Regardless of the type of surgery, it is a relatively safe, but lengthy operation that takes from six to 10 hours.

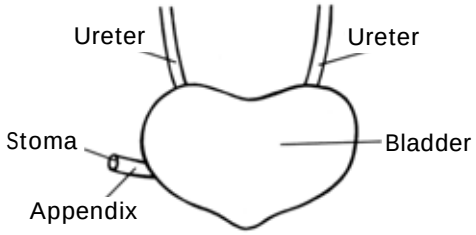
The continent urostomy procedure creates a reservoir (pouch) from segments of the



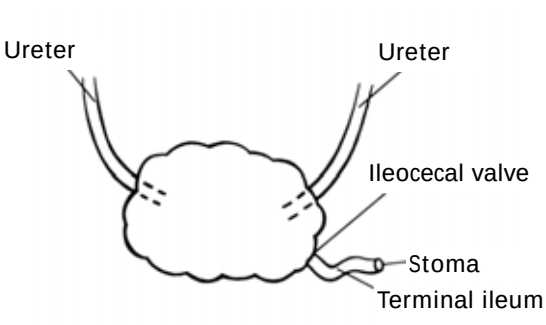
Gastrointestinal tract used to create continent urostomies



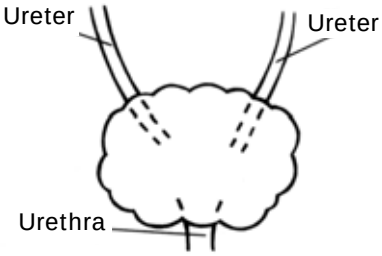
Kock Pouch. Pouch, valves and outlet are made from terminal ileum.



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).

Continent Urostomy surgery options.

large and/or small intestine. A continence mechanism is surgically established to store your urine and prevent leakage. The pouch collects urine, prevents urinary reflux (back-flow) to your kidneys and should be easy to catheterize. With time, the pouch's capacity enlarges. This increases the volume of urine it can hold. It reaches its permanent size about four months after surgery.

In a traditional urostomy, urine flow is continuous into an external pouch. With all types of continent urostomies, the end result is to give you control of when your urine is eliminated.

THE STOMA

A stoma is the surgically created opening from which you drain your urine. The word "stoma" is derived from the Greek word meaning "mouth" or "opening." The stoma is made from a piece of your intestines and, therefore, it appears moist and dark pink or red. Although it is similar to the tissue that lines the inside of your mouth, the stoma has no pain or other sensations because it has no nerve endings. You may sometimes see

a small amount of bleeding when you are cleaning the stoma because of its rich blood supply. This is perfectly normal. Also the stoma produces mucus since this is a normal function of your intestines.

Your stoma requires very little care. The small amounts of mucus produced can be wiped clean or washed with soap and water. Because of the continent valve and the stoma's gentle outward contractions, water cannot enter the stoma. Therefore, showering, bathing and swimming are normal activities which are not harmful to the stoma.

The stoma is on your lower abdomen or in your navel. It may be flush (even) with your abdomen or sticking out slightly. The size and shape vary from person to person. The stoma slowly shrinks, reaching its permanent size about two months after surgery.

AFTER THE SURGERY

When you awaken from your operation, you will probably be in the recovery room and later, depending on your condition, may be moved to the intensive care unit. If so, within one to two days you are usually back on the general surgical floor. During this time right after your surgery, you will have:

- Intravenous lines (IV lines) for fluids, nourishment and medicines
- A nasogastric tube (NG tube) that is inserted down one nostril and into your stomach or a gastrostomy tube (G-tube) that is inserted directly into your stomach through your abdomen. This tube drains your stomach contents and prevents nausea and vomiting
- A drain or drains in your abdomen to remove any excess fluid, prevent swelling and promote healing
- Abdominal dressings which protect your incisions and drains
- One or two catheters (tubes) which go into your newly created pouch and two smaller tubes called stents which go into your ureters. These tubes may exit though your stoma and/or abdomen and continuously drain urine allowing the internal tissues to heal. For the first few weeks after surgery, these tubes are connected to a continuous drainage system and you are not yet able to control the release of urine.

