PATIENT INFORMATION BOOKLET

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Pouch Surgery

(RESTORATIVE PROCTOCOLECTOMY)

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Contents

Introduction

This booklet has been written for patients with Ulcerative Colitis (UC) and Familial Adenomatous Polyposis (FAP) when their disease process has reached a stage that surgery is necessary.

A medical glossary is included at the back of this booklet to assist your understanding of medical terminology along with a series of frequently asked questions.

This booklet is not intended to be a comprehensive guide; rather it is intended to be used in conjunction with visits/discussion with your healthcare professionals in St Vincent's University Hospital (SVUH).

The Digestive System

The Digestive System is a hollow tube that connects the mouth to the anus. It is responsible for the digestion of food and absorption of nutrients into the body and the passage of waste matter out of the body.

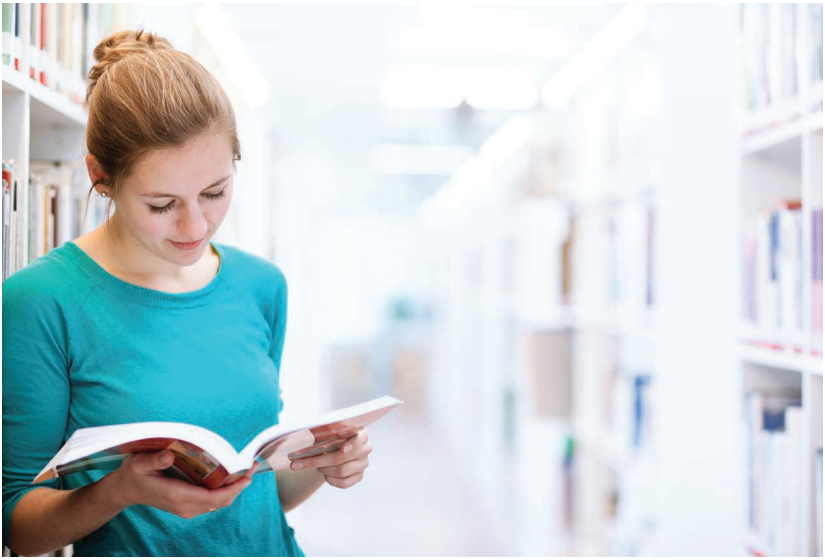
Food that is eaten passes from the mouth through the oesophagus (gullet) and into the stomach. Here it mixes with a number of digestive juices that help break the food into digestible components. It then passes into the small bowel (small intestine). From here essential nutrients are absorbed, and the remainder passes into the large bowel (colon) where water and salt are reabsorbed and waste matter stored. It can then be expelled via the anus when it is convenient for the person to do so.

Ulcerative Colitis

Ulcerative Colitis (UC) is a condition that results in inflammation of the lining of the large bowel. Ulcerative Colitis is characterized by periods of relapse and periods of remission. During a flare the bowel becomes inflamed and ulcerated - which may result in symptoms including, frequent passage of loose stool (diarrhoea), sometimes with blood or mucous, abdominal pain, tiredness and lack of energy. Like other inflammatory bowel conditions the actual cause is unknown - however genetic factors seem to play a role, different races have different incidence rates and clusters can occur in families.

People with Ulcerative Colitis also have an increased risk of developing bowel cancer, which is usually related to the extent and duration of the condition.

what you need to know about UC



Familial Adenomatous Polyposis

Familial Adenomatous Polyposis (FAP) is an inherited condition that may or may not have bowel symptoms. It is diagnosed by colonoscopy when multiple polyps (wart-like protrusions) are seen on the wall of the bowel. This is a pre cancerous condition therefore patients are advised to have surgery. Screening is also advised for all family members where there is a diagnosis of FAP.

There are a number of surgical options that may be available to you. These are;

Panproctocolectomy - this is where the large bowel (colon) is removed with your rectum and back passage (anus). This leaves you with a permanent stoma (ileostomy).

