

Ulcerative colitis

CCSG Information pamphlet No. 2

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This booklet sets out to answer the questions most commonly asked about ulcerative colitis. You may have been told that you have this condition, or you may have a close relative, friend or partner with it. If you are a patient, your specialist or surgeon will probably have told you the basic facts about ulcerative colitis, but you may have held back from asking for more details because you felt that you did not want to take up too much of the doctor's time. If this booklet can both fill in some of the gaps in your knowledge, and help to allay your natural anxieties, then it has served its purpose.

Ulcerative colitis

Ulcerative colitis (U.C.), is a condition with which you may have to live for many years. Therefore, you will naturally want to understand the nature of the disorder and the effects it may have on your life. For this reason we have prepared a series of "Questions and Answers" which you can read and absorb at your leisure. This should not be a barrier to more personal communication with your doctor rather look upon it as something extra.

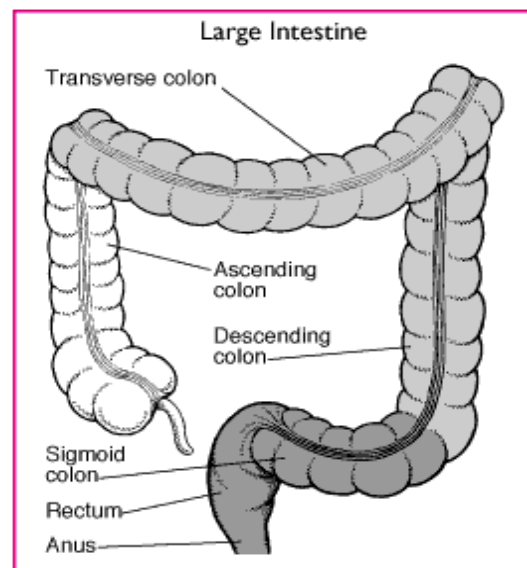
What is ulcerative colitis?

Ulcerative colitis (U.C.) is a disease of the lining layer (mucosa) of the large bowel or colon. This layer becomes inflamed and develops many tiny breaks in its surface (ulcers) which may bleed. The inflamed lining also produces an excess amount of normal intestinal lubricant -mucus - which may contain some pus. U.C. is a chronic condition - that is to say that it has a tendency to flare up from time to time over many years.

What is the colon?

The colon is that part of the intestine between the small intestine (where most of

your digested food is absorbed into your system), and the anus or back passage, from which faeces (stools, motions, wastes) are discharged. The part of the colon immediately above the anus is the rectum. U.C. almost always involves the rectum, but involvement of the rest of the colon varies from patient to patient. The figure below shows inflammation in the rectum and the lower colon.



The colon.

What does the colon do, and how does U.C. alter its functions?

The colon does two things. Firstly, it extracts fluid from the liquid waste which enters it from the small intestine, concentrating this waste down to make solid faeces. In more severe U.C., this concentrating function becomes defective and the patient has liquid diarrhoea in addition to the discharge of blood and mucus. Secondly, the colon acts as a reservoir for solid faeces, allowing about 1-3

bowel motions daily. In active or longstanding U.C., this reservoir capacity is decreased, leading to more frequent bowel motions even in the absence of diarrhoea.

What causes U.C.?

We do not know what causes U.C., therefore our treatment for it is based purely on experience of many trials of anti-inflammatory drugs. The disease probably represents an abnormal and prolonged response of the body to various forms of damage, infections and other similar injuries to the bowel wall that would normally be of trivial importance.

Is U.C. infectious?

No, it is not infectious, though various acute infectious diarrhoeas - usually acquired from contaminated food or water, can closely mimic the beginning of chronic ulcerative colitis. For this reason you may well have had samples of faeces sent to the laboratory at the onset of your illness in order to determine whether you have infectious diarrhoea, or U.C.

Does stress or worry cause U.C.?

No, almost certainly not. However, flare-ups of colitis often occur at times of personal stress, though usually the condition flares up for no obvious reason. Colds and the flu may spark off attacks. For more information see CCSG Information Leaflet No.5 - *Emotional Factors*.

Can I pass U.C. on to my children?

