

Ulcerative Colitis: A Surgical Guide for Patients

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Most patients today want to know a lot more about their disease than used to be the case. This is especially so when there is the possibility of an operation. In the case of diseases of the bowel, surgery may sometimes involve the patient having to have the end of the intestine brought out onto the front of the abdomen. The medical term for this is a stoma, from the Greek meaning 'a mouth'. Where the stoma is formed from the large bowel, or colon, it is called a colostomy. Where it is formed from the small bowel, or ileum, it is called an ileostomy. Developments in surgery over the last twenty years have made it possible in suitable cases to avoid a permanent stoma. This applies to the diseases of ulcerative colitis, familial adenomatous polyposis ("polyposis") and occasional cases of constipation. It applies less to Crohn's disease.

Today the patient's wishes are taken much more into consideration than used to be the case, because in certain circumstances the choice of operation is up to him or her.

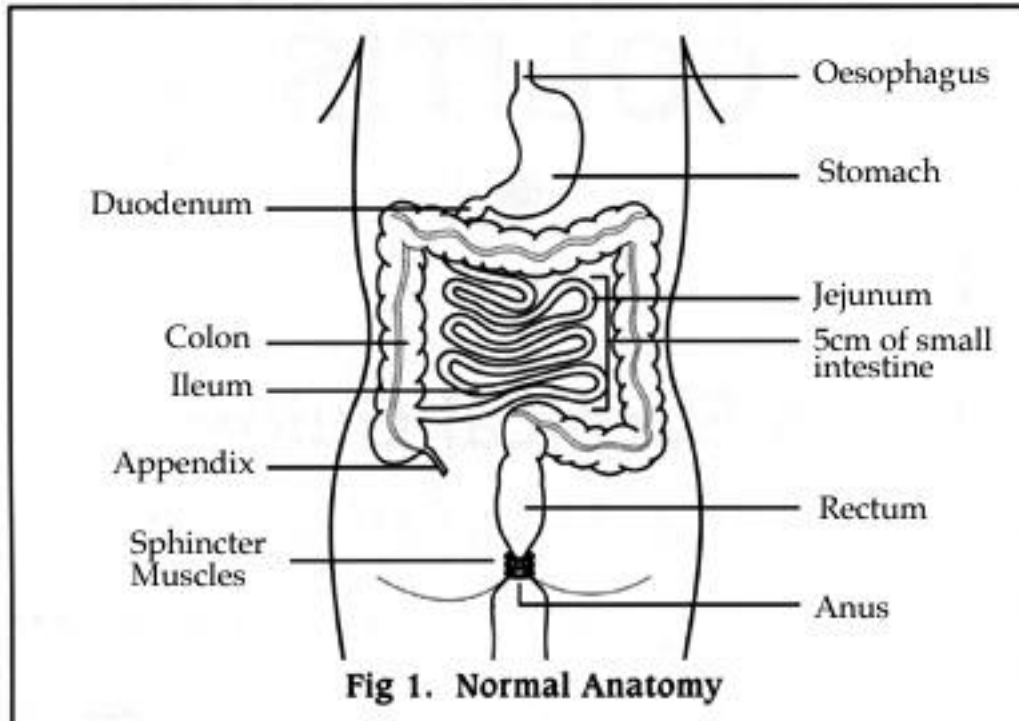
You cannot appreciate the various possible operations without knowing something about how the diseases behave (pathology) and the structure of the intestines (anatomy). It also helps if you know the meaning of some of the medical terms used and these will be defined.

Anatomy

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The intestine, or alimentary tract, starts at the mouth and ends at the anus. Food enters the mouth and after being chewed it is swallowed straight down the gullet (oesophagus) and goes into the stomach. It stays there for some time where it is liquefied by digestive juices (including acid) produced by the lining of the stomach, and then it is slowly released into the next part of the intestine called the duodenum. Here more digestive juices, including bile from the liver and pancreatic juice from the pancreas, continue the process of digestion. After the duodenum comes the small intestine. This is about five metres long. In its upper half (jejunum) more juices are released to complete digestion. In the lower half (ileum) the minute particles of digested food are absorbed into the blood stream to give nutrition to the whole body.

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After the goodness has been removed from the digested food there is a certain amount of waste matter and this passes on to the next part of the intestine called the colon. The colon absorbs water from the waste to convert it into the solid stools that we are familiar with. These are called faeces (pronounced feeseas). The faeces pass from the colon to the rectum which is the last part of the bowel and acts as a reservoir. Here they are stored until a convenient moment when they are excreted in the lavatory (defaecation).

Faeces in the rectum would leak out of the anus causing incontinence if it were not for the presence of the anal sphincter muscle. This surrounds the anus and keeps it shut both day and night except during defaecation when it relaxes to allow the faeces to pass out of the body.

The alimentary tract is lined by a sort of skin called mucous membrane (mucosa). Depending on the particular part of the intestine, it can secrete juices, absorb food particles and produce mucus or slime which acts as a lubricant.

You can see that the alimentary tract is rather like a production line where food is processed as it goes along it (digestion) and the goodness extracted into the blood stream (absorption). The waste products (faeces) which are left are then passed on to be excreted through the anus (defaecation). It is important to have an understanding of the anatomy of the alimentary tract as it will help you appreciate your diagnosis, proposed operation and implications for that operation.

Ulcerative Colitis

The word 'ulcerative' refers to the fact that the lining (mucosa) of the bowel breaks down in places leaving raw areas or ulcers. The word 'colitis' means inflammation of the colon (itis = inflammation). The cause of ulcerative colitis is unknown.

The disease affects the mucosa of the large bowel. The mucosa becomes inflamed and bleeds. More mucus (slime) than usual is produced because it is irritated and the irritation leads to the bowel acting more often. Diarrhoea is noticed by the patient as frequency (going to the toilet more often than normal) and urgency (having to rush to the toilet because of the urge to go). The faeces are also liquid. Ulceration results in bleeding.

The inflammation in ulcerative colitis affects the large bowel only. The small bowel does not become diseased. The inflammation starts in the lowest part of the rectum and spreads upwards.

In most people only the rectum and the last part of the colon are involved. These are able to be treated successfully by medical means. In some (approximately 20-30%) the inflammation extends from the rectum into all or almost all of the colon. In a proportion of cases with this extensive disease medical treatment may not be adequate to control the disease and it is here that surgery will be needed.

Choice of operation can be made in discussion with your Consultant Surgeon, but will depend on your disease and to some extent your choice.

Reasons For Surgery

Extensive disease can have several effects on the patient. Each of them can be a reason for surgery.