Total Colectomy and Ileorectal anastomosis - this is where the large bowel is removed and the small bowel (ileum) is joined to the remaining rectum. A temporary stoma (ileostomy) may be required.

Restorative proctocolectomy (pouch surgery) is the option discussed in this booklet. This surgery involves removing the diseased colon and rectum and constructing a new rectum (pouch) from a length of small bowel.
The anal sphincter mechanism is left intact to ensure normal continence of waste matter (faeces).

Note: *(It is important to remember that a person can lead a normal life after the large bowel (colon) has been surgically removed.)*

BEFORE
COLECTOMY

STAGE 1:
COLECTOMY AND ILEOSTOMY FORMATION

Stage 1/2/3

The formation of a pouch is usually a three-staged operation over a period of time (in St Vincents University Hospital this is about 12-24 months) but will vary depending on individual cases.

Pouch surgery indicated for FAP often can have stages 1 & 2 completed together.

Stage 1

Total Colectomy and formation of end Ileostomy.
This surgery involves the removal of the diseased large bowel leaving the rectum and anus in place.

The end of the small bowel (Ileum) is brought out on to the abdomen as a temporary end Ileostomy (stoma).

restorative proctocolectomy is usually a three-staged operation

STAGE 2:
FORMATION OF THE POUCH,
TEMPORARY ILEOSTOMY FORMATION

Stage 2

Pouch formation and formation of loop Ileostomy.

This surgery involves the removal of the existing rectum and formation of the new pouch using part of the small bowel (Ileum).

A loop of small bowel is brought out onto the abdomen as a temporary loop Ileostomy (stoma) to divert the contents of the bowel away from the new pouch, which gives it time to heal.

STAGE 3:
CLOSURE OF THE ILEOSTOMY

Stage 3

Closure of loop Ileostomy.

This loop ileostomy will be surgically closed to restore bowel function via the new pouch.

This surgery will be performed 3-4 months after pouch formation if there are no postoperative complications.

Recovery
Following **Stage 1 & 2**

Pouch surgery is a major operation therefore expect to stay in hospital for approximately 7-10 days. After surgery you can expect to feel drowsy and weak for the first few days and you may wake up with one or more of the following;

- **A patient controlled analgesia (PCA) pump. After your operation you will have some discomfort, which will be relieved with medication via the (PCA) pump. You will be instructed how to use the pump following your surgery. Other pain management interventions are also available initially post-surgery.**

- **An intravenous line (drip). As you will not be eating or drinking you will have a drip, this is usually inserted in your arm, to replace your fluids. This will be removed when you are able to drink satisfactorily, usually within the first few days.**

- **A urinary catheter (tube into your bladder), which monitors your urinary output. This is usually removed within 48 hours.**

- **A drain. This is a tube, which allows drainage of fluid from your abdominal cavity following the operation. It is removed when all drainage has diminished usually within 3-5 days.**

- **An abdominal wound. Your wound will be closed with stitches or staples. It will be covered with a dressing. Staples are usually removed at 7-10 days postoperatively.**

the colorectal nurse will ensure you can care for your stoma

- **A stoma (Ileostomy), which will be covered in theatre with a clear plastic drainable appliance (bag). This is to allow the colour and output of your stoma to be observed by nursing/medical staff. Initially your stoma will be a little swollen and red, and the stitches that hold it in place will be visible. These stitches will dissolve within about six weeks and the stoma will reduce in size gradually. For the first few days the nursing staff and the colorectal nurse specialist will tend to the bag and look after your stoma.**

The type of stoma formed will vary in **Stage 1 & Stage 2.** An end-ileostomy is usually formed following **Stage 1**.
A loop ileostomy is formed following **Stage 2** to allow the newly constructed pouch to rest to accommodate appropriate healing.

You may experience a minimal discharge of blood or mucous from the back passage (anus) this is normal and nothing to worry about. When you get the urge to pass from the passage, go and sit on the toilet as normal however do not strain. Maintain anal hygiene to prevent irritation from the discharge.

