



COLOSTOMY GUIDE

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

“SEIZE THE OPPORTUNITY...”

A Message To You...

Colostomy 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

COLOSTOMY GUIDE

Reviewed by:

**Nancy Gutman, RN, CWOCN
2011**

**Adapted and revised from existing UOA materials:
Colostomy A Guide, 1971, 1991
Colostomy Guide, 2004
Jan Clark, RNET, CWOCN
Peg Grover, RNET**



This guidebook is available for free, in electronic form, from the United Ostomy Associations of America (UOAA). It was originally produced, copyrighted and sold by the United Ostomy Association (UOA), the national US ostomy organization from 1962 to 2005, which released its copyrights on this material.

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

CONTENTS

- INTRODUCTION 1**
- FACTS ABOUT COLOSTOMY SURGERY. 2**
- NORMAL DIGESTIVE SYSTEM 3**
- TYPES OF COLOSTOMIES AND METHODS OF CARE 4**
 - Ascending colostomy 4
 - Transverse colostomy 4
 - Caring for the transverse colostomy 5
 - Descending or sigmoid colostomy 6
 - Caring for the sigmoid colostomy 7
 - natural evacuation 7
 - irrigation guidelines. 7
 - irrigation information. 8
- COLOSTOMY MANAGEMENT 9**
 - Pouches 9
 - Stoma covers / Caps 9
 - Storage 9
 - Ordering supplies 10
 - Pouch seal 10
 - Peristomal skin 10
 - Intestinal gas 11
 - Odor 11
 - Constipation and diarrhea. 11
 - “Phantom” rectal sensation. 12
- COLOSTOMY COMPLICATIONS. 12**
 - Seeking medical assistance 12
 - Being hospitalized again. 13
- LIVING WITH A COLOSTOMY 13**
 - Telling others about surgery 14
 - Clothing and appearance 14
 - Eating and digestion 14
 - Returning to work 15
 - Intimacy and sexuality 15
 - Participating in sports 16
 - Bathing and swimming 16
 - Children with ostomies 16
 - Travel 17
 - Traveling by plane. 17
 - Traveling abroad 17
- RESOURCES AVAILABLE. 18**
- GLOSSARY OF TERMS 19**

INTRODUCTION

A colostomy is a lifesaving surgery that enables a person to enjoy a full range of activities, including traveling, sports, family life and work, even though they have a stoma and may wear a pouching system.

Colostomy surgery is performed for many different diseases and conditions. Some colostomies are done because of malignancy (cancer). In children, they may be created because of birth defects. Colostomies can be temporary or permanent. Some colostomies appear large, others small. Some are on the left side of the abdomen, some are on the right, and some in the middle.

Think of your colostomy's function as you do of a natural bowel movement. You still have the same bowel, just less of it. The real change is having a bowel movement from an opening made in the abdomen. Learning how to care for your colostomy will help you adjust.

There are several ways to take care of your colostomy. As colostomies differ, so does taking care of them. This booklet offers suggestions and ideas for managing a colostomy. Please read the following pages carefully. The included glossary will help explain the technical terms – use it as a guide rather than a textbook. Discuss ideas with a physician or WOCN, hereinafter referred to as ostomy nurse, then adapt them to your situation.

There are many ways to gain a greater understanding of your life with a colostomy. This guide will give you helpful facts. Your physician, ostomy nurse, or other nurses are important sources of information and support. A special source of help with your adjustment is an ostomy visitor. The visitor is a person who has had colostomy surgery. He or she is well qualified to answer your questions and share tips on living with an ostomy.

Taking part in an ostomy support group may also help. A support group allows you to share your feelings and ask questions. It also allows you to share your successful adjustment with others who may need the benefit of your experience.

Most ostomy visitor programs and support groups are sponsored by local support groups of the United Ostomy Associations of America (UOAA). If you would like to see a visitor or take part in a support group, ask the physician, ostomy nurse, or other nurses. You or your family may also locate a local support group by calling 800-826-0826 or visiting the UOAA Web site, www.ostomy.org.

FACTS ABOUT COLOSTOMY SURGERY

A colostomy is created when a portion of the large intestine is removed or bypassed. The remaining portion of the functioning large intestine (colon) is brought through the abdominal wall, creating a stoma. This results in a change of normal body function to allow elimination of bowel contents following disease, injury, or birth defect.

When certain conditions are present in the large intestine, it may be necessary to give that portion a rest. This is done by preventing stool from reaching it. To do this, a *temporary colostomy* is created so that healing may take place. Depending on the healing process, this may take weeks, months or even years. Eventually the temporary colostomy is reversed (removed) and normal bowel movements are restored.

When the end portion of the colon or the rectum becomes diseased, construction of a *permanent colostomy* may become necessary. The diseased portion must be totally removed or permanently bypassed. Such a colostomy provides an exit for stool that will not be closed at any time in the future.

Where on the abdomen the colostomy is located depends on which part of the colon is used to create it. The ostomy nurse or surgeon will determine the correct location for your stoma. The appearance of the stoma depends on the type of colostomy and on individual differences in the human body. While the stoma may be quite large at first, it will shrink gradually and attain its final size in six to eight weeks.