During the first few days after surgery you tend to have the most discomfort. Pain medicine should be taken at this time to help ease this so you can breathe deeply and cough, move more easily in bed, and increase your activity. You are not allowed to eat or drink anything while an NG tube or G-tube is used to collect fluid. When some bowel function returns, the NG tube is removed; the G-tube may be clamped first for a number of days and then removed. Your diet then changes slowly from small amounts of liquid to your normal diet. It is common for your bowel movements to be very loose at first. A low residue diet which produces very little output may help reduce this.

By the time you are discharged from the hospital, all lines and drains are removed except the catheter(s) in your pouch and/or the stents. These are left in place for approximately three weeks after surgery to allow swelling to decrease, prevent over distention of the pouch and pressure on internal suture lines, and enhance healing of the pouch and valve(s).

During your hospitalization, the catheters are initially cared for by your ostomy nurse as well as the other nurses caring for you. They will involve you in the care as soon as you are ready so you will be more comfortable with caring for yourself by the time you go home.

At home, the tubes require the same care as in the hospital. Your responsibilities

include irrigation of the catheters, care of their drainage receptacles, and care of the stoma. It is very important for you to wash your hands thoroughly before handling the catheters or stoma.

Irrigation of the catheter(s)

Irrigation begins during your hospitalization and continues until the catheter(s) is removed. Irrigation is done to prevent mucus from clogging the tubes and from accumulating along the lining of the pouch. The catheter(s) is generally irrigated every four to six hours even during the night. Your doctor or ostomy nurse will provide you with a schedule to follow.

To irrigate:

1. Gather equipment:
   a. normal saline solution or solution specified by your doctor or ostomy nurse
   b. container
   c. catheter-tip syringe or turkey baster
2. Wash your hands.
3. Pour the solution into the container.
4. Draw up 50-60 cc of the solution into the syringe.
5. Disconnect the catheter(s) from the drainage bag.
6. Gently push the solution into the catheter(s).
7. Gently withdraw the solution into the syringe or allow it to drain into the toilet.
8. Repeat steps 5 and 6 until almost no mucus is observed.
9. Reconnect the catheter(s) to the drainage bag
10. Wash your hands.

Care of the drainage receptacles

If NO external stents are present: During the day, connect the catheter(s) to a leg bag. The small size of the leg bag does not show under your clothing but does require periodic emptying. At night, connect the catheter(s) to a larger drainage container that sits on the floor or hangs from your bed and allows you to sleep uninterrupted. Both these drainage bags require the same daily care. Use a funnel or a turkey baster and rinse through the tubing and the drainage bags with these solutions in the following order:

1. Mild soap (liquid dish detergent or ostomy pouch cleanser) and warm water
2. Clear, warm water
3. A vinegar solution of one-half white vinegar and one-half water
   (allow this solution to remain in the bags for about 15 minutes)
4. Clear, warm water

After these four steps, allow the drainage containers to air dry. This daily care will keep the drainage bags clean and free of odor.

If external stents ARE present: To contain the urine from the stents during the day, you may wear an ostomy pouch or the stents may be connected to collection bags. Both of these do not show under your clothing and need periodic emptying. An ostomy pouch is disposable and should be changed once to twice a week or according to instructions given by your ostomy nurse. At night, connect this ostomy pouch to a larger drainage container that sits on the floor or hangs from your bed. This will allow you to have uninterrupted sleep. See the previous section for care of this container. If the stents are connected to drainage bags, they rarely require any special care. This will be determined by your doctor or ostomy nurse.

Care of the stoma

Your stoma requires care at least once a day and more often if needed. This can be combined with one of your daily irrigations. If you are wearing an external pouch, follow these instructions with each pouch change.

You should:

1. Wash your hands.
2. Gently remove the old dressing (or pouch).
3. Wipe away any mucus that has collected on the stoma and catheter with a tissue or a face cloth.
4. Wash surrounding skin with mild soap and water, rinse thoroughly then dry
5. Inspect stoma and skin. Notify your ostomy nurse or doctor of any changes.
6. Perform special skin care as instructed by your ostomy nurse.
7. Cover the stoma with a new dressing (or pouch) and secure with tape.
8. Wash your hands.