The colorectal nurse specialist will ensure you can care for your stoma before you are discharged from hospital.

Recovery Following **Stage 3**

Bowel function will usually resume 2-3 days following your ileostomy closure. However initially you will experience a sense of urgency and your bowel movements will be looser, more erratic and more frequent (compared to someone who does not have a pouch) – up to 10-15 times per day and 2-3 times per night. For the first 7-10 days it is advised that you go to the toilet to have your bowels opened as needed. Thereafter try 'putting off' or 'holding on' for a short while and the feeling of urgency should pass and the number of times you need to have your bowel opened should decrease. Your healthcare professional will advise on how long you should maintain this practice.

Stool (Faeces) Consistency

As you return to a normal diet your bowel output should thicken to porridge - like consistency and your bowel control should improve. Pouch functioning may be erratic for an extended period following stage 3. It may take a number of months along with possible diet adaptations/medications to facilitate appropriate management.

It will take approximately 12-18 months for you to adapt to your new pouch. By this time you may have 5-8 bowel movements per 24 hours, which is considered normal. However if you have persistent frequency or loose bowel movements your doctor can recommend/prescribe medications.

Peri-anal Skin Care

Following stage 3 surgery, it is important to take care of your peri-anal area (the skin around your back passage) by washing the area with warm water or non-alcohol baby wipes and patting it dry after each bowel movement. You should also protect this area by applying a barrier cream. Your colorectal nurse specialist will advise you further.

Diet and Health Guidelines

- A balanced diet and eating at regular times is most important.
- Eat small meals and take your time, ensuring that you chew your food well before swallowing it.
- Ensure that you drink 6-8 cups of fluid per day (this does not include alcohol).
  Drink more if you are perspiring heavily e.g. in hot weather or after exercise.
- Minimize the intake of fizzy drinks, as these will increase both wind and loose output.
- Try new foods one at a time and if any food presents a problem then temporarily avoid it. You may want to try and reintroduce it to your diet when your pouch has settled down.

ADVANTAGES AND DISADVANTAGES OF POUCH SURGERY

Advantages include;

- Removal of the diseased bowel.
- Eliminate the risk of bowel cancer.
- Restoration of controlled bowel movements.

Disadvantages include;

- Requires 3 operations over a period of approximately 1-2 years.
- Adaption of pouch can take 12-18 months following stage 3 surgery.
- Increased bowel movements.
- Risk of major / minor complications.
- Possibility of pouch failure and permanent stoma.

Note: *Surgery is only performed if absolutely necessary.*

Small Bowel Obstruction

Small bowel obstruction is unfortunately a common complication following any major surgery and there is an increased incidence with pouch surgery. It may happen at any time and it may recur. As its name suggests it is a blockage in the small bowel. This can occur;

- **When there is formation of internal scar tissue (adhesions), which can cause narrowing of the bowel wall.**
- **If there is a bolus (a soft mass of undigested food) in the small bowel.**

The symptoms include loss of function of the pouch (unable to pass stool/faeces or wind) abdominal swelling and stomach cramps.

Treatment - Most patients need to be admitted to hospital to allow the bowel to rest. This involves fasting, the need for an intravenous line /drip and possibly a naso gastric tube to prevent vomiting. A small percentage of patients need surgery to relieve the blockage.

Pouchitis

Pouchitis refers to inflammation of the pouch. If you develop pouchitis you may experience some or all of the following symptoms:

- **Stomach cramps**
- **Bloating**
- **Diarrhoea (sometimes bloody)**
- **Raised temperature**
- **Generally feeling unwell.**

The cause of this condition is unclear and up to 40% of patients develop it. It may be diagnosed on symptoms alone or your doctor may ask to examine the pouch under anaesthetic and a biopsy of the pouch will be taken to confirm the diagnosis. In this case you will have to be admitted to hospital for a day.

Treatment - Most patients are put on a course of antibiotics and occasionally need to take a course of steroids.

Cuffitis

Cuffitis is an inflammation of the anastomosis (join) between the pouch and the back passage (anus). Symptoms and treatment are the same as those for pouchitis.