Acute Colitis

Occasionally the inflammation may be so aggressive with such severe diarrhoea and blood that the patient becomes very ill. This has three main effects. First there is protein loss in the diarrhoea causing malnutrition which, aggravated by the loss of appetite, leads to a loss of weight and wasting of muscles. Secondly the diarrhoea also results in loss of water and salt from the body which causes it

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to dry up and reduces the blood circulation to the tissues. Thirdly germs from the diseased bowel can enter the blood stream, something which does not happen to any important degree in healthy people. This leads to the body becoming toxic with fever.

The patient will have to come into hospital straight away and if medical treatment does not produce a rapid improvement removal of the colon is necessary.

Chronic Colitis

More commonly, the inflammation remains at a less intense level, tending to smoulder on. Medical treatment often successfully controls the activity of the disease. In some cases however, it gradually becomes apparent that treatment is not working, at which point surgery may be considered. This decision can usually be taken in the outpatient department.

General ill health

While the diarrhoea may not be very bad, the inflammation causes weakness and tiredness. The patient may feel 'one degree under' and often has a low blood count (anaemia). These symptoms may prevent the patient from doing his or her work properly and from leading a normal life in general. In children chronic colitis can result in poor growth and delayed sexual development. Chronic colitis can flare up into an acute attack.

Severe symptoms

Life may become very difficult just because of the need to always rush to the lavatory. General health may be perfectly satisfactory but having to go to the toilet every few hours during the daytime and at night can be severely disruptive.

Involvement of other organs

Sometimes in extensive ulcerative colitis other organs can develop problems. These include the joints, skin, eyes and liver. Joint disturbances (arthritis) are the most common and there are two types. The first (ankylosing spondylitis) unfortunately does not go away when the bowel inflammation is dealt with. The second, on the other hand, is related to the activity of the colitis. Thus it will settle as the bowel inflammation responds to treatment. Sometimes surgery may be advised when medical treatment fails to control such a disorder.

Large Bowel Cancer

The first thing to emphasise is that cancer is rare. However, it is a risk that has to be taken seriously but with regular supervision by the doctor, action can be taken before cancer develops.

The medical facts are as follows. Cancer is a risk only in patients with extensive disease. There is no increased risk in the first eight years after the start of the disease. Every year after that about 1% of patients will develop it so that at about 20 years after the illness started about 10% of patients will be affected.

It is now possible to examine the whole large bowel with a lighted instrument (colonoscope). This has enabled a very accurate assessment of the state of the mucosa. Biopsies (tissue samples) can be taken from any area of mucosa and these can then be examined under the microscope. Changes suggesting that cancer may be imminent can be seen by the pathologist.

Thus it is now possible in some cases to anticipate the development of cancer and therefore to enable action to be taken before it actually occurs. The action is surgery to remove the large bowel.

Crohn's Disease

The behaviour of Crohn's disease differs from ulcerative colitis. This means that the possible operations are somewhat different. In particular pouch procedures are not advisable for all cases. Patients will be assessed on an individual basis.

Crohn's disease is an inflammation of the intestine and like ulcerative colitis, we do not know the cause. Unlike ulcerative colitis it can affect any part of the intestine, not just the large bowel. It is therefore quite possible for the small bowel to be involved. The inflammation in Crohn's disease is not just limited to the mucosal lining of the intestine, it goes all the way through the bowel wall. This is particularly important in the anal region where penetration of the bowel wall by the inflammatory process can lead to abscesses. When anal abscesses are present, the anal sphincter muscle may not work properly to maintain continence of faeces.

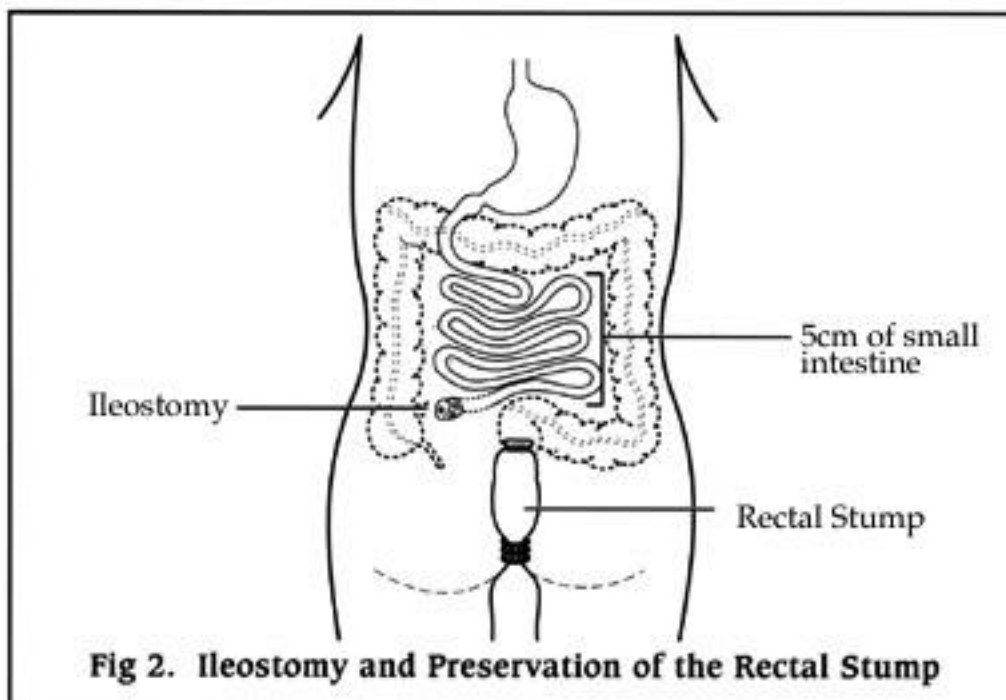
Choice of Operation

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Acute Colitis

When somebody is so ill with acute colitis that an operation is needed, the aim of the operation must be to get the person better with the least procedure possible.

The operation used generally today is shown in Figure 2. It involves removing the colon, giving the patient an ileostomy, but leaving the rectum and anus behind. By this means the majority of the inflammation is removed leading to recovery of the patient. Depending on how severely diseased the rectum is, the surgeon will decide whether to sew it up and leave it inside or whether to bring it out onto the front of the abdomen as another stoma. When this operation is done, the stoma is referred to as a mucous fistula.



By leaving the rectum behind, all possibilities are still open to the patient. When recovery has occurred it will then be possible to decide whether the bowel can be joined up or not, thus getting rid of the ileostomy. Recovery means return to normal health and energy without medication. The patient will regain self confidence and will have had the opportunity to experience life with an ileostomy. Any subsequent decision then can wait several months to allow for full recovery

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of the general health of the patient. This operation is known as colectomy with ileostomy and preservation of the rectal stump.

Chronic Colitis

The same operation might also be advised for a patient with chronic colitis who is on high doses of steroids. With recovery the steroids can be stopped and any subsequent operation can be carried out with the patient in the fittest possible condition. The operations available are almost identical to those for patients with chronic colitis who still have an intact large bowel.