Other important information

During this initial period at home, call your doctor or ostomy nurse with any questions or concerns you may have. Notify your doctor or ostomy nurse if you have any of the following conditions:

- Fever
- New abdominal or back pain
- Increase in abdominal size
- Cloudy, foul-smelling urine
- Nausea and vomiting
- Dramatic change in the color of your stoma
- Catheters or stents that come completely out
- Significant decrease in the amount of urine from the catheters or stents
- No fluid returns after catheters' irrigations
- Large amount of bright red bleeding
- Urine-like drainage from your incision or drain sites
- An increased amount of drainage from around the catheters or stents

In about three weeks, your doctor may perform a pouchoscopy by inserting a lighted tube into your stoma to look at the inside of your continent urostomy pouch. A pouchogram (x-ray taken after special fluid has been put into your pouch) may be done. An x-ray of your new urinary tract may also be done. These procedures reveal if the pouch is healed and is working properly. They are neither painful nor time- consuming. After your doctor has checked the results of these tests, your catheters and stents may be removed. It is now that the continent urostomy pouch begins to store your urine and you regain continence.

ROUTINE CARE AT HOME

When the catheter and stents have been removed and continence is reestablished, you will be given instructions for draining urine from your continent urostomy pouch by intermittently catheterizing it. At first, your pouch needs frequent catheterizations because it holds only a few ounces of urine. Within four to six weeks, catheterizations are generally

done three to five times a day because the pouch slowly increases to hold as much as 600-1000cc of urine.

These catheterizations are not painful. They are usually done in the bathroom. You can sit on the toilet (normally or facing the tank) or stand in front of it. Use the position you are most comfortable with. This allows you to drain your urine right into the toilet.

The following timeframe for catheterizing your pouch provides a guideline for avoiding too much pressure on your pouch and for slowly increasing its size. Your doctor or ostomy nurse will give you a specific schedule to follow. If you feel pressure or fullness, empty your pouch despite your catheterizing schedule.

Catheterization schedule

	Daytime	Nighttime
Week 1	Every 2-3 hours	Every 3-4 hours
Week 2	Every 3-4 hours	Every 4-5 hours
Week 3	Every 4-5 hours	Every 5-6 hours
Week 4	Every 4-6 hours	Every 6-8 hours
Week 5	Every 4-6 hours	None

After the fourth week, you will catheterize yourself about four to six times a day, allowing for some flexibility. This flexibility depends on the instructions you are given; your daily schedule, (i.e., the times when you awaken, eat meals and go to bed); your food and fluid intake, and a feeling of fullness from the area of your pouch.

How to catheterize your pouch

1. Wash your hands.
2. Gather equipment needed.
3. Remove stoma covering.
4. Wipe any mucus from the stoma using tissue.
5. Apply a small amount of water soluble lubricant onto a clean catheter. Gently insert the catheter into your stoma, about three to five inches, until urine appears. This insertion becomes routine as you become more familiar with the sensation of catheterization, the location of your continence mechanism and the angle you must insert the catheter.
6. Hold the catheter in place until urine stops draining. Gently insert the catheter ½" to 1" further into your pouch to drain all of the urine out.
7. Remove catheter.
8. Apply stoma covering.
9. Wash hands.

Special considerations when catheterizing

At first, catheterizations may seem somewhat scary or difficult. It is normal to feel some resistance when the catheter reaches the continence mechanism. Never force the catheter. If you are having trouble with the insertion, do not panic! Relax and take a few deep breaths. Try looking up at the ceiling to help relax your abdominal muscles. If you

are tense, these muscles tighten and make insertion more difficult.

Water or water-soluble lubricants such as Surgilube® or K-Y jelly®, are used to make it easier for the catheter to enter into the pouch. Do not use Vaseline® or other petroleum products because they can clog the catheter.

With time, your pouch may shift its location and may be felt lower in your pelvis. Because of this, the angle that you insert the catheter may need to be adjusted. Also, the angle may vary depending on whether you are sitting or standing. You may need to try changing your position or the catheter's direction if you are having trouble with insertion.

Once insertion is achieved, urine should flow freely. If not, mucus may be clogging the catheter and you should try irrigating the catheter. Another possibility is the catheter tip may not be in good position. Try to rotate the catheter, slide the catheter back and forth slightly once or twice, or completely remove the catheter and then re-insert.

At the end of each catheterization, remove the catheter slowly to ensure complete emptying of your pouch. This decreases the risk of infection.

