

Improving life for
people affected
by inflammatory
bowel diseases



Ulcerative Colitis



Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help the work of the Association are always welcomed.

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Introduction

If you have recently been diagnosed with Ulcerative Colitis (UC) or even if you have had UC for some time, you may have many questions about the condition. Knowing more about your condition can help you to lead a full and active life and to make informed decisions about your treatment. We hope this booklet will give you more understanding about Ulcerative Colitis and how it is treated.

What is Ulcerative Colitis?

Ulcerative Colitis is a condition that causes inflammation and ulceration of the lining of the colon and rectum, which make up the large bowel or intestine. Inflammation is the body's reaction to injury or irritation and can also cause redness, swelling and pain. Tiny open sores, or ulcers, develop on the surface of the lining, which may bleed and produce pus. When the lining becomes inflamed it produces extra mucus.

Inflammation usually begins in the rectum and lower colon, but it may affect the entire colon. If UC only affects the rectum, it is called proctitis.

Ulcerative Colitis is one of the two main Inflammatory Bowel Diseases (IBD); the other being Crohn's Disease. IBD is not the same as IBS (Irritable Bowel Syndrome). IBS can cause similar symptoms, but there is no bleeding, ulceration or inflammation. IBD is not infectious.

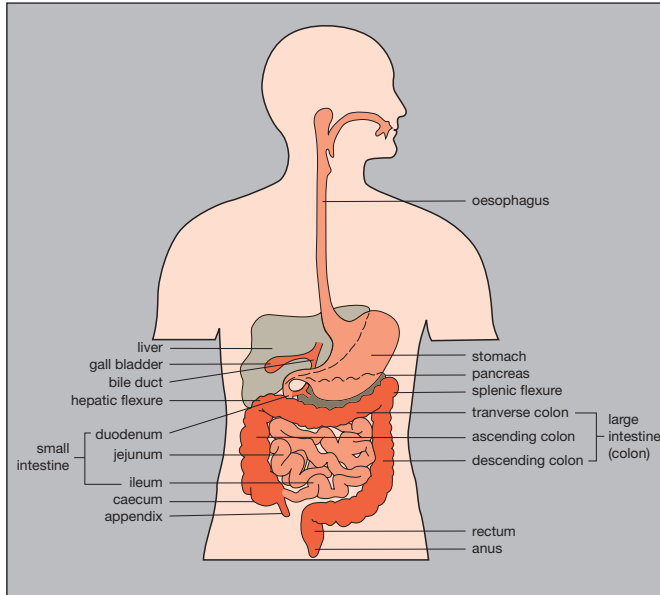
UC is sometimes described as a chronic condition. This means that it is ongoing and usually lasts throughout your life, but you may have long periods of good health, alternating with times when your symptoms flare up.

What causes UC?

Although there has been much research, the cause of UC is still uncertain. However, over the past few years, there have been major advances, particularly in genetics. Researchers now believe that UC is caused by a complex interaction of factors: the genes a person has inherited and an abnormal reaction of the immune system to certain bacteria in the intestines, triggered by something in the environment. The immune system is the body's protection system against harmful substances. So it could be that something in the environment may stimulate the body's defences to produce inflammation that continues without control: once the immune system of someone with UC is 'switched on' it does not know how to 'switch off' properly at the right time. Viruses, bacteria, the use of antibiotics, diet and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these is the cause of UC.

Who gets UC?

UC affects about one in every 500 people in the UK. It affects women and men equally. UC can start at any age, but it is rare in children under five and usually appears for the first time between the ages of 10 and 40. The condition is most common in white people of European descent, especially those descended from Ashkenazi Jews (those who lived in Eastern Europe and Russia). We do not know why, but it is more common in urban rather than rural areas and in northern developed countries, though the numbers are beginning to increase in developing nations. The disease occurs more frequently in non-smokers than smokers, but health professionals would not advise you to take up smoking or to continue to smoke, as the risks of smoking to your health far outweigh any benefits seen in UC (see our information sheet: *Smoking and IBD*).



What happens in the colon?