For these patients there are three possibilities. In the first all the large bowel including colon, rectum and anus is removed. Since the anal sphincter muscle is also removed, the patient will be left with a permanent ileostomy. This operation, is called **proctocolectomy with permanent ileostomy**.

The other two possibilities aim to avoid a permanent ileostomy. In the first, the colon is removed and a surgical join (anastomosis) made between the last part of the small bowel (ileum) and the rectum. This is called **colectomy with ileo-rectal anastomosis**.

Alternatively, the colon and rectum can be removed down to the level of the anal sphincter which is left behind. The small bowel (ileum) is then joined to the anal sphincter. This operation is combined with making a reservoir or 'pouch' from the last part (40-50cm) of the small bowel. It is **called restorative proctocolectomy with ileal reservoir** or the '**ileo-anal pouch operation**'. The reason for making a pouch is to create a 'new' rectum which will allow faeces to be stored until it is convenient for the patient to go to the lavatory. The small bowel is about 500cm long so the 40-50cm for a pouch is only a small fraction of the total length.

Proctocolectomy with Permanent Ileostomy

This operation was the first successful procedure to be used for ulcerative colitis. It was introduced about 50 years ago, but only became routine in the 1950s with advances in the technique of ileostomy construction.

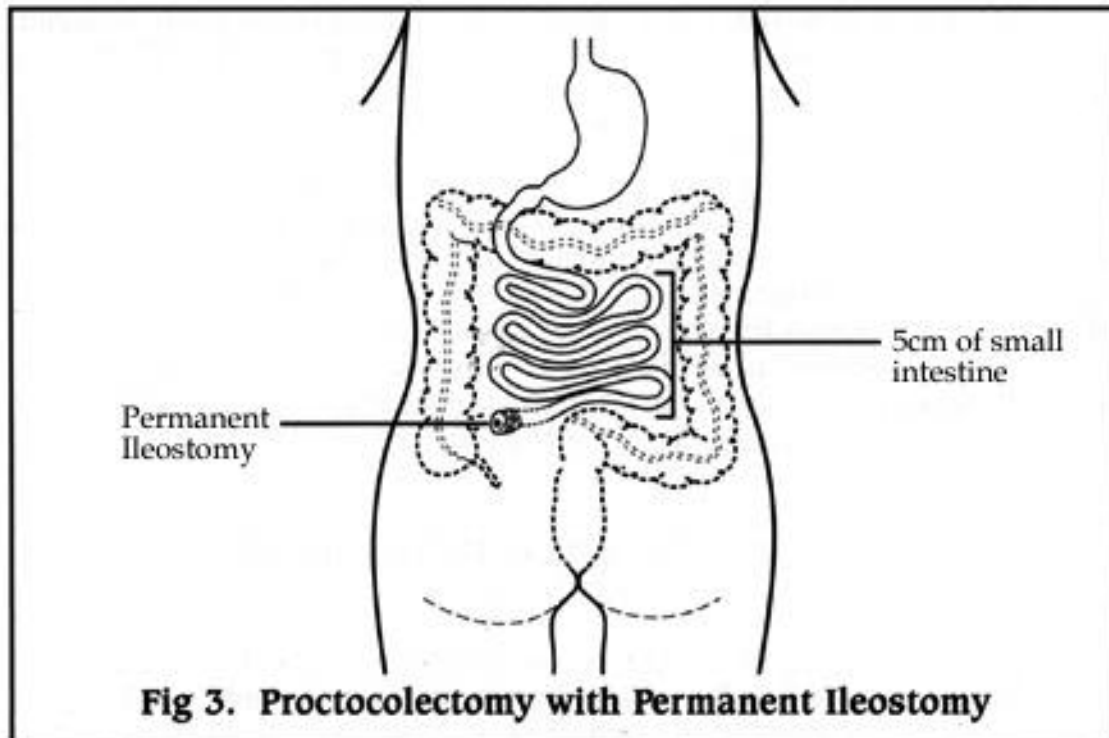
Indications

By removing all the large bowel including colon, rectum and anus, ulcerative colitis is eradicated. The patient is however left with a permanent ileostomy and a wound where the anus used to be (the penneal wound).

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Technique

The operation starts with the abdominal incision. The colon and the rectum as far down as possible are freed. The anus and the lowest part of the rectum are freed at the same time by a second surgeon working from below and the whole large bowel is removed and sent for examination under the microscope by the pathologist. The ileostomy is made to create a spout which projects about 2.5cms from the surface of the skin and the abdominal and anal wounds are sewn up.



The average stay in hospital is about two weeks. During this time the patient will be instructed in the care of the ileostomy and he or she must be confident in its management prior to discharge home. About two months convalescence at home may be necessary. After recovery no further operation should be needed and the operation is therefore a 'one-stage procedure'.

No surgical procedure is free of complications. In the case of proctocolectomy with permanent ileostomy there are three main problems that can occur. The first is blockage of the intestine due to kinking. After any bowel operation, the surface of the intestine left behind becomes tacky and sticks to itself and other structures by tissue referred to as adhesions. If the adhesions cause twisting or kinking of the intestine, then the channel down the middle can become narrowed, causing a blockage. This occurs in about 10% of cases. It may settle on its own after a few days. If it does not, an abdominal operation to unkink the

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point of blockage may be necessary. Adhesion obstruction is most likely soon after the colitis operation, but can occur at any time in the future.

Secondly, there may be a delay in the healing of the perineal wound. This occurs in 20-40% of cases and it can take months in some cases for the wound to heal finally. While not serious it is an irksome complication, requiring regular dressings until it has healed.