Stricture

A stricture is a narrowing of the anastomosis (join) between the pouch and the back passage (anus). Symptoms include;

- **Difficulty in emptying the pouch.**
- **Faecal soiling from the back passage (anus).**
- **Frequent bowel movement.**

Treatment - Your doctor may request to examine the pouch under anaesthetic (see under Pouchitis) and dilate (stretch) the anastomosis. This procedure may have to be repeated, as strictures tend to recur.

Abscess

An abscess (collection of pus) can sometimes develop around the pouch (in the pelvis) after surgery. Symptoms include:

- **Generally feeling unwell**
- **Raised temperature**
- **Pain**

Treatment - Your doctor will request a special Xray (CT scan) to confirm diagnosis. You will be prescribed a course of antibiotics and in some cases you may need to have the pus removed via a tube which is inserted in the Xray Dept. Occasionally some patients require further surgery for this problem.

Pouch Failure

For some patients the above complications do not respond to treatment and after detailed discussion with your doctor it may be decided to remove your pouch, thus leaving you with a permanent end ileostomy (stoma).

Note: *These are the known common pouch complications. Before your operation your doctor will discuss the risks associated with surgery.*

Q. Do I have to follow a special diet?

You must eat a balanced diet at all times. However it is advisable to eat a low fibre diet for the first 2-4 weeks. Finding a diet that suits you will usually take some trial and error and we advise that you introduce a variety of foods one at a time. Patience is needed during this period. Useful hints include;

FOODS THAT INCREASE OUTPUT

- **Beans**
- **Green vegetables**
- **Spicy food**
- **Chocolate**
- **Beer**
- **Fizzy drinks**

FOOD THAT DECREASES OUTPUT

- **Bananas**
- **Rice pasta**
- **Creamy peanut butter**
- **Potatoes**
- **White bread**
- **Cheese**

Further information about diet can be obtained from your colorectal nurse specialist and dietitian.

Q. Will I be able to go on holidays?

Yes, is the simple answer - but you will have to do a bit of extra planning if it is a foreign holiday. It will be necessary to bring a supply of medication with you in case you acquire a 'tummy bug', or develop dehydration or pouchitis. Your GP will prescribe the medication. It is advisable to only drink water from a known safe source - i.e. bottled water that has an unbroken seal. You should also use this water for washing your teeth. Avoid large meals before going on long journeys where toilet facilities may be in short supply.

Q. Will my sex life be affected?

Many people experience a temporary loss of sex drive following illness or surgery. In most cases a normal loving relationship can be resumed however there are risks of temporary or permanent nerve damage with pelvic surgery. Your surgeon and colorectal nurse specialist will discuss these risks with you pre operatively. It is also important to talk to your partner about these issues.

Q. Will I be able to have children?

Yes - a number of women have successfully become pregnant and given birth following pouch surgery. Research shows that the ability to conceive may be affected. Again you will need to discuss this with your surgeon and your obstetrician.

Q. When will I be able to return to work?

This will depend on what sort of work you do. It is best to discuss this with your surgeon and colorectal nurse specialist at your first outpatient's appointment 4-6 weeks post discharge. It may be advisable to return to work on a part time basis until you regain full strength.

Q. Can I return to sport and exercise?

Yes - but it will be necessary to take it easy in the beginning. It may be advisable to seek medical advice before participating in any new sports. Return to swimming when all wounds have healed.

Q. I am a smoker will this affect my recovery?

Yes - most definitely. The adverse effects of smoking on health have been well publicised over the years but it is even more significant for those patients who have undergone major surgery.

Smoking reduces the oxygen carrying capacity of the blood and will increase the risk of developing postoperative chest infections, pneumonia and deep vein thrombosis.

Abscess
A collection of pus.

Adhesions
Internal scar tissue.

Anal sphincter
The muscle around the anus, which controls faecal output.

Anastomosis
Surgically joining two ends of healthy bowel together.