Care of the catheter

Catheters are reusable and will last many months with proper care:

1. Wash the used catheters with warm soapy water. A catheter-tipped syringe or a turkey baster can be used to flush through and clean the inside of the catheters.
2. Rinse them thoroughly with water.
3. Let them air dry on a clean surface.
4. They should be discarded if they:
   - can no longer be thoroughly cleaned
   - smell bad
   - become too soft
   - become too stiff (brittle)

Other routine care

It is recommended that you irrigate your continent urostomy pouch at least once a day to prevent infection and the accumulation of excess mucus in the pouch. Your doctor or ostomy nurse will tell you how often you should irrigate. Irrigations are done with your catheterizations. Once you have completely drained the urine from your pouch, leave the catheter in place for the irrigation. Irrigate with 50-60 cc of normal saline solution or any other solution specified by your doctor or ostomy nurse. Repeat several times until output is clear of mucus. Then remove the catheter. Refer to the section on irrigations in "After your Surgery," for more detailed instructions.

After irrigating your pouch, you should always inspect your stoma and the skin around the stoma. The skin should be intact and without any redness. Your stoma should be dark pink or red and moist. If you have any problems, contact your ostomy nurse or doctor. Daily care of the skin surrounding the stoma is the same as stated in the section "Care of the Stoma."

Catheterizing



Inserting the catheter into the stoma



Draining urine into the toilet

HELPFUL HINTS

Store your clean catheters in reclosable food storage bags or rectangular plastic containers. Keep used catheters separated from clean ones. Do not soak them in water as this causes them to soften.

When you are going out, be sure to take the necessary equipment along with you to catheterize and care for your continent urostomy pouch. Catheters can easily be carried in a reclosable sandwich bag to keep them clean. Never put a catheter on the toilet, sink or floor in a public restroom. If you need to put the catheter down, place it on a clean paper towel. The used catheter can be stored in a separate reclosable bag until it is properly cleaned. Never place used catheters in the same bag with clean ones.
Think of your continent urostomy pouch in the same way you would think of your bladder. Regardless of your catheterization schedule, empty your pouch before activities such as going out, traveling, having sex, playing sports, etc. This could save you both time and aggravation by avoiding the need to empty your pouch when it is less convenient.

If you have skin irritation around your stoma from tapes or adhesives, protective skin barrier wipes are available and should be used before you secure your stoma covering. Apply the wipe and let it dry completely. To avoid using any tape, you can wear elastic style underwear which should hold the covering securely in place. A skin irritation or an allergic reaction can also occur around the stoma due to certain products used. If you can determine the cause, avoid that product. For example, people who use deodorant maxi-pads or panty-liners as a stoma covering may react to the deodorant. These people should be sure to buy deodorant-free products.

Catheter extenders are available if you need extra tubing to reach the toilet when you are draining your pouch. Pay attention to your daily fluid intake. It may be easier to increase your fluid intake if you consume small amounts of fluids often during the day.
Be sure to contact your doctor if you have any of the following:

- urinary tract infection symptoms: fever and/or chills, abdominal or back pain, cloudy or foul-smelling urine, a large amount of blood in the urine.
- nausea/vomiting
- diarrhea
- weakness
- extreme thirst

Get a MedicAlert® bracelet or necklace and always wear it. You can get an application for these items from your ostomy nurse, most pharmacies or by writing or calling:
MedicAlert® Foundation
2323 Colorado Avenue
Turlock, California 95382
MedicAlert® Telephone: 800-ID-ALERT (432-5378)
A sample inscription on the bracelet might say: Continent Urostomy
Catheterize every 4-6 hours with a 1 4Fr. catheter.

More specific details of your medical history and current care can be kept on record at MedicAlert® and on your MedicAlert® ID card.

SUPPLIES FOR YOUR CONTINENT UROSTOMY

If you are hospitalized for any reason, take supplies for catheterizing your pouch with you. The hospital may not carry your brand or size equipment. Also, you may go to a hospital that is not familiar with your type of continent urostomy or with your routine in caring for it. Be your own advocate on your specific care and ask to have the information written in your medical record.