When you look at a stoma, you are actually looking at the lining (the mucosa) of the intestine. It is warm and moist and secretes small quantities of mucus. Unlike the anus, the stoma has no valve or shut-off muscle. For this reason, willful control of the passage of stool is not possible.

The colon's work consists primarily of absorbing water from, transporting and the storage of stool. There are two major types of activities in the colon: peristalsis and mass reflex. These movements occur throughout the different parts of the colon, but are not noticed. The purpose of peristalsis is to mix and knead the food and to extract water, thus forming the end product, stool. When stool collects in a portion of the colon, muscles in that part relax and stretch to accommodate it. Pressure builds as the limit of stretching approaches. At this point, a mass reflex, stronger than peristalsis, propels the stool into the next portion of the colon. From there, it moves into the rectum. This occurs automatically several times a day and usually follows a meal or drink.

The end portion of the digestive tract is the rectum and anus. Special nerve pathways to the brain make us aware when the stool reaches this section. Only then is the digestive process subject to our will. As the stool enters the rectum, we feel the desire to have a bowel movement. The anal sphincter allows us to control this desire. Unlike the digestive tract, it contracts or relaxes at our will.

NORMAL DIGESTIVE SYSTEM

Although a colostomy creates an important change for a patient, the body's chemistry and digestive function are not significantly altered by it. In order to appreciate how the body can function with a colostomy, let us review the normal function of the digestive tract.

Small Intestine: Approximately 20 feet long, consisting of:

- Duodenum (first part) 10-12 inches beginning at the outlet of the stomach.
- Jejunum (second part), about 8-9 feet.
- Ileum (third part) about 12 feet, connected to the large intestine at the cecum.

Food nutrients are digested and absorbed in the small intestine as food is moved through by peristalsis.

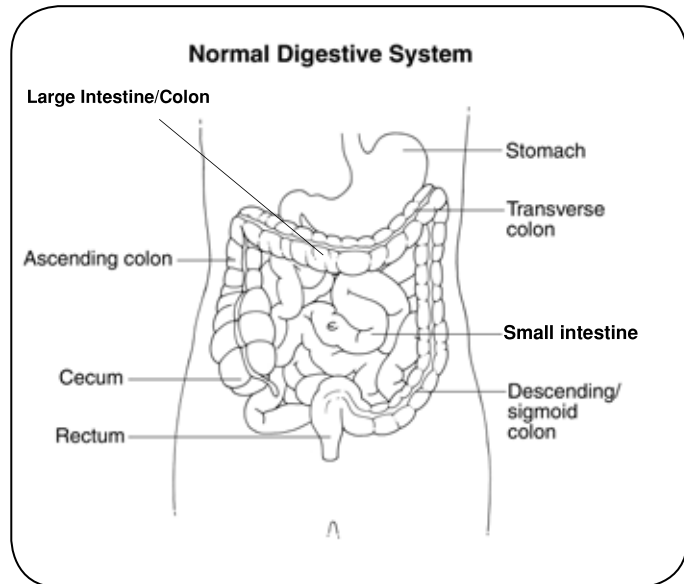
Large Intestine: Approximately 5-7 feet long, consisting of:

- Cecum – contains the ileocecal valve, which prevents reflux into the ileum; contents are highly acidic liquid.
- Ascending colon – contents are acidic liquid.
- Transverse colon – contents are less acidic liquid.
- Descending/sigmoid colon – contents become more formed.
- Rectum – formed stool.

The primary functions of the large intestine are absorption of water and electrolytes, transport of stool by peristalsis, and storage of digestive waste until it is eliminated from the body.

Since nutrients are absorbed in the small intestine, a colostomy does not affect the body's ability to be nourished. When a colostomy interrupts the passage of stool, storage becomes more difficult. The higher up in the colon the colostomy is made, the less time the bowel has to absorb water and the more liquid (or soft) the stool is likely to be. Therefore, a colostomy in the transverse colon will discharge a softer and more voluminous stool and will require the use of a collection pouch.

A colostomy far down in the colon, near the rectum, will discharge stool that has been in the intestine a longer time and barring the effects of illness, medications or other forms of treatment, may produce a more formed stool. Some colostomates find that they are able to pass this stool at regulated times with or without the help of irrigation (an enema through the stoma).



After the operation, if the rectum is intact, patients may feel urges and even have some discharge from the anal area. It may continue to secrete mucus that can be harmlessly passed whenever the urge occurs.

Care of the Posterior Wound

In some patients, the rectum and anus are removed and there will be a posterior wound. Care of the posterior wound is based on simple hygiene and the use of dressings or pads to collect and contain any secretions. Persistent infections or drainage may be treated by antibiotics or sitz baths. Your physician should outline a treatment to follow.

