LIVING WITH AN ILEO-ANAL POUCH
(RESTORATIVE PROCTOCELECOLECTOMY)

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PREFACE

When faced with the possibility of an operation for the treatment of bowel disease individuals naturally have many questions and concerns. This booklet was written for the patient to help him/her understand the ileoanal reservoir procedure. This is also commonly known as the “S”, “J” or ileal pouch procedure. Over the past ten years, the ileo-anal reservoir/pouch procedure has become widely accepted as the procedure of choice for certain patients requiring surgical treatment for ulcerative colitis and familial polyposis coli.

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.

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Healthy digestive tract

The digestive tract is a hollow tube which stretches from the mouth to the anus. 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.

From stomach food is passed into the small bowel or small 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 the large bowel or large 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.

Human gastro intestinal system
INTRODUCTION

The ileo-anal 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 the anus, with the formation of an ileostomy. Through the years however, alternatives have been developed. These include total removal of the large bowel and the rectum with immediate restoration of continuity by joining the ileum to the anus or total removal of the large bowel with preservation of the rectum and joining the ileum to rectum or total removal of the large bowel and fashioning a continent ileostomy or a Kock pouch.

In 1978, the late Sir Alan Parks developed the ileoanal pouch procedure which is now known widely as the Park’s pouch, pelvic pouch, or
The ileo-anal reservoir. The ileo-anal reservoir with the “S” or “J” configuration are the most commonly performed.

**INDICATIONS FOR AN ILEOANAL POUCH**

01. **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 diarrhoea with frequency and urgency. Frequency of diarrhoea 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 risk for cancer in the large bowel.

Colon affected by Ulcerative colitis
02. Familial Polyposis Coli (Familial Adenomatous Polyposis, FAP) -

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 the bowel at a very young age.

Polyps of colon seen during a colonoscopy test.

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.

**CONTRAINDICATIONS FOR AN ILEO-ANAL POUCH**

01. 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. However some consider this a relative contraindication and not an absolute contraindication (provided there is no small bowel or anal disease).

02. Anal Incontinence –

Individuals who have serious problems with rectal control are not candidates for this procedure.
03. 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.

04. Obesity – The operative procedure is made more difficult in persons who are grossly over-weight and who have a thick abdominal wall.

**Total Colectomy with Ileoanal Reservoir (Restorative Proctocolectomy)**

The pouch operation called restorative proctocolectomy essentially involves removal of large bowel and rectum and replacement of the rectum with a reservoir made out of the small intestine. This is connected to the anal sphincter muscle which preserve continence. This can be performed in 1, 2 or 3 stages.

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 and the “J” pouch. 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.

Fig:- Different configurations of the pouches

**Stages of the operation**

Surgery for creation of an internal pouch or a reservoir
may be performed in 1, 2 or 3 stages. 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.

- **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 an 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.

- **Two stage procedure**

**First stage (Creation of the pouch)**

First operation comprises of the following steps:

1. Through an incision made on your abdomen, the entire large bowel and the upper rectum are removed (A).

2. Through an incision made on your abdomen, the entire large bowel and the upper rectum are removed (A).
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 (B),

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 (C). 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.

**Connecting the newly created pouch to the rectum**
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 (D).

**Second stage (closure of the ileostomy)**

After approx. eight to twelve weeks, when the pouch is found to be leak proof and healthy, the second operation is performed. The temporary 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.

**One Stage Procedure**

In the 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 low 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.
Preparing for Surgery

Several tests take place to determine your physical readiness for the closure of your ileostomy. First, you will have an X-ray of your new pouch, called a pouch-o-gram, to make sure it is well healed and has no leaks.

The pouch-o-gram is done in the hospital and takes about an hour. After this your doctor will inform you as to whether you are ready for the ileostomy closure.

If you are ready for the closure, you will then undergo your preoperative laboratory tests, which include blood and urine tests, chest X-ray etc. There is no pre-operative bowel preparation required, but you will be instructed not to eat or drink after midnight.