1. Catheters - Your doctor or ostomy nurse will suggest which catheter you should use. There are various types, brands, sizes and styles of catheters available. Catheters have either a straight or coude (curved) tip. Sizes vary depending on the type of continent urostomy you have.
2. Water-soluble lubricant.
3. Irrigation syringe (50-60cc catheter-tip) or turkey baster
4. Water or a normal saline solution - You can either purchase normal saline or make your own by dissolving 2 teaspoons of table salt in one-quart of water, boil it, and allow it to cool.
5. Stoma coverings - There are various products that may be suggested by your ostomy nurse such as: adhesive bandages, panty-liners or maxi-pads cut in half or in thirds, disposable diapers cut in small squares, or commercially made dressings.
6. Basin or container, soap and water
7. Tissues and/or face cloths
8. Tape (if needed)
9. Reclosable sandwich bags
10. Protective barrier wipes (if needed)

There are many places where you can buy your ostomy supplies and many insurance plans cover at least a portion of the cost. Use the phrase “prosthetic devices for ostomy” when asking about your individual plan for reimbursement. Use this same phrase when submitting insurance forms

Medical supply companies carry a wide variety of products for your needs. Many specialize in ostomy supplies and some have an ostomy nurse on staff. Most supply companies accept telephone orders, ship orders to your home via UPS and offer third party billing, such as billing your health insurance provider.

Also, your local pharmacy may either carry the supplies you need or order them for you. Your ostomy nurse will provide you with information on where to get supplies.

Always remember to pack enough supplies when you are traveling. However, supply companies and distributors are available throughout the United States and overseas.

LIFE WITH YOUR CONTINENT UROSTOMY

Now that you have started the routine care of your continent urostomy, it's time to put it all in perspective. At first, the care probably seems monumental to you, but it becomes as ordinary as other everyday activities like brushing your teeth, showering and toileting. These activities, although important, are not the focal point of your life nor do they interfere with your living. You can usually do whatever you want to. You are still you. The way you urinate may have changed, but you have not.

Clothing

There is no reason to change your style of clothing or your wardrobe. You can wear anything you want, including a bikini if your stoma is low enough. Since your stoma is protected with a small, inconspicuous covering, it will not be noticeable to anyone.

Diet

There are no dietary restrictions because of your continent urostomy. It is essential, however, to drink enough fluids to lessen the chances of a urinary tract infection. You should drink a variety of liquids, such as juices and water that equals two to three quarts per day. A moderate amount of alcohol is allowed but you should check with your doctor first.

Activity and exercise

Following your recuperative period (about six to eight weeks), you can go back to your usual activities and exercises. You may even decide to take up some new ones. Pace yourself slowly. This way you will not over exert yourself and will slowly build up your endurance and strength. After that, the sky's the limit.

Swimming and other water sports will not harm your stoma. You should waterproof your stoma covering to keep mucus from getting into the water and to keep your stoma covering dry and secure. This can be done with a variety of surgical or waterproof tapes available on the market. If you scuba dive, check with your doctor before doing this activity because the pressure may affect your internal pouch. Check with your surgeon before participating in rough contact sports such as football, hockey, basketball, wrestling etc.. Your stoma will need extra coverings over it for protection when these activities are resumed.

Driving is usually allowed after six to eight weeks, but check with your doctor. The same holds true for abdominal exercises.

Get back into your social life and favorite activities as well! You can still enjoy all the things you did before your surgery, from attending meetings, sporting events, social gatherings, parties, religious or community functions, shows or concerts to volunteering, gardening, biking, playing cards, bowling, dining out or just spending some relaxing time with friends. Remember, do not try to make your life fit around your ostomy. Make your ostomy fit into your life.

Work

There is no reason that having a continent urostomy should affect your job. After your recuperative period, you can work just as you did before. You may even find that now you can go to the bathroom less often than your fellow employees.

Travel

You can travel as long or as far as you like, across town or around the world. You can travel by any means (bike, car, bus, train, boat or plane) as well. Just remember to pack enough supplies for your trip plus a few extras for any unforeseen delays or problems that may occur. Find out where supplies will be available when you plan a long trip or vacation. You can get this information from your ostomy nurse or your supplier.

Empty your pouch before traveling, even by car or public transportation. Seat belts will not harm your stoma or pouch so be sure to wear them as recommended. When storing your supplies in the car, avoid extremes of temperature which can decrease the longevity of your catheters. To prevent loss of your supplies when traveling by air, always pack them with your carry-on luggage.