TYPES OF COLOSTOMIES

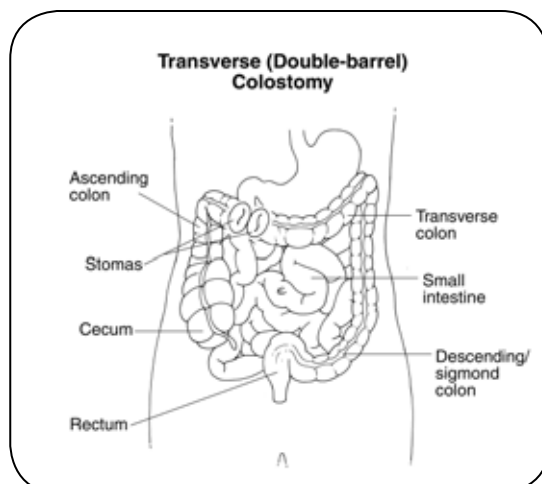
A colostomy can be temporary or permanent and can be in any portion of the large intestine depending upon the cause for the surgery. The types of colostomies are usually identified by the location of the stoma: ascending, transverse, descending/ sigmoid.

Ascending Colostomy

The ascending colostomy is located on the right side of the abdomen. The discharge is very liquid. A drainable pouch is worn for colostomies of this type. This type of stoma is rarely used since an ileostomy is a better stoma when the discharge is liquid. When a colostomy is located in the right half of the colon, only a short portion of colon remains.

Caring for an ascending colostomy is similar to caring for a transverse colostomy.

Transverse Colostomy



Indications:

- diverticulitis
- trauma (injury)
- birth defects
- cancer/descending or sigmoid colon
- bowel obstruction
- paralysis

Discharge:

- semi-solid
- unpredictable
- contains some digestive enzymes

Management:

- skin protection
- drainable pouch
- closed-end pouch for convenience or special moments

The transverse colostomy is in the upper abdomen, either in the middle or toward the right side of the body. Diverticulitis, inflammatory bowel disease, cancer, obstruction, injury or birth defects can lead to a transverse colostomy. This type of colostomy allows stool to exit the colon before it reaches the descending colon.

When conditions such as those listed are present in the lower colon, it may be necessary to give the affected portion of the colon a rest. A transverse colostomy may be created for a period of time to prevent stool from passing through the area of the colon that is inflamed, infected, diseased or newly operated on, thus allowing healing to occur. Such a colostomy is usually temporary. Depending on the healing process, the colostomy may be necessary for a few weeks, months, or even years. Eventually given your good health, the colostomy is likely to be closed and normal bowel continuity restored.

A permanent transverse colostomy is made when the lower portion of the colon must be removed or permanently rested. This may also be the case if other health problems make it unwise for the patient to have further surgery. Such a colostomy provides a permanent exit for stool and it will not be closed at any time in the future.

There are two types of transverse colostomies: "loop transverse colostomy" and "double-barrel transverse colostomy."

Loop colostomy: entire loop of bowel is brought to the skin surface and opened to create a distal, or nonfunctional end. The distal side is also called a mucus fistula due to the normal mucus secretions it produces. The proximal or functioning end expels stool. Patients with intact rectums may experience passage of mucus through the rectum.

Double-barrel: similar to a loop colostomy, except the bowel is divided into two stomas, a *proximal* and a *distal* stoma. The distal stoma functions as a mucus fistula. The proximal stoma expels stool. Double-barrel stomas may present management challenges due to the proximity of the stomas to each other.

Generally, a transverse colostomy will be placed higher on the abdomen so concealing the pouch may be more of a challenge.

Caring for a Transverse Colostomy

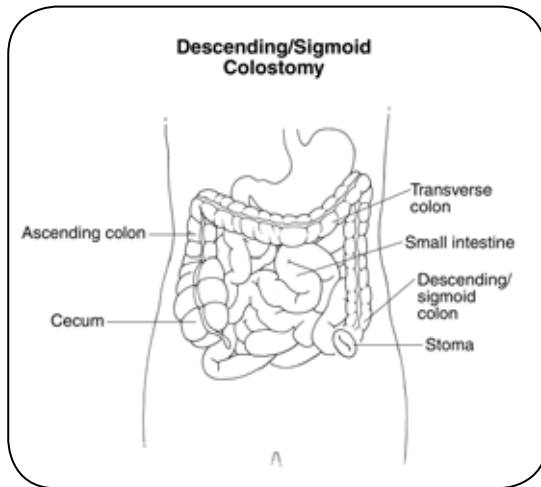
The discharge from the transverse colostomy is semi-solid, unpredictable and contains some digestive enzymes. The management of the transverse colostomy consists of skin protection and a drainable pouch. A closed-end pouch can be used for convenience during special activities.

Skin irritation can usually be prevented by having a correctly fitted pouch.

The consistency of stool is influenced to some extent by what you eat. Gas and odor are part of the digestive process and can be somewhat controlled by your selection of foods. Certain foods tend to produce more gas and odor (i.e., onions, beans, cabbage, broccoli, eggs, fish).

Emptying the pouch several times a day reduces the risk of leakage and bulges underneath your clothing. A one-piece pouch should not be changed more than once a day, unless using a pouching system designed for disposal (closed-end), to prevent skin irritation. A two-piece pouch should be changed every three to five days.

