

# ILEOSTOMY GUIDE

REBORN FROM THE ASHES OF DISEASE

# **ILEOSTOMY GUIDE**

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# CONTENTS

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<b>INTRODUCTION</b> .....	<b>5</b>
<b>FACTS ABOUT ILEOSTOMIES</b> .....	<b>6</b>
<b>NORMAL DIGESTIVE SYSTEM</b> .....	<b>7</b>
Small intestine .....	7
Large intestine .....	7
<b>TYPES OF SMALL BOWEL DIVERSION</b> .....	<b>8</b>
Standard or Brooke ileostomy .....	8
Continent ileostomy .....	8
Ileoanal reservoir .....	9
<b>MANAGEMENT FOR STANDARD ILEOSTOMIES</b> .....	<b>9</b>
Choosing a pouching system .....	9
Pouches .....	10
Measuring for a proper fit .....	10
Belts and tape .....	10
Changing the pouching system .....	11
Factors that influence pouching system seal .....	11
Emptying the pouch .....	11
Ostomy supplies .....	11
<b>HELPFUL HINTS</b> .....	<b>12</b>
Protecting the skin around the stoma .....	12
Spots of blood on the stoma .....	12
Shaving hair under the pouch .....	13
Flatulence (gas) .....	13
Odor .....	13
Medications/absorption .....	14
<b>ILEOSTOMY COMPLICATIONS</b> .....	<b>14</b>
Severe skin problems .....	14
Obstruction/Blockage .....	14
Diarrhea .....	15
Electrolyte balance .....	15
Phantom rectum .....	16
Short bowel syndrome .....	16
Medical emergencies .....	16
Hospitalization .....	16
<b>LIVING WITH AN ILEOSTOMY</b> .....	<b>17</b>
Telling others .....	18
Clothing and appearance .....	18
Eating and digestion .....	18
Returning to work .....	19
Intimacy and sexuality .....	19

# CONTENTS Cont.

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## LIVING WITH AN ILEOSTOMY cont.

- Participating in sports . . . . . 20
- Bathing and swimming . . . . . 20
- Travel . . . . . 21

## FOR PARENTS OF CHILDREN WITH ILEOSTOMIES . . . . . 22

- Psychosocial issues . . . . . 23
- Management issues . . . . . 23
- Everyday living . . . . . 24

## RESOURCES AVAILABLE . . . . . 25

- International Ostomy Association . . . . . 25
- Wound Ostomy Continence Nurses Society . . . . . 25
- Agencies . . . . . 26
- Medicare, Medicaid and Social Security in the United States . . . . . 26

## GLOSSARY . . . . . 26

# INTRODUCTION

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An ileostomy is a life-saving surgery that enables individuals to enjoy a full range of activities including traveling, sports, family life and work, even though they have a stoma and wear a pouching system. They continue to enjoy an expected life span.

Ileostomy surgery is performed for many different diseases and conditions. Some of the indications for ileostomy surgery are ulcerative colitis, Crohn's disease, familial polyposis and complications of cancer.

There is no one way to take care of an ileostomy. Just as ileostomies differ, so does how to take care of them. This guide book gives you suggestions and ideas for managing your ileostomy. Discuss the ideas with a physician or a Wound Ostomy Continence Nurse (WOCN), hereinafter referred to as ostomy nurse, and adapt them to your situation. Give new things a fair trial, but do not insist on them if they fail to make you more comfortable. What is good for someone else may not be good for you. The sooner you learn to take care of your ileostomy, the better you are likely to feel about yourself. In time, you will gain confidence in your self-care.

There are many ways to gain a greater understanding of your life with an ileostomy. Your physician and ostomy nurse are important sources of information and support. In addition, much information is available at various Web sites (see Resources).

Taking part in an ostomy support group allows you to share your feelings and ask questions as you make progress with your adjustment. 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 ostomy support groups.

## FACTS ABOUT ILEOSTOMIES

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An ileostomy is a surgically created opening in the abdominal wall. The end of the ileum (the lowest portion of the small intestine) is brought through the abdominal wall to form a stoma, usually on the lower right side of the abdomen. When you look at your stoma, you are actually looking at the lining (or mucosa) of the intestine, which is like the lining of your cheek. Generally, the colon and rectum are removed and normal colon and rectum functions are no longer present.

The stoma will appear pink to red and will be moist and shiny. It will reduce in size over a short period of time after surgery. The shape will be round to oval and may protrude or be flush with the skin.