When traveling abroad, It is important to carry a note from your doctor stating that your ostomy supplies are medically necessary. This will help prevent problems when going through customs. Keep this note with your certificate of vaccinations and your passport. When traveling in foreign countries, never use water you wouldn't drink to wash your catheters or irrigate your pouch. You should also remember to avoid contaminated water for your catheter or pouch care when camping, backpacking or trekking.

Telling others

As with other personal issues, only you can decide if you want to share the type of surgery you had. No one will know unless you want them to know. However, it may be unreasonable as well as uncomfortable for you to keep your ostomy a secret from everyone. Explaining your surgery and sharing your feelings with your spouse, loved one, or children can not only help dispel their fears and misunderstandings but also help you to cope with your feelings and adjust to your ostomy. You may also wish to confide in a friend or co-worker. Even after you adapt to your ostomy, feelings of insecurity and discouragement can occur and it helps to talk to someone you are close to and can trust.

Social relationships

Our attitudes influence how we relate to others and how others relate to us. This is true whether one has an ostomy or not. Your ostomy itself has no affect on your social relationships but your attitude towards it may. This is not to make light of the fact that a change has occurred in your body. This change in your body image may initially cause you to have negative feelings about yourself. People often feel anger, depression or low self-esteem temporarily after ostomy surgery. It is normal to need time to adjust to the change. This is similar to adjusting with other changes, such as getting braces, having acne or getting grey hair. With time, you will integrate the surgery and its changes into your self-concept. You will be able to resume your life and relationships as you did before with a positive attitude.

All kinds of relationships are still available to you. Your stoma does not decrease your capacity to be involved with family, friendships, dating situations, sexual encounters and marriage. There comes a time in some new relationships when you feel close enough that you want to share your type of ostomy with the other person(s). This may or may not be difficult, but it certainly should not affect the relationship negatively. However, even an understanding person may need time to adjust to the ostomy just as you did. You are no different now than you were before your surgery. Now, you are a person who happens to have a stoma which changes the way you urinate, not the way you are.

Sexual relations and intimacy

Your ability to express love and feelings is not affected by your surgery. Your attitude is a key factor in re-establishing sexual expression and intimacy in your life. As with any intimate relationship, maintaining open and honest communication with your loved one is essential. Clarify any mixed messages you may be getting rather than try to second guess them. What you may think is rejection may be your partner's fear of hurting you. Hugging and other forms of physical contact will not harm your stoma.

Sexual relationships and intimacy are important and fulfilling aspects of life that should continue after your surgery. The small protective covering on your stoma does not interfere with any sexual positions, yet it hides your stoma from view and protects you both from any mucus discharge. Before engaging in sexual activity, you may want to empty your pouch. This is similar to emptying a full bladder before sex to prevent discomfort from pressure. You should check with your doctor to find out how soon after your surgery you can resume sexual relations. This is also a good time to ask any questions you may have. Feel free to contact your doctor or ostomy nurse at any time to discuss any of your sexual concerns. You can also arrange to see a counselor. The American Cancer Society has two books (one for men and one for women) that deal with sexuality in detail; you may find the information helpful. Contact the American Cancer Society for a copy of one or both of these books

For some women, extensive malignancy may necessitate the removal of the bladder and the female sexual organs. In these cases, intercourse may initially be uncomfortable due to decreased vaginal lubrication and possibly a shortened vagina. A water-soluble lubricant should be helpful and, if necessary, dilators may be used as prescribed by your physician.

Men may have problems with erections after their bladder is removed. The nerve sparing technique now being offered by many physicians can help prevent this. Still, there are a number of factors, both physical and psychological, that can contribute to a problem with erections. It is important to give yourself plenty of time, even up to a year, to recuperate from your surgery before coming to any decisions about a permanent erection problem. Even if you cannot maintain an erection, you may still experience an orgasm with or without an ejaculation. If traditional penile-vaginal penetration is not possible, you and your partner may want to experiment with variations to achieve sexual enjoyment and satisfaction. There are many options available to you if a problem does exist. These options include oral medications, penile injections, penile implants, or vacuum therapy. Problems with ejaculation will also occur which may be an issue if a man wishes to father children. Be sure to speak with your surgeon about this before surgery.