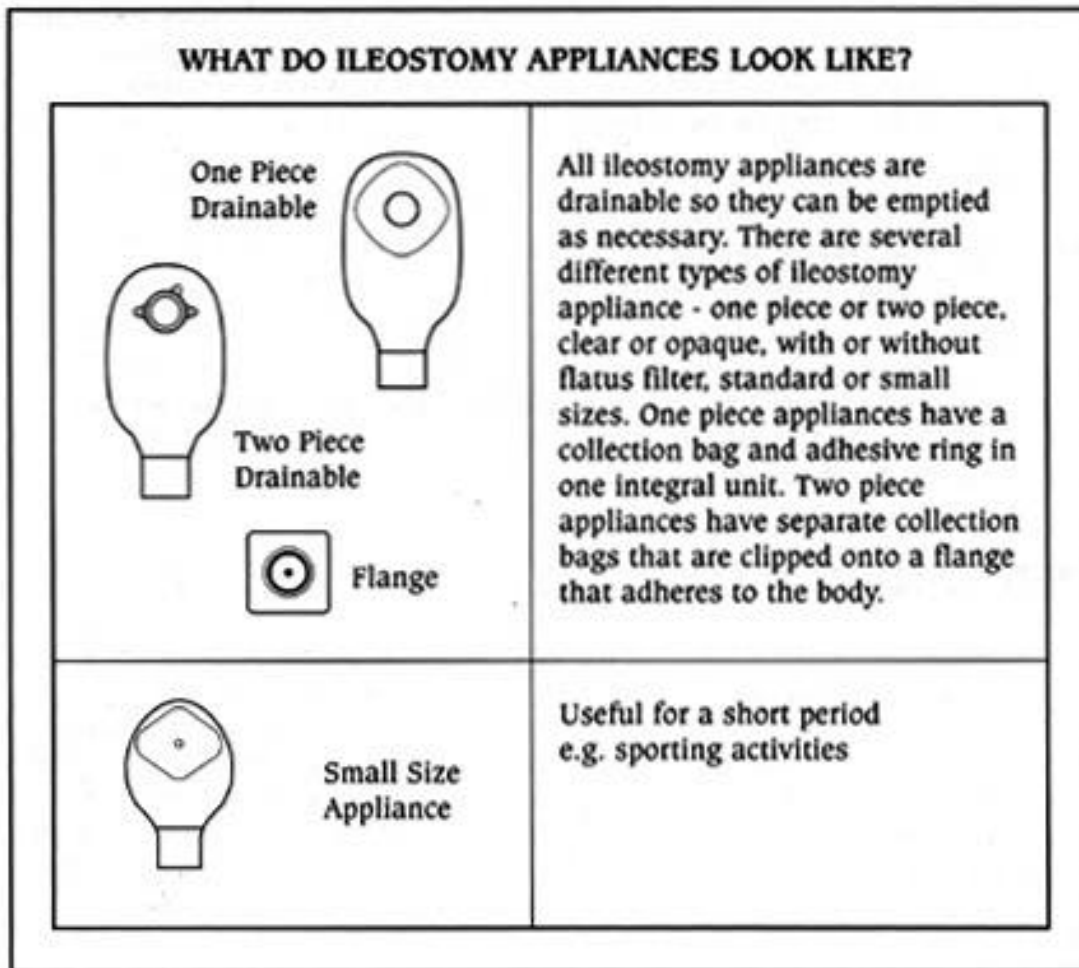
Thirdly, complications of the ileostomy can occur. It can narrow down (stenose), fall back (retract), come out too far (prolapse) or develop a rupture (hernia). Over a five year period from the operation there is about a 20-30% chance of having to have another operation, usually minor, to deal with an ileostomy complication.

Permanent Ileostomy

The ileostomy is usually sited on the right side of the lower abdomen. It is always pink in colour and at times can be seen to pulsate following the natural movement of the intestine. There is no control over the evacuation of the bowel and therefore the faeces need to be collected into an appliance. The appliance adheres to the skin and should fit snugly around the ileostomy. The adhesive of the appliance also provides skin protection from the waste excreted. The Stoma Care Nurse in the hospital will assist in the choice of a suitable appliance as there are several types manufactured.

With a well-constructed and well-sited ileostomy, looking after it should be relatively trouble-free. All ileostomy appliances have a clip at the bottom which allows emptying without having to change the whole appliance each time. The number of times it is necessary to empty varies from person to person, but should be about 4-5 times per 24 hours. Again the Stoma Care Nurse will assist in the learning of skills to empty and change the appliance ensuring feeling of confidence in the practical aspects of ileostomy care, prior to discharge home. Appliances are available on prescription via the General Practitioner and ileostomists are exempt from paying any prescription charges (please ask the Stoma Care Nurse for the appropriate form). Appliances can be obtained from the local chemist or alternatively, home delivery can be arranged by the Stoma Care Nurse (via a separate company).

The Stoma Care Nurse will be able to guide and support in ileostomy management and also to answer any queries. Having an ileostomy should not preclude anyone from any activities previously enjoyed.



The Kock Ileostomy

A conventional ileostomy produces faeces without control and is therefore acting most of the time. For this reason an appliance has to be worn constantly. The Kock ileostomy aims to produce an ileostomy which is continent until such time as the person wishes to empty it. Therefore, it is not necessary to wear an appliance.

Indications

For those patients who have had their anal sphincters removed or have too poor anal muscle tone to have an ileo-anal pouch, the Kock ileostomy provides an alternative to a conventional ileostomy.

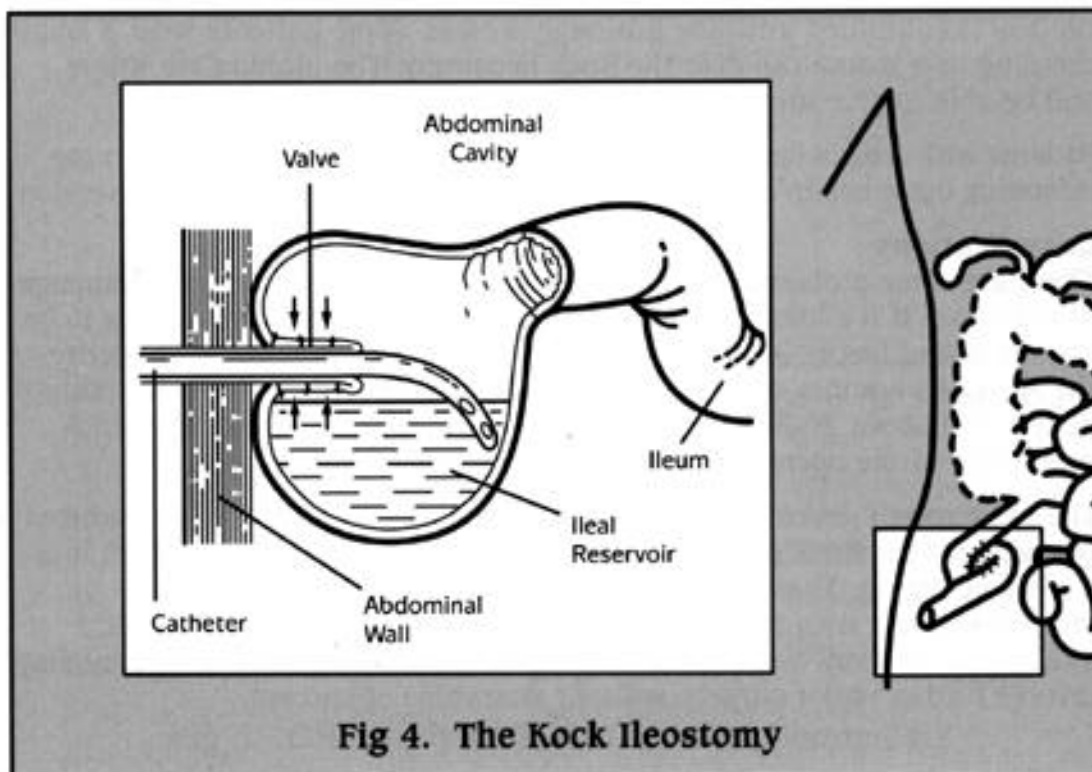
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Technique

The abdomen is opened and the large bowel is removed as for a proctocolectomy. The last 45cm of small intestine are used to construct the reservoir. The end piece of the intestine is pulled back into the reservoir to make a valve. A flush ileostomy is made from the small intestine leading away from the pouch and the valve. When the pressure in the reservoir builds up as it fills with faeces, the valve is squeezed shut and faeces cannot escape. A special tube (catheter) is inserted into the pouch and sometimes secured to the skin with a stitch before closure of the abdominal wound.

