

ILEOANAL RESERVOIR GUIDE

REBORN FROM THE ASHES OF DISEASE

A PATIENT HANDBOOK FOR THE ILEOANAL RESERVOIR PROCEDURE

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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 her/him understand the surgical options that are currently available. In particular it focuses on the ileoanal reservoir procedure. This is also commonly known as the “S”, “J” or pelvic pouch procedure.

Over the past ten 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, along with the lining of the 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 which are the most commonly performed at the Calgary District Hospital Group. "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.

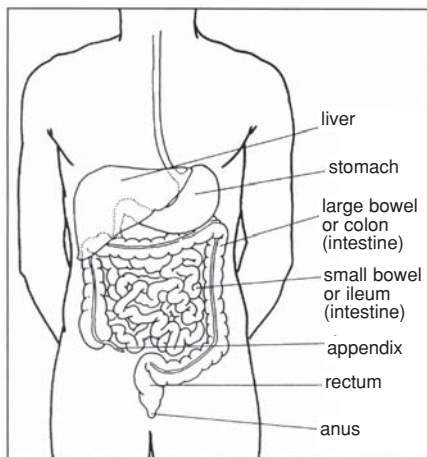


Figure #1

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 bowel. Therefore, if there is a need for the removal of the large bowel 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 bowel, 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 bowel. 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 bowel is affected. Since the underlying layers, including the muscles, are not affected, the rectal muscle, 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 have the opportunity 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 bowel 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 - 45 year age group, where the individuals usually have the best anal sphincter control. This 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 over-weight and who have a thick abdominal wall.

SURGICAL ALTERNATIVES

Ulcerative colitis and familial polyposis coli affect only the lining of the large bowel 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 bowel, including the 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, has 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.

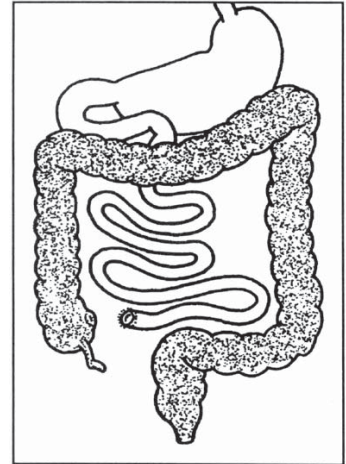
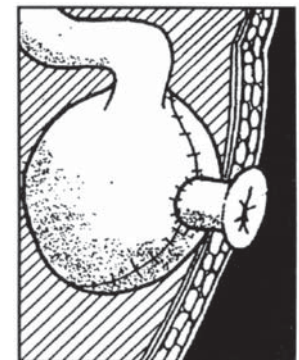


Figure #3
Shaded portion removed

II. Kock Pouch (figure 4)

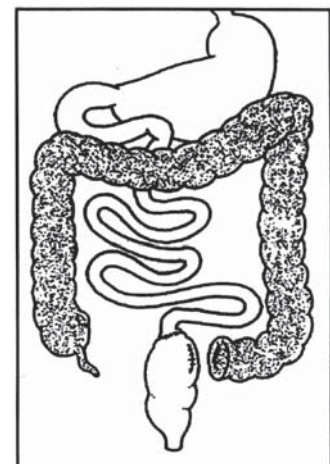
This is the complete removal of the large bowel, including the rectum and the anal sphincter. An internal reservoir is created which must be drained by inserting a catheter through an abdominal stoma on a regular routine, several times a day.



Kock Pouch
Figure #4

III. Total Colectomy With Ileorectal Anastomosis (figure 5)

This procedure involves the complete removal of the large bowel. The small bowel 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 continuing surveillance for the risk of rectal cancer.