Pregnancy

Many women have questions about pregnancy. Your ability to conceive does not change and pregnancy and delivery should be normal. Just as pregnant women empty their bladders more often, you will need to empty your pouch more often because the capacity is decreased by the baby's growth. Catheterizations can be more difficult when pregnant, but after delivery they should return to normal. If you are thinking about becoming pregnant, you should first.check with your doctor

We encourage you to ask any questions about your particular lifestyle that may not have been answered in this section.

RESOURCES

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.

International Ostomy Association (IOA)

The International Ostomy Association provides information regarding ostomy associations worldwide. For membership information visit the web site at www. ostomyinternational.org

Wound, Ostomy and Continence Nurses Society (WOCN)

The WOC(ET) nurse is a specialist in the care and rehabilitation of people with ostomies. In addition to serving individual's with stomas, ostomy nurses coordinate patient care, teach nursing personnel in hospitals and clinics and work closely with the nursing and medical professions to improve the quality of ostomy rehabilitation programs everywhere. You can contact the WOCN national office for information and local referrals at 1-888-224- 9626 or visit the web site at www.wocn.org

A number of cancer centers may have clinics which provide services to patients with all types of ostomies, whether or not they are caused by cancer. Check for available services such as pamphlets or ostomy supplies for the medically indigent. You can also contact the American Cancer Society (1 -800-ACS-2345) for information regarding ostomy support groups.

Home health care is generally set up for you before being discharged from the hospital. The social worker or discharge planner can answer questions about this and other resources you may need at home.

Medicare, Medicaid, and Social Security in the United States

Urostomy 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.

GLOSSARY OF TERMS

Common ostomy terms that may be used by your healthcare team.

Appliance/Pouch - An external collection device

Catheter - Special flexible tube used for draining continent reservoir

Carcinoma - Cancer, malignant growth

Congenital - Present or existing at the time of birth

Continence - Controlling the release of urine until an appropriate time

Cystectomy - Removal of the bladder, requiring some kind of urinary diversion

Enterostomal Therapy (ET) Nurse - See WOC(ET) nurse

Interstitial Cystitis - Inflammation of the bladder wall of unknown cause

Malignancy - A cancerous growth

Neurogenic Bladder - Bladder disorder due to abnormal nerve function

Ostomy Visitor - Person with an ostomy 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

Ureters – Two small tubes that connect the kidneys to the bladder

Stents - Small tubes to continuously drain urine to allow the internal tissues to heal.

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

Wound, Ostomy and Continence Nurse (WOCN) - Also known as WOC(ET) nurse or ostomy nurse. A person who takes care of and teaches patient’s with ostomies. A special training course for registered nurses is required for certification.

BIBLIOGRAPHY

Berglund B, Kock N, Norlen L, Philipson, B: Volume Capacity and Pressure Characteristics of the Continent Ileal Reservoir Used for Urinary Diversion. J Urology 1987; 137:29-34.

Bloch W, Bejany D, Penalver M, and Politano V: Complications of the Miami Pouch. J Urology 1992;147:1017-1019.

Boyd S, Feinberg S, Skinner D, Lieskovsky G. Baron D, Richardson J: Quality of Life Survey of Urinary Diversion Patients: Comparison of Ileal Conduits Versus Continent Kock Ileal Reservoirs. J Urology 1987; 138:1386- 1389.

Brogna L, LaKaszawski M: The Continent Urostomy. American Journal of Nursing 1 986;Feb:1 60-163.

Choudhury M: The Indiana Pouch: A Continent Urinary Reservoir. Progressions 1989;1(3):12-15.

Crawford D, Davis M: New Directions in Urinary Diversion. Ostomy Quarterly 1 984;21 (3):72-75.

Duckett J, Snyder H: Use of the Mitrofanoff Principle in Urinary Reconstruction. Urologic Clinics of North America 1986;13(2):271 --274.

Duckett J, Snyder H: Continent Urinary Diversion: Variations on Mitrofanoff Principle. J Urology 1986;136: 58-62.

Gerber A: The Kock Continent Ileal Reservoir: An Alternative to the Conventional Urostomy. J Enterostomal Therapy 1 985;1 2:15-17.

Ghoneim M, Shaaban A, Mahran M, and Kock N: Further Experience with Urethral Kock Pouch. J Urology 1992;147:361 -365.