The post-operative period

As soon as the bowels start working again, as shown by the production of flatus (wind) and, eventually, the appearance of faeces from the catheter, the patient may start drinking and eating. Once bowel activity returns, the faeces drains out of the pouch, through the catheter that was inserted during the operation. The catheter remains in the pouch for four to six weeks from the operation to allow the valve to heal.



To ease the management of this it is recommended that an ileostomy appliance is initially worn to collect the faeces. Prior to discharge from hospital the Stoma Care Nurse will teach on how to manage the practical

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aspects of Kock pouch care including cleaning and changing the ileostomy appliance and irrigation of the pouch (see below). This is necessary as the catheter may block with faeces and it is important that the faeces are able to flow freely so as not to put the pouch under any pressure. Patients can usually leave hospital after two weeks and will therefore need to manage the catheter at home for a further two to four weeks.

At home

A low residue diet is advised. Foods that are hard to chew and hard to digest may not easily pass through the catheter. The hospital dietician will be able to advise on dietary needs.

At the follow-up out-patient appointment, the catheter is removed, rinsed and reinserted by the surgeon or Stoma Care Nurse. This enables the surgeon or nurse to teach how the catheter should be inserted.

When the reservoir is full, the sensation felt by the patient is of an abdominal fullness. To empty, the person inserts the catheter through the ileostomy into the reservoir and drains off the contents into the lavatory. This is usually necessary about three to five times per day.

If the stool is especially thick then irrigation may be necessary to ensure complete emptying. This is done by inserting the catheter into the reservoir and, with the aid of a syringe, instil tap water into the reservoir. The process is continued until the drainage is clear. Some patients wear a small dressing or a stoma cap over the Kock ileostomy. The Stoma Care Nurse will be able to give instructions in carrying out this procedure.

Patients with a Kock ileostomy are strongly advised to wear a medialert tag informing other health care professionals that they have a continent diversion.

Complications

There are some problems with the operation. The most common is slippage of the valve. If it slides out of the reservoir then the ileostomy ceases to be continent and faeces leaks out. An appliance is then necessary. To rectify the situation another operation will be required to replace the valve. This happens in about 20-30% of cases, but is less frequent as the surgeon's experience of the operation increases.

The more recent development of the ileo-anal pouch operation has reduced the need for the Kock ileostomy, but there are still instances in which it is a suitable option. These mostly include patients who have had a proctocolectomy with

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permanent ileostomy who wish to improve their quality of life. They must appreciate, however, that the Kock ileostomy may involve further major surgery without guarantee of success.

Colectomy with Ileo-Rectal Anastomosis

This operation began to be used in the early 1950s as a means of avoiding a permanent ileostomy. At first it was not generally accepted because it did not remove all the disease since the rectum was left behind. However it is now felt that the operation does have a place in particular cases.

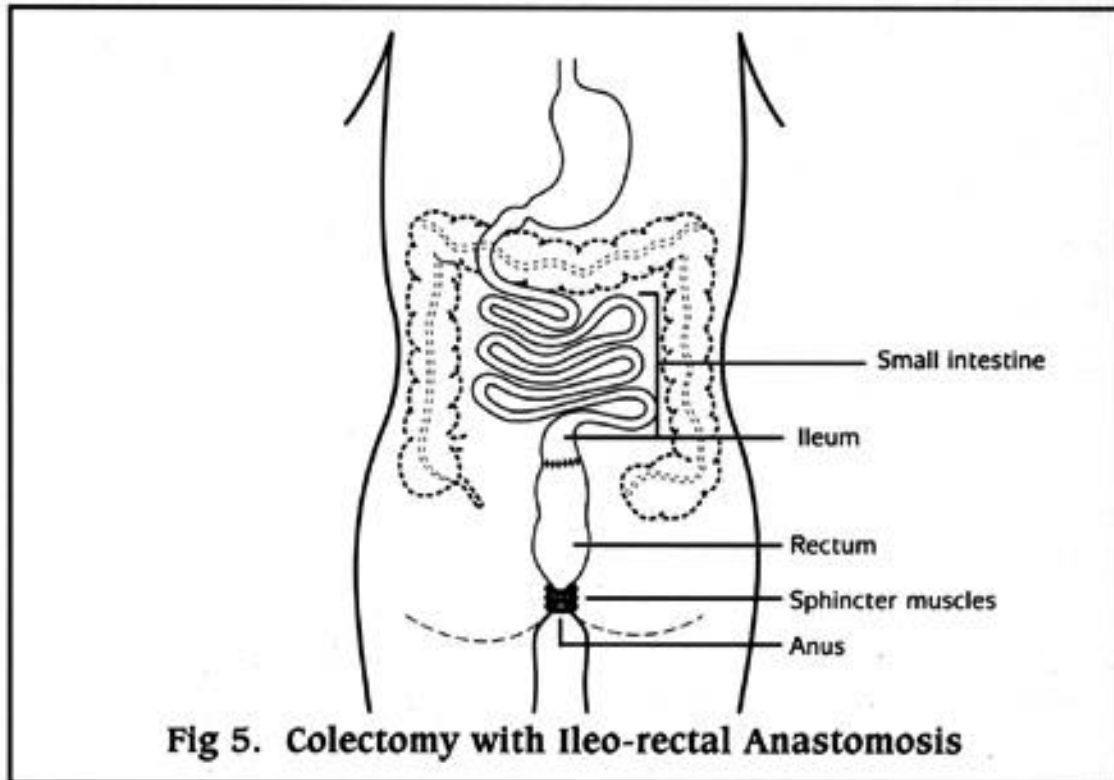
Indications

Only a minority of patients with ulcerative colitis are suitable for this procedure. They should have a rectum which the surgeon thinks will function adequately as a reservoir after the operation. It should therefore not be too inflamed and narrowed down by the effects of the disease. The anal sphincter must be adequately strong and there should be no suggestion of impending or actual cancer.

Technique

The procedure involves removal of the colon through an abdominal incision with the immediate joining (anastomosis) of the last part of the small bowel (ileum) to the rectum with stitches. No surgery on the anal area is carried out.