An ileostomy may be permanent or temporary depending upon the reason for surgery. The entire colon, rectum, and anus are removed or bypassed with a permanent ileostomy. With a temporary ileostomy, all or part of the colon is removed, but part or all of the rectum is left intact.

Ileostomy surgery is usually performed when a diseased or injured colon cannot be successfully treated by other methods. The most frequent reason for surgery is inflammatory bowel disease (IBD) which includes Crohn's disease and ulcerative colitis. Ileostomies are also created because of birth defects, familial polyposis, injury or complications from cancer.

Occasionally, a temporary ileostomy is performed in order to protect and rest the colon or small intestine while it is healing, or as the first stage in the formation of an ileal anal reservoir (J-pouch).

The major function of the small intestine is to absorb the body's nutrients and water. Enzymes released into the small intestine break food into small particles so that vitally needed proteins, carbohydrates, fats, vitamins and minerals can be absorbed. These enzymes will also be present in ileostomy discharge, and they can cause skin breakdown. This is why the skin around an ileostomy must always be protected (see Skin Protection).

After removal of the colon and rectum, digestive contents pass out of the body through the stoma and are collected in an individually fitted drainable pouch, which is worn at all times. The consistency of the ileostomy output will be liquid to pasty, depending on one's diet, medications and other factors. Because the output is constant, the pouch will need to be emptied 5-8 times a day.

# NORMAL DIGESTIVE SYSTEM

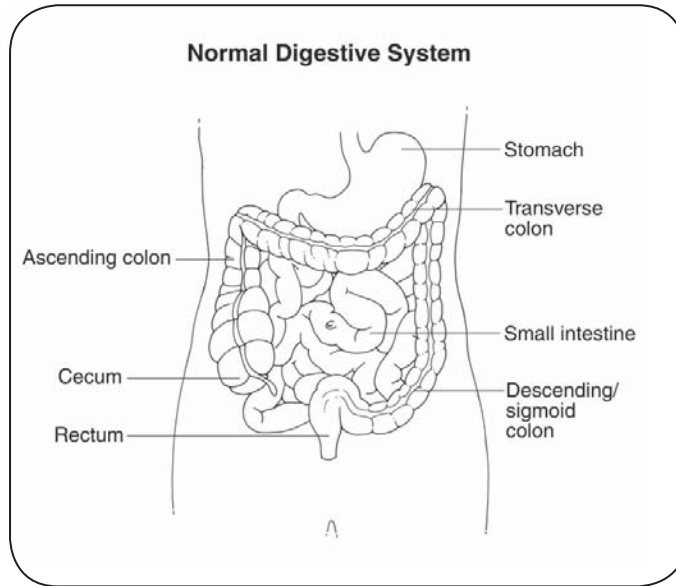
Although an ileostomy creates an important change for a patient, the body's chemistry and digestive function are not significantly altered by it. A description of the large and small intestine may help you understand the changes to your body.

## Small Intestine

- Approximately 20 feet long, consisting of:
- Duodenum (first part) 10-12 inches long beginning at the outlet of the stomach.
- Jejunum (second part), about 8-9 feet long.
- Ileum (third part), about 12 feet long connecting 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 5-6 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.

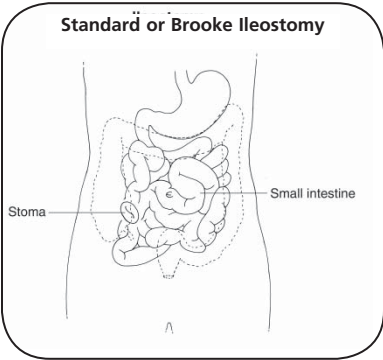


# TYPES OF SMALL BOWEL DIVERSIONS

There are three major types of small bowel diversions (when the entire colon is removed). The surgeon and the patient should determine the most appropriate surgery for the patient. Some of the selection criteria for the type of diversion are the disease process, age, general health and the preference of the patient.