Goldwasser B, Webster G: Continent Urinary Diversion. J Urology 1985;134:227-236. Heneghan G, Clark N, Hensley B, Yang T: The Indiana Pouch: A Continent Urinary Diversion. J Enterostomal Therapy 1990;17:231 --236.

Kock N, Nilson A, Nilsson L, Norlen L, Philipson B: Urinary Diversion via a Continent Ileal Reservoir: Clinical Results in 12 Patients. J Urology 1982;128:469-475. Kramer D: Pediatric Urinary Undiversions—An Update. Expanding Thought 1 984;Nov:9-1 3.

Light J, Engelmann U: Le Bag: Total Replacement of the Bladder Using an Ileocolonic Pouch. J Urology 1 986;1 36:27-31.

Lockhart J: Remodeled Right Colon: An Alternative Urinary Reservoir. J Urology 1 987;1 38:730-734.

MacGregor P: The Continent Urostomy: Criteria and Considerations. Abstract. 198. Mitchell M: Construction of a Continent Ileo-cecal Reservoir. Urologic Surgery 1987. Pow-Sang J, Helal M, Figueroa E, Sanford E, Persky L, Lockhart J: Conversion from External Appliance Wearing or Internal Urinary Diversion to a Continent Urinary Reservoir (Florida Pouch I and II): Surgical Technique, Indications and Complications. J Urology 1 992;1 47:356-360.

Pressel P: The Continent Urostomy. J Enterostomal Therapy 1 984;1 1:152-153. Pressel P: The Continent Vesicostomy. J Enterostomal Therapy 1 983;1 0:207.

Ralls P, Barakos J, Skinner D, Boswell W, Radin D, Colletti P, Halls J: Imaging of the Kock Continent Ileal Urinary Reservoir. Radiology 1986; 161:477-483.

Rowland R, Mitchell M, Bihrle R: Alternative Techniques for Continent Urinary Reservoir. Urologic Clinics of North America 1987; 14:797-804.

Rowland R, Mitchell M, Bibrle R, Kahnoski R, Piser J: Indiana Continent Urinary Reservoir. J Urology 1987;137:1136-1139.

Schlegel P. Walsh P: Neuroanatomical Approach to Radial Cystoprostatectomy with Preservation of Sexual Function. J Urology: 1987;138:1402-1 406.

Skinner D, Lieskovsky G, Boyd S: Technique of Creation of a Continent Internal Ileal Reservoir for Urinary Diversion. Urologic Clinics of North America 1 984;1 1 (4):741 - 749.

Skinner D, Boyd S, Lieskovsky G: Clinical Experience with the Kock Continent Ileal Reservoir for Urinary Diversion. Abstract. Los Angeles, California, 1984.

Skinner D, Lieskovsky G, Boyd S: Continuing Experience with the Continent Ileal Reservoir (Kock Pouch) as a Alternative to Cutaneous Urinary Diversion: An Update After 250 Cases. J Urology 1987;137:1140-1145.

Smith D, Babaisan J: Patient Adjustment to an Ileal Conduit After Radial Cystectomy. J Enterostomal Therapy 1989;16:244-246.

Thuroff J, Alken P, Riedmiller H, Engelmann U, Jacobi G, Hohenfellner R: The Mainz Pouch (Mixed Augmentation Ileum and Cecum) for Bladder Augmentation and Continent Diversion. J Urology 1986;136:17-26.

Tomaselli N, McGinnis D. Urinary Diversions: Surgical Interventions. In Colwell J, Goldberg M, Carmel J. Fecal & Urinary Diversions: Management Principles (pp.184-204), St. Louis, MO, 2004, Mosby.

Weingarten J, Cromie W: The Mitrofanoff Principle: An Alternative Form of Continent Urinary Diversion. J Urology 1988;140:1529--1531.

WOCN Guidelines/Standards Committee. Guidelines for Management: Caring for a Patient with a Continent Diversion. WOCN: Laguna Beach, CA, 1996; pgs. 1-25; 70-74; 89-101.

Woodhouse C, Malone P, Cumming J, Reilly T: The Mitrofanoff Principle for Continent Urinary Diversion. British J Urology 1 989;63:53-57.

Young N, McRae K: Self-Catheterization of Continent Diversions for Patients with Quadriplegia. Progressions 1991 ;3(4):3-1 3.