Hospital stay is about 6-8 days and convalescence is usually about two months. As with any bowel operation, adhesion obstruction is a possible complication and rarely a leak from the anastomosis occurs. This latter complication is serious and usually requires another operation, often including a temporary ileostomy.



Results

Although every effort is made in selecting patients there is almost always some degree of inflammation still present in the rectum. Even after recovery from the operation this can flare up causing diarrhoea with urgency. There is still also the risk of cancer developing in the rectal stump, although it is rare. However, because of this regular follow-up checks are obligatory. This will involve examination of the rectum by a sigmoidoscope, taking a biopsy at the same time for the pathologist to look at.

Followed over several years, persisting rectal inflammation leads to failure owing to uncontrollable diarrhoea in about 25% of cases. A few more cases fail because of the development of impending cancer. Thus about two thirds of patients are well served by the operation. Failure means the need for a further operation. This could be either removal of the rectum with a permanent ileostomy or a 'pouch procedure'. Colectomy with ileo-rectal anastomosis is therefore a compromise operation. The surgeon accepts that some disease remains in exchange for avoiding a permanent ileostomy.

Restorative Proctocolectomy with Ileal Reservoir - The 'Pouch' Procedure

This operation has been in use for over twenty years and there is now considerable experience from surgical departments in several countries. Its aim is to achieve the best of both worlds; first to avoid a permanent ileostomy (in contrast with proctocolectomy and permanent ileostomy) and secondly to remove all the diseased bowel (in contrast with colectomy with ileo-rectal anastomosis).

The operation is more involved than the other two and is done in two stages by most surgeons. These include the pouch operation itself with a temporary ileostomy to allow healing of the surgical joins, and then after a few months closure of the ileostomy. The first procedure is major and the second is much less difficult being an intermediate operation. The treatment time is therefore longer than proctocolectomy with permanent ileostomy since an interval of two months between the two operations is required. Some surgeons do not feel that the temporary ileostomy is necessary. Most however do, since they regard a temporary stoma as the safer option.

Indications

The only reason for doing the operation is to avoid a permanent ileostomy in cases not suitable for colectomy with ileo-rectal anastomosis. It is therefore an alternative to proctocolectomy with permanent ileostomy and not to colectomy with ileo-rectal anastomosis. Many patients will see this as something really worth achieving but others may not. The decision is therefore to a large extent up to the patient. It can only be made by them having enough information on the pros and cons of the procedure. The operation is equally possible for patients who have had no operation before or for those who have already had a colectomy with ileostomy and preservation of the rectal stump or colectomy with ileo-rectal anastomosis where this has not been successful.

To be eligible from the medical point of view the disease should be ulcerative colitis and not Crohn's disease. The other main criterion for successful pouch surgery is that of adequate anal sphincter control. If there is any doubt of the latter the surgeon will request special tests that will investigate the strength of the anal sphincter (physiology).

Anyone who is acutely ill or on high doses of steroids should have a colectomy with ileostomy and preservation of the rectal stump as a first operation. When they have recovered, a pouch procedure can be considered at about six months later.

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Practical Management:

Before the operation

On admission to hospital, members of the nursing and medical team will be available to help minimise anxieties and to answer any questions.

Convalescence will be discussed and the social worker will be available to sort out financial worries, or problems concerning the care of small children. The physiotherapist will visit to teach deep breathing exercises and to encourage mobility after the operation. The physiotherapist may also instruct in pelvic floor exercises. The Pouch/Stoma Care Nurse will visit to give all the information required and also to mark the site of the temporary ileostomy on the abdomen.

The management of a temporary ileostomy is sometimes a little more difficult than a permanent one. Therefore, if a permanent stoma is required in the future, any expectations should not be based on the experience of the management of a temporary loop ileostomy.

Technique

Stage 1 (The Pouch Operation)

The abdomen is opened and the colon and rectum are freed just as with an ordinary proctocolectomy. However, the operation then differs. The bowel is cut across just above the anal sphincter. The colon and entire rectum are removed and sent for analysis leaving the small bowel and anus still in place. The next stage involves joining the end of the small bowel to the anus, after making a reservoir of the last 15-40 cm or so of the small bowel. This is done by folding it onto itself and then joining the folds together with stitches to form a bag-like structure.

There are two ways to join the reservoir to the anus (ileo-anal anastomosis). In the first, the reservoir is joined to the anus by putting stitches up through the anus. Immediately before making the anastomosis, the surgeon removes the mucosa lining the upper part of the anal sphincter with scissors so that all the inflamed tissue has been excised. In the second the ileal reservoir is joined using mechanical sutures (staples) by an instrument called the stapler. With this the mucosa in the anal canal is not removed. Whatever the technique used, it is important to join the pouch to the anal canal. If any rectum is left behind, the patient is likely to have difficulty with pouch function.

The reservoir and ileo-anal anastomosis require a lot of stitches and most surgeons will perform a temporary ileostomy. By being diverted into the ileostomy appliance, the faeces do not come into contact with the stitches during the healing period after the operation. In patients who have not had an operation before, the ileostomy is usually placed just below and to the right of the umbilicus

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(navel). In patients who have had an ileostomy before the same position on the abdomen will be used unless the original ileostomy site was troublesome.

The post-operative period

If all goes well the temporary ileostomy should start to work in a few days and the wounds should heal satisfactorily. When this occurs drinking and then eating can be resumed and the intravenous drip taken down. All patients have a catheter in the bladder for a few days. There is often a discharge of blood and mucus from the back passage which is usually nothing to worry about. It tends to stop within a few weeks but can cause soreness of the skin around the anus. Washing and drying the anal skin thoroughly and the use of barrier creams help to minimise this problem. The sensation of wanting to defaecate can be relieved by sitting on the lavatory allowing mucus from the pouch to be expelled, although straining should be avoided.

At first the faeces from the ileostomy will be watery, but with normal eating they will become thicker. A loop ileostomy has a higher output and remains more fluid in consistency than a permanent ileostomy and sometimes Loperamide (Imodium) or codeine phosphate will be needed to reduce output. The ileostomy will usually have a rod or bridge to support the stoma and this is removed between the third to fifth day after the operation. At first the ileostomy will be swollen, but it will usually shrink over the next few weeks. As with any stoma the Stoma Care Nurse will be available to assist with the practical aspects of stoma care, and to provide support and advice for any concerns or worries both during the hospital stay and also once returned home.

Discharge from hospital will happen once mobility and healthy eating and drinking are resumed, and confident and independent ileostomy management is achieved. This is usually 8-14 days after the operation provided there are no significant complications. For those who have already had an ileostomy, the stay might be shorter.

The usual routine after leaving hospital involves an outpatient visit about a month later. This is important because the surgeon then checks if the ileo-anal anastomosis has healed. Checking is done by examining the pouch via the back passage, initially with a finger examination and then a sigmoidoscope. X-ray of the pouch may also be carried out. If there is no evidence of leakage the ileostomy can be closed.

