ILEOANAL RESERVOIR GUIDE

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

“SEIZE THE OPPORTUNITY...”
ILEOANAL RESERVOIR GUIDE

Written By:

Georgina M. Chapman R.N. ET
Colorectal Unit Holy Cross Hospital, Calgary District Hospital Group, Calgary, Alberta

Lorraine Sinclair R.N. ET
Foothills Hospital, Calgary, Alberta

Dr. J.M. Langevin, Assistant Professor of Surgery
University of Calgary, Colorectal Unit, Department of Surgery, Calgary District Hospital Group.

Revised 2009 by Barbara J. Hocevar, BSN, RN, CWOCN, Manager, ET/WOC Nursing, Cleveland Clinic

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

When faced with the possibility of an operation for the treatment of bowel disease, individuals naturally have many questions and concerns. An understanding of the operative alternatives, expected results, and possible complications will assist the patient and the surgeon in choosing the operation best suited to a particular individual. This booklet was written for the patient to help them understand the surgical options that are currently available. In particular it focuses on the ileoanal reservoir procedure. This is also commonly known as the ileal pouch anal anastomosis, IPAA, “S,” “J” or pelvic pouch procedure.

Over the past twenty years, the ileoanal pouch procedure has become widely accepted as the procedure of choice for certain patients requiring surgical treatment for ulcerative colitis and familial polyposis coli. Removal of the colon and rectum is curative for these diseases. The creation of an internal pouch allows the individual to regain health and a normal lifestyle without a permanent ileostomy.

This booklet also includes the information that you will require to learn how to care for yourself following your operation. Please keep it with you, especially when you are admitted to the hospital, as you will want to refer to it as you recover from your operation. There are blank pages in the back of the booklet where you can make note of any questions you may have. There is also a glossary of terms that may be unfamiliar to you to help you more fully understand the information in this booklet.
HISTORY

The ileoanal pouch has become an exciting development in the surgical management of patients who have ulcerative colitis or familial polyposis coli. It avoids the necessity of a permanent stoma, maintains bowel continence and is a cure for these diseases.

Traditionally, the treatment of choice for patients with ulcerative colitis was complete removal of the colon, rectum and anus, with the formation of an ileostomy. Through the years however, alternatives have been developed. These include total colon and rectum removal with straight ileoanal anastomosis, total colon removal with preservation of the rectum and ileorectal anastomosis, and the continent ileostomy or Kock pouch. In 1978, the late Sir Alan Parks developed the ileoanal pouch procedure which is known widely as the Park’s pouch, pelvic pouch, or ileoanal reservoir. In this booklet, our reference will be to the ileoanal reservoir with the “S” or “J” pouch. “Pouch” and “reservoir” are terms which are used interchangeably in this booklet.

ANATOMY OF A HEALTHY DIGESTIVE TRACT

The digestive tract is a hollow tube which stretches from the mouth to the anus and is lined with mucous membrane. As food travels through the system, enzymes are added which break down the food into a form that can be absorbed and used by our bodies. Digestion begins in the mouth, where mechanical breakdown is begun by chewing. The food is then passed through the esophagus to the stomach, where it is broken down into a semi-liquid form by churning and the addition of enzymes. At this point, it is passed into the small bowel or intestine, which is divided into three sections. These are the duodenum, which is approximately ten inches long, the jejunum, which is approximately eight feet long, and the ileum, which is approximately twelve feet long.

The digestion and absorption of nutrients takes place mainly in the small intestine. It should be noted that the process of digestion and absorption is almost completed before the products of digestion enter into the large bowel or intestine. The large intestine is approximately five feet in length and is responsible for absorption of fluids and storage of stool.

The rectum, which is approximately eight inches in length, is primarily an organ of elimination. The muscular walls of the rectum expand as it fills with stool, giving you the urge for a bowel movement. After a bowel movement, the rectum relaxes. The rectum is a compliant sac, like a balloon, which expands as it fills and relaxes when empty. The anus, which contains the muscles necessary for bowel control, is the end of the digestive tract.

It is important to remember that digestion and absorption of nutrients takes place in the small intestine. Therefore, if there is a need for the removal of the large intestine because of disease, the normal digestive process is essentially unchanged.
INDICATIONS FOR AN ILEOANAL POUCH

I. Ulcerative Colitis - Ulcerative colitis is an inflammatory disease of the lining of the large intestine, including the rectum. Symptoms of this disease may include crampy abdominal pain and bloody diarrhea with frequency and urgency. Frequency of diarrhea may be as often as 25 movements per day. The disease may be chronic or acute and persons with ulcerative colitis are at a higher than average risk for cancer.

II. Familial Polyposis Coli (Familial Adenomatous Polyposis) - Familial polyposis coli is an inherited disease in which the individual develops an unusually large number of polyps in the large intestine. Polyps are small projections which grow from the inner lining of the bowel into the lumen. These persons show few symptoms and the disease is found on a routine check-up or by following individuals known to be at risk. If the disease is left untreated these people have a 100% risk of developing cancer.

In both these diseases only the mucosal or inner lining of the intestine is affected. Since the underlying layers, including the muscles, are not affected, the sphincter, the nerves and the anus can be saved. This allows the individual to maintain control of their bowel movements.

Personal motivation is also an important consideration in patient selection. It is important that the person is eager to avoid a permanent ileostomy if possible. To achieve this, the individual must be well informed and willing to follow the necessary routines.

CONTRAINDICATIONS FOR AN ILEOANAL POUCH

I. Crohn's Disease - Crohn's disease is an inflammatory condition which affects the entire digestive tract, involving all the layers of the bowel. Because of the high risk of recurring disease, the small intestine must not be used to construct the reservoir.

II. Anal Incontinence - Individuals who have serious problems with rectal control are not candidates for this procedure.

III. Advanced Age - Optimum results with this surgery have found to be in the 20 - 50 year age group, where individuals usually have the best anal sphincter control. Age is a relative contraindication. Selected patients up to 70 years old have had the procedure done with favorable results. The actual function of the anal sphincters, not necessarily age, is the important factor. Anal sphincter function will be assessed by your surgeon at the time of your initial assessment.

IV. Obesity - The operative procedure is made more difficult in persons who are grossly overweight and who have a thick abdominal wall.
Ulcerative colitis and familial polyposis coli affect only the lining of the large intestine and, therefore, are cured by the following surgical procedures.