Descending or Sigmoid Colostomy



Indications:

- cancer of rectum or sigmoid colon.
- diverticulitis
- trauma (injury)
- congenital defects
- bowel obstruction
- paralysis

Discharge:

- resembles normal bowel movements
- regulated in some persons, not in others

Management:

- natural evacuation or irrigation
- protective cover or closed-end pouch if regulated. If not, use open-end drainable pouch.

Located on the lower left side of the abdomen. Generally, the discharge is firm and can be regulated. The sigmoid colostomy is probably the most frequently performed of all the colostomies.

The stool of a descending or sigmoid colostomy is firmer than that of the transverse colostomy and does not have the caustic enzyme content. At this location, elimination may occur on a reflex basis at regular, predictable intervals. The bowel movement will take place after a considerable quantity of stool has collected in the bowel above the colostomy. Spilling may happen between movements because there is no anus to hold the stool back. Many people use a lightweight, disposable pouch for security. A reflex will set up quite naturally in some people. In others, mild stimulation, such as juice, coffee or food is effective for elimination. Others may prefer the irrigation method of management.

While many descending and sigmoid colostomies can be managed to move regularly, others cannot. You must realize that satisfactory management, with or without stimulation, is likely to happen only in those people who have had regular bowel movements before they became ill. If bowel movements have been irregular in earlier years, it may be quite difficult, or impossible, to have regular, predictable colostomy function. Spastic colon or irritable bowel are conditions in which the patient may have bouts of constipation or loose stool. A person, who has had such a condition in the past, before he became ill, may not achieve regularity.

It is often said that a person must have a bowel movement every day. Actually, this varies from person to person. Some people have two or three movements a day, others have one every two or three days or even less often. You must judge by what is usual for you, not what is usual for others.

Caring for a Descending or Sigmoid Colostomy

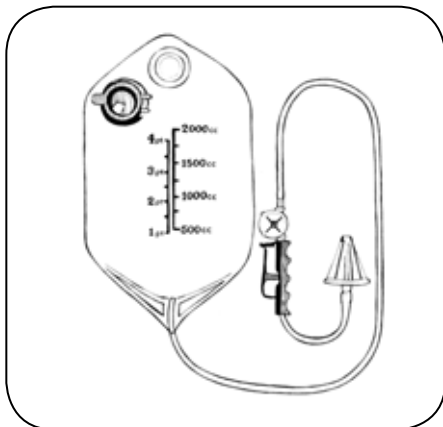
Natural Evacuation

The descending or sigmoid colostomy can be managed by *natural evacuation*, that is, just let it happen naturally. This method will require a collection pouch to be worn at all times. Many individuals with a descending or sigmoid colostomy will return to a predictable bowel movement pattern. (see More Information About Colostomy Management)

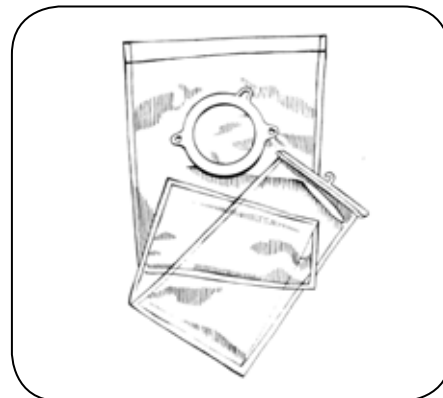
Irrigation

Irrigating (an enema through the stoma) to have regulated bowel movements is up to the individual. It should be discussed with your physician or ostomy nurse before deciding. A physician or ostomy nurse should instruct you with this procedure.

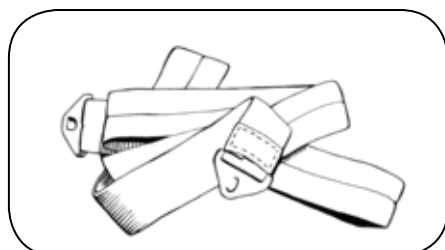
There are specific ostomy supplies needed for this procedure that will include: 1) plastic irrigating container with a long tube, and a cone to introduce water into the colostomy, 2) an irrigation sleeve is worn to direct the output into the toilet, 3) an adjustable belt to attach the irrigation sleeve and 4) a tail closure for the end of the irrigation sleeve. Then a closed-end pouch or stoma cover can be worn until the next irrigation.