## 1. Standard or Brooke Ileostomy

<p><b>Indications:</b>          Ulcerative Colitis;          Crohn’s Disease;          Familial Polyposis;          Cancer complications</p>	<p><b>Discharge:</b>          Liquid or paste consistency;          Unpredictable drainage;          Contains residual digestive enzymes</p>	<p><b>Management:</b>          Skin protection;          Open-end, drainable pouch</p>
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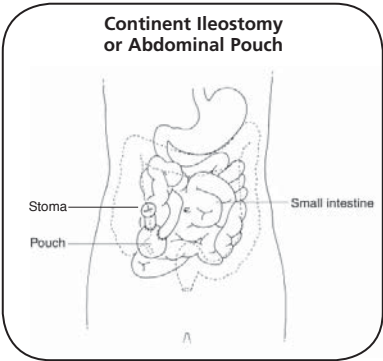


The standard ileostomy is the more prevalent type of ileostomy surgeries. The terminal ileum is pulled through the abdominal wall and a segment is turned back and sutured to the skin, leaving a smooth, rounded, everted ileum as the end of the ileostomy.

The stoma is usually placed in the right lower quadrant whenever possible and located on a flat surface sufficiently free from irregularities. The fecal output is not controlled and will require wearing a collection pouch.

## 2. Continent Ileostomy (Abdominal Pouch)

<p><b>Indications:</b>          Ulcerative Colitis;          Familial Polyposis;          Cancer complications</p>	<p><b>Discharge:</b>          Liquid or paste consistency</p>	<p><b>Management:</b>          Drain periodically with intubation tube;          Stoma covering</p>
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A continent ileostomy is a surgical variation of the standard ileostomy. Patients do not need to wear an external pouch. Created when a portion of the ileum is looped back on itself so that a reservoir is formed inside the abdomen. A nipple valve is constructed with part of the ileum. The ostomate inserts a catheter a few times each day to drain contents from the reservoir.



### 3. Ileoanal Reservoir (J-Pouch)

**Indications:**

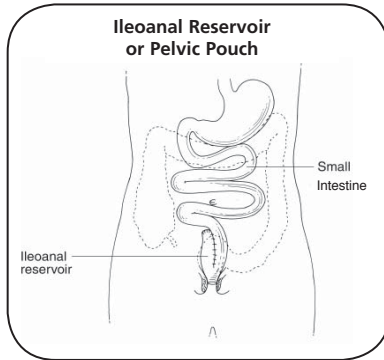
Ulcerative Colitis  
6-8 per day

**Discharge:**

Soft, formed stool

**Management:**

Natural evacuation;  
Peri-anal skin  
protection



Another option for some patients is the ileoanal reservoir (pelvic pouch) which is an internal pouch made of the ileum and placed in the pelvis. Other names for pelvic pouches include J-pouch and S-pouch depending on the surgical procedure. The sphincter muscle surrounding the anal opening must be intact to keep the pouch from leaking. The consistency of the output of the pelvic pouch depends on diet and may be aided by medications.

## MANAGEMENT FOR STANDARD ILEOSTOMIES

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

A successful pouching system should provide the following:

- Security with a good leakproof seal (lasting for 3-7 days)
- Odor resistant pouch
- Skin protection
- Be inconspicuous and unnoticeable
- Easy to apply and to remove

### Choosing a pouching system

Many factors can influence selection. The length of the stoma, abdominal firmness and contours, the location of the stoma, scars and folds in the abdominal area and your height and weight all must be considered in determining what is best for you. Special adaptations may have to be made for stomas located near the hipbone, waistline, groin, scars, etc. Custom-made products to fit unusual situations can be obtained from some companies.

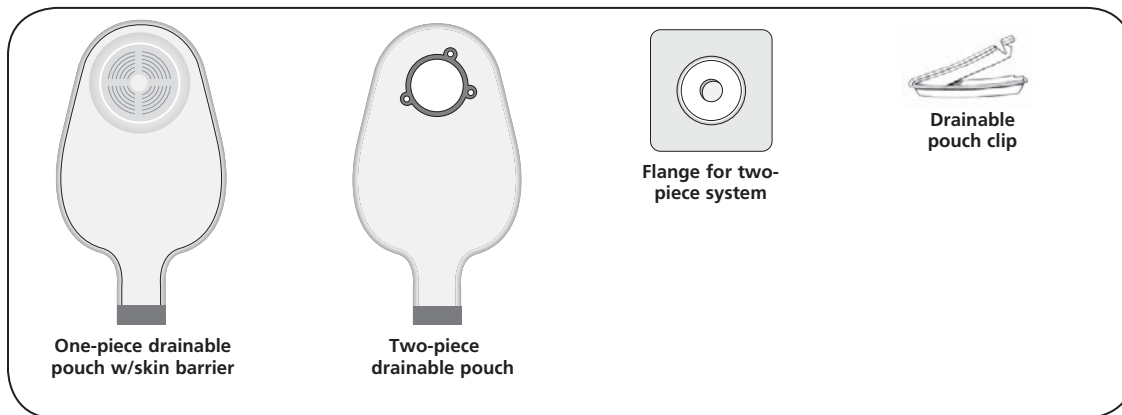
The best pouching system for you is a very personal matter. It is important that you are properly fitted, just as for eyeglasses. When you are selecting your first pouching system, it is best to consult with an ostomy nurse or someone who has experience in this area.