U.C. is not strictly hereditary, for its transmission from one generation of a family to the next cannot be accurately predicted. However, it may occur in more than one member of the same family (for example, father and son, two sisters). The likelihood of your children inheriting or developing U.C. is small. For more information see CCSG Information Leaflet No. 4 - *Sexuality, Fertility & Pregnancy*.

Is U.C. to do with something in my diet?

Special diets have little part to play in the treatment of U.C., and we know of nothing definite in the diet which might cause or worsen the condition, though it is logical to go on looking. However,

- a) Carageen, a seaweed extract used as a stabiliser in manufactured puddings and in ice creams, will cause a colitis when given in large enough amounts to experimental animals. Perhaps people with colitis should avoid such foods.
- b) Occasionally, colitis patients who are not responding satisfactorily to treatment improve greatly on cutting one type of food, such as milk products out of their diets. However, this is a very variable and individual response.
- c) A high fibre (bran) diet helps the constipation which often accompanies cases of colitis limited to the rectum and lower colon.

Is U.C. a form of cancer?

No. Cancer is an uncontrolled excess growth of one part of tissue - colonic inflammation of U.C. is quite a different process.

Can U.C. go on to bowel cancer?

Occasionally patients whose entire colon is diseased and who have had colitis for many years may develop cancers in the colon lining. This group of patients will be followed and examined closely and carefully by their specialist, because the lining of their bowel can develop 'pre-cancerous' changes, often years before the appearance of an actual tumour growth. By looking for these changes, the doctor can decide which patients are at risk and need surgery to remove the diseased part of the colon.

How is U.C. diagnosed?

U.C. is suspected on the basis of a history of bleeding from the colon, with or without diarrhoea and pain. Once infection has been ruled out, then the diagnosis is confirmed by the typical abnormal appearances of the rectal mucosa as seen by direct inspection with a special instrument - a sigmoidoscope, which is rather like a telescope. At the same time a snip of mucosa (biopsy) is often taken to be looked at in the laboratory. The mucosa of patients with U.C. has a particular appearance when examined under the microscope. Sigmoidoscopy will need to be repeated at future dates to assess whether the colitis is

active or quiescent (inactive), and to gauge response to treatment. Initially it may be an embarrassing and uncomfortable test, but with continuing experience and a more relaxed attitude most patients learn to accept it as a minor inconvenience.

A barium enema X-ray examination may be used both at the onset of U.C. and from time to time in subsequent years to assess how much of the colon above the rectum is affected by the disease. Many patients just have rectal disease (proctitis) and the barium enema shows a normal colon.

More commonly a colonoscopy (examination using a flexible telescope passed up the back passage) is now used to assess a patient with colitis.

Does local colitis spread further up the colon over the years?

Usually the amount of colon involved remains more or less the same from one attack to the next. Sometimes, in a minority of patients, it spreads with successive attacks.

Will my colitis ever leave me completely?

The symptoms and signs of U.C. can certainly disappear for many years and even for a lifetime without any treatment. Unfortunately the more usual course is one of periodic flare.

Is U.C. treatable?

Yes, very much so. However, it is not curable because a short course of treatment will not stop it from ever coming back again - very few chronic medical conditions are curable. In this sense the only "cure" is to remove the diseased colon by surgery.

Treatment with tablets and self administered liquid or foam enemas is aimed at settling down flare-ups of the disease, though many flare-ups would probably settle eventually on their own but usually more slowly. Long term treatment with medicines such as Salazopyrin®, Pentasa®, Dipentum® or Asacol® is aimed at reducing the likelihood of a flare-up.

Why do some patients with U.C. have operations?

All or most of the colon may be removed at an operation for various reasons:

- a) If a very severe attack of U.C. is not getting better in spite of intensive medical treatment.
- b) If repeated attacks over the years are harming the patient's well-being and not responding quickly to medical treatment, particularly in patients with involvement of most or all of the colon.
- c) If the patient has repeated attacks of inflammation in other systems, such as the eyes, skin or joints, accompanying their attacks of U.C.
- d) If there are serious pre-cancerous changes in the colon.

What operations are available to treat U.C.?

The three alternatives are:

- 1) Total proctocolectomy and ileostomy
- 2) Sub-total colectomy and ileorectal anastomosis
- 3) Ileoanal anastomosis ("pouch operation")

These rather formidable-sounding names are easily explained (See CCSG Information Leaflet No. 9 - *Surgery in IBD*, for more details).