Ileorectal Anastomosis
Figure #5

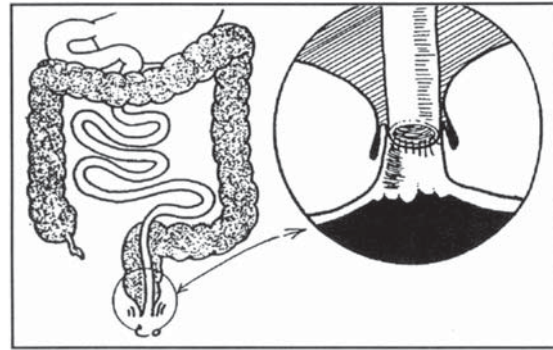
IV. Total Colectomy With Ileoanal Anastomosis (pull-through) (figure 6)

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

V. Total Colectomy With Ileoanal Reservoir (figure 7)

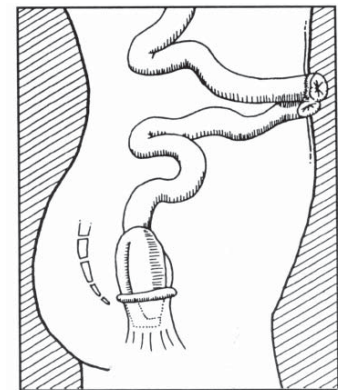
Removal of the entire large bowel and inner lining of the rectum, leaving a rectal cuff. Preserves the nerves and muscles necessary for continence. This procedure is a cure for ulcerative colitis and familial polyposis coli. The last portion of the small bowel is used to construct an internal pouch. This pouch has a short spout which is brought down through the rectal cuff and joined to the anus.

This 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. Other pouch configurations include the “W” pouch and the lateral (side by side) reservoir.



Total Colectomy With Ileoanal Anastomosis Figure #6
Shaded portion removed

In the more than two hundred ileoanal pouches created by the colorectal surgeons of the Calgary District Hospital Group, a success rate of 93% has been achieved and the patient satisfaction remains very high. There is, however, the possibility of failure (7%). Most failures are due to misdiagnosis (Crohn’s disease), persistent disease in the small bowel (pouchitis) or complications of the operation.



Total Colectomy With Ileoanal Reservoir Figure #7

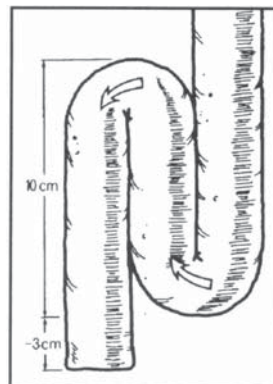
In this situation and after a trial period of resting the pouch or use of medication, surgery may be needed to repair the pouch, remove the pouch and create a new pouch, or convert to a permanent ileostomy

STAGING

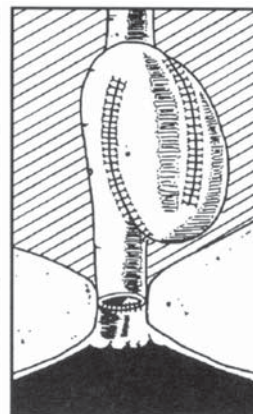
Surgery for creation of an internal pouch or reservoir may be performed in one, two or three stages.

I. One Stage Procedure

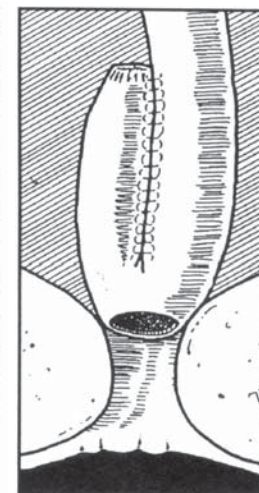
In a one stage procedure, the whole large bowel and the rectal lining are removed. The reservoir is created from the last twenty to thirty centimeters of the small bowel and joined to the anus without a temporary ileostomy. It has also been found, in the past, that when the operation is done without a temporary ileostomy to allow the pouch to heal, there is an increased risk of pelvic infection which usually leads to pouch failure. Therefore, a one stage procedure is rarely done.