I. **Total Proctocolectomy With End Ileostomy (figure 3)**

   This procedure involves the complete removal of the large intestine, rectum, and the anal sphincter. This results in the creation of a permanent stoma and the necessity of wearing an external appliance. This, for many years, had been one of the few options available to cure ulcerative colitis or familial polyposis coli. The major advantage of this procedure is that it is generally performed as a one stage operation. It allows for a quick return to good health and normal activities.

II. **Kock Pouch (figure 4)**

   This is the complete removal of the large intestine rectum and the anal sphincter. An internal reservoir is created which must be drained by inserting a catheter through an abdominal stoma on a regular basis several times a day.

III. **Total Colectomy With Ileorectal Anastomosis (figure 5)**

   This procedure involves the complete removal of the large intestine. The small intestine is then connected to the rectum, which has been left intact. The disadvantage of this procedure is the possible recurrence of disease in the rectum. The individual also requires yearly surveillance for the risk of rectal cancer.

IV. **Total Colectomy With Ileoanal Anastomosis (pull-through) (figure 6)**

   This is the removal of the entire large intestine and rectum. The small intestine is joined directly to the anus. The disadvantage of this procedure is an excessively high stool frequency with resulting perianal skin irritation. This procedure is rarely done.

V. **Total Colectomy With Ileorectal Reservoir or Ileal Pouch Anal Anastomosis (IPAA) (figure 7)**

   In this procedure, the entire large intestine and rectum are removed, preserving the nerves and muscles needed for continence. The last 12-18 inches of the small intestine is used to construct an internal pouch or reservoir. This internal pouch is then attached to the top of the anal canal in an area called the anal transition zone or ATZ. Long term surveillance, that is, biopsies of tissue in this area, is recommended to check for dysplasia or precancerous cells.
The internal pouch may be constructed in several different ways. The pouches most commonly used are the “S” pouch (figures 8A and 8B) and the “J” pouch (figure 9). The choice of which pouch is best for you is made by your surgeon during your operation.

Patient satisfaction with the IPAA procedure is very high. There is, however, the possibility of failure (5-7%). Most failures are due to misdiagnosis (Crohn’s disease), persistent disease in the reservoir (pouchitis), or complications of the operation.

For those with problems after pouch construction, a trial period of medication and/or resting the reservoir may be required. If this trial period fails, surgery may be needed to repair the pouch, remove the pouch and create a new pouch, or convert to a permanent ileostomy.

STAGING

Surgery for creation of an internal pouch or reservoir may be performed in one, two or three stages.

I. One Stage Procedure

In a one stage procedure, the whole large intestine and rectum are removed. The reservoir is created from the last twenty to thirty centimeters of the small intestine and joined to the top of the anal canal without a temporary ileostomy. A person is a candidate for the one stage procedure in certain select situations based upon overall health, treatment methods used before surgery, and how things go during the course of the operation itself. Those having a one stage procedure tend to have a longer postoperative recovery time as well as an increased risk for pelvic infection. A one stage procedure is rarely done.
II. Two Stage Procedure
The most commonly performed procedure is the two stage operation in which the large intestine and rectum are removed. A reservoir is created from the terminal end of the small intestine and joined to the top of the anal canal. A temporary loop ileostomy is created above the pouch; to do this, a loop or knuckle of small is intestine is brought out through an opening on the abdomen, separate from the incision and usually on the right side. After approximately eight to twelve weeks, when the internal pouch is found to be leak proof and healthy, the second operation is performed. The ileostomy is then taken down or closed and the continuity of the bowel is re-established. The stool now passes through the small intestine into the reservoir and out through the anus.

III. Three Stage Procedure
In some cases of severe disease poor physical health due to a prolonged illness or other health problems, or high doses of steroids or other immunosuppressant medications, the surgeon may prefer to operate in three stages. In the first stage, the large intestine will be removed, leaving the rectum intact. An end ileostomy will be created. In the second stage the rectum will be removed. A reservoir will be created from the terminal end of the small intestine and joined to the top of the anal canal. At this time a loop ileostomy will be fashioned at the site of the original end ileostomy. After approximately eight to twelve weeks the ileostomy is taken down or closed and the patient will begin to use the reservoir.

The type of surgery you have, that is, one, two or three stage, will be made by your surgeon and discussed with you. Be sure and ask your surgeon any questions you may have about the procedure selected.

EXPECTED OUTCOME
You are probably wondering how all this will affect you and your life style! Your recovery will be longer than those who have a conventional ileostomy because of the two stages of surgery which you require. There will also be a period of adaptation of your new reservoir after your ileostomy is closed. Generally over the course of one year, the size of the pouch increases and the number of bowel movements per 24 hours decreases. Eventually, most patients experience 4 to 6 bowel movements daily, have good control and are not troubled by night time incontinence. However, initially there could be up to 15 bowel movements a day with some problems of control and the need to get up several times at night. This all improves with time as the pouch capacity gradually increases in size.

It is important to remember that the time that elapses from your surgery to complete pouch adaptation can be up to a year. However, during this time you will be able to return to your previous activities and work. This will be due to your new feelings of health and well-being after the removal of your diseased large intestine. It is very important to practice perseverance, tolerance and patience with a liberal dash of good humor during this period of personal adjustment and pouch adaptation.
THE TWO STAGE OPERATION

This booklet will outline the specifics of your ileoanal reservoir. General information pertaining to your hospital stay will be given to you by the staff nurses on your preoperative visit.

Stage One - This is the term which refers to your first operation. You will likely be in the hospital 5-7 days.

Prior To Your Surgery

The initial visit with your Wound, Ostomy, and Continence/Enterostomal Therapy Nurse (WOC/ET) is usually before your admission to the hospital. This visit is intended to be an informative session and help you with your decision making. It should answer many of your questions and ease your fears. Your, spouse, significant other, or parent(s) are more than welcome to be present for your pre-operative teaching. Arrangements can also be made for you to speak with or have a visit from a person of your own age and sex who has had the operation. You will also be given pamphlets and booklets to read about your upcoming surgery.

