Faecal leakage can occur in early stages during sexual intercourse, but this will improve with time. It helps to empty the pouch beforehand.

Fertility is not usually affected in women, although a caesarean is often recommended. There is a 3% risk of impotence in men. Consult your doctor for advice.

Chronic bowel disorders, such as ulcerative colitis, are usually a long-term problem and can be very debilitating. Surgery, too, can take its toll and may result in weakness, fatigue and depression. Give yourself enough time to convalesce and you will soon find your health much improved.

It does help if you can take a positive attitude. Take time to talk to your family and close friends to explain and discuss with them what is happening. They will be extra supportive if you share your problems and feelings with them. Simple explanations of operations to children will also help to allay their fears. Accept any assistance offered -people like to be involved and it will help you to get better quicker.

Background information.

Although only one quarter of all patients with ulcerative colitis will ever require surgical treatment, the long-term consequences of an operation may have a profound impact upon the

Until 25 years ago the removal of the rectum resulted in the patient having a permanent ileostomy. Thanks to the pioneering work of the late Sir Alan Parks in the early 1970s, an alternative operation has been developed which avoids the need for a permanent ileostomy. A new rectum is fashioned from the healthy small intestine and joined internally to the anus to form a 'pouch' or reservoir. Since 1976 these operations have been carried out in centres throughout the world. It is clear that the operation is safe and in the vast majority of cases is effective in providing a reasonable quality of life, without a permanent ileostomy.

However, the operation is prone to complications. particularly in the early stages after surgery. It is for this reason that the pouch operation is usually considered only to be suitable for those patients who are very strongly motivated to avoid a permanent ileostomy. It is now recognised that a small proportion of pouch operations result in failure and approximately 6% of all pouches are eventually removed resulting in a permanent ileostomy.

Whilst there must be considerable medical input into the process of deciding upon a particular operation, it is ultimately the choice of the patient, and therefore a realistic insight into the nature of pouch surgery should be readily available. This informative booklet will be of great value to patients who are considering the different surgical options for the treatment of their colitis.

DR MATLEY&PARTNERS
SPECIALIST SURGEONS
Practice Number: 4208293

Harfield House, Kingsbury Tel 021 683 3893 127 Vincent Pallotti Tel 021 506 5108

Ulcerative colitis and an ileo-anal pouch

If you suffer from chronic problems with a condition such as ulcerative colitis or familial adenomatous polyposis (F.A.P.), you may be advised that you must undergo surgery to remove the diseased bowel. This will usually mean having an ileostomy -the end of the small intestine is brought to the surface on the abdomen and a 'stoma pouch' is worn. Many thousands of people have ileostomies and have found that after the operation they enjoy a new improved quality of life -relieved of a constant preoccupation with bowel problems and reeling better than ever before.

Depending on your type of problem, however, you may be offered the option of having an ileo-anal 'pouch' instead of an ileostomy. This is where the diseased bowel is removed, but instead of bringing the end of the small intestine to the outside of your abdomen, a pouch is created internally (a little like a man-made rectum) and connected to the back passage, or anus. Waste matter, or faeces, can then be passed in much the same way as usual, although it will be more liquid and more frequent.

The pouch is not a perfect solution -no surgery will replace completely normal function of the colon and rectum -but for selected patients it can be an acceptable alternative to a permanent ileostomy.

This gives you further information about the ileo-anal pouch option and what is involved.