Terminal Ileum Figure #8



“S” Pouch Figure #8B



“J” Pouch Figure #9

II. Two Stage Procedure

The most commonly performed procedure is

the two stage operation in which the diseased bowel and rectal mucosa or lining are removed. A reservoir is created from the terminal end of the small bowel and its spout is directed through the rectal cuff and joined to the anus. A temporary loop ileostomy is created above the pouch and brought out to the skin level through an opening on the abdomen, separate from the incision and usually on the right side. After approx. eight to twelve weeks, when the pouch is found to be leak proof and healthy, the second operation is performed. The ileostomy is then taken down and the continuity of the bowel is re-established. The stool now passes through the small bowel into the reservoir and out through the anus.

III. Three Stage Procedure

In some cases of severe disease or if the individual is in poor physical health due to a prolonged illness or on high doses of steroids (a medication used to treat ulcerative colitis), the surgeon may prefer to operate in three stages. In the first stage, the large bowel will be removed, leaving the rectum intact. An end ileostomy will be created. In the second stage the lining will be removed from the lower rectum and the upper rectum will be removed. A reservoir will be created, brought through the rectum, and sewn to the anus. 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 and the patient will begin to use the reservoir.

The decision on which type of surgery you have, One, Two or Three Stage, will be made by your surgeon and discussed with you. Performing the operation in two or three stages gives a person the opportunity of living temporarily with a stoma. The time spent caring for and living with a stoma gives the person an additional perspective regarding the primary alternative to the ileoanal reservoir procedure.

EXPECTED OUTCOME

You are probably wondering how all this will affect you and your life style! Your recovery will be prolonged compared to 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. This reservoir adaptation refers to changes which occur after your second operation as the size of the pouch increases and the number of bowel movements per day decreases. Eventually, most patients experience 4 to 6 bowel movements per day, have good control and are not troubled by night time incontinence. However, initially there could be up to 20 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 from 300-600 c.c.'s.

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 bowel. 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 surgery will be given to you by the staff nurses on admission to the hospital.

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

Prior To Your Surgery

The initial visit with your Enterostomal Therapy Nurse (ET) is usually shortly after your admission to the hospital. However, you may be referred, by your doctor, to visit your ET nurse before your hospital admission. This visit prior to, or upon hospitalization, is intended to be an informative session. It is intended to be helpful in your decision making, and hopefully answer many of your questions and ease your fears. In either case your parent(s), spouse, or significant other is more than welcome to be present for your pre-operative teaching. Arrangements will be made for you to 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 which may be helpful.

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 characteristics of the stoma and what to expect in the way of function.
3. A demonstration regarding the ostomy appliances available, their application, source, and cost.
4. A discussion about the effect of a temporary ileostomy on your diet, medication, hygiene, sexuality and daily living in general.
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 ET nurse will mark a place on your abdomen where the stoma will be. She will ask you to lie, sit and stand as she observes the changes in your abdomen with regard to skin folds and scars. She will choose a place, usually in the lower right quadrant that you can see well for easy management. 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 that will not wash off during the pre-operative skin preparation and will be easily identified by the surgeon in the operating room.

7. Probable pre-operative preparation. On admission to the hospital, you will have a chest X-ray and an E.C.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 empty the bowel of stool. This is usually given in the form of Magnesium Citrate or GoLytely, a large bottle of liquid laxative which you must drink in its entirety. This is in order to have the bowel as clean as possible to decrease the risks of post operative infections. You will have a liquid diet for two days until midnight the night before surgery and then you will be N.P.O. which means nothing to eat or drink until after your operation.

You will be required to have a shower with a special antibacterial soap the night before and the morning of your operation. Your abdomen may or may not be shaved. This may be either on the unit or in the operating room.

An intravenous (IV) will be started the evening prior to surgery. This prevents you from becoming dehydrated prior to and during surgery. It also remains in place for several days after surgery, until you are able to take fluids by mouth. Before you go to surgery, antibiotics are given via the IV to decrease the risks of infection after surgery. In the operating room, a tube is placed into your bladder to collect and record the amount of urine output and kidney function. This catheter remains in place for three to four days and relieves you of the discomfort of having to get out of bed to empty your bladder in the first few days after surgery. While you are in the operating room a nasogastric (N.G.) tube will be passed through your nose, down your throat and into your stomach. This tube removes secretions from your stomach which may cause post-operative nausea and vomiting.