PRE-OPERATIVE TEACHING

1. A review of the anatomy and physiology of the digestive tract. (its appearance and how it works.)
2. A description of the stoma and what to expect in the way of function.
3. A general description of ostomy pouches, their application, insurance coverage, sources of supply, and cost. If you choose, an example of an ostomy pouch.
4. A discussion about living with an ileostomy including diet, medication, hygiene, sexuality, and clothing. Be sure to bring up any particular concerns or issues you may have.
5. A preview of what to expect in the way of tubes, catheters and pouches when you awaken from surgery.
6. At this time, the WOC/ET nurse will mark a place on your abdomen where the stoma will be. You will be asked to lie down, sit, and stand so that changes that occur with natural body movement can be observed. A site is chosen that is away from bony areas, skin folds, and scars. The ileostomy site is usually chosen in the lower right quadrant of your abdomen in an area that you can readily see. This allows for easy ostomy self care after the surgery. The mark is usually below the waist so that the waist lines and belts of clothing will not interfere with the stoma or pouch. The stoma will be marked with a small tattoo or indelible marker that will not wash off during the preoperative skin preparation and will be easily identified by the surgeon in the operating room.
7. Probable preoperative preparation. Before admission to the hospital, you will have a chest X-ray and an E.K.G. (heart tracing). Blood will be drawn for laboratory tests and you will be asked to give a urine specimen. You will be given a bowel prep to cleanse the bowel of stool. The specific bowel prep will be given to you by your physician. Be sure to drink all of the prep as directed so that your bowel is as clean as possible at the time of surgery. This helps decrease the risks of postoperative infection. Your physician will give you specific preoperative diet instruction which usually includes 1-2 days of a clear liquid diet before the day of surgery. In addition, you can have nothing to eat or drink after midnight the night before your operation. You may also be asked to shower with a special antibacterial soap before your surgery. Your abdomen is shaved, if needed, in the operating room.
8. An intravenous (IV) line will be started before surgery. This prevents you from becoming dehydrated prior to and during surgery. It also remains in place after surgery until you are able to take fluids by mouth. Before you go to the operating room, antibiotics are given via the IV to decrease the risks of postoperative infection. In the operating room, a tube is placed into your bladder to collect and record the amount of urine output and monitor kidney function. This catheter remains in place until shortly before discharge. You may also have a nasogastric (NG) tube placed after you are put to sleep. The NG tube is passed through your nose, down your throat and into your stomach. This tube removes secretions from your stomach which may cause postoperative nausea and vomiting.

**THE OPERATION**

The length of surgery varies from patient to patient and is determined by their general condition, type of surgical technique used, and how complicated the surgery is. It usually takes about 2 - 4 hours. The exact technique used depends upon whether the surgery is done through a conventional incision or through a minimally invasive, also known as laparoscopic, technique. Discuss with your surgeon the particular details of the surgery planned for you.

**What Is An Ileostomy?**

An ileostomy is an opening in the small intestine that is brought out to the skin as a stoma (a Greek word meaning mouth). (figures 10, 11)

In surgery, either an end of the small intestine or a loop of small intestine is brought to the surface of the skin through a small separate circular incision.

The intestine is then turned back on itself, like a cuff, and sewn to the skin. Therefore, when you look at your stoma, you are actually seeing the inner lining of your small intestine, which is made of tissue like the inside of your mouth known as mucosa. The stoma will be red since the blood supply is very close to the surface; it will be shiny and moist. Stomas do not include nerves sensitive to pain, so you will feel no pain even though it looks like it should hurt. The stoma should also protrude slightly above skin level.
A temporary loop ileostomy will have two openings. One opening leads down into the pelvic pouch and secretes a little mucus. The second opening is the one from which the bowel contents will empty.

In the case of a three stage operation, only the colon is removed in the first stage; the rectum and anus remain intact. Because your rectum is left in place, you will pass small amounts of mucus from the anus from time to time. The ileostomy created in this situation is an end ileostomy. It has only one opening from which the bowel contents will empty.

**POST-OPERATIVE PERIOD**

1. **Drain Tubes**
   You may also have abdominal drains placed during surgery. They are necessary to remove collections of fluid in the operative area and promote healing of tissue. These drains are brought out through small incisions in the lower abdomen. There will also be a rectal tube placed into the pouch itself through the anus to drain the pouch. These will all be removed before you go home.

2. **Progression Of Diet**
   The normal function of the bowel is called peristalsis, a process by which food and waste is passed through the digestive tract. After an abdominal operation, it takes a few days before peristalsis resumes, and during this time you will be given nothing to eat or drink. Nourishment will be provided to you by your intravenous line. Once activity returns to the bowel you will begin to pass gas and stool into the external pouch. If an NG tube was placed in surgery, it will now be removed. You will begin to take fluids by mouth. Your diet will then be gradually increased.

3. **Stoma Assessment**
   After surgery, your WOC/ET nurse or staff nurse will assess your stoma to make sure it is healthy and correctly fitted with a postoperative pouch. Initially your stoma will be swollen, but this will gradually decrease and your stoma will shrink in size. This takes about 6-8 weeks. A few days before you go home, your stoma and abdomen will be assessed by your WOC/ET nurse and self care teaching will begin. A pouching system which is custom fitted to your needs will be chosen. This pouching system is designed to contain your stool in an odor proof pouch and protect your skin from irritation.

4. **Ileostomy Function**
   Ileostomies created with ileoanal reservoirs are located higher in the intestine than end ileostomies and will produce a more liquid effluent (stool). Most patients will need to empty their external pouch six to eight times in a twenty-four hour period. This effluent is rich in digestive enzymes which can irritate the skin if it comes in contact with your skin. Protecting the skin by getting the best seal possible on your pouching system is vitally important.

5. **Rectal Drainage**
   One of the normal functions of the intestine is to produce mucus to lubricate the passage of stool. Even though the new pelvic pouch is not operative until after the second surgery, mucus continues to be produced. As there is a lot of manipulation of the anal canal during surgery it is not unusual to have a period of temporary bowel incon-
CARE OF YOUR ILEOSTOMY

Even though you knew from the beginning that you would have an ileostomy, it takes time to adjust to the presence of a stoma and your altered bowel function and body image. It is normal to feel apprehensive about wearing an external pouch, even though it will likely be a temporary situation. While you are in the hospital, you will be given the necessary information to help you learn to live with your stoma. This information includes stoma assessment, skin care, pouch application, diet, odor control, exercise and activity. You will also learn where to obtain your supplies on discharge from the hospital and the expected expenses.

1. Peristomal Skin Care

The prime concern of a person with an ileostomy is the protection of the skin surrounding the stoma (peristomal skin). The skin must be kept clean, dry and intact. The three main sources of peristomal skin injury are: ileostomy output, pouch adhesives and possible reactions to skin care products.