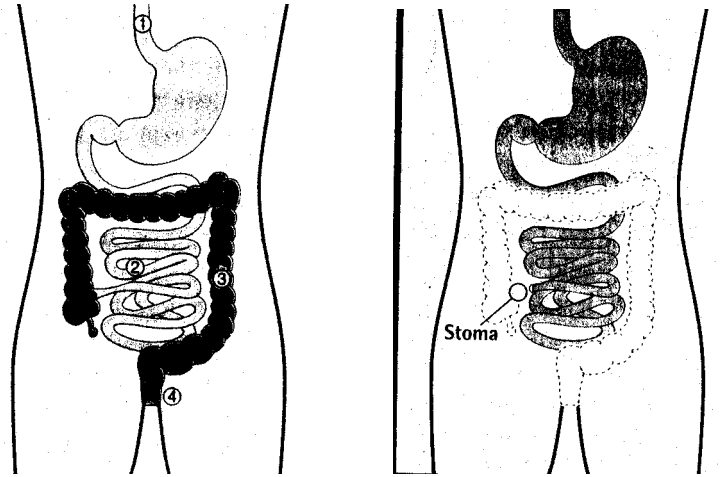
Food that you eat passes down the oesophagus (1) into the stomach. Here it is churned in digestive juices until it is reasonably liquid and passes into the sma11 intestine (ileum) (2). During its journey through the sma11 intestine most of the nutrients in the food are absorbed into the body leaving a semi-solid mixture of indigestible waste matter and water.

The large intestine, (colon) (3) absorbs much of the water, leaving the waste matter (faeces) in a more solid form. At the end of the colon, waste matter is stored in the rectum before being expelled through the anus (4) at a convenient time.

If the large intestine is diseased and needs removing, surgery must be carried out so that waste matter from the small intestine, which at this stage is still only semi-solid, can be expelled from the body. This is usually achieved by forming a permanent ileostomy. In certain cases, however, a patient may be offered pouch surgery.

An i1eostomy

An ileostomy usually involves removing the entire large intestine. Faeces cannot be passed in the usual way and, because the faeces no longer pass round the large intestine, they also remain semi- solid. The surgeon makes a small opening on the outside of the abdomen, brings through the end of the small intestine and attaches it to the outside to form a small spout where the faeces can be expelled. This is a stoma (meaning opening) and because it is a stoma created using the ileum, it is called an ileostomy. A stoma bag is worn on the abdomen around the stoma to collect the faeces.



An ileo-anal pouch

With a pouch, the diseased bowel is removed, but instead of creating a permanent stoma on the outside of the abdomen, the surgeon uses part of the healthy sma11 intestine to form a pouch, or reservoir, inside the body and this is attached to the anus. The waste matter from the sma11 intestine goes into this pouch and is passed in the usual manner -although the faeces wi11 be more liquid and passed much more frequently.

Not everyone is, or can be, offered an ileo-anal pouch but if your doctor thinks you may be suitable, he/she will discuss both procedures fully with you and explain what is involved. It is a worrying time when you learn that you need to undergo major surgery. Information gathering is important to relieve anxieties, so don't be afraid to talk as much as you need with

Another great help is pelvic floor muscle exercises. These improve control and need to be practised regularly over a long term as do the exercises described below:

Identify the anal sphincter muscle by imagining you have diarrhoea and need to hold on until it is convenient to go. Once identified -squeeze and hold the anal muscle for a slow count of four, release for a count of four. Do this 4 times.

Identify the urinary sphincter muscle by the same method, i.e. imagine that you have to pass water, and exercise as for the anal muscle.

One of the benefits of your operation is that you will be able to eat a normal well-balanced diet again. As with everyone's digestive system, however, bowels can be affected by several factors, including diet (e.g. curries or large amounts of alcohol), exercise, stress, or problems such as gastro-enteritis.

Foods that can generally be taken without affecting bowel function include potatoes, bananas, lamb, beef, eggs, bacon, tinned peaches, fried foods, rice and rice-based cereals.

There are four groups of food which may affect pouch output and these are detailed in the table below. Individuals vary, however, so these are only general guidelines.

Dietary hints

You may find it helpful to cut down on fluids late in the evening to help avoid bowel evacuation at night -having your main meal early and a snack in the evenings also helps.

Eat small meals at first to prevent feeling bloated.

Eat regular meals -don't omit meals if you have frequent bowel movements, because more wind may be produced when the bowel is empty and the faeces will be more liquid.

Foods-affecting bowel function

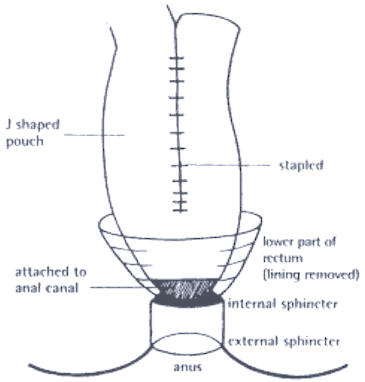
Beer, carbonated drinks, beans, peas, green vegetables, milk and milk products, onions, sweet corn, bran.