# MANAGEMENT FOR STANDARD ILEOSTOMIES cont.

## Pouches

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

Pouches for one- and two-piece systems are drained through an opening in the bottom. Pouches are made from odor resistant materials and vary in cost. Pouches are either transparent or opaque and come in different lengths.



## Measuring for a proper fit

Pouching systems come with either a pre-cut opening or can be cut to fit the stoma size and shape. Immediately after surgery the stoma may be swollen for approximately 6 to 8 weeks. During this post operative period the stoma should be measured about once a week. A measuring card may be included in boxes of pouches or you may create your own template which matches your stoma shape. The opening on the skin barrier or flange should be no more than 1/8 inch larger than the stoma size.

## Belts and tape

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



## **Changing the pouching system**

There may be a decrease in bowel activity at certain times in the day. During these times will be the easiest to change the pouching system. You may find that early morning before you eat or drink is best. Or allow at least one hour after a meal when peristalsis is slowed. After surgery ileostomy output may be thin and watery. As the discharge thickens, you will be in a better position to determine the best time for changing your system.

## **Factors that influence pouching system seal**

There are several factors that can influence how long the pouch will stay sealed. These include weather, skin condition, scars, weight changes, diet, activity, body shape near the stoma and the nature of the ileostomy output.

- Perspiration during the summer months in warm humid climates will shorten the number of days you can wear the pouching system. Body heat, in addition to outside temperature, will cause skin barriers to loosen more quickly than usual.
- Moist, oily skin may reduce wearing time.
- Weight changes will also affect your wearing time. Weight gained after ileostomy surgery changes abdominal contours. You may need an entirely different system. Weight loss may also have the same effect.
- Diet may influence your seal. Foods that cause watery discharge may prevent a long lasting seal.
- Physical activities may have some influence on wearing time. Swimming, very strenuous sports or work that causes perspiration may shorten wearing time.

## **Emptying the Pouch**

Emptying the pouch when it is 1/3 full will prevent bulging and possibility of a leak. Also consider your comfort and convenience.

To empty, follow these steps:

1. Sit on the toilet.
2. Place a small strip of toilet paper in the toilet to minimize splashing.
3. Hold the bottom of the pouch up and open the pouch at the tail.
4. Slowly unroll the tail over the toilet.
5. Gently empty contents.
6. Clean the outside and inside of the pouch tail with toilet paper.
7. Close the pouch at the tail.

## **Ostomy Supplies**

For the sake of convenience, keep all your equipment together on a shelf, in a drawer or in a small box away from hot or cold temperatures.

## **MANAGEMENT FOR STANDARD ILEOSTOMIES cont.**

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It is a good idea to order supplies several weeks before you expect to run out, thus allowing enough time for delivery. It is best to avoid stockpiling of supplies because they may be influenced by changes in temperatures. Supplies do not need to be sterile. The stoma and surrounding skin are not sterile and require only cleanliness.

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

## **HELPFUL HINTS**

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### **Protecting the skin around the stoma**

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

- Use the right size pouch and skin barrier opening. An opening that is too small can cut or injure the stoma and may cause it to swell. An opening that is too large exposes the skin to possible irritation. In both cases, change the pouch or skin barrier and replace with one that is properly fitted. See the section in this booklet on measuring for a proper fit.
- Itching or burning are signs that the pouching system should be changed. Change the pouch regularly to avoid leakage and skin irritation.
- Remove the pouch or skin barrier by gently pushing your skin from the pouch or barrier rather than pulling it away from the skin.
- Clean the skin surface around the stoma with water. A mild soap may be used, but rinse thoroughly. Dry well before applying the skin barrier or pouch.
- Watch for sensitivities and allergies to adhesive, skin barrier, paste, tape or pouch material. They can develop weeks, months or even years after use of a product since the body can become gradually sensitized. You can test different products to see if your skin will react to them.