It is essential to protect the peristomal skin from the ileostomy output. Your WOC/ET nurse will make the initial assessment of your stoma and choose the best pouching system for you. Your pouch must be carefully fitted and will require adjustment as the stoma decreases in size and abdominal contours change after surgery. Modifications to the pouching system may also occur if there is any major weight gain or loss.

Your ileostomy pouch is held in place around your stoma by skin adhesives. If your pouch is removed improperly or too frequently, a thin layer of skin may be removed with each change, interrupting the integrity of the skin. Therefore, the pouch should be removed by gently pushing the skin away from the pouching system. It should be changed as needed in the case of leakage or for general hygiene, usually two times per week.

There are numerous skin care products available on the market. Your WOC/ET nurse will help you choose the products necessary for you. The fewer products you use on your skin, the less likely you are to develop sensitivities. Unnecessary products also add to the cost of having a stoma.

2. Changing The Pouching System

Purpose:
• Removal of soiled pouch.
• Cleansing of peristomal skin.
• Assessment of stoma and skin.
• Application of clean pouch.

Considerations:
• Choose a time when the ileostomy is least active e.g.: before breakfast.
• Choose a quiet, convenient place with good light and a mirror.
• Collect and assemble all necessary equipment before removing the soiled pouch.

The longer time is spent without a pouch in place, the more likely that the ileostomy will start to function and pass stool.
Procedure for Changing a One-Piece Pouch:
1. Assemble all equipment:
   - One piece pouch
   - Soft washcloth/paper towels
   - Stoma measuring guide
   - Non-oily soap
   - Plastic bag in which to dispose old pouch
   - Scissors
   - Accessory products if used such as skin barrier paste, skin barrier powder, adhesive remover, deodorant
2. Empty the pouch into the toilet. Remove the pouch by gently pressing the skin away from the adhesive, starting at the top. Use adhesive remover wipe if needed. If using a pouching system with a clamp, be sure to take the clamp from the bottom of the pouch before placing the pouch in the plastic bag.
3. Inspect skin and stoma for signs of irritation or trauma. Small amounts of bleeding from the outside of the stoma when cleansing it are normal.
4. Measure the stoma carefully for up to six weeks after surgery. If no change in stoma size is noted for 2-3 weeks, stoma size will usually not change so further measuring is not needed.
5. Trace shape on paper backing of the pouch; cut tracing on the outside of the drawn line.
6. Remove paper backing from the skin barrier of the pouch. If you are using skin barrier paste, apply a thin bead around the cut opening. Allow paste to dry to touch.
7. Cleanse skin gently with non-oily soap. Rinse thoroughly; pat skin dry.
8. If open skin is noted around stoma, apply small amount of skin barrier powder; brush off excess powder.
9. Center pouch over your stoma onto abdomen. Smooth the skin barrier into place. Hold your hand over barrier for about 30 seconds; the warmth from your hand helps the adhesive properties of the skin barrier work better.
10 Close the drainage spout: if using a pouch with an integrated closure, follow manufacturer’s guidelines; if using clamp, apply now.
11. Gather trash and throw away.

Procedure for Changing a Two-Piece Pouch
1. Assemble all equipment
   - Two piece pouching system
   - Soft washcloth/paper towels
   - Stoma measuring guide
   - Non-oily soap
   - Plastic bag in which to dispose old pouch
   - Scissors
   - Accessories (if used): skin barrier paste, powder, adhesive remover, deodorant, etc.
2. Empty the pouch into the toilet. Remove the pouch by gently pressing the skin away from the adhesive, starting at the top. Use adhesive remover wipe if needed. If using a pouching system with a clamp, be sure to take the clamp from the bottom of the pouch before placing the pouch in the plastic bag.
3. Inspect skin and stoma for signs of irritation or trauma. Small amounts of bleeding from the outside of the stoma when cleansing it are normal.
4. Measure the stoma carefully for up to six weeks after surgery. If no change for 2-3 weeks, stoma size will usually not change so further measuring is not needed.
5. Trace shape on paper backing of the skin barrier; cut tracing on the outside of the drawn line.
6. Remove paper backing from the skin barrier. If you are using skin barrier paste, apply a thin bead around the cut opening. Allow paste to dry to touch.
7. Cleanse skin gently with non-oily soap. Rinse thoroughly; pat skin dry.
8. If open skin is noted around stoma, apply small amount of skin barrier powder; brush off excess powder.
9. Center skin barrier over your stoma onto abdomen. Smooth the skin barrier into place. Hold your hand over barrier for about 30 seconds; the warmth from your hand helps the adhesive properties of the skin barrier work better.
10. Snap pouch onto flange of skin barrier. Test for a secure seal.
11. Close the drainage spout: if using a pouch with an integrated closure, follow manufacturer's guidelines; if using clamp, apply now.
12. Gather trash and throw away.

3. Possible Complications
Peristomal Skin Irritation/Leakage due to:
- Stoma construction – A loop ileostomy may function at skin level which makes it more difficult to get a good seal on the pouching system.
- For six to eight weeks after surgery, the stoma shrinks and the abdominal shape changes as swelling decreases. As a result, the type of pouching system used when discharged from the hospital may need to be modified or changed.
- Obesity - Skin folds or creases present around the stoma in an obese abdomen makes it more difficult to get a good seal on the pouching system.
- Poor measuring of stoma; poor cutting and application of pouching system.

Treatment -
- Careful fitting and application of pouching system.
- Use of a convex pouching system when advised to do so by WOC/ET nurse.
- Use of skin barrier paste or wedges of skin barrier wafer to fill skin defects.
- Use of skin barrier powder to treat open, moist skin.

4. Non-Functioning Ileostomy / Blockage
Signs and Symptoms -
- Abdominal pain
- Distended (bloated) abdomen
- Nausea and vomiting
- No output or high volume, watery output from stoma that tends to have a foul odor
- Decreased urine output
- Occurs in the immediate postoperative period
Cause - Ileus
An ileus refers to inactivity of the bowel when peristalsis ceases. This may be due to rapid withdrawal of steroids (e.g. prednisone), excessive handling of the intestine during surgery, prolonged anesthesia, opioid pain medication, or a local inflammatory response in the intestine.