Your job will be to exercise your lungs with the spirometer and to walk as much as possible. Both of these activities will help to maintain your muscles and energy levels, and help prevent complications.

We will usually offer you a clear liquid diet on the second postoperative day. If you tolerate it, you will be
advanced to a regular diet. After five to six days, when you are on a regular diet, you are passing stool and all drains are removed, you will be permitted to go home.

You will be given oral pain medicines to take home. You also may be given Lomotil or Imodium to slow your stool output. If your hemoglobin level is low, you will go home with iron pills.

**POST OPERATIVE PERIOD**

1. **Drain Tubes**

As you awake you will find three more tubes in addition to those previously mentioned (naso-gastric 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. 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 doctor will assess your stoma to make sure it is healthy and correctly fitted with a post-operative appliance.

   - **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 it can cause irritation to the skin.
surrounding the stoma and do create the necessity for good skin care.

CARE OF YOUR ILEOSTOMY

Before you discharge your doctor will give you necessary advices regarding this (please refer to the booklet on ostomy care).

Rectal Drainage

One of the normal functions of the bowel is to produce mucus 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.
DISCHARGE PREPARATION:

The length of surgery varies from patient to patient and is determined by their general condition and how complicated the surgery is.

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

1. Information regarding future supplies
2. Printed guidelines for care of your stoma, diet and sexual concerns (please refer to the booklet on ostomy care).
3. Instructions regarding activities.
4. Instructions when to return to surgery clinic.

❖ 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 preparation, explain to the personnel involved that you will not be following the preparation. If there are any concerns, contact your doctor.

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 your doctor before beginning a new medication.

3. **Do not irrigate** or allow anyone else to irrigate your ileostomy.

**Coping with a leaking ileo-anal pouch**

You may experience this initially, especially during night when you are asleep and relaxed. It may just be the occasional leak and this will improve over a period of time as muscle strength and control improves.

Most pouches do not leak stool, but unfortunately a few people do experience problems. This may be a passive passage during the day or when you are asleep at night.
or more rarely, difficulty in getting to the toilet in time when the pouch is full. This can be a problem as it is both uncomfortable and embarrassing but in most patients it improves with time. There are no ideal answers to a leaking pouch. It is always worth discussing the problem with your doctor.

**Ways of cope with leakage**

- Pads and pants – i.e. wearing a small pad, (sanitary towels are ideal)
- Emptying your pouch before going to bed
- Avoiding alcohol, sedatives, and food before going to bed.
- Avoid foods that loosen your stools.
- If you are prescribed gut slowing down medications like loperamide, take an extra one before going to bed.
- Pelvic floor exercises may help you to improve muscle tone and avoid leakage.
• **Sphincter strengthening exercises**

Sometimes doing some exercises to strengthen the anal sphincter muscles and their speed of reaction can improve your control. These exercises are very similar to pelvic floor exercises, but concentrating on the muscles around the anus. You will need to do a lot of exercises to make a difference. Please ask from your doctor for more information.

• **Controlling or disguising smells**

If you are leaking stool and are worried about others noticing an odour, some of these ideas may be of help:

- Try to ensure good ventilation of the room you are in.
- There are some deodorants specially designed to control smells from faeces

**Skin care**

If you are leaking pouch contents onto your skin, there is a possibility that you will become sore. This is more so than with ordinary stool as pouch contents contain digestive enzymes and can be quite corrosive. The best way to prevent soreness is by cleaning as soon as you can, and meticulous
attention to removing all trace of stool. There are also many different creams that can help with sore skin, or used as a barrier.

**Healthy eating for people with pouches**

One benefit of this operation is that you will be able to return to a regular diet. The otherwise healthy person with a stoma has the same nutritional needs as other patients of the same age and sex. Diet is unique to each person, however following instructions may be useful.