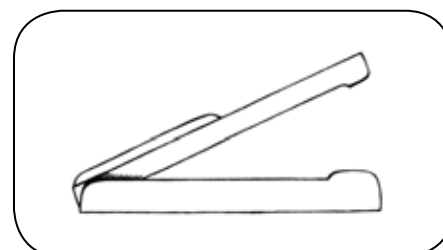
Irrigation system



Irrigation sleeve



Adjustable belt



Tail closure

Irrigation Information Only for Those Who Irrigate

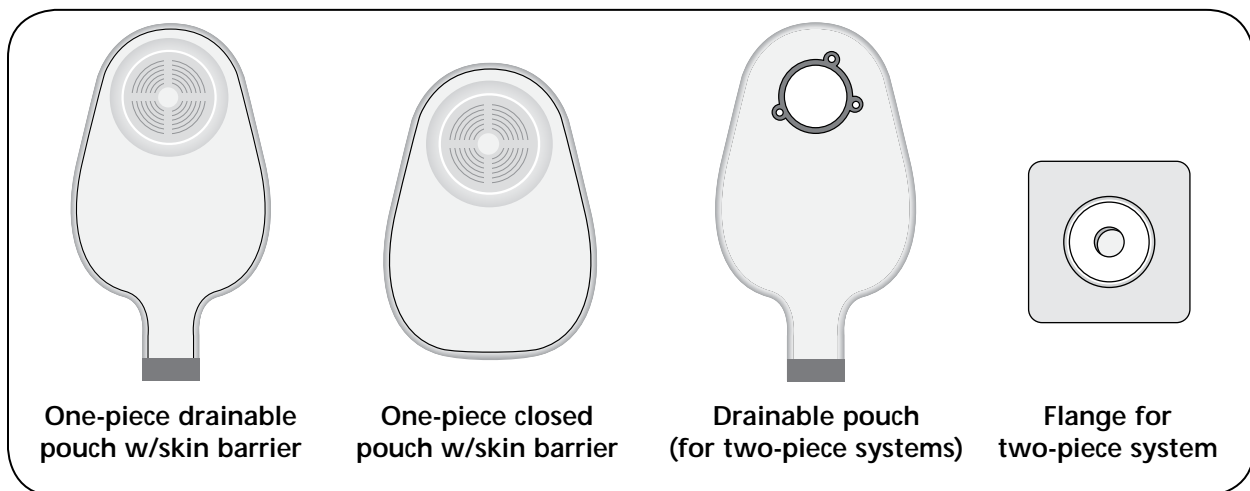
- First, speak to your physician and ostomy nurse before irrigating your colostomy.
- Choose a consistent time of day when you will have uninterrupted bathroom accessibility.
- Irrigation may be more satisfactory if it follows a meal or hot/warm drink.
- Instill 1,000 cc (one quart) of lukewarm (not hot) water into your irrigating container.
- Hang the container at such a height that its bottom will be at the level of your shoulder when you are seated.
- Sit up straight on the toilet or on a chair next to the toilet.
- Attach the adjustable belt to the plastic irrigation sleeve and place the bottom end of the sleeve in the toilet bowl.
- Wet or lubricate the end of the cone with water or water-soluble surgical lubricant.
- To remove air bubbles from the tubing, release the clamp on the tubing and let a small quantity of water escape into the sleeve. Reclamp the tubing, insert the cone into the colostomy to a snug fit, but do not apply too much force. Again, release the clamp on the tubing and allow the water to flow in.
- The water must go in slowly. You may shut the clamp or press the walls of the tube together to slow or stop the water flow. It takes about five to ten minutes to drip in 1,000 cc of water. Hold the cone in place for at least an additional 15 seconds.
- The amount of water you need depends on your own body. Begin with 1,000 cc and adjust to obtain successful returns.
- You should not experience cramps or nausea while the water flows in. Both these symptoms indicate a flow that is too rapid, too much water, or water that is too cold. Once the water has been instilled, a bowel-movement-type cramp may precede the return of the water and stool. (Nausea may be experienced the first time.)
- Remove the cone and attach the irrigation sleeve over the stoma. Returns will come in spurts over a period of approximately 45 minutes. As soon as the major portion of stool has been expelled, you may clip the bottom of the irrigating sleeve to the top with a clasp. You may move around, bathe or anything else to pass the time.
- In time, you will know when all the water and bowel movement has been expelled. A squirt of gas or a quiet appearance of the stoma may indicate completion.
- If the complete irrigation always takes much more than an hour, consult your physician or ostomy nurse to evaluate your procedure.

It is best to seek guidance from an ostomy nurse before beginning this process.

COLOSTOMY MANAGEMENT

Pouches

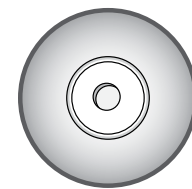
Pouches come in a variety of styles and sizes that do not show under clothing. They are made of disposable materials and designed to be worn once and then discarded. Many colostomates wear a pouch. For example, those who have a transverse colostomy, those who do not wish to irrigate and those who have some output between irrigations.



Basically, they all do the same job. They collect stool that may expel expectantly or unexpectedly. Some are open at the bottom for easy emptying. Others are closed and are removed when filled. Others allow the adhesive face plate or flange to remain on the body while the pouch may be detached, emptied or replaced. Pouch flanges are available in both convex and flat surfaces. Everyone, including those who irrigate, needs some type of stoma pouch on hand, if only for emergency purposes.

Stoma Covers/Caps

A gauze-type covering can be placed over the stoma and held in place with a water-proof tape or underclothing. Stoma caps are also available for purchase. This method may be used when colostomies are regulated and irrigation is used.



One-piece stoma cap

Storage

For the sake of convenience and discretion, keep all your equipment together on a shelf or in a small box in a cool dry area. Excessive heat may cause deterioration of plastic items and skin care products.