Stage 2 (Closure of the temporary ileostomy)

Closure of the ileostomy is a relatively minor procedure. A cut is made around the ileostomy itself and the bowel is then closed by stitches and the hole in the abdomen is also closed. Only rarely is it necessary to open the abdomen more extensively.

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The post-operative period

Bowel function through the anus usually starts within 12-48 hours after closure of the temporary ileostomy and the patient can usually go home four to seven days after the operation. Returning to work will differ from person to person but a further month is usually recommended. During these first few weeks bowel function is sometimes rather erratic with frequency and some soiling. Thereafter it tends to settle.

Anal soreness can occur with diarrhoea and anal skin care with washing and application of barrier creams is essential. Antidiarrhoeal drugs may also help. In the majority of cases it settles over the first few weeks. There are no special rules about diet. About 20% of patients find that certain foods upset them but 80% have no restriction. Foods that cause difficulties should be avoided but the patient must find this out for him or herself.

Results

Before making a decision, consideration of both the advantages and disadvantages of the operation is needed, including the sort of function of the 'pouch' that can be expected. To assist this decision-making process the next section is divided into complications of the pouch, failure of the pouch and function of the pouch.

Failure

Failure is defined as the need to remove the pouch and to give the patient a permanent ileostomy. In most of the hospitals doing a lot of this type of surgery, failure within the first year is 5-10%. Over the next five to ten years it rises to 15% which is usually due to sepsis (acute or chronic) within the pouch and poor bowel function of the pouch. Failure can also be caused by pouchitis and initially unrecognised Crohn's disease, but this is uncommon.

Early Complications

There is no doubt that complications immediately after the pouch operation are more common than after a proctocolectomy with permanent ileostomy. Approximately 30% of patients get a significant complication when the two stages of the operation are considered together.

The two main complications include adhesion obstruction and infection. As with conventional proctocolectomy, adhesion obstruction is due to kinking of the bowel. Following the pouch procedure the rate of having to operate to relieve obstruction is about 5-10%. This is most common within the first few weeks of the operation. Once operated on the obstruction does not tend to come back. The

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second important complication is some degree of breakdown of the ileo-anal anastomosis. This occurs also in about 5-10% of cases. Usually it is minor and heals on its own in a few weeks at the most. Sometimes it is major with the formation of significant infection and pus. In some cases it may take more than a few weeks for healing to occur and surgical examination with drainage of pus under anaesthetic may be necessary. The breakdown may be so bad that the pouch has to be removed.

Long-Term Complications

Pouchitis

This is the name given to a condition in which there is inflammation in the pouch. The cause of pouchitis is unknown. Some 10-20% of patients get episodes of inflammation in the pouch and patients may experience more than one episode. The inflammation occurs more often with patients who had ulcerative colitis and those having the operation for other diseases are less likely to get it.

Symptoms of pouchitis include episodes of diarrhoea with liquid faeces tinged with a little blood. The patient may generally feel unwell and a fever may be present. Occasionally a joint that previously gave trouble may flare up. The treatment of pouchitis includes antibiotics but in severe cases steroids may be necessary. The majority of cases resolve with treatment but very rarely, excision of the pouch may be necessary. More research is needed into this condition.

Defaecation problems

Some patients experience difficulty in emptying the pouch, so much so that they feel they have not completely emptied the pouch and need to return to the toilet to achieve complete emptying.

The reasons include stricture (narrowing) of the ileo-anal anastomosis and other causes of mechanical blockage or factors that are not understood. In either case investigations and tests may need to be carried out to determine the most suitable treatment.

Occasionally spontaneous defaecation may not occur. In these uncommon cases the patient may have to use a catheter to assist in evacuation; others may need a further operation in order to correct the problem.

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Anal skin soreness

As stressed previously it is important to maintain good anal skin hygiene. In order to understand why such good skin care is needed, it may help to know a little about the digestive process and how that may have changed following the final stage of the operation.

After eating, food is mixed with digestive juices (acids and enzymes) to liquidise and break down the food ready for the intestines to start absorbing the nutrients. In the upper small bowel (jejunum), digestive juices are produced to break down food absorption. In the lower small bowel (ileum) most of the products of digestion are absorbed into the blood stream. The large bowel then reabsorbs most of the remaining water to give a formed motion. Without the large bowel the faeces are usually fluid and still contain digestive juices. After the operation these are very easily able to damage normal skin. If pouch frequency is high (more than 8 times per 24 hours) then sore skin around the anus is inevitable.

Some guidelines to help maintain good skin follows:

1. Keep the area clean by washing (not too vigorously) and drying after every bowel motion.
2. Avoid rubbing with soap or rough flannel.
3. Use moist toilet paper for that softer touch (available at chemists).
4. Keep the anal area dry.
5. Avoid perfumed talcum powder.
6. Wear cotton underwear.
7. Avoid excessive use of ointments and creams and ensure they are completely washed away prior to re-application.
8. Consider thickening bowel motions by changing diet and/or taking antidiarrhoeal drugs.
9. Seek medical/nursing help should the problem persist.

Pouch fistula

A fistula is an abnormal opening (hole) from one cavity tracking through to another. Sometimes infection around the join between the pouch and anus can track its way out to the exterior. In females this usually comes out of the vagina.

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In males, it does so through the tissues near to the buttock. By whatever route, the effect is for faeces to leak out causing incontinence. Management of the condition can be difficult; most surgeons would recommend a further operation to form a temporary ileostomy in order to allow a resting period with the hope that the fistula will heal. Further surgery to close the fistula may be necessary. If this does not work then the pouch may need to be removed.

Function

Function refers to the activity of the bowel after closure of the ileostomy. It can be assessed in terms of frequency of going to the lavatory, urgency, continence (the ability to hold the faeces) and the need or not for medication to control diarrhoea. There is a tendency for the function to improve during the months and even up to a year after closure of the ileostomy

Frequency

Frequency is expressed as the number of visits to the lavatory every 24 hours and is anything from 2 to 8 times. The average figure should be around 4 to 5 times per 24 hours. Most patients (about 75%) go between 2 and 6 times. Having to get up at night is probably the best judge of frequency because nobody wants to do so. About 20-40% of patients have to get up at night more than once a week. Some patients have a higher frequency but most do not experience urgency.

Urgency

The type of motion passed is described as being soft to loose in consistency and the average time spent at the lavatory is about 10 minutes. Patients can usually hold on for at least 40 minutes sometimes more, thus urgency is not usually troublesome. This is perhaps the most important benefit of the operation since it allows the patient greater freedom in life than they had before.

Continence

Continence can be defined as being normal or disturbed. Disturbed continence may simply be a minor leakage of mucus (slime) or a significant inability to hold faeces.