Anus
The external opening of your back passage.

Appliance
An adhesive plastic bag, which is designed to be attached to the abdomen and collect the contents of the bowel.

Barrier Cream
A waterproof cream, which is used to protect the skin.

Bolus
A soft mass of undigested food.

Colorectal Nurse Specialist
A nurse who is qualified in the care of patients who experience problems with their bowel function that may require surgery with the formation of a stoma.

Continence
The ability to control urinary or faecal output.

CT Scan
This stands for 'computerised tomography' which is a specialised Xray examination that produces images of the body in cross sections.

Cuffitis
Inflammation of the join between the newly created rectum or pouch and the opening of the back passage.

Colon
The main part of the large bowel which is approximately 1.5 metres long. Its main function is to reabsorb water and salts.

Colonoscopy
An investigation looking directly at the whole of the large bowel using a long flexible tube (colonoscope).

Colitis
Inflammation of mucous membrane (lining) of the colon.

Dilate
To stretch the anastomosis.

Deep Vein Thrombosis
The formation of blood clots in the deep veins especially of the lower leg or calf. Also referred to as DVTs.

Dysplasia
Abnormal development of cells.

Exacerbation
An increase in the severity of the symptoms of a disease - also known as a 'flare up' of the condition.

Faeces
This is your bowel output, which can also be referred to as motions, stool, waste products.

Familial Adenomatous Polyposis (FAP)
This is an inherited condition that may or may not have bowel symptoms. It is diagnosed when multiple polyps are detected in the large bowel following a colonoscopy.

Ileostomy
A surgically created opening where an end or a loop of small bowel (ileum) is brought out onto the surface of the body and fashioned into a spout (stoma).

Inflamed
A series of changes in body tissue, which is characterised by heat, swelling, pain and redness.

Intravenous Line
It is a tube, which is inserted into a vein to allow the replacement of fluids.

Inflammatory Bowel Disease (IBD)
It is the name used for a group of disordes which causes inflammation of the intestine. It is the term used for the conditions known as Crohn's disease and Ucerative Colitis & Indeterminate Colitis.

Mucous
A jelly like substance secreted from a mucous membrane (lining).

Nausea
A feeling of sickness, which may result in vomiting.

Oesophagus
The narrow tube connecting your mouth to your stomach.

PCA Pump
This is also known as a pump for patient controlled analgesia. It allows the patient to administer a controlled dose of pain relief during their postoperative recovery via an intravenous pump system.

Pelvis
Lower abdominal cavity between the hip bones.

Peri-anal Area
Area around your back passage.

Pouchitis
Inflammation of the pouch characterised by abdominal cramps, bloating, diarrhoea, temperature and feeling generally unwell.

Polyp
A small growth arising from a mucous membrane (lining).

Rectum
The lower part of the large bowel just inside the back passage. Its main function is to store faeces.

Remission
A decrease in the severity of the symptoms of a disease for a period of time.

Restorative Proctocolectomy
The surgical removal of the colon and rectum and formation of a new rectum or pouch from the remaining small bowel.

Small Bowel
Also known as the intestine, which is made of duodenum, jejunum and ileum. Its main function is to digest and absorb food.

Small Intestine
See small bowel.

Small Bowel Obstruction
This is a blockage of the small bowel, which interferes with normal bowel function.

Stoma
A surgically created opening where the bowel is brought onto the surface of the body to which a bag is attached to collect the contents of the bowel.

Staples
A form of surgical wound closures made from metal used in place of stitches. Also known as clips.

Stool
See Faeces.

Stricture
A narrowing.

Total Colectomy
The surgical removal of the colon.

Ulcerated
An erosion of mucous membrane (lining).

Ulcerative Colitis
A disease in the lining of the large bowel only. The bowel becomes inflamed and ulcerated, leading to diarrhoea, blood and mucous, abdominal pain, tiredness and lack of energy.

Urinary Catheter
A tube, which is inserted into your bladder to allow the free passage of urine out of the body. It is attached to a collection bag.

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