THE OPERATION

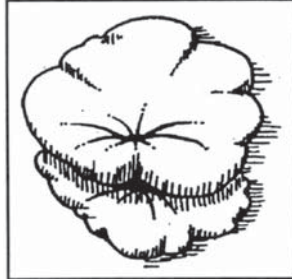
The length of surgery varies from patient to patient and is determined by their general condition and how complicated the surgery is. It usually takes about 2 - 3 hours and is comprised of the following steps:

1. Through an incision that reaches from about two inches above the umbilicus down to just above the pubic bone, the entire large bowel and the upper rectum are removed. The entire abdominal cavity is explored at this time.
2. Through the anus, the lining of the rectum is removed along with some of the rectum itself, leaving a five to seven centimeter rectal cuff and the entire anus intact, This retains the nerves and muscles (sphincters) necessary for voluntary control of bowel movements.
3. From the last portion of the small bowel a reservoir is constructed. This will be either an "S" or a "J" pouch according to the surgeon's assessment. The end of the reservoir is passed down through the rectal cuff and sewn to the anus.
4. Finally, to allow all the suture lines in the pouch and anus to heal properly a temporary ileostomy will be constructed. This will be either a loop or a divided (end) ileostomy.

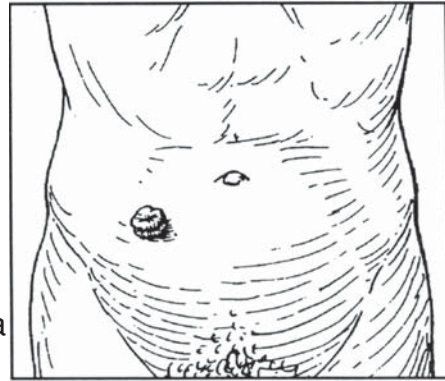
What Is An Ileostomy?

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

In your surgery, either an end of the small bowel or a loop of small bowel is brought to the surface through a small separate circular incision. The bowel 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 inside of your bowel and because it has a good blood supply, it is red in color. The bowel is lined with mucous membrane and so the stoma is moist and shiny. However, because there are no nerves in the bowel lining, there is no feeling in the stoma and no pain when it is touched.

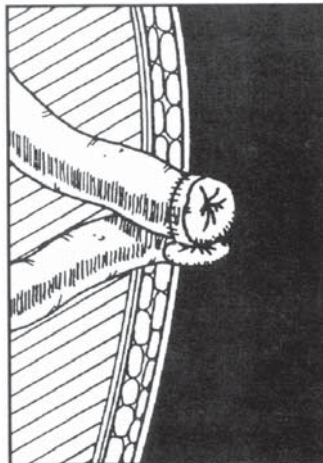


Loop Ileostomy Stoma
Figure #10

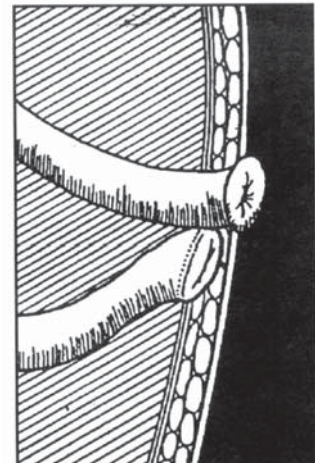


Stoma Position
Figure #11

A temporary loop ileostomy will protrude about one half inch and have two openings. One opening is at skin level, leads down into the pelvic pouch and does not function. The top opening is above skin level and is the opening from which the bowel contents empty into the external appliance.



Loop Ileostomy
Figure #12



End Ileostomy
Figure #13

In the case of a three stage operation the first stage is comprised of the removal of the large bowel only. The rectum and anus are left intact. The ileostomy which is then created is an end ileostomy with only one opening which functions to pass stool into an external appliance.

POST-OPERATIVE PERIOD

1. Drain Tubes

As you awaken you will find three more tubes in addition to those previously mentioned (nasogastric and urinary catheter). Some of these are abdominal drains which 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 within the first few days.