Treatment -
• Maintain N.P.O. (nothing by mouth).
• Insertion of a nasogastric (NG) tube may be needed to if vomiting occurs to empty the stomach and control vomiting.
• Anti-nausea medication
• Intravenous fluids.
• Correction of any deficiencies (electrolytes, steroids etc.).
• Treatment of any inflammation or infection e.g. antibiotics or operation (rare).

Cause - Mechanical Obstruction
Mechanical obstruction refers to the actual blockage of the passage of bowel content. This may be due to undigested food that cannot pass easily through the ileostomy. Adhesions (scar tissue in the abdomen) or a twist in the bowel as the result of surgery may also cause a mechanical obstruction.

Treatment -
• Maintain N.P.O. (nothing by mouth).
• Insertion of nasogastric (NG) tube if vomiting occurs.
• Intravenous fluids.
• Lavage, that is a flushing out, of the ileostomy by a WOC/ET nurse or physician.
• Possible surgery if adhesions or bowel twisting is thought to be the cause.

NOTE: If you think you have either an ileus or a mechanical obstruction:
• Drink small amounts of warm fluids.
• Have a warm bath to promote relaxation.

If there is no ileostomy output in 4 to 5 hours or if you become nauseated and start vomiting, call your surgeon.

Proper dietary management will be discussed in a following section. You must remember to chew everything very thoroughly and introduce new foods gradually to avoid blockage.
DEHYDRATION AND ELECTROLYTE IMBALANCE

During normal digestion the colon absorbs fluid and electrolytes (chemicals needed for many important body processes). Because your colon was removed you need to increase fluid intake to avoid fluid and electrolyte imbalance. Dehydration is more common prior to closure of the temporary ileostomy. This occurs because at least two feet of small bowel is bypassed and not being used.

Notify your physician if you have high ileostomy output (over 1000cc /24 hours) or any of the symptoms listed below. It is generally not enough to correct these types of imbalances with dietary intervention alone. It is often necessary to take a bowel slower medication or stool thickener to allow your intestine to absorb the appropriate amount of fluids and electrolytes.

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Diagnosis</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>increased thirst, dry mouth &amp; skin, decreased urine output, fatigue, shortness of breath, abdominal cramps.</td>
<td>Dehydration</td>
<td>Increase fluid intake to 8 - 10 glasses per day</td>
</tr>
<tr>
<td>appetite loss, abdominal cramps, feelings of drowsiness, faintness, cold feelings in arms &amp; legs.</td>
<td>Sodium loss</td>
<td>Increase fluids high in sodium e.g. chicken soup, low sugar sport drinks, or bouillon</td>
</tr>
<tr>
<td>fatigue, muscle weakness, gassy bloated feeling, shortness of breath, decreased sensation in arms &amp; legs.</td>
<td>Potassium loss</td>
<td>Increase foods high in potassium, e.g. orange juice, bananas, and low sugar sport drinks</td>
</tr>
</tbody>
</table>

RECTAL DRAINAGE

The mucous membrane or lining of the intestine secretes mucus to lubricate food and stool as it passes through the digestive tract. Prior to closure of the ileostomy, the mucus from the unused portion of the small intestine (from ileostomy through the pelvic pouch) is watery in consistency and hard to hold in. The sphincter muscles have also been stretched during the surgery. As a result, you may have seepage of mucus through the anus. This is a temporary condition and, once the ileostomy is closed, the mucus mixes with the stool and is much easier to control. Sitting on the toilet first thing in the morning and right before bedtime may help you to expel any mucus, thus decreasing any incontinence you may be experiencing. As the pelvic pouch capacity increases over time, the amount of seepage usually decreases.

The treatment for rectal drainage is adequate protection of perianal skin with the use of skin barrier ointments or non-sting skin sealant. Check with your WOC/ET nurse or physician for the brand of ointment that will work best for you. Containment of drainage with panty liners may also be needed particularly while you sleep. Some physicians
may want you to learn perianal muscle strengthening exercises. Check with your doctor to see if you should be doing these.

COMPLICATIONS
Report any of the following to your WOC/ET Nurse:
1. Excessive and/or persistent stomal bleeding.
2. Swelling or elongation of the stoma.
3. Changes in the color of the stoma (particularly to maroon, purple, or black).
4. Cuts or ulcerations of the stoma.
5. Skin irritation or ulceration.
6. Any bulging of the skin around the stoma.
7. Persistent burning or itching under your pouch.
8. Severe odor

Report any of the following to your physician:
1. Severe watery discharge lasting more than four to five hours.
2. No stoma output for 4-6 hours.
3. Nausea/vomiting in combination with 2, 3, or 6 above.
4. Abdominal cramps lasting longer than three to four hours.
5. Distended abdomen.
6. Excessive and/or persistent stomal bleeding
7. Changes in the color of the stoma (particularly to maroon, purple, or black)

DISCHARGE PREPARATION:
When you are medically ready, you will be discharged from the hospital. You must know how to empty your pouch independently before you leave. You may require some assistance with changing your pouch. If this is the case, arrangements for home health nursing care will be arranged. Before you are discharged, you will be given:
1. One to three pouch changes, dependent on the policies of the hospital you are in.
2. Information regarding future supplies, their ordering and cost.
3. Printed instructions on care of your stoma.
4. Information on activities of daily living: bathing, showering, diet, etc.
5. Phone number of WOC/ET nurse for questions or problems.
6. Instructions for your follow-up visit with your surgeon and WOC/ET nurse.

SPECIAL REMINDERS
1. Never take a laxative. This is usually given to clean the large intestine which you no longer have. If you should happen to have X-rays ordered which include a bowel prep, explain to the personnel involved that you will not be following the prep. If there are any concerns, contact your physician.
2. Be aware of what form of medication you are taking as you may need to alter this. Liquid forms of medication tend to work best for individuals with ileostomies. Time released or enteric coated pills will no longer be effective. Consult with your physician or pharmacist before beginning a new medication.
3. Do not irrigate or allow anyone else to irrigate your ileostomy. If you are obstructed, your physician or WOC/ET nurse will use a soft catheter, a syringe and small amounts of normal saline to gently wash the blockage out.
DIETARY ISSUES

Concern with diet is evident even prior to surgery and is reflected in the statement “Food does not cause inflammatory bowel disease and diet does not cure it.” The otherwise healthy person with a stoma has the same nutritional needs as other patients of the same age and sex.

Principle Aim of Diet

• Provide adequate nutrition.

Prime Concerns of a Person with an Ileostomy

1. Avoidance of blockage.
2. Preservation of skin integrity.

Remember, you are not on a special diet but your ileostomy will be affected by the foods you eat. There are only two main rules to be followed.

1. Chew everything very thoroughly.
2. Introduce new foods gradually. Try only one new food at a time. In this way, if a problem arises, the cause is easily identified and may be deleted from your diet. However, that doesn't mean that you will never be able to eat that food, only that you should wait a while before trying that food again.

The following is a list of foods to be considered when preparing a diet for a person with an ileostomy/ileoanal pouch.

1. Foods high in roughage may cause blockage, therefore, refrain from eating them in the immediate postoperative period (4-6 weeks), then introduce these foods to your diet gradually: bran, nuts, dried fruits and raisins, seeds, skins, beans, pineapple, popcorn, asparagus, oranges, shrimp, kernel corn, raw vegetables, Chinese food, celery, coleslaw, salad, mushrooms, lentils, tomatoes, raw fruits except banana, and fruit cocktail

2. Foods that increase output: raw fruits/vegetables, chocolate, leafy green vegetables, caffeinated beverages, spicy foods, carbonated beverages, foods high in refined sugar or that contain sorbitol

3. Foods that slow output/increase transit time: bananas, cheese, applesauce, tapioca, smooth peanut butter, boiled white rice, marshmallow

4. Foods that may cause gas: onions, carbonated beverages, cabbage family, dairy products, dried beans/ peas, cucumbers, radishes

MISCELLANEOUS RECOMMENDATIONS:

1. Avoid ingestion of large amounts of fluid with meals.
2. Drink plenty of fluids (especially between meals) to decrease risk of dehydration and obstruction.
3. Begin with small meals to avoid feeling bloated and gradually increase the amount you eat at each meal.
4. Eat regularly. If you are troubled with a high output, skipping meals will not stop output and more gas is produced in an empty gut. Also, limiting intake increases the risk of dehydration. Instead try increasing foods that slow output. (See above)
5. Avoid high fiber foods on an empty stomach as eating them may increase the risk of obstruction.
6. Experiment with meal timing. With the traditional meal patterns, output tends to be high in the afternoon and increases in the evening. This is undesirable if a person wants uninterrupted sleep. The problem is decreased by adjusting meal times and limiting foods and fluid towards the end of the day.
7. Chew everything thoroughly.
8. Introduce new foods gradually.

FOLLOW-UP TO FIRST OPERATION
You will return for a follow-up physician and WOC/ET nurse visit as per their instruction at the time of your hospital discharge:

PELVIC MUSCLE EXERCISES – ALSO KNOWN AS KEGEL EXERCISES
The purpose of pelvic muscle exercises is to strengthen the tone of your anal sphincter muscles. These are the muscles that allow you to control your bowel function. Pelvic muscle exercises may be initiated before surgery and resumed several weeks after surgery. During the immediate postoperative phase major tissue repair and healing is occurring. Check with your surgeon as to when you can begin or resume pelvic muscle exercises after your surgery.

Pelvic muscle exercise involves:
- Tightening your anal muscle or sphincter as though you are attempting to prevent a bowel movement. You should get the same sensation as you do when you stop your urine stream when voiding. Don't just squeeze the buttock muscles.
  - Hold to the count of ten while squeezing tightly, then
  - Relax for a count of ten....
- Repeat each step ten (10) times to make one set of exercises. You should complete four sets a day. They may be performed any time during the day and while you are in any position. For example, you may do them while watching television, riding in a car, sitting at your desk, or while talking on the telephone.

STAGE TWO (ILEOSTOMY CLOSURE)
This is the term that refers to your second operation and you will likely be in the hospital for 3-5 days. Before admission to the hospital, a pouchogram will be ordered by your surgeon.

This is to ensure that the pelvic pouch has healed and that there are no leaks. This is a special X-ray and is done by instilling fluid into your pouch from below, via your anus, and taking an X-ray. The procedure takes about ten to fifteen minutes and is painless.

Note: Be sure and empty your ostomy pouch prior to the procedure and have a spare appliance with you in case a change is needed.

Every surgeon has a slightly different preoperative protocol. Be sure you understand the instructions your surgeon has given to you. Usually, an individual is placed on a clear liquid diet for 2-3 days before surgery. A mild laxative may be prescribed for you by your surgeon; some do not do this. Lab work may be ordered. You will be NPO (nothing by mouth) from midnight of the night before your surgery. Upon arrival to the hospital, an IV will be started. You will be given IV antibiotics when you are called to go to the operating room. The antibiotic helps prevent infection.
THE OPERATION
This final operation is the takedown or closure of the ileostomy. It is a much smaller procedure, taking about an hour, and is comprised of the following steps:

1. In most instances the ileostomy is closed by making an incision around the stoma and freeing it down to the abdominal cavity. Closure of the ileostomy usually does not require an abdominal midline incision.

2. The two ends of the bowel, one leading from the stomach and one leading to the ileoanal pouch, are rejoined so that the stool will pass through the small bowel, the ileoanal pouch, and out through the anus.

3. The former stoma site may be closed, or the muscle layer may be closed and the skin and subcutaneous tissue layer is left open, allowing the area to heal from the bottom up. This is an individual surgeon preference.

POSTOPERATIVE PERIOD
Your post operative care will be similar to that which you received after your first operation, except that you are unlikely to have any tubes. Following the closure of the ileostomy, passing gas and intestinal function begin about the second day and frequent loose movements are to be expected. As diet is advanced, bulk forming agents and/or antidiarrheal medications may be given to decrease bowel frequency and to avoid dehydration. You will be asked to keep track of your bowel movements. At first you may have as many as twelve to fifteen bowel movements a day, but this number will decrease by the time you leave the hospital and will eventually average four to six per day.

PERIANAL SKIN CARE
As initial ileoanal pouch function begins, aggressive perianal (around the anus) skin care is started to prevent perianal skin irritation. This can become severe and there are specific times when you are at greater risks of developing perianal skin irritation or breakdown.

- When mucus is discharged with temporary incontinence following the first surgery.
- Immediately following ileostomy takedown.
- During bouts of gastroenteritis (inflammation of the stomach or intestines).
- During bouts of pouchitis (inflammation of pouch).
- After indiscriminate eating.

The risk of developing skin irritation is directly related to an increase in bowel action. Decreased transit time results in increased skin irritation due to the presence of digestive enzymes in the stool and on the perianal skin. If perianal skin irritation develops, it is usually temporary. However, certain foods such as spicy foods (tomatoes, onions) coffee and tea cause irritation and should be avoided until the irritation improves.
POSSIBLE COMPLICATIONS

Perianal Skin Irritation is recognized as an uncomfortable, frequently painful problem. Fortunately, it can be controlled and it generally becomes less of a problem with time. Prevention focuses on three main points:
• Controlling bowel frequency.
• Good perianal skin care
• Application of occlusive skin protectants such as ointments, pastes, and liquid skin sealants without alcohol. Unless an occlusive barrier is applied to protect the skin from contact with bowel content, the skin remains unprotected and WILL become irritated.

Prevention And/Or Treatment Of Perianal Skin Irritation
1. Cleanse and dry skin thoroughly once a day. Gentleness is the key; Pat the area rather than rubbing or wiping.
2. Moistened cotton balls or soft tissue are ideal for cleansing and are less abrasive than toilet tissue.
3. Warm water is generally all that is needed. Soap and scented tissue may be irritating to the skin and leave a residue resulting in itching. Skin care cleansers can be used as an alternative to soap. Skin cleansers contain surfactants, substances that help to gently remove stool and other irritants from the skin.
4. It is not necessary or advised to cleanse to skin level after each bowel action. Remove any soiled layers of ointment or paste and apply a fresh coat on top.
5. Pads or panty liners should be changed frequently to keep skin clean and dry.
6. Cotton underwear rather than nylon or polyester are advised as cotton absorbs perspiration and allows air to circulate.
7. Use of skin protectants is essential to protect perianal skin.
8. Sitz baths may be advised and are a gentle and thorough way to cleanse and soothe irritated skin.
9. To protect the skin from small amounts of seepage a cotton ball may be gently placed over the anal opening.

If you experience continual perianal skin irritation even after taking special precautions, you should consult your physician or WOC/ET nurse who will reassess the problem and suggest further care.

Pouchitis is an inflammation of the ileoanal reservoir. Incidence of pouchitis has been reported from 15-44%. The exact cause of pouchitis isn't definitely known, but is attributed to unrecognized Crohn's disease, indeterminate colitis, bacterial overgrowth, alteration in bile salt metabolism, immunologic changes, and pouch ischemia.

Symptoms:
• significant increase in stool frequency with watery diarrhea
• urgency or pressure sensation in the pouch
• cramping
• bleeding
• low grade fever
• malaise (general unwell feeling)
• dull pelvic pain and pressure
**Treatment:**
90% of cases are temporary and respond to antibiotics. If there is little or no response to antibiotics, anti-inflammatory medications may be used. Diversion with an ileostomy or pouch excision may become necessary for cases of pouchitis with intolerable symptoms not responsive to medical therapy.

It is important for you to recognize the difference between the above symptoms and those of simple excess frequency as might occur with gastroenteritis. The symptoms listed above should alert you to contact your surgeon.

Bleeding is caused by irritation of the reservoir lining. It may accompany pouchitis but most frequently is due to excessive straining or vigorous cleaning with irritation of the sensitive small bowel lining. It should be reported to your surgeon.

**FOLLOW-UP**
Some form of identification stating you have had IPAA surgery is advised. There are many companies that provide bracelets or necklaces that can have this information imprinted on them. At the very least, carry an ID card in your wallet. The card should have the contact information for your surgeon as well as state:

**TOTAL COLECTOMY – ILEOPOUCH ANAL RESERVOIR**

Medications: you should discuss any medications you are taking with your doctor or pharmacist to be sure they are not absorbed in the large intestine e.g., coated tablets or sustained release capsules.

**ONGOING CONSIDERATIONS**

**Pouch Adaptation**

Pouch adaptation is a process which continues for six months to a year following surgery. During this time the pouch increases in capacity. The number of bowel movements per 24 hours decreases to about four to six and the stool becomes thicker in consistency. You should not respond to every urge to evacuate the pouch in order to begin increasing the size of the reservoir, thereby decreasing the number of trips to the bathroom. You can also help with pouch adaptation by learning to control pouch function with diet and, if necessary, medication.

The majority of people do not have any major problems with control. However, some night time seepage or incontinence may be experienced. This generally will pass with time. You may wish to wear a pad to prevent soiling of your clothing. You will also want to pay special attention to your perianal skin care (see page 13).

**Diet Guidelines**

1. Follow a low fiber diet for approximately four weeks following closure of the temporary ileostomy. After this, gradually increase fiber as tolerated until you are eating a regular diet.
2. Emphasis is placed on good eating habits, eating meals at regular time intervals, eating in a relaxed atmosphere and chewing thoroughly. Skipping meals will not stop pouch output. In fact, this practice may result in greater production of gas and increase the risk of dehydration.
3. Eat moderate amounts and chew your food well!
4. Some individuals find pouch output to be high in the afternoon and increasing towards the evening. You may wish to try experimenting with timing of meals. Perhaps try your larger meals earlier in the day or limiting the amount of food and fluid intake towards the end of the day.

5. If a particular food is not tolerated try it again at a later date.

6. Drink at least six to eight glasses of fluid each day. Between meal consumption of fluids is recommended over large volumes with meals.

7. There may be an increased requirement for sodium; use salt with meals unless otherwise indicated.

8. High potassium foods will be required in the presence of diarrhea. Good sources of potassium include: meat, fish, poultry, dried fruits, bananas, oranges, tomatoes, fruit juices, milk, potatoes, and sweet potatoes.

9. Limit the intake of foods high in simple sugars since these can aggravate diarrhea: e.g. sugar, honey, candy, jam, jellies, pastries and sweetened beverages (soda).

Dietary modifications may help in relieving problems with high pouch output, anal irritation and gas. The following food lists have been compiled based on individual experiences of others with an ileoanal pouch. Temporary exclusion of certain foods may or may not be effective in helping to control these problems. Experiment and find out what works for you!

**Foods Which Increase Pouch Output**

- raw fruits and vegetables (especially broccoli, beans and spinach)
- leafy green vegetables
- spicy foods
- beer
- chocolate
- wine
- caffeinated beverages

**Foods Which May Decrease Pouch Output**

- bananas
- cheese
- boiled white rice and rice dishes (e.g. rice pudding)
- tapioca pudding
- creamy peanut butter
- applesauce

**Foods Which May Contribute To Anal Irritation**

- certain raw fruits and vegetables (e.g. oranges, apples, coleslaw, celery and corn)
- popcorn
- Chinese/oriental vegetables
- nuts
- coconut
- dried fruits (e.g. raisins, figs)
- foods with seeds
- spicy foods
- coffee and tea
Foods Which May Cause Gas

• onion
• vegetables of the cabbage family
• dried beans and peas
• baked beans
• cucumbers and radishes
• beer
• carbonated beverages
• milk and milk products

SEXUAL ADJUSTMENT

Concerns about sexual activity is of prime importance. The removal of the diseased colon and rectum quickly restores the feeling of well-being and most people are anxious to resume their previous sexual activity. Check with your surgeon as to when it is safe to begin sexual relations after surgery. Some people even find their sex life improved without the problems and pain of inflammatory bowel disease. Keep in mind that this operation eliminates the need of a permanent ileostomy and the body image problems this sometimes creates.

Menstrual cycles are usually disrupted following any operation. Your menses may be irregular for up to one year following surgery.

In the initial postoperative period, the transit time of the digestive tract is usually very rapid. For this reason, birth control pills probably will not be completely absorbed, therefore, it is wise to use other methods of contraception. In males, there is a reported 1.5% sexual dysfunction resulting in impotence or infertility due to retrograde ejaculation.

Discuss with your surgeon your desire to become pregnant after pelvic pouch surgery. Techniques can be used during the operation to help prevent the ovaries and tubes from becoming trapped in the scar tissue that forms after abdominal surgery. Pregnancy following ileoanal pouch surgery is certainly possible but it is advisable to wait for at least 6 months after surgery to become pregnant. Colorectal surgeons may recommend that your baby be delivered by Caesarean section as this avoids any possibility of injury to the anal muscles and nerves that can occur during a vaginal delivery. Women have had vaginal deliveries without adverse outcomes. Talk with your surgeon regarding what is the best delivery method for you.
GLOSSARY

Anal sphincter - the muscles surrounding the anus that contract or close the opening.
Anastomosis - the union of one structure to another.
Anus - the opening in the rectum through which stool is eliminated from the body.
Appliance - the device used to collect discharge such as stool, mucous, gas, or urine; it consists of a pouch, skin barrier, etc.
Blockage - obstruction
Bowel - the intestine; the part of the digestive tract between the stomach and the anus.
Colitis - inflammation of the colon (large bowel).
Colon - the last four to five feet of the digestive tract; the large bowel or large intestine.
Continence - the ability to keep stool, gas, or urine inside the body voluntarily.
Crohn's Disease - an inflammatory disease that can involve the entire digestive tract but that usually occurs in the small bowel, colon, or rectum and/or anus. It is characterized by diarrhea, fever, weight loss and pain. The cause is unknown.
Distended - bloated
Effluent - excretion from the small bowel.
Electrolytes - electrically charged chemicals essential to the functioning of many complex processes in the body.
Enterostomal Therapy Nurse (ET Nurse) - a registered nurse with expertise and special education in the field of colon surgery and the care of the stoma.
Familial Polyposis Coli - an inherited disease characterized by a tendency to develop masses of polyps in the colon.
Frequency - the number of bowel movements that occurs in a given period.
Gastrointestinal - pertaining to the digestive system.
Ileoanal anastomosis - joining the ileum to the anus following removal of the colon and the rectum.
Ileorectal anastomosis - joining the ileum to the rectum following removal of the colon.
Ileostomy - a surgically created opening from the ileum to the skin.
1. end ileostomy- the cut end of the small bowel is brought out to the surface of the skin, turned back on itself like a small cuff and stitched to the skin.
2. loop ileostomy - a loop of small bowel is brought out to the surface of the skin, cut half way through, leaving the ileum otherwise intact but with two openings. As with an end ileostomy the bowel is turned back on itself like a small cuff and stitched to the skin.
Ileostomy Takedown - removal of an ileostomy by rejoining the bowel and placing it back in the abdomen.
Ileum - the last twelve to fifteen feet of small bowel.
Ileus - intestinal obstruction due to failure of peristalsis.
Incontinence - the inability to control the elimination of urine, stool, or gas.
Kegel exercises - alternate contraction and relaxation of the floor of the pelvis.
Large Bowel - the last four to five feet of bowel that extends from the small bowel to the anus, also referred to as large intestine or colon.
Lumen - the space in the center of a tubular structure ie. the intestine.
Mucus - a lubricating substance produced by the digestive tract.
Mucosa - the lining of the digestive tract and of other organs of the body.
Ostomy - a surgical opening, usually on the abdominal wall, for the drainage of body wastes. - Colostomy - a surgical opening into the colon or large bowel. - Ileostomy - a surgical opening into the ileum or small bowel.
Pelvic pouch - an ileoanal reservoir created from the ileum. Also known as J-Pouch.
Perianal - located around the anus.
Peristalsis - the progressive movement of the intestine by which the contents are pushed toward the outlet.
Peristomal - located around a stoma.
Polyp - small projection inside the bowel, may be flat or mushroom shaped, usually benign but may be malignant.
Pouchitis - inflammation of a reservoir.
Proctocolectomy - removal of the colon, rectum, and anus with the creation of a permanent ileostomy.
Rectal cuff - the portion of the rectum, consisting of sphincter muscle, that is retained after the lining of the rectum has been removed.
Rectum - the last part of the large bowel which joins the colon to the anus.
Reservoir - an anatomic structure that serves as a place to collect or retain fluid.
Small bowel - the twenty-two to twenty-five feet of intestine between the stomach and the large bowel. Also referred to as the small intestine.
Stoma - 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.
Transit Time - minutes and hours that elapse from eating of food until the waste is passed, either through the anus or the stoma.
Ulcerative colitis - an inflammatory disease of the colon and rectum in which ulcers form in the intestinal lining. Bleeding, cramping and diarrhea are the primary symptoms of the disease.
Urostomy - a surgical procedure in which urine is diverted from its normal path through the bladder and is brought through the abdominal wall for collection.
Wound, Ostomy, Continence /Enterostomal Therapy Nurse (WOC/ET Nurse) - a registered nurse with expertise and special education in the care of individual’s with stomas,
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