Remember, you are not on a special diet as required before your surgery, 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—specially when you eat food high in fiber.
2. Introduce new foods gradually.
**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.

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

- **Foods that increase pouch output:** raw fruits/vegetables, chocolate, leafy green vegetables, spicy foods, carbonated beverages, wine, beer, caffeinated beverages

- **Foods that decrease output:** bananas, cheese, boiled rice, marshmallow

- **Foods high in roughage may cause blockage** therefore, introduce these foods to your diet gradually: nuts, dried fruits and raw fruit skin, seeds, beans, pineapple, oranges, raw vegetables, Chinese food, salad, mushrooms, tomatoes

- **Foods that may cause anal irritation:** foods with seeds, Chinese/oriental vegetables, coconut, nuts, spicy foods,
dried fruits (raisins, figs, etc.), certain raw fruits & vegetables (oranges, apples), foods with seeds

- **Foods that may cause gas:**
onions, carbonated beverages, cabbage, dairy products, dried beans/peas, cucumbers, milk and milk products, beer.

**DIETARY RECOMMENDATIONS:**

**Introduce new foods gradually** - by this we mean try only one new food at a time. In this way you can identify foods that cause problems. However, that doesn’t mean that you will never be able to eat that food, it only means that you should wait a while before trying that food again in the future.

1. **Avoid ingestion of large amounts of fluid with meals.** Try to drink water after food is swallowed, so that you are not washing down lots of half chewed food.

2. **Drink plenty of fluids (especially between meals)** to decrease risk of dehydration and obstruction of the intestine.

3. **Begin with small meals to avoid feeling bloated and gradually increase the amount you eat at each meal.**

4. **Eat regularly** - don’t skip meals. If you are troubled with a high output (i.e. frequent bowel movements), 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 decrease pouch output/increase transit time.

5. Avoid high fiber foods on an empty stomach which may increase the risk of obstruction of the intestine.

6. If your pouch output becomes so thick that it is difficult to pass, drink plenty of water to avoid or ease this. Also eat food which may increase pouch output.

7. 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.

Many people have not had to make any changes to their eating and drinking habits.

**The New Patient**

After surgery, it is important to take a well balanced diet to help healing and to enable you to regain any weight lost before surgery. It is a good idea to reintroduce food gradually, starting with a light, soft diet which is easy to digest and will not disturb the internal surgical joint (anastomosis) during healing:
Include protein foods such as meat, fish, eggs, cheese and milk to help wound healing.

Eat starchy carbohydrates such as potatoes, and rice to give you energy and to help thicken your pouch output. Build-up or take other supplements as recommended by your dietician.

It takes time for your pouch to adapt and therefore, you may experience loose, frequent stools for several weeks. During this time you may be losing more fluid and salt than is normal and therefore be at risk of developing dehydration. To prevent this, you should increase your fluid and salt intake:

Aim for at least 6 - 8 cups of fluid per day (1'/2 - 2 litres) including, water, tea, coffee.

Add extra salt to your meals. One teaspoon of salt spread evenly throughout the day is adequate.

As your pouch settles, your stool will thicken and become less frequent, but you should continue to ensure that you have an adequate fluid and salt intake.

**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/volume. 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.

POTENTIAL COMPLICATIONS

❖ **Pouchitis** - is an inflammation of the pouch causing some or all of the following symptoms. Many of these symptoms are similar to ulcerative colitis. The cause of pouchitis is not properly understood and is generally due to bacterial overgrowth. Fewer than 20% with pouches are likely to suffer from pouchitis. It is also difficult to predict people who will develop pouchitis.

**Symptoms:**
- rapid onset of frequent bowel movements with watery diarrhoea
- urgency or pressure sensation in the pouch
- cramping pain
- bleeding
• low grade fever
• malaise (feeling of being unwell)

**Treatment:**

Most episodes can easily be treated with metronidazole or ciprofloxacin (antibiotics). Occasionally steroid foam enemas may also be used.