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. Once activity returns to the bowel you will begin to pass gas and stool into the appliance. At this time the N.G. tube will be removed and you will begin to take fluids by mouth. Your diet will then be gradually increased.

3. Stoma Assessment

After surgery, your ET nurse or staff nurse will assess your stoma to make sure it is healthy and correctly fitted with a post-operative appliance. Initially your stoma will be swollen, but this will gradually decrease and your stoma will shrink in size. After a few days, when your abdomen becomes less tender, your ET will select the pouching system with which you will go home and your self care teaching will begin. This system, which is custom fitted to your stoma, 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 bowel than end ileostomies and will produce a more liquid effluent (stool). Most patients will need to empty their appliance six to eight times in a twenty-four hour period. This effluent is rich in digestive enzymes which are proteins that breakdown other substances. These can cause irritation to the skin surrounding the stoma and do create the necessity for good skin care.

5. Rectal Drainage

One of the normal functions of the bowel is to produce mucous to lubricate the passage of stool. Even though the new pouch is not operative until after the second surgery, mucous 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 incontinence (lack of rectal control). This incontinence is a passage of the mucous produced by the bowel and not stool. This is especially bothersome at night, but its frequency usually decreases by the time of the second operation.

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 ET nurse will make the initial assessment of your stoma and choose the best appliance for you. Your appliance must be carefully fitted and will require adjustment as the stoma decreases in size or if there is any major weight gain or loss.

Your ileostomy appliance is held in place around your stoma by skin adhesives. If your pouch is removed improperly or too frequently, a thin layer of skin will be removed with each change, interrupting the integrity of the skin. Therefore, the appliance should be changed only as needed in the case of leakage or for general hygiene.

There are numerous skin care products available on the market. Your 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 appliance.
- Cleansing of peristomal skin.
- Assessment of stoma and skin.
- Application of clean appliance.

Considerations:

- Choose a time when the ileostomy is least active eg: 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 spent without a pouch in place, the more likely that the ileostomy will start to function and pass stool.

Procedure:

1. Assemble all equipment;
 - Skin barrier wafer (ConvaTec Sur-Fit* or Durahesive* with or without Convex-It* if required)
 - Stoma measuring guide
 - Open end pouch and clamp (Sur-Fit*)
 - Skin protective paste (Stomahesive*)
 - Skin protective powder (Stomahesive*)
 - Skin protective wipe (Allkare*)
 - Adhesive remover wipe (Allkare*)

- Non-oily soap (Peri Wash II*)
 - Garbage bag with twist tie
 - Scissors or seam ripper
 - Q-tips[®]
2. After emptying, remove the appliance by gently pressing the skin away from the appliance, starting at the top and using adhesive remover wipe if needed. Take the clamp from the bottom of the pouch before placing it in the garbage bag.
 3. Inspect skin and stoma for signs of irritation or trauma. Minute amounts of bleeding are normal.
 4. Measure the stoma carefully and trace shape on paper backing of the wafer.
 5. Cut hole in wafer, add insert if needed for convexity and remove protective paper. Add paste to back of wafer if needed and set aside.
 6. Paint skin protective wipe on the skin for extra protection and let dry (optional).
 7. Remove remainder of paper backing from wafer - center over the stoma and press firmly onto skin, especially inside plastic ring with Q-tip[®]. Add powder to any exposed skin (optional).
 8. Snap pouch on (plastic ring on wafer and plastic ring on pouch fit together).
 9. Apply clamp to bottom of pouch.
 10. Add cleaning cloths and soiled Q-tips to pouch in garbage bag and close with twist tie. Dispose of in covered garbage can.

3. Changing The Pouch Only

1. Remove pouch and place in garbage bag, saving the clamp.
2. Clean around the stoma, inside of the plastic ring.
3. Gently wipe around the stoma, inside wafer with a Q-tip[®], especially at the bottom edge.
4. Fill exposed skin areas with protective powder.
5. Apply clean pouch and secure clamp at bottom.
6. Dispose of garbage bag in covered garbage can.