In 1) the whole colon, including the rectum, is removed. The cut end of the lower small intestine is brought out onto the wall of the abdomen as a permanent spout-like opening (or "ileostomy") over which a small bag is fitted to collect the discharge from the small intestine which would previously have passed on into the colon. An ileostomy and its bag can be sufficiently discrete not to show through the lightest of clothes, even bathing costumes, and should not interfere with any activities.

In 2) about 90% of the diseased colon is removed, leaving the rectum and anus behind. The cut end of the lower small intestine is then joined to the upper end of the rectum.

The operation of choice for many years has been total proctocolectomy (removal of the entire colon and rectum) with ileostomy.

Proctocolectomy with ileostomy is a permanent cure for ulcerative colitis. This operation has been performed safely and with few complications for many decades and is the "gold standard" against which the newer operations are measured.

In 3) the surgeon removes the diseased colon, retains the anal canal, and allows faecal elimination to occur through the anus in the usual way. In most cases, the surgeon fashions an internal pouch using about 30-40 cm of ileum. This reservoir is then pulled down and stitched directly to the interior wall of the anus, where it imitates the storage function of the absent colon. Because this operation preserves intestinal continuity, no permanent external ileostomy is required.

What are the pros and cons of an ileostomy?

After total proctocolectomy and ileostomy, U.C. has been cured, and with the cure goes a well-being often denied patients with recurrent bloody diarrhoea, poor appetite and weight loss. No longer is there any risk of bowel cancer. No longer does the patient need a mental map of all the toilets to which he or she may need to rush, sometimes to arrive "too late". The price for this return to good health is an abdominal stoma (the opening in the side of the abdomen where waste matter is discharged into a disposable plastic bag). The stoma will need care and attention often with the help of a special "stoma therapy" nurse. Both the physical, and of course the psychological, needs of the new ileostomate will be met by the very active Ostomy Societies, run by patients for patients. This operation of course is irreversible.

What are the pros and cons of an ileorectal anastomosis?

This operation just leaves a scar on the abdomen; no artificial opening. Faeces empty from the back passage normally but because most of the colon has been taken away, faeces are usually loose or liquid, and some increase in the number of bowel movements per day is likely. The remaining rectum is as liable to flare-ups of colitis as it was before the operation, and also to pre-cancerous change. The patient with this operation may thus benefit greatly, but will continue to need specialist supervision. If necessary, further surgery can be performed to remove the remaining rectum and create an ileostomy. In general, this operation is not recommended.

What are the pros and cons of a "pouch" operation?

As in the ileorectal anastomosis surgery this operation just leaves a scar on the abdomen and no artificial opening. Faeces empty from the back passage normally. The entire colon and rectum have been removed and so the U.C. has been cured with the benefits listed above.

One issue that is important to people considering this operation is that the ileoanal anastomosis is usually performed in two stages and hence may take the best part of 12 months to complete. First, the diseased colon and rectum are removed, and the ileal reservoir is constructed and joined to the anus. To allow the stitches in the newly constructed reservoir to heal, the surgeon usually fashions a temporary loop ileostomy to divert faecal flow. The ileostomy is closed at a second operation several months later. It can take up to six more months for this new arrangement to settle down.

Severe infection occurs at the site of the stitches in 5% of cases and post-operative obstructions occur in 10% of patients.

Another significant complication is an inflammation of the reservoir called *pouchitis*. While pouchitis is not a recurrence of ulcerative colitis, its exact cause is not known. In approximately 10% of patients where the surgery was planned, complications arise after the operation that result in the necessity of further surgery and the formation of a permanent ileostomy.

Is U.C. a dangerous illness?

U.C. is most dangerous if the attack is very severe, particularly if this attack fails to come under control with medical treatment and requires emergency surgery. In the long term relapsing disease is a threat to good health rather than to life. In patients with rectal disease (proctitis) only, good health is generally maintained and the only problems are an urgent need to open the bowels, and rectal bleeding.

What side effects should I expect from treatment?

Obviously your doctor tries not to make the treatment worse than the disease! (See CCSG Information Leaflet No. 8 - *Drugs in IBD*, for more details)

Corticosteroid drugs (eg. prednisone), which may be needed in large doses to control acute attacks of U.C., will often produce rounding of the face, excess appetite and mood changes. Doctors aim to avoid the long-term use of very high doses of steroids, which lead to thinning of the bones, muscles and skin, high blood pressure and occasionally temporary diabetes.