### **Spots of blood on the stoma**

Spots of blood are no cause for alarm. Cleaning around the stoma as you change the pouch or skin barrier may cause slight bleeding. The blood vessels in the tissues of the stoma are very delicate at the surface and are easily disturbed. The bleeding will usually stop as easily as it started.

## Shaving hair under the pouch

Excessive hair around the stoma area can interfere with the skin barrier and may be painful when removing. Shaving with a razor or trimming hair with scissors is helpful. Caution should always be taken when using a straight edge or safety razor. A mild soap or shaving cream may be used. Rinse well.

## Flatulence (Gas)

Immediately after surgery, it may seem that you have excessive gas almost all the time. Most abdominal surgery is followed by this uncomfortable, embarrassing, yet harmless symptom. As the tissue swelling goes down, gas will occur less often. Certain foods may cause intestinal gas: eggs, cabbage, onions, fish, baked beans, milk, cheese and alcohol.

Eating regularly will help prevent excessive gas. Skipping meals to avoid gas or discharge is unwise because your small intestine will be more active and more gas and watery discharge might result. Some people find it best to eat a lesser amount of food 4 to 5 times a day.

You may be worried about the response others may have to gassy noises. You will find that these noises sound louder to you than to others and may sound like stomach rumbling to them. If you are embarrassed by these rumblings when others are nearby you can say, "Excuse me, my stomach's growling." If you feel as though you are about to release gas when you are with people, casually fold your arms across your abdomen so that your forearm rests over your stoma. This will muffle most sounds. Check with your ostomy nurse about using oral products such as Beano®.

## Odor

Many things, such as foods, normal bacterial action in your intestine, illness, different medicines and vitamins can cause odor. Some people with ileostomies have more trouble with odors than others. Individual experimentation is the only solution to this problem. The odor of ileal contents is not the same as that of a normal stool because the bacteria that cause food breakdown (and odor) in the colon are not present in the small intestine. Here are some hints for odor control:

- Use an odor resistant pouch.
- Check to see that the skin barrier is securely sealed to the skin.
- Empty the pouch frequently.
- Place special deodorant liquids and/or tablets in the pouch.
- Oral preparations are available. Check with you physician or ostomy nurse about the suitability of these products and recommended dosage. Among those that many have found effective are chlorophyll tablets, Devrom® (bismuth subgallate), and bismuth subcarbonate.

## **HELPFUL HINTS cont.**

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- Air deodorizers are available that effectively control odor when emptying the pouch.

### **Medications/Absorption**

Medication in the form of coated tablets or time release capsules may come out whole in the pouch and be of no benefit at all. Discuss this with your healthcare provider or pharmacist if this occurs. There may be alternative medications that you can use to avoid this problem. Liquid or liquid gel medications provide faster and more effective absorption.

## **ILEOSTOMY COMPLICATIONS**

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### **Severe Skin Problems**

Large areas of skin that are reddened, sore and weeping (always wet) will prevent a good seal around the stoma. It is therefore important to treat minor irritations when they first occur. If you have a large irritated area, contact your physician or ostomy nurse. They may prescribe topical medication such as Mycostatin® powder or Kenalog® spray.

For deep pressure ulcers caused by a very tight belt, loosen or remove the belt and call your physician or ostomy nurse immediately, treatment is needed.

### **Obstruction/Blockage**

There are occasions when the ileostomy does not function for short periods of time. This is normal. However, if the stoma is not active for 4 to 6 hours and is accompanied by cramps and/or nausea, the intestine could be obstructed. An obstruction (or blockage) may be partial; that is, some liquid may pass through. Call your doctor or ostomy nurse in either case to discuss the situation.

Watch for swelling of the stoma and adjust the opening of the pouch accordingly until the problem has passed. Take a warm bath to relax the abdominal muscles. Sometimes a change in body position, such as assuming a knee to chest position, may encourage movement of the bolus of food. Do not take a laxative.

Obstruction can be caused by high-residue foods such as Chinese vegetables, pineapple, nuts, coconut and corn. It can also be caused by internal changes such as adhesions.

### **Diarrhea**

When diarrhea occurs, the intestinal contents pass through the small intestine too quickly for the absorption of fluids and electrolytes to take place and may cause

excessive loss of fluids and electrolytes. You must quickly replace these electrolytes to avoid becoming ill from dehydration and mineral deficiency.

However, loose stool can come from eating certain foods and is usually temporary. Raw fruits and vegetables, milk, fruit juice, prune juice or contaminated drinking water are examples. Loose stool may also be caused by emotional stress. Some people with ileostomies may always have “watery discharge” and this is normal for them.