Ordering Supplies

It is a good idea to reorder supplies several weeks before you expect them 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 recommended shelf life and are influenced by changes in temperature. You do not have to use sterile supplies. The stoma and surrounding skin are not sterile and require only cleanliness. Ostomy supplies can be ordered from pharmacies, medical supply distributors and on the Internet. *The Phoenix* ostomy magazine and www.ostomy.org are excellent resources.

Pouch Seal

In addition to the type of seal and proper fit, there are several other factors that can influence how long the pouch will stay sealed. These include weather, skin peculiarity, scars, weight changes, diet, activity, body contours near the stoma and the nature of the stool.

Perspiration during the summer months in warm, humid climates may shorten the number of days you can wear the pouching system. Moist, oily skin may reduce adhesion time.

Weight changes will also affect the wearing time of your pouch. Weight gained or lost after colostomy surgery changes abdominal contours. You may need to modify your pouching system.

Physical activities will have some influence on the length of time you can wear your pouch. Swimming, very strenuous sports or work that causes perspiration may cut down on wearing time.

Peristomal Skin

A colostomy that discharges firm stool usually causes few, if any, skin problems. If the stool is loose, as is often the case with transverse colostomies, it can irritate the skin. Here are some ways to prevent skin problems:

- Use the correct size of pouch opening and skin barrier opening. Allow no more than 1/8 inch larger than the stoma.
- Change the pouch regularly to avoid leakage and skin irritation. It is recommended to change the pouch if itching and burning occurs.
- Remove the pouch by gently pushing your skin away from the pouch. This helps prevent excessive skin irritation.

- 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. Make sure the skin is dry and cool before applying the pouch or stoma covering.
- Watch for sensitivities and allergies to adhesives, skin barriers, tape or pouch material. They can develop weeks, months, or even 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.

Intestinal Gas

During the early weeks and months after surgery, you may experience excessive gas. This will lessen after the bowel has had time to heal and you have resumed a regular diet. To help prevent excessive gas, eat leisurely in a relaxed atmosphere with your mouth closed and chew well. Carbonated drinks and chewing gum should be used in moderation. Certain foods, such as cucumbers, cabbage, broccoli, onions, fish and dried beans may cause intestinal gas. Large amounts of vegetables or sweets can create gas. Constipation or unsatisfactory irrigation may also cause gas.

If you continue to be troubled, write down what you eat and how it is prepared. From this journal you may learn what causes the problem. To muffle noisy discharges of gas, put your hand discreetly over the stoma. Eat regularly and avoid gassy foods.

Odor

Certain foods tend to produce more gas and odor than others, i.e., onions, beans, cabbage, broccoli, eggs and fish. Some medicines such as vitamins and antibiotics also cause stools to have odor. Discuss this problem with your physician. He or she may be able to prescribe another type of medication.

Some options for odor management include oral products (bismuth subgallate) and deodorant drops in the pouch. These products are more effective with transverse colostomies because of the liquid consistency of the output.

Constipation and Diarrhea

Constipation is often the result of an unbalanced diet, too small an intake of food or liquids or certain medications. These are matters to talk over with your ostomy nurse or physician. If you have had constipation problems in the past, before surgery, remember how you solved them and try the same methods. DO NOT use laxatives without asking your physician.

Diarrhea is usually a warning that something is not right. Diarrhea is defined as frequent or watery bowel movements in greater amounts than customarily experienced. Diarrhea must be distinguished from loose bowel movements. Loose bowels are common in transverse colostomies. This is due to the shortened length of the colon and is not a sign of sickness or disease.

If you have persistent diarrhea or constipation, you should talk with your physician or ostomy nurse. Discuss your diet, your eating schedule and any medications you might be taking. Something may be prescribed to help manage the situation. Remember, you need a well-balanced diet and sufficient fluids to obtain good output.

Occurrence of the “Phantom” Rectal Sensation

“Phantom” rectal sensation is similar to the “phantom” limb sensation of amputees who feel as if their removed limb is still there. It is normal for you to feel as if you need to evacuate. This can occur for years after surgery. If the rectum has not been removed, one may also have this feeling and may pass mucus when sitting on the toilet. Some who have had their rectum removed say that the feeling is relieved somewhat by sitting on the toilet and acting as if an evacuation is taking place.

COLOSTOMY COMPLICATIONS

The most common problem after colostomy surgery is the development of a hernia around the stoma site. This is manifested as a bulge in the skin around the stoma, difficulty irrigating and partial obstruction. Heavy lifting should be avoided immediately after surgery and should only be resumed under a physician’s guidance.

Many of these problems can be avoided if the stoma site is marked by the ostomy nurse before surgery. The preferred site lies within the rectus abdominus muscle near the midline. The ostomy nurse is also helpful in managing complications.