• If due to bacterial overgrowth, the treatment is Metronidazole and possibly reservoir irrigation.

• If the pouchitis is due to Crohn’s disease, 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. If you experience any of those symptoms contact your doctor as soon as possible, so if necessary, treatment can be started immediately.

❖ **Bleeding**

This 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.

❖ **Dehydration**

Dehydration is the loss of too much fluid from the body. It is important that you carefully balance fluid intake so as not to become dehydrated.
When the colon has been removed, less water and electrolytes will be absorbed and more will pass through the body. Gradually, your small intestine will take over more of the function of absorption. You will notice stool thickening as absorption increases.

Loose, liquid stools can be the result of certain foods, viruses, medications or even emotional stress. Dehydration occurs when you have increased stool output and do not adequately replace the lost fluids.

**Signs of dehydration:**
- Feeling thirsty
- Dry skin and/or dry mouth
- Decreased urination and dark-coloured urine
- Feeling lightheaded when sitting or standing

If you are dehydrated, you need to drink extra fluid and replace lost electrolytes, sodium and potassium. Electrolyte drinks, broth and bananas are good sources for replenishment.

**Blockage**

Blockage of the bowels is rare, but does occur. The signs and symptoms of blockage of the intestines include, nausea and vomiting (for more than 24 hours), abdominal cramping, pain, bloating, and decrease in bowel activity.
You will need to stop eating and drinking immediately. Contact your doctor as soon as possible.

**LONG-TERM COMPLICATIONS**

You should not be concerned with long-term complications. As previously mentioned, there is a small risk that the small section of rectum left in place could develop cancer. The ultimate risk is unknown, but it would seem that it would be less than the normal population risks of developing colorectal cancer. Therefore, the risks are small and acceptable.

Nevertheless, you should be checked at regular intervals (every six months to one year or as directed) by your doctors. This would require a brief office visit with a digital examination and examination of the pouch with an endoscope.

**ACTIVITIES**

Activities should be limited. You should not drive a car until you are off of all pain medications and you can move about freely. You should avoid lifting anything
heavy or any other activities that cause you discomfort. Generally, your body will tell you when you are ready to do more. We would hope that after six weeks you will return to normal activities, but many patients find they are able to do most of their activities well in advance of this time.

**DRIVING**

You may travel in a vehicle following your surgery, but do not drive until you are off all pain relieving medication and until you are sure that you can drive safely. In particular, your mobility must have returned to the point where you can hit the brake quickly.

**RETURNING TO WORK**

Most likely, you will be able to return to work approximately six weeks following surgery. If you have a job that does not require a lot of activity or require long
hours, you may find you can return to work as early as three to four weeks following surgery. Overall, let your body be your guide. If you feel worn out or tired, you are doing too much too soon.

**SEXUAL HEALTH**

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. Most people experience temporary loss of sex drive (loss of libido) after operation or illness. Keep in mind that this operation eliminates the need of a permanent ileostomy and therefore the body image problems.

**FERTILITY AND PREGNANCY**

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, transit time of the digestive tract is usually very rapid. For this reason, birth control pills probably will not be completely absorbed and therefore, it is wise to use other methods of contraception.

- Following surgery, in males, there is a very small risk of sexual dysfunction such as impotence or 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.
IMPORTANT THINGS TO REMEMBER!

• This operation is a cure for ulcerative colitis and definitive treatment for familial polyposis coli.

• This operation involves removal of large bowel, rectum & replacement of the rectum with a reservoir made out of the small intestine.

• It avoids the necessity of a permanent stoma and it maintains bowel continence.

• Pouch operation can be performed in 1, 2 or 3 stages.

• It is wise to use other methods of birth control by females other than oral pills.

• Digestion & absorption of nutrients takes place in the small bowel. Therefore removal of the large bowel because of disease, doesn’t change the normal digestive process.

• Most pouches do not leak stool, but unfortunately a few people do experience problems.