**Diarrhea has these characteristics:**

- The intestine discharges great quantities of watery stool.
- It comes on suddenly and may be accompanied by cramps.

**Diarrhea can be caused by:**

- Intestinal flu which may be accompanied by fever and vomiting.
- Antibiotics, penicillin and other prescription medications.
- Partial obstruction characterized by odorous discharge, cramps, forceful liquid output and excessive noises from the stoma. It can be caused by food or other factors. You should seek medical attention if this occurs.

If diarrhea persists, consult your physician or ostomy nurse. Take medications as prescribed. Then replace fluids by taking one cup of sweetened, clear tea or one glass of orange juice followed the next hour by one cup of salty broth. Continue alternating the drinks until diarrhea subsides.

**Electrolyte Balance**

Electrolyte balance (especially potassium and sodium) is important. When the colon (large intestine) is removed, a greater risk for electrolyte imbalance can occur. Diarrhea, excessive perspiration and vomiting can increase this risk. Your diet should include fluids and foods rich in sodium and potassium.

Dehydration is a common concern with symptoms of increased thirst, dry mouth, decreased urine output and fatigue. Increase any type of fluids such as Gatorade<sup>®</sup>, PowerAde<sup>®</sup> or Pedialyte<sup>®</sup> which is high in potassium and sodium. Daily intake of fluids should be 8-10 (8 oz.) glasses. Any liquid containing water (soda, milk, juice, etc.) helps to meet your daily requirement. Loss of appetite, drowsiness and leg cramping may indicate sodium depletion. Fatigue, muscle weakness and shortness of breath may indicate potassium depletion.

# **ILEOSTOMY COMPLICATIONS cont.**

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## **Phantom Rectum**

Phantom Rectum is similar to the “phantom limb” 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.

## **Short Bowel Syndrome**

This condition happens in Crohn’s disease or diseases of the small intestine when surgery is required to remove a substantial amount of the small bowel. This condition merits special attention because of the loss of the intestine’s vital absorptive function.

People with this condition must remain under a physician’s supervision. They can live a normal life but must be careful to maintain adequate nourishment, avoid diarrhea and to be within reach of medical care. The shorter the small intestine, the more liquid the discharge will be. This may reduce the time a pouch can be worn because of more rapid undermining of the skin barrier. Special pouching systems are available for high, liquid ileostomy output.

## **Medical Emergencies**

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

- Cramps lasting more than 2 or 3 hours.
- Continuous nausea and vomiting.
- The ileostomy does not have any output for 4 to 6 hours and is accompanied by cramping and nausea.
- Severe watery discharge lasting more than 5 to 6 hours.
- Severe odor lasting more than a week (may indicate infection).
- A deep cut in the stoma.
- Severe skin irritation or deep ulcers.
- Excessive bleeding from the stoma opening (or a moderate amount in the pouch at several times of emptying).
- Continuous bleeding at the junction between stoma and skin.
- Unusual change in stoma size (prolapse or retraction) and appearance (color).

## **Hospitalization**

Take your ostomy supplies with you since the hospital may not have your type. Prepare to do some expert communicating, especially if you go into a hospital where ileostomy patients are rare or if you go for a condition not related to your ostomy.



Do not submit to any procedures you think may be harmful such as taking a laxative, taking an enema through the stoma or rectum, or insertion of a rectal thermometer. 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 or continent diversion 2) whether or not your rectum has been removed or is intact 3) details of your management routine and products used 4) procedures to be avoided (see above).

## **LIVING WITH AN ILEOSTOMY**

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Learning to live with an ileostomy 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.

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 real and 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 those feelings. You may discover new hope and encouragement.

Your social life can be as active as it was before surgery. You can enjoy all activities such as travel, sporting events, eating at restaurants or whatever you enjoyed before. The first time you go out of the house after surgery, you may feel as if everyone is staring at your pouch even though it is not visible under your clothing. You may feel your pouch on your body, but no one can see it. Keep these questions in mind: Did you know what a ileostomy 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 rest room 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 ileostomies often need to go to the rest room 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.

## **LIVING WITH AN ILEOSTOMY cont.**

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### **Telling Others**

You might be worried about how others will accept you and how your social role may be changed. It is natural to wonder how you will explain your surgery. Your friends and relatives may ask questions about your operation. You can tell them as much as you want them to know. You need not feel you have to explain your surgery to everyone who asks. A brief explanation would be that you had abdominal surgery, or that you had part or all of your 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 an ileostomy 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 that might they have. They will accept your ileostomy much the same way you do.