When leakage occurs it is more likely to be at night than during the day. Patients with a significant leakage have to wear a pad.

With these definitions of continence, the various reports show that up to 80% of patients are completely normal after the operation. About 5% have a significant leakage of faeces and 10-20% have a mucus leakage. The latter is not much of a

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problem but faecal leakage is. Leakage is more likely if the sphincter muscle is weak. Very occasionally incontinence is a reason for failure of the pouch.

Whatever the leakage, either faeces or mucus, it is important that anal skin hygiene is maintained by cleansing and drying the anal area each time the pouch is emptied and also by using a suitable barrier cream. If pads are worn they must be changed regularly.

Antidiarrhoeal medication

Antidiarrhoeal medication is necessary in about 20-50% of patients. For those patients requiring antidiarrhoeal medication, such as Loperamide (Imodium) or Codeine Phosphate, frequency is reduced without exceeding the recommended dose. Most patients, however, do not need antidiarrhoeal medication.

Quality of life

Patients have been asked about their quality of life after the operation compared with life with an ileostomy. It must be appreciated that these patients had a strong desire to avoid a permanent ileostomy. They may therefore be prejudiced towards feeling the pouch operation has been worthwhile. Nevertheless all have experienced an ileostomy at some stage during their treatment.

The results of such surveys have shown that about 90% of patients, who have not had to have a subsequent permanent ileostomy think that their quality of life is better after the pouch operation than it was when they had the temporary ileostomy. This is on the basis of such aspects as body image, clothing, sport, work and sexual appeal.

Patients may be concerned about sexual function as disturbances can occur after some rectal operations. Male patients particularly may worry about erection and ejaculation. The technique used by the surgeon in most cases avoids these problems. It is only in those few patients with cancer that they might occur. The surgeon or Stoma Care Nurse will be happy to discuss these aspects in more detail.

Little is documented with regard to sexual difficulties experienced by women. However, it is recognised that the vagina may become dry after surgery and a lubricating jelly may assist this. In addition, because of the nature of the surgery the vagina may tilt slightly causing some discomfort initially at sexual intercourse. If at all concerned, the surgeon or Stoma Care Nurse will be happy to discuss anxieties, privately and at an appropriate time.

Long-Term Follow-Up

Patients are routinely followed up because of the need to know the longterm effects of a new procedure. The patients generally have been well although a few have needed treatment for iron and vitamin deficiency anaemia. There has been no case of cancerous changes in the pouch, although most surgeons will advise a regular check-up.

The choice between the pouch procedure or a proctocolectomy with permanent ileostomy is very much up to the individual provided the surgeon is trained to do either procedure and provided the medical conditions are suitable for either.

PATIENT SUPPORT GROUPS

Throughout the country there are now several patient groups providing a support network for patients and their families, who have undergone the pouch procedure or who are contemplating the operation. Further information with address/details are available in the back of this booklet. The support groups listed are the most well-known groups within the UK, however contact with local individuals may be possible via the Stoma Care Nurse.

Useful Addresses

Red Lion Group

Liaison Officer - Red Lion Group
c/o St. Mark's Hospital
Watford Road
Harrow
Middlesex HA1 3UJ
Telephone and Fax 0181 235 4110
(A national and international support group for patients with internal pouches)

The Pouch Owner's Club

9 Westview Road
Warlingham
Surrey CR6 9JD
(A south-east London based internal pouch support group)

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Plymouth Possums

c/o Gill Tomlin
2 Valletort Cottages
Valletort Lane
Stoke
Plymouth PL11 5PU
(A South Devon based internal
pouch support group)

Ileostomy and Internal Pouch Support Group

P.O. Box 132
Scunthorpe
North Lincs
DN15 9YW
Telephone 01724 720 150
(A nationwide support group for those with
ileostomies as well as internal pouches)

Joey Pouch Association

c/o Beryl Farmer
Lyndhurst
Chester Road
Kelsall
Tarporley CW6 0SD
(A Manchester based
internal pouch support group)

The Kangaroo Club

c/o Stomatherapy Department
Room 6306, Level 6
John Radcliffe Hospital
Oxford OX3 9DU Telephone and Fax 01865 221839
(An Oxford based internal pouch
support group)

continued...

Glossary

A

adhesions	scars within the abdomen which cause the intestine to stick to other structures, sometimes becoming kinked as a result.
anatomy	the normal construction of the body
anaemia	low blood count
anastomosis	a surgical join between two pieces of bowel
arthritis	inflammation in joints

B

biopsy	a specimen of tissue taken by a specially designed instrument for examination under the microscope
bowel	intestine

C

catheter	a narrow tube for draining urine or faeces
colectomy with ileo-rectal anastomosis	the operation in which the colon is removed and a surgical join made between the last part of the small bowel and the rectum
colon	the part of the large bowel between the small bowel and the rectum
colonoscope	a flexible lighted instrument used to look at the inside of the rectum and colon
colostomy	the colon when brought out onto the abdomen
Crohn's disease	a type of inflammation of the intestine

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continence the ability of the anal sphincter muscle to hold on to the faeces

D

defaecation the act of expelling faeces

F

faeces motions (waste from the bowel)

frequency the number of times the bowels are opened in a 24 hour period

fistula an abnormal communication between two tissue linings

I

ileostomy the ileum when brought out onto the abdomen

ileum the small intestine above the start of the colon

-itis a suffix denoting inflammation, e.g. colitis = inflammation of the colon

L

large bowel colon and rectum

M

mucous membrane (mucosa) the internal skin lining the intestine

mucus slime produced by mucous membrane

O

oesophagus gullet

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P

pathology	the study of disease
polyposis	a disease inherited from an affected parent in which the large bowel is liable to develop warts or polyps which can become cancerous
pouch	small bowel or ileal reservoir made from the ileum to form a substitute for the rectum ("new" rectum)
pouchitis	inflammation in the small bowel reservoir
proctocolectomy with permanent ileostomy	the operation in which all the large bowel (colon and rectum) and also the anus are removed

R

rectum	the last part (15cm, 5-6 inches) of the large bowel. It lies between the colon and anus
restorative proctocolectomy with ileal reservoir	the operation in which the colon and rectum are removed leaving the anus. An ileal reservoir is then made and joined to the anus

S

sigmoidoscopy	a rigid instrument used to look inside the rectum/pouch
small bowel	the part of the intestine between the stomach and duodenum above and the colon below. The last part is called the ileum
sphincter	the muscle' in the anus which keeps it shut and prevents leakage of faeces
stoma	any opening of the bowel on the surface of the abdomen

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U

ulcerative colitis a type of inflammation which affects the large bowel (colon and rectum)

umbilicus navel

urgency the need to rush to the toilet owing to the urge to defaecate

Original booklet produced for St. Mark's NHS Trust in association with **Convatec**, A Bristol Myers Squibb company

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