Sexual function

After most surgical procedures sexual activity is reduced and it can take some time to get back to normal. Many who have had pouch surgery (or temporary or permanent ileostomies),

however, find that health and vigour is much improved when the incapacitating disease has been removed.

medical and nursing staff -they will only be too happy to help. In many areas there are nurses who specialise in stoma care



. These stoma care nurses give information and advice alongside practical and emotional support -and will usually be able to arrange for you to talk to others who have an ileo-anal pouch or a permanent ileostomy.

Whatever surgery you have the nurse will usually visit you in hospital and at home until you are confident and independent. You will also be given contact telephone numbers of the nurse and/or clinic so that advice and assistance is always available.

Ileostomy

Although it is major surgery, an ileostomy is comparatively straightforward. After initial worries, subsequent surgery and convalescence, most ileostomists find that they soon get used to managing their stoma and that their quality of life improves dramatically. With an ileostomy, a discreet, odour-proof, rustle- free stoma pouch is worn that adheres to the abdomen around the stoma. The pouch is drainable and can be quickly and simply emptied. The pouch can be changed for a new one every 2- 3 days.

If you are having an ileo-anal pouch created, you will usually at some stage have an ileostomy as a temporary measure.

. If you have an ileostomy, permanent or temporary, the stoma care nurse, or nursing staff, will give further information, care for you and make sure you know how to manage. CliniMed has a publication called 'Ileostomy -a practical guide to stoma care', which is a useful reference source and is available from your stoma care nurse or direct from the company. The rest of this booklet provides information on the ileo-anal pouch option.

An outpatient appointment will be arranged, usually around 6-8 weeks after the operation, where the surgeon will check the stitches in your back passage have healed. Often a special X-ray of the pouch is done. If no leaks or problems are evident, the "closing" or "reversal" of your ileostomy will be arranged.

The next stage -closing the ileostomy

The ileostomy closure is a relatively minor procedure but it does involve a general anaesthetic. A bowel preparation is not required. A cut is made round the stoma and the opening in the small intestine is closed. The small intestine is then put back inside the abdomen and the hole on the skin of the abdomen is closed. Waste matter can now pass from the small intestine into the ileo- anal pouch. The pouch will begin functioning through the anus in a few days. If there are no further problems you will then return home to convalesce and get used to your pouch.

Possib1e comp1ications

If complications do arise it is usually immediately after surgery and they are treated before discharge home. They can include:

Infection or wound infection -antibiotics are usually given

"Pouchitis" -around 20% of cases have episodes of inflammation of the pouch. This is usually treated with medicine and with pouch irrigation.

Bleeding, caused by irritation of the suture line or the pouch, may accompany "pouchitis".

This is the time when patience is important. Don't expect too much too soon. The pouch has to expand and initia11y bowel movements wi11 be erratic and very frequent -10-20 times in the day and 2-3 times during the night -and soiling can also be expected. Within 4 weeks manageable frequency usua11y returns and by 6-12 months after surgery 80% of patients can control bowels 4 to 8 times daily and once at night.

Some degree of faecal incontinence may be experienced at first and it may take some time to get this under control. The faeces are fairly liquid and more difficult to retain. Some pouch patients can experience leakage at night when the muscles around the anus (the anal sphincter) relax. Bowel function can, however, go on improving for up to 18 months.

You can wear pads to protect underclothing and bedding -the nursing staff who support you after your surgery will give you further information.

What can help? Drugs such as loperamide or codeine phosphate (sometimes called 'stoppers' or 'bulkers') may be prescribed by the doctor to help make the faeces more solid. Most people find

that they need to take these from time to time, but the amount needed and frequency taken varies.