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

### **Clothing and Appearance**

You need no special clothing because ileostomy pouches are fairly flat and inconspicuous. The pressure of undergarments with elastic will not harm the stoma or prevent function of the bowel.

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 shorts.

### **Eating and Digestion**

After healing is complete and the ostomy is functioning normally, most people with ileostomies 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 for you. 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 temporarily and try it again in a few weeks.
- Drink plenty of liquids. A minimum of 8-10 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 if perspiring or in hot climates.

Beets will make ileostomy output turn a reddish color rather like blood, but there is no harm done. Tomato juice and food dyes may change the usual color of ileostomy output as well.

## **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 ileostomy will help educate others. Keeping it a complete secret may cause practical difficulties.

Persons with ileostomies 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 ileostomies do heavy lifting, such as firemen, mechanics and truck drivers. There are athletes who have stomas. Check with your doctor about your type of work. As with all major surgery, it will take time for you to regain strength after your operation. A letter from your doctor to your employer may be helpful should the employer have doubts about your physical capabilities.

Employability and insurability are issues for some individuals. If these issues develop, seek help from healthcare professionals and/or talk with others who have found solutions to these issues.

## **Intimacy and Sexuality**

Sexual relationships and intimacy are important and fulfilling aspects of your life that should continue after ostomy surgery. Your attitude is a key factor in re-establishing sexual expression and intimacy. A period of adjustment after surgery is to be expected. Sexual function in women is usually not impaired, while sexual potency of men may sometimes be affected, usually only temporarily. Discuss any problems with your physician and/or ostomy nurse.

## **LIVING WITH AN ILEOSTOMY cont.**

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

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

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

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

Pregnancy in women who have had ileostomy surgery is not uncommon. Before pregnancy is considered, it should be discussed with your doctor. The ileostomy 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 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. Normal exposure to air or contact with soap and water will not harm the stoma and water does not enter the ostomy opening.

Remember these points;

- If you use a support belt, you may or may not remove it.
- You may want to protect the barrier by taping the edges with waterproof tape.
- You may want to choose a swim suit that has a lining for a smoother profile.
- Women may wear stretch panties made especially for swim suits.
- 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.

## **Travel**

All methods of travel are open to you. Many people with ileostomies travel extensively including camping trips, cruises and air travel. Travel suggestions:

Take along enough supplies to last the entire trip plus some extras. Double what you think you may need, because they may not be easy to get where you are going. Even if you don't expect to change your pouch take along everything you need to do so. Zip-Lock® bags may be used for pouch disposal. Leave home fully prepared. Find out if and where supplies are available before a long trip. Seat belts will not harm the stoma when adjusted comfortably. You may place a clothes pin near the retraction slot to relieve tension on the belt. When traveling by car, keep your supplies in the coolest part. Avoid the trunk or back window ledge.

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

To avoid problems with 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(s) you are visiting.

## **LIVING WITH AN ILEOSTOMY cont.**

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

Traveler's diarrhea is a common problem in foreign countries, 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 unpeeled fruits and raw vegetables.

Persons with ileostomies 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.

## **FOR PARENTS OF CHILDREN WITH ILEOSTOMIES**

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

Talking to a good friend, your doctor, clergy, ostomy nurse, or the parents of a child who has an ileostomy helps. This will prepare you to help your child adjust to the ileostomy. Deal with your own feelings first, then you may give your child the emotional support he or she needs.

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

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

Be prepared for how you will feel seeing an opening on your child's abdomen with bowel contents running into a pouch. Your first reaction, in your child's presence, is vitally important and must be as positive and casual as possible.

If your child has a fever or other symptoms, don't panic. He or she will have all the aches and pains that other children have. When in doubt, call your physician.

## **Psychosocial Issues**

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

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

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

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

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

## **Management Issues**

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

A very important person to help with care of your child is the ostomy nurse. This is a person who has received special training in ostomy management. To find an ostomy nurse, call 888-224-9626 or visit [www.wocn.org](http://www.wocn.org).

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

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

### **Everyday Living**

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

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

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

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

Each summer, a Youth Rally for ages 11-17 is held on a college campus. This is a camp for young people with ostomies, alternate procedures and other related conditions. Planned educational sessions on self-esteem, body image, hygiene, ostomy issues plus discussion sessions, craft projects, tours and sports are offered. Visit [www.rally4youth.org](http://www.rally4youth.org) for more information.