Seeking Medical Assistance

You should call the doctor or ostomy nurse when you have:

- Severe cramps lasting more than two or three hours
- Unusual odor lasting more than a week
- Unusual change in stoma size and appearance
- Obstruction at the stoma and/or prolapse of the stoma
- Excessive bleeding from the stoma opening, or a moderate amount in the pouch in several emptyings (Note: eating beets will lead to some red discoloration)
- Severe injury or cut to the stoma
- Continuous bleeding at the junction between stoma and skin
- Watery discharge lasting more than five or six hours
- Chronic skin irritation
- Stenosis of the stoma (narrowing)
- Unable to wear your pouching system for 2-3 days without leakage

Being Hospitalized Again

Take your ostomy supplies with you as the hospital may not have your brand. You may find that you are the expert on colostomies, especially if you are in a hospital where ostomy 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) type of ostomy
- 2) whether or not your rectum has been removed or is intact
- 3) details of your management routine and products used.

LIVING WITH A COLOSTOMY

Learning to live with a colostomy may seem like a big undertaking. It is similar to other major changes in your life. Beginning a new job, moving to another city, marriage and having children are all examples of adapting to a new way of life. Initially, you have to adjust to the unfamiliar aspects of these experiences and this may take some time. Having a positive outlook on life, patience and a sense of humor are keys to adjusting to any new situation. You can find support through the www.ostomy.org website and local, affiliated support group meetings. Call 800-826-0826 for more info.

There are times after surgery when you may feel discouraged. You may feel alone and isolated. Because the whole experience is so new to you, you may feel awkward, frustrated and uncertain. Feeling discouraged is normal. You might cry, be hostile or angry and react in ways that are unusual for you. Talking to a trusted friend, nurse, clergy and certainly another person with an ostomy may help you work through these feelings. You may discover new hope and encouragement.

Your social life can be as active as it was before surgery. You can enjoy traveling, 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. Keep these questions in mind: Did you know what a colostomy was, or where a stoma was located, or what it looked like, before you had surgery?

You may also worry about your pouch filling with gas and bulging under your clothing. A quick trip to the restroom can take care of this problem. If you are worried about your pouch filling up immediately after eating at a social event, remember, people without colostomies often need to go to the restroom after eating and nobody will think it unusual if you do the same. You will probably find that you need to empty your pouch of contents and gas less often than you need to urinate.

Telling Others About Surgery

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 you have to explain your surgery to everyone who asks. A brief explanation would be that you had abdominal surgery, or that you had a part of or your entire colon removed.

If you have children, answer their questions simply and truthfully. A simple explanation will be enough for them. Once you have explained what a colostomy is, they may ask questions about it and want to see your stoma or the pouch. Talking about your surgery in a natural way will dispel any misconceptions they might have. They will accept your colostomy much the same way you do.

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

Clothing and Appearance

One does not need to purchase special clothing after colostomy surgery, but some minor adjustments may be needed for comfort and preference. The pressure of undergarments with elastic will not harm the stoma or prevent function of the bowel; however, tight waist bands directly on the stoma should be avoided.

If you were ill before surgery, you may find you can now begin to eat normally for the first time in years. As your appetite returns, you may gain weight. This can affect the clothes you choose more than the pouching system itself.

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 underwear.

Eating and Digestion

After healing is complete and the ostomy is functioning normally, most people with colostomies can return to a regular diet. If you have a special diet because of heart disease, diabetes or other health problems, you should ask your doctor about a diet that will work with both that problem and your colostomy.

You may wonder if you will be on a limited diet after surgery. Here are a few simple guidelines about your diet:

- Doctors often have their patients follow a low residue diet the first weeks after any abdominal surgery. This includes only foods that are easily digested and excludes raw fruits and vegetables. Be sure to find out when you can start a regular diet. Eat all foods that you like except those restricted by your physician.

- Try one food a day that you have not eaten since surgery. Eat small portions at first, then gradually increase the amount. If a small serving gives you cramps or diarrhea, eliminate that food from your diet temporarily and try it again in a few weeks.
- Drink plenty of liquids. A minimum of 5-6 eight ounce glasses of water per day is recommended. Dehydration and loss of electrolytes (salts and minerals) are possible if not enough fluids are consumed in a day. Increase your fluid intake with hard work or hot climates.
- Additional dietary guidelines may be found in the *Diet and Nutrition Guide* published by the United Ostomy Associations of America.

Returning to Work

As your strength returns, you can go back to your regular activities. If you return to work, you may wish to confide in your employer or a good friend. Being open about your colostomy will help educate others. Keeping it a complete secret may cause practical difficulties.

Persons with colostomies 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 colostomies do heavy lifting, such as firemen, mechanics and truck drivers. Belts may be worn to support the abdomen when lifting. 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 health care professionals and/or talk with others who have found solutions to these issues. Call UOAA at 800-826-0826 for assistance.

Intimacy and Sexuality

Sexual relationships and intimacy are important 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 temporarily. Discuss any problems with your physician and/or ostomy nurse.

Sexuality concerns 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 two people communicate openly and honestly.

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. Special garments are available that can be worn to secure or hide the pouch. Mini pouches or stoma caps are also available for use during intimate times.

Ostomy surgery may present more concerns for single individuals. When to tell 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. For more information, consult the *Intimacy, Sexuality and Ostomy* guidebook published by the UOAA.

Pregnancy in women who have had colostomy surgery is not uncommon. Before pregnancy is considered, it should be discussed with your doctor. The colostomy 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.