Liquid steroid enemas are effective but rather inconvenient; there is a newer foam enema (Colifoam®) which is simpler and quicker to use.

Salazopyrin® (sulfasalazine) is usually well tolerated but in some patients can produce rashes, headaches, nausea and stomach aches or anaemia. It has been in use for over 30 years and its continuous use over months or years in low dosage (4 tablets daily) is very safe. In some men, Salazopyrin® causes a temporary reduction in fertility though this returns to normal within three months of stopping the drug. Many patients note orange discolouration of the urine, which is quite harmless.

The active part of sulfasalazine is 5-aminosalicylic acid (5-ASA). Newer formulations of 5-ASA have been developed to decrease side-effects and target drug delivery to specific parts of the intestine. These include:

Dipentum® (olsalazine), a drug developed from Salazopyrin®, is available as an alternative for those patients who suffer from side effects while taking Salazopyrin®. Both Dipentum® and Salazopyrin® tablets are broken down by bacteria in the colon which releases their active ingredient, 5-ASA. In addition to tablet treatment, there is also local treatment - usually an enema or suppository, which is administered into the rectum to help relieve inflammation in the bowel.

Pentasa® (mesalazine), is a slow release tablet which is designed to release 5-ASA throughout the intestine and colon. In contrast, Asacol® (mesalazine) is contained within an acrylic-based resin that dissolves at pH7 releasing most of the active ingredient at the

end of the small intestine and allowing the 5-ASA to enter the colon as a bolus.

If I have a mild U.C. does it need treating?

Many patients accept rectal bleeding or diarrhoea without seeking medical advice for surprisingly long periods. However, regular bleeding leads to anaemia. Also it is likely that continuing colonic inflammation leads to scarring and narrowing of the lower colon and rectum with the likely consequence of irreversible frequency and urgency of bowel action.

Will U.C. affect my marriage?

Though U.C. may start at any age from newborn to well over eighty, it most commonly appears for the first time in the 20-40 age group, when one hopes for good health in order to cope with career, marriage and bringing up a family. As with any other chronically recurring disorder sympathy and understanding from the patient's partner and family will help greatly to lessen the strains imposed by that feeling of "not being quite up to it". The intimate details of one's bowel functions are not something easily discussed even with a marriage partner, and it is hoped that this booklet will give not only you, but also your partner, insight into U.C. while saving you having to describe your problems in detail.

Will U.C. prevent or affect a pregnancy?

Pregnancy in U.C. should be a planned event and discussed with your specialist first. You are less likely to get pregnant if your U.C. is active however contraception should be used even when the disease is active.

Pregnancy should be planned for when your disease is inactive or only mildly active. In general, if you require drugs (eg. Salazopyrin®, Pentasa®, azathioprine) to control your disease then these will need to be continued during the pregnancy. A flare of disease carries more risk to mother and baby than the risks of continuing the drugs (which are considered small).

Flares of disease during pregnancy are managed in the same way as prior to pregnancy.

There may be some precautions regarding some medications and breastfeeding but these should be discussed with your specialist before attempting to become pregnant. (Also see CCSG Information Leaflet No. 4 - *Sexuality, Fertility & Pregnancy*, for more details)

Regarding contraception, the “pill” will not worsen your colitis.

Do I need to make adjustments in my lifestyle in order to bring about improvements in the disease?

Except for severe flare-ups of U.C., you will probably not require bed-rest in hospital or at home or absence from work. However, U.C. patients will naturally make adjustments in their patterns of work, domestic and social activities in order to help cope with the frequency and urgency of bowel actions which accompany active phases of the disease. Prolonged travel and visits to supermarkets, for example, may be distressing prospects. Here again, the sympathy and understanding of your family will lessen the stress of desperate searches for a ‘toilets’ sign.

Is any research done on U.C.?

A considerable amount of research is being done on U.C. and a related bowel disorder called Crohn’s disease. It doesn’t make headline news in the media because diarrhoea and rectal bleeding lack the emotional appeal of heart disease or nerve paralysis.

Research both in the laboratory and on the ward is directed towards trying to find the cause or causes of the disease, in order to plan more effective treatment.