I1eo-anal pouch

Pouch surgery is less straightforward than having an ileostomy and is more prone to complications. It is lengthier, often being carried out in stages, and can take some time to settle down -the full benefits of pouch surgery may not be realised until 6-12 months after it has been carried out and may take even longer. Having said that, for those who are motivated and determined, the pouch can be a satisfactory alternative. If the pouch fails (approximately 6% risk), an ileostomy provides a permanent solution.

The exact surgical procedure varies according to the hospital or surgeon and will also depend on the patient's physical condition, but generally it is divided into stages -usually two or three (but sometimes just one) -your surgeon wilt advise, Before surgery, routine tests will be performed, physiotherapy exercises given and information about management of a temporary loop ileostomy provided; bowel preparation carried out so that the bowel is empty etc. Certain drugs, such as hormone replacement therapy or the contraceptive pill, are usually discontinued 4 weeks prior to surgery.

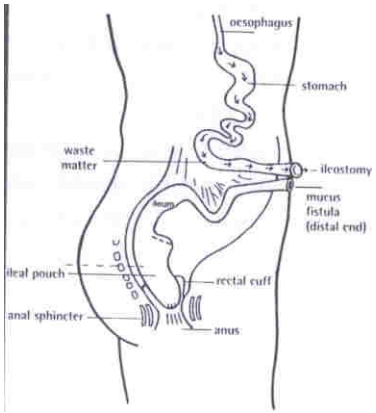
Removing diseased tissue

An incision is usually made down the middle of the abdomen. The large intestine and any other diseased tissue is removed, leaving in place the healthy small intestine, the anus and surrounding muscles, and in some cases part of the rectum.

Forming a pouch

The pouch is constructed using the end of the small intestine and it is a-attached to the anus. At this stage a temporary ileostomy is usually carried out further up the small intestine. The ileostomy allows waste matter to be diverted out on to the surface of the abdomen and means that the newly formed pouch is given the chance to heal before it is used.

Temporary loop ileostomy



This is formed by bringing a loop of the small intestine on to the surface of the skin through a small incision on the abdomen. To prevent the loop slipping back inside the abdomen a 'bridge' is placed under the loop. The bridge will be removed after a period of 5- 10 days, after which time the skin and muscle will keep the ileostomy in place. A small incision is made in the loop to allow waste matter or faeces to be passed and collected in a stoma pouch.

Recovering before the next stage

When you come round after surgery, you will have a number of drips, tubes, catheters etc. attached to you and you will feel some discomfort and weakness. The tubes and drains will gradually be removed over the next few days and you will start to take fluids and light foods.

Your temporary ileostomy will begin to be active immediately. The nurses wi11 manage your ileostomy at first until you are taught how to do so. You wi11 soon learn how and when to change the pouches. At first the stoma wi11 be swollen and surrounded by stitches and for easy monitoring the pouches used at this stage are transparent. The swe11ing of the stoma will soon go down, however, and the stitches dissolve. You wi11 then be able to use a standard beige stoma pouch. There is often a discharge of blood and mucus from the back passage, but this stops within a few weeks. A barrier cream helps to prevent soreness.

This is a major operation -you are likely to be in hospital for about 14 days and you will need to convalesce before any further surgery is carried out. You will also be learning to cope with an ileostomy, which you will probably have for at least a couple of months until the next stage.

The stoma care nurse will help you, advising you on the appropriate ileostomy pouches and accessories to suit you and ensuring that the pouches adhere properly to the abdomen so that no leakage, odour or sore skin occurs. The stoma care nurse will also tell you how to obtain the pouches, all of which are available on prescription.

Convalescing

During the following weeks, you will be convalescing and you will begin to feel healthier than you have in a long time. To aid recovery, however, it is important to rest, eat a well-balanced

diet and take gentle exercise such as walking. As with any other abdominal surgery, avoid lifting (such as shopping or picking up children), stretching, mowing the lawn, vacuuming or similar activities for 3 months. You may be advised to wait for around 3-6 weeks until you are strong enough to drive a car again.

During your convalescence, you may experience some leakage of mucus from the empty pouch. This is quite normal. Mucus is a clear jelly-like substance produced by the lining of the small intestine. It is very beneficial during the time between operations to practice the pelvic floor muscle exercises you have been given to help improve control around the anus.