The colon is part of the digestive system, which is also known as the gastrointestinal tract or gut. You will see from the diagram that the gastrointestinal tract is like a long tube that starts at the mouth and ends at the anus. The gut breaks down the food we eat so that our body can absorb its nutrients to give us good health and energy. The first stage of breaking down food is chewing. As food is swallowed it goes down the oesophagus into the stomach, where digestive juices break it down further over 2-4 hours. The stomach then empties the food into the small intestine, where the main digestion and absorption takes place. The waste products from this process, which include liquid and undigested parts of food, are then pushed into the large intestine. This is made up of the caecum, the colon – the ascending, transverse, descending (distal) and sigmoid colon – and the rectum. The colon absorbs some vitamins and minerals and water from

the liquid waste to make solid faeces (stools), which are stored in the rectum until they pass out of the body through the anus in a bowel movement. The colon also normally contains good bacteria which ferment and digest some of the hard-to-digest parts of food. This helps us to absorb additional key nutrients.

How does UC affect the colon?

When UC is active, the colon becomes less able to absorb the liquid from the stools, resulting in a larger volume of watery stools. Also, because the inflamed colon cannot hold as much waste as normal, there will be more frequent bowel actions. This need to empty the bowels may be extremely urgent, particularly if the rectum is inflamed.

What are the symptoms?

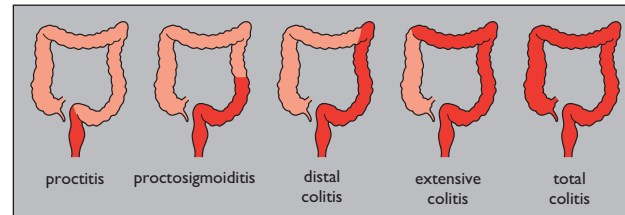
Because UC is an ongoing condition, you may have times of good health, called remission, when there are few or no symptoms, alternating with times when your symptoms are more active, called relapses or 'flare-ups'. It is a very individual condition with some people remaining well for a long time, even for many years, while others have frequent flare-ups.

The common symptoms during a flare-up are diarrhoea, usually with blood, mucus and pus, and cramping pains in the abdomen, which can be very severe and often occur before passing a stool. The diarrhoea may begin slowly or quite suddenly. Having diarrhoea means that it is harder to hold on to the liquid stools and, with the need to get to the lavatory quickly, people may occasionally experience incontinence (accidents). Some people find that their stools are particularly smelly.

People with active UC often feel extremely tired and lethargic. This can be due to the illness itself, as well as a number of other things such as a lack of sleep because of pain and getting up at night with diarrhoea. You may also have a fever and feel generally unwell, and lose your appetite, so you may lose weight. If you lose a lot of blood you may develop anaemia (a reduced number of red blood cells), which can also make you feel very tired.

What are the types of UC?

The symptoms of UC can vary depending on the extent and severity of the inflammation. Because of this, it helps to know which part of your colon is affected. The diagram shows the types of UC, from the most limited, proctitis, involving just the rectum, to the most extensive, pancolitis, involving the entire colon. In general, if you have



extensive disease your symptoms will be more severe, but there are exceptions. For example, you could have severe proctitis or mild pancolitis. In most people UC does not become more extensive over time, but in about two people out of ten it spreads up the colon after 10 years.

- **Proctitis**

Because inflammation is limited to the rectum in proctitis, the rest of the colon is unaffected and can still function normally, so symptoms tend to be milder. For many people with proctitis the only symptom is bright red bleeding that may be mixed with mucus. You may get diarrhoea, but you may have normal stools and in fact you may get constipation. If the inflammation is severe, you may feel pain in the rectum and an urgent need to rush to the loo, but pass only wind. Also, the skin around the anus may become irritated.

- **Proctosigmoiditis**

This type of UC affects the rectum and sigmoid colon. Like proctitis, symptoms include bleeding and a sense of urgency.

- **Distal or Left-sided Colitis**

In this type of UC the inflammation starts at the rectum and continues up the left side of the colon – the sigmoid colon and the descending colon. Symptoms include diarrhoea with blood and mucus, loss of appetite, weight loss and severe pain on the left side of the abdomen. Diarrhoea tends to be less frequent with fewer than six loose stools a day.