Participating in Sports

An ostomy should not limit your participation in sports. There are a few precautions, however. Many physicians do not allow contact sports because of possible injury to the stoma from a severe blow or because the pouching system may slip. However, these problems may be overcome with special protection. Weight lifting could result in a hernia at the stoma. Check with your doctor about such sports. Indeed, people with ostomies are distance runners, weight lifters, skiers, swimmers and participate in most other types of athletics.

Bathing and Swimming

You may bathe with or without your pouching system in place. If you wish to take a shower or bath with your pouch off, you can do so. Normal exposure to air or contact with soap and water will not harm the stoma and water does not enter the ostomy opening. You can also leave your pouch on while bathing.

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.
- For swimming, empty your pouch beforehand and remember to eat lightly.
- For sanitary reasons, you should always wear a pouch when you go swimming.

Children with Ostomies

Guidelines for management of colostomies in children are the same as those for adults. For further information contact The Youth Rally Committee, Inc. visit www.rally4youth.org.

Travel

All methods of travel are open to you. Many people with colostomies 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. 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. Call 800-826-0826 or go to www.ostomy.org to find the nearest support group.
- Seat belts will not harm the stoma when adjusted comfortably.
- When traveling by car, keep your supplies in the coolest part. Avoid the trunk or back window ledge.

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. Place scissors in your checked luggage to avoid security problems.

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. Further problems might be avoided by having this information translated into the language or languages of the country (countries) you are visiting.

Traveling Abroad

In foreign countries, traveler's diarrhea is a common disease of tourists, whether you have 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 whole fruits and raw vegetables.

Persons with colostomies lose water and minerals quickly when they have diarrhea. For this reason you may need medication to stop the fluid and electrolyte loss. Your physician can give you a prescription for medication to control diarrhea. It should be filled in your home state, since the prescription may not be valid elsewhere. Be sure drinking water is safe. If the water is not safe, do not use the ice either. Bottled water or boiled water is recommended. It is suggested to always use safe water for colostomy irrigations.

Before traveling abroad, get a list of the current English-speaking physicians in various foreign cities who charge a standard fee. The International Association of Medical Assistance to Travelers (IAMAT) publishes lists of English-speaking physicians in over 2,500 cities around the world, www.iamat.org or 716-754-4883.

RESOURCES AVAILABLE

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.

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

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

Wound, Ostomy and Continence Nurses Society (WOCN)

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

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.

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, Medicaid and Social Security in the United States

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

GLOSSARY OF TERMS

Anus: the terminal part of the rectum.

Benign: not cancerous, not malignant.

Carcinoma: cancer, malignant growth.

Colon: part of the intestine which stores digested food and absorbs water. Also referred to as the large intestine or the large bowel.

Colostomy: surgical opening of colon/large intestine brought to the abdominal surface:

- permanent (end colostomy): loss of part of the colon, and usually, the rectum.
- temporary: allows lower part of the colon and/or rectum to heal or rest
- sigmoid: opening in the lower or end portion of the colon
- transverse: opening in transverse colon (upper abdomen, middle or right side).

Cone: part of an irrigation set for sigmoid colostomy. Plastic cone-shaped piece at end of tubing, fits snugly against stoma to keep solution in the colostomy.

Diverticulitis: inflammation of diverticula (little sacs in the colon); can cause abscess, scarring with stricture or perforation of the colon with peritonitis in severe cases.

Diverticulosis: presence of diverticula (little sacs on the colon).

Electrolytes: salts and minerals needed by the body for health.

Enzyme: substance formed in animal and plant cells that starts or speeds up specific chemical reactions.

Face Plate/Flange: molded plastic component of a two-piece pouch system that connects to the ostomy pouch. The face plate adheres to the skin around the stoma.

Familial Adenomatous Polyposis (multiple polyps): rare disease that runs in families where the colon and rectum contain many polyps. It requires regular medical supervision of all members of the family because of serious complications and a strong tendency to develop into cancer.

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

Hernia: the protrusion (bulging) of an organ or tissue through a structure which usually contains it.

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

Ileum: lowest part or end of the small intestine.

Irrigation: an enema through the stoma, used by some colostomates to regulate the passage of stool.

Low residue diet: a dietary regimen which eliminates bulk-forming food, hard-to-digest food and high-fiber food.

Malignancy: a cancerous growth.

Mucous: fluid secreted from glands or cells. It lubricates membranes, including the digestive tract.

Obstruction: any blockage in the digestive tract. Symptoms include no ostomy output over several hours, or spurts of watery stool combined with abdominal cramping and nausea.

Ostomate: a person who has a colostomy, ileostomy or urostomy.

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

Peristalsis: progressive waves of motion which occur without voluntary control, to push contents through the intestine.

Polyp: small projection inside of bowel, often mushroom shaped or may be flat. It is usually benign, but can be malignant.

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

Rectum: lowest portion of the large intestine.

Resection: surgical removal or excision.

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

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

Skin Barrier: any one of several substances used to cover skin around the stoma. Can be wafers, pastes, wipes, 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.

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