4. Possible Complications

Peristomal Skin Irritation/Leakage due to:

- Stoma construction - a loop ileostomy may drain at skin level and it may be more difficult to contain than end ileostomy drainage.
- Obesity - skin folds or creases present in an obese abdomen add to problems of maintaining a good seal around the stoma.
- Poor measuring of stoma or poor cutting and application of skin barrier wafer.

Treatment -

- Careful fitting and application of wafer.
- Use of convex insert where needed.
- Use of paste or wedges of skin barrier wafer to fill skin defects.
- Use of powder to cover exposed skin.

5. Non-Functioning Ileostomy / Blockage

Signs and Symptoms -

- abdominal pain
- distended (bloated) abdomen
- nausea and vomiting
- no output or high volume, watery output
- decreased urine output

Cause - Ileus

An ileus refers to inactivity of the bowel when peristalsis ceases.

This may be due to rapid withdrawal of steroids (eg. prednisone), or may result in a blockage, infection, or inflammation of or around the bowel.

Treatment -

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

Cause - Mechanical Obstruction

Mechanical obstruction refers to the actual blockage of the passage of bowel content. This may be due to an accumulation of food particles in the bowel that have not been broken down in digestion and cannot pass easily through the ileostomy. Another cause may be adhesions or a twist in the bowel as the result of your operation.

Treatment -

- Maintain N.P.O. (nothing by mouth).
- Insertion of nasogastric tube may be necessary.
- Intravenous fluids.
- Irrigation of ileostomy.
- Possible surgery.
- Irrigation of ileostomy by an ET or staff nurse.

NOTE: If you think you have either an ileus or a mechanical obstruction:

1. Take a noncodeine analgesic (eg. extra strength Tylenol*).
2. Drink warm, sweetened tea.
3. Have a warm bath to promote relaxation.

If there is no ileostomy output in 4 to 6 hours or if you become nauseated and start vomiting, call your surgeon.

Proper dietary management will be discussed in a following section. However, once you advance to a regular diet you will be able to eat almost anything with the exception of high fiber foods. 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 by-passed and not being used.

Symptoms	Diagnosis	Treatment
increased thirst, dry mouth & skin, decreased urine output, fatigue, shortness of breath, abdominal cramps.	Dehydration	Increase fluid intake to 8 - 10 glasses per day
appetite loss, abdominal cramps, feelings of drowsiness, faintness, cold feelings in arms & legs.	Sodium loss	Increase fluids high in sodium eg. chicken soup, Gatorade* or bouillon
fatigue, muscle weakness, gassy bloated feeling, shortness of breath, decreased sensation in arms & legs.	Potassium loss	Increase foods high in potassium, eg. orange juice, bananas, prunes, apricots & Gatorade*

RECTAL DRAINAGE

The mucous membrane or lining of the bowel secretes mucous to lubricate the food and stool as it passes through the digestive tract. Prior to closure of the ileostomy this mucous from the unused portion of the small bowel (from ileostomy through the pouch to the anus) is watery in consistency and you may have rectal seepage that is hard to control. This is temporary and once the ileostomy is closed the mucous is mixed with stool and is much easier to control.

The treatment for rectal drainage is adequate protection of perianal skin with use of skin barrier, eg. Sween Peri Care* and containment of drainage with mesh panties and liners.

COMPLICATIONS

Report any of the following to your ET Nurse:

1. Excessive and/or persistent stomal bleeding.
2. Swelling or elongation of the stoma.
3. Changes in the color of the stoma.
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 when associated with numbers 3, 4 or 5 above.
3. Nausea/vomiting in combination with 1 or 2 above.
4. Abdominal cramps lasting longer than three to four hours.
5. Distended abdomen.

DISCHARGE PREPARATION:

When you are able to change your appliance with confidence, you are ready for discharge and you will be given:

1. Supplies ordered from a vendor and delivered to you in hospital for review with your ET nurse.
2. Information regarding future supplies, their ordering and cost.
3. Printed guidelines for care of your stoma, diet and sexual concerns.
4. Phone number of ET nurse in case of problems arising.
5. Instructions regarding activities.
6. Instructions to return to your surgeon and ET clinic in two weeks.