- **Extensive and Pancolitis or Total Colitis**

When UC affects most of the colon or the entire colon, this usually causes very frequent watery diarrhoea with blood and mucus. If the inflammation is severe you may have diarrhoea as often as 20 times a day, and you may become dehydrated (see our information sheet: Dehydration). You may also have severe abdominal pain, cramps, fever, and extensive weight loss. Milder flare-ups may cause diarrhoea or looser stools without blood. Very rarely, when inflammation is severe,

gases can get trapped in the colon causing it to swell. This is known as toxic megacolon and causes a high fever and pain and tenderness in the abdomen. It is essential to get treatment quickly as there can be complications.

Can UC affect other parts of the body?

Ulcerative Colitis can cause problems outside the gut. Some people with UC get other conditions, mainly affecting the joints, eyes and skin. These often occur during active disease, but they can develop before any signs of bowel disease or during times of remission. UC can also affect the bones, mouth, kidneys, liver, and blood circulation.

• Joints

Inflammation of the joints, which we know as arthritis, is the most common of the other conditions related to UC and affects about one out of 10 people with UC. Research has shown that you are more likely to get joint problems if you have more extensive disease, if you smoke or if you have had your appendix removed.

Inflammation usually affects the large joints of the arms and legs, including the elbows, wrists, knees and ankles. Fluid collects in the joint space causing painful swelling, though there can be pain without obvious swelling. A few people develop swelling and pain in the joints of the hands or feet, similar to that caused by rheumatoid arthritis. Symptoms usually improve with treatment for intestinal symptoms, and there is generally no lasting damage to the joints.

More rarely, there may be inflammation of the joints in the spine and pelvis – a condition called ankylosing spondylitis. Symptoms from this condition are not usually related to a flare-up of UC and may develop many years before or after bowel symptoms occur. The most common problem is the pain over the sacro-iliac joints, which are on either side of the lower part of the spine. Stiffness and pain in the spine itself may eventually lead to loss of movement.

- **Skin**

UC can also cause skin problems. The more common skin problem seen in UC is erythema nodosum. This condition causes painful red swellings, usually on the legs, which then fade, leaving bruises. It tends to occur during flare-ups of UC and generally improves when the bowel is treated.

Less commonly, a condition called pyoderma gangrenosum starts as small tender blisters, which become painful, deep ulcers. These usually appear on the lower leg near the ankle, but they can occur in any area of the skin or around a stoma. The condition is not usually related to active bowel inflammation.

- **Eyes**

Eye problems are less common. A condition called episcleritis affects the white of the eye, which becomes red, sore and inflamed. A more serious condition, called uveitis, affects the iris. Both conditions usually occur when UC is active and can be treated with steroid drops given into the eye. If you get any kind of eye irritation or inflammation, always mention it to your doctor, who may refer you to an eye specialist.

- **Bones**

People with UC may be more at risk of developing weakened bones. Bone loss is not caused by UC itself, but can develop if you use steroid medication or avoid dairy foods. See our Information Sheet: *The Bones and IBD*.

- **Mouth**

About one out of 10 people with UC get painful sores in the mouth usually when the condition is more active. These sores are like the mouth ulcers that are common in the general population. However, unlike the common mouth ulcers which usually last a few days and appear one at a time, the mouth sores associated with UC may last for many days, even a few weeks, often in a mass and may be unusually large.

Liver

A condition called Primary Sclerosing Cholangitis (PSC) affects about one out of 20 people with UC. PSC is a rare disease that causes inflammation of the bile ducts and can eventually affect the liver. Treatment is usually with ursodeoxycholic acid.

Kidneys

There is a risk of developing kidney stones if you have loose stools and do not drink enough liquid.

Veins

People with UC are at increased risk of forming clots in the veins, usually in the legs, which can cause pain and swelling. You are about three times more at risk if you are in hospital, due to lack of movement, but you may also be at risk at any time when your UC is active. If you get these symptoms or develop chest pain or shortness of breath you should see a doctor straight away. You can reduce the risk by not smoking, and by keeping as mobile as possible, drinking plenty of fluids and wearing support stockings. This is particularly important when travelling by air, which increases the risk of blood clots for anyone. See our information sheet: *Travel and IBD*.