## **RESOURCES**

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If your problem is medical, you should seek help from your physician, surgeon, or clinic. If you cannot make contact with them, try to find a doctor or clinic specializing in ostomy care. If that fails, get in touch with a WOCN (ET) nurse to ask for advice in finding a physician.

### **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](http://www.ostomyinternational.org).

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

The WOC(ET) nurse is a specialist in ostomy care and rehabilitation. In addition to serving individual ostomates, 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.

### **Agencies that may be helpful**

A number of cancer centers may have ostomy rehabilitation programs which include all types of ostomies, whether or not they are caused by cancer. Check for available services such as pamphlets, ostomy supplies for the medically indigent or assistance in contacting the local UOA chapter. You can also contact the American Cancer Society (800-ACS-2345) for information regarding ostomy support groups.

For immediate assistance, before being discharged from the hospital, the hospital social worker or discharge planner can answer questions and offer information.

For home health care, the Visiting Nurse Association (VNA), Public Health Nurses or other home care agencies provide valuable services. They are listed in the business section of your telephone book.

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

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

## **GLOSSARY OF TERMS**

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**Anastomosis:** the surgical formation of a passageway between two normally distant spaces or organs. A “hooking-up” of bowel, ureter, artery, vein, etc., after a section is removed.

**Benign:** not cancerous, not malignant.

**Carcinoma:** cancer, malignant growth.

**Colectomy:** removal of all or part of the colon.

**Colitis:** inflammation of the large intestine. A particularly severe type is ulcerative colitis, which may require an ileostomy.

**Colon:** part of the intestine which stores digestive material and absorbs water. Also referred to as the large intestine or the large bowel.

**Congenital:** present or existing at the time of birth, such as a deformity, disease, or tendency.

**Crohn’s Disease:** ileitis, regional enteritis or granulomatous disease of the bowel: inflammatory bowel disease which penetrates the deep lining of any part of small or large bowel. In selected cases, ileostomy becomes necessary; Crohn’s can flare up after ileostomy surgery, however.

**Diverticulitis:** inflammation of the diverticula (little sacs on 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 start or speeds up specific chemical reactions.

**Familial Polyposis** (multiple polyps): rare disease; runs in families. The colon and rectum contain many polyps. This is a different condition from merely the presence of a small number of polyps in the colon. Familial polyposis requires regular medical supervision of all members of the family because of serious complications and strong tendency to malignancy.

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

**Gastroenteritis:** an inflammation of the stomach and the intestines.

**Hernia:** the protrusion (bulging) of a loop or knuckle 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.

**Ileostomy output:** waste matter from the ileum (small intestine). Also referred to as intestinal contents, discharge, drainage, body waste, stool, feces.

**Ileostomy:** an “opening of the ileum” in which the end of the small intestine (ileum) is brought out surgically through an opening in the abdomen. Intestinal contents are expelled from the body through this opening.

**Ileum:** lowest part or end of the small intestine.

**Inflammatory Bowel Disease (IBD):** general term for ulcerative colitis and Crohn’s disease.

**Malignancy:** a cancerous growth.

**Obstruction:** blockage of ileostomy indicated by partial or complete stoppage of ileal flow.

**Ostomy:** surgically created opening through the abdominal wall for the elimination of body waste. Refers to ileostomies, colostomies and urostomies. Also referred to as stoma.

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

**Peristalsis:** progressive waves of motion which occur without voluntary control to push waste material through the intestine.

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

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

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

**Rectum:** lowest portion of the large intestine.

**Resection:** surgical removal or excision.

**Retraction:** the stoma draws back into the body.

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

## **GLOSSARY OF TERMS cont.**

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**Skin Barrier:** any one of several substances used to cover skin around the stoma. Can be pliable sheets, pastes, etc.

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

**Stoma (opening):** the end of the ureter, ileum, or colon which may be seen coming through the skin. It often protrudes like a nipple and is 3/4" to 1-3/4" in diameter. It is usually pink to red in color. There are no nerve endings in the stoma; therefore, it is not a source of pain or discomfort.

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

**Ulcerative Colitis:** one form of inflammatory bowel disease in which ulcers form in the intestinal lining of the colon and rectum. Severe, often bloody, diarrhea is the primary symptom of the disease, which occurs most often in young adults.

**Wound, Ostomy and Continence Nurse, or 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.





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