SPECIAL REMINDERS

1. Never take a laxative. This is usually given to clean the large bowel - you no longer have a large bowel. 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 or ET nurse.
2. Be aware of what form of medication you are taking as you may need to alter these. For example - 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, ET nurse, or staff nurse, will use a soft catheter, a syringe and small amounts of normal saline to gently wash the blockage out.

DIETARY CONCERNS

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 Aims of Diet

1. Reduce excessive bowel stimulation.
2. Produce 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 as required before your surgery if you were suffering with Inflammatory Bowel Disease, 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 - by this we mean 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 in the future.

The following is a list of foods to be considered when preparing diets for an ileoanal/ileostomy patient.

1. Foods high in roughage may cause blockage, therefore, 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

2. Foods that increase output:

raw fruits/vegetables, chocolate, leafy green vegetables, caffeinated beverages, spicy foods, carbonated beverages

3. Foods that slow output/increase transit time:

bananas, cheese, applesauce, tapioca, smooth peanut butter, boiled rice, marshmallow

4. Foods that may cause skin irritation:

foods with seeds, celery, Chinese/oriental vegetables, coconut, nuts, spicy foods, dried fruits (raisins, figs, etc.), certain raw fruits & vegetables (oranges, apples, coleslaw & corn)

5. 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, remember 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 which 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 visit the ET clinic two weeks after discharge for:

1. Reinforcement of discharge teaching and appliance fitting.
2. Removal of peristomal sutures.
3. Sphincter muscle exercise instruction.

PELVIC EXERCISES - KEGEL'S

The purpose of pelvic exercises is to strengthen the tone of your anal sphincter muscles. These are the muscles that allow you to control your bowel function. Pelvic exercises may be initiated before surgery and resumed several weeks after surgery. During the immediate postoperative phase, up to three weeks after surgery, major tissue repair and healing is occurring. When healing has occurred, you may resume or start the exercises.

The Kegel 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.

IRRIGATION

Most people will never need to use a catheter to empty their reservoir. However, it is sometimes useful to irrigate or wash out the reservoir and your ET nurse will teach you this procedure if necessary.

Prior to takedown of the ileostomy for:

1. Removal of bothersome mucous.
2. Evaluation of continence (the ability to hold stool or gas in the pouch.)
3. Increase the capacity of the pouch.

Following takedown of the ileostomy for:

1. Blockage of reservoir.
2. Numerous small bowel movements due to incomplete emptying of the reservoir.

Procedure

1. A large catheter is introduced into the pouch.
2. Warm tap water is instilled into the pouch.
3. The catheter is removed.
4. Fluid is expelled from the pouch spontaneously.

If a pouch irrigation becomes necessary, your surgeon will ask you to visit your ET nurse for detailed instructions. The entire procedure takes about five to ten minutes and is usually done two to four times daily. As reservoir capacity and function changes you will no longer need to perform irrigations.

STAGE TWO (ILEOSTOMY CLOSURE)

This is the term that refers to your second operation and you will likely be in the hospital for about a week.

Before admission to the hospital, a pouchogram will be ordered by your surgeon.

This is to ensure that the 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.

After admission to hospital you will not require a major bowel prep as you no longer have a large bowel. However, you will be given a clear fluid diet and antibiotics to prevent infection. Your ET nurse will visit and discuss post-op care concerning diet and perianal skin care. She will give you a stool chart to record your bowel movements post-operatively and skin care products with instructions for their use.

Example 1. Sween cream* to sooth red, sore, irritated skin. 2. Sween Peri Care* to provide a barrier between your skin and the frequent passage of stool.

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 pouch, and out through the anus.
3. The former stoma site is closed.

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 except for the wound drain. Following the closure of the ileostomy, passing gas and bowel function begin about the second day and frequent loose bowel movements are to be expected. As diet is advanced, bulk forming agents eg. metamucil* and/or antidiarrheal medications eg. immodium* are given to decrease bowel frequency and to avoid dehydration. You will be asked to keep a Stool Chart to monitor your progress. At first you may have as many as twenty to twenty-four bowel movements a day, but this number will decrease by the time you leave 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 may be severe and there are specific times when you are at greater risks of developing perianal skin irritation or breakdown.

- When mucous is discharged during 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 after each bowel movement.
- Application of occlusive skin barriers eg. Sween Peri Care* or Critic Aid*.

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 following each bowel movement or mucous discharge.
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.
4. Pads or panty liners should be changed frequently to keep skin clean and dry.
5. Cotton underwear rather than nylon or polyester are advised as cotton absorbs perspiration and allows air to circulate.
6. Use of skin barriers is essential to protect perianal skin.
7. Sitz baths are a gentle thorough way to cleanse and soothe irritated skin and may be used after each bowel movement.
8. 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 ET nurse who will reassess the problem and suggest further care.

Pouchitis is an inflammation of the ileoanal reservoir. It occurs in up to thirty percent (30%) of the patients and is generally due to bacterial overgrowth. However, it may be secondary to Crohn's disease or ulcerative colitis occurring in the small bowel (backwash ileitis).

Symptoms:

- rapid onset of frequent bowel movements with watery diarrhea
- urgency or pressure sensation in the pouch
- cramping
- bleeding
- low grade fever
- malaise (general unwell feeling)

Treatment:

- If due to bacterial overgrowth, the treatment is Metronidazole (Flagyl*) and possibly reservoir irrigation.
- If the pouchitis is due to Crohn's disease or backwash ileitis, removal of the pouch may be required.

It is important for you to recognize the difference between the above symptoms and those of simple excess frequency as might occur with gastroenteritis. These features 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

Medic alert bracelet: you would be well advised to wear a bracelet or carry an ID card in your wallet. It should read:

TOTAL COLECTOMY - ILEOANAL 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 bowel eg. 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 which time the pouch increases in capacity. During this time the number of bowel movements per day decreases to about four to six and the stool consistency thickens. You are encouraged not to respond to every urge to evacuate the pouch in order to begin increasing the size of the reservoir and thereby decreasing the number of trips to the bathroom. You can also help with the pouch adaptation by learning to control pouch function with diet and medication if necessary.

You are unlikely to have any major problems with control. However, you may continue to experience some night time seepage or incontinence. This too will pass with time. However for a while 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 two 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 volume 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: eg. 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 rice and rice dishes (eg. rice pudding)
- tapioca pudding
- creamy peanut butter
- applesauce

Foods Which May Contribute To Anal Irritation

- certain raw fruits and vegetables (eg. oranges, apples, coleslaw, celery and corn)
- popcorn
- Chinese/oriental vegetables
- nuts
- coconut
- dried fruits (eg. raisins, figs)
- foods with seeds
- spicy foods

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

As the ileoanal pouch is generally a surgical procedure of young adults the concerns for their sexual health is of prime importance. The removal of the diseased colon quickly restores the feeling of well-being and most people are anxious to resume their previous sexual activity. You may even find your sex life improving 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.

Pregnancy following ileoanal surgery is certainly possible and in fact you may now be more fertile with the elimination of Inflammatory Bowel Disease. Colorectal surgeons generally recommend that your baby be delivered by Caesarean section as this avoids any possibility of injury to the anal muscles during a vaginal delivery.

GLOSSARY

Anal sphincter - the muscles surrounding the anus that are able to contract or close the opening.

Anastomosis - the union of one structure to another.

Anus - the opening at the end of 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, clip, etc.

Blockage - obstruction

Bowel - the intestine; the part of the digestive tract that lies between the stomach and the anus.

Colitis - inflammation of the colon (large bowel).

Colon - the last four to five feet of the digestive tract, also called 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's - alternate contraction and relaxation of the muscles 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.

Mucous - 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, or sac, created from the ileum. Also referred to as Park's Pouch, "J" or "S" 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 - a Greek word meaning mouth which is the opening from the ileostomy.

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.

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