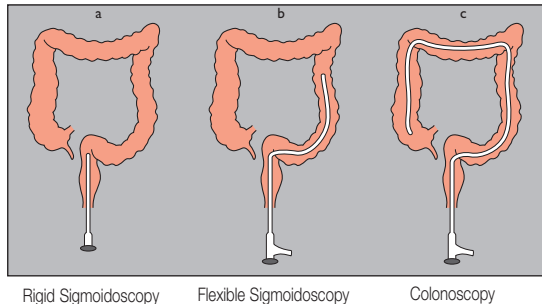
Can UC lead to bowel cancer?

UC is not a form of cancer. However if you have had extensive or total colitis for many years, you have a greater risk than normal of developing cancer in the colon or rectum. It is possible to develop dysplasia (pre-cancerous changes) before the growth of an actual tumour. By looking for these changes during a colonoscopy (see *How is UC diagnosed?*), the doctor can check whether it is advisable to have surgery to remove the colon. If you have had extensive UC for eight years or more it is advisable to speak to your doctor. We have an Information Sheet on *Bowel Cancer and IBD*.

How UC is diagnosed?

If you have diarrhoea, with bleeding and abdominal pain, your doctor may suspect you have UC, particularly if you are a young adult or have a family history of IBD. You will need tests and physical examinations to confirm a diagnosis. Initially routine blood tests can show whether there is inflammation in the body and whether you have anaemia. Your stools may also be tested to check whether your diarrhoea is caused by an infection. There are specific stool tests that can show signs of inflammation, such as Faecal Calprotectin and Lactoferrin, but they are only available in some centres.

If there is inflammation, you will need a further test to confirm the diagnosis by looking directly at the inside of your colon, using a special instrument called an endoscope. This is a thin rigid or flexible tube containing a tiny camera which a doctor or nurse specialist inserts into your rectum. The test allows the specialist to see any inflammation, bleeding or ulcers on the lining of the colon.



From the diagram you will see that there are three types of examinations using different endoscopes. If you have a flexible sigmoidoscopy or colonoscopy you will have to take laxatives to clear your bowel. The specialist may also take biopsies (small samples of tissue) from the bowel lining. Biopsies are sent to a laboratory for examination under a microscope to confirm the diagnosis.

Sometimes you may have a barium enema x-ray to help show how much of the colon is affected. To obtain the x-ray pictures, the specialist places a small tube in your anus. They then insert liquid barium (a white, chalky, harmless substance) and air through the tube to outline the colon and rectum.

You can find more detailed information on tests in our booklet: *Investigations for IBD*.

Sometimes it is not possible to distinguish between UC and Crohn's Disease and then the diagnosis Indeterminate Colitis or IBD unclassified is used. This diagnosis is commonly given to children.

Will I need repeated tests?

You may need to have tests repeated from time to time to check on your condition and to monitor how your treatment is working. Some drug treatments require tests beforehand and regular ongoing tests to check for any potential side-effects. Generally, your specialist will try to avoid repeated endoscopy or x-ray examinations. A colonoscopy can be time consuming and unpleasant, as it needs thorough bowel preparation. Although complications are rare, there is a small risk of damaging the bowel during the procedure. It is important not to use x-rays unless they are necessary. While small amounts of radiation are not harmful, larger amounts are believed to increase the risk of cancers.

How will I know if I am having a flare-up?

Sometimes people with UC get bowel symptoms when their disease is not active. This can be due to IBS, which may be even more common in people with IBD than in the general population. There is no blood loss in IBS, but common symptoms include abdominal pain, bloating and a varying bowel habit with diarrhoea and/or constipation, which can be confused with IBD. It is important to identify the cause of your symptoms, so that you get the right treatment. A stool test can show whether you have an infection. If there is no infection, then a sigmoidoscopy (see *How is UC diagnosed?*) can often show whether there is a flare-up of UC. If your symptoms are not due to inflammation, then it is possible that you also have IBS. Anti-spasmodic drugs, such as mebeverine (Colofac), hyoscine butylbromide (Buscopan) and alverine citrate (Spasmonal) can help to relieve IBS symptoms.

What is the treatment for UC?

Treatment for UC depends on the severity of the condition. It is normally managed by medication, but surgery may become necessary when there is severe inflammation and in some other situations which are described below (see *What about surgery?*). Medication cannot cure UC, but aims to suppress inflammation to reduce symptoms and to control a flare up or to prevent a relapse once the disease is under control. Research has shown that medication to treat UC reduces the likelihood of the disease becoming active again and might even reduce the small chance of bowel cancer developing. This means that taking medication continually, even when your UC is inactive, should help to keep you in remission and may help to prevent bowel cancer. However, if your condition is mild and limited to a small part of your colon, you may be able to stop treatment, if you have been free of symptoms for more than a year.

What drugs are used to treat UC?

Three main types of drugs are most commonly used to treat UC: aminosalicylates, corticosteroids (steroids) and immunosuppressants. Aminosalicylates are the first treatment option for mild to moderate UC. If your condition is more severe or is not responding to aminosalicylates, then steroids may be used. If your condition is still not responding to treatment or if you wish to stop steroids because of side effects, you may be offered immunosuppressants. Occasionally, a fourth type of drug – biologics – is used for severe cases of UC. These are also known as Anti-TNF (Tumour Necrosis Factor) drugs.

There are different ways of taking these drugs, depending on which part of your colon is affected or depending on your preference. For some people, a combination of topical (applied just to the affected area) and oral (by mouth) treatment may be suggested. Aminosalicylates and corticosteroids can be taken topically as suppositories or liquid or foam enemas, or orally as tablets, capsules or granules.

If your UC is limited to the rectum you can use suppositories or foam enemas. If you have distal colitis affecting the first part of the colon, the sigmoid colon, you can use liquid or foam enemas. However, if the disease is further round in the descending colon, liquid enemas are needed. If you cannot or do not like to use suppositories or enemas you can take medication orally. If you have extensive or total colitis, you will need to take medication orally, as enemas will not reach this part of the large bowel. Special coatings on some steroids and aminosalicylates help the drug to be released in the affected part of the bowel. Immunosuppressant drugs are taken orally. If you are in hospital with a severe flare up, corticosteroids (usually hydrocortisone) or immunosuppressants, such as ciclosporin, may be given by intravenous drip (an injection directly into a vein). The biologic used for UC is given in hospital by infusion.

All drugs can have unwanted side effects, but not everybody gets them. If you do, the more common ones usually improve as your body gets used to a drug. Some possible side-effects are listed here and you can check the manufacturer's information provided with your medicine for extra details. You can also get more information about drugs from our booklet: *Drugs used in IBD* and our information sheets: *Azathioprine and 6-mercaptopurine; Ciclosporin; Infliximab and Taking Medicines for IBD*.

The following table gives you details of the various types of drugs used to reduce inflammation:

Drug	What they do	Possible side-effects
<p>Aminosalicylates (5-ASAs) Aminosalicylates (5-ASAs) sulphasalazine (Salazopyrin) mesalazine (Asacol, Ipocol, Mesren, Mezavant XL, Pentasa, Salofalk) olsalazine (Dipentum) balsalazide (Colazide)</p>	<ul style="list-style-type: none"> • Reduce inflammation and maintain remission • Do not have the side effects of corticosteroids, and therefore can be used for longer periods of time • Continued use may help to protect against bowel cancer 	<ul style="list-style-type: none"> • Headaches and skin rash • Indigestion, nausea and diarrhoea • Sulphasalazine may temporarily reduce fertility in men; colour urine orange; stain soft contact lenses.
<p>Corticosteroids (steroids) hydrocortisone prednisolone budesonide (Budenofalk, Entocort) beclometasone dipropionate (BDP) (Clipper)</p>	<ul style="list-style-type: none"> • Reduce inflammation which stops pain, reduce diarrhoea and restore appetite • May also help mineral (sodium) and water uptake • Also reduce inflammation of eyes and joints (Except Entocort and BDP) 	<ul style="list-style-type: none"> • Weight gain • 'Mooning' of face • Growth of facial hair and acne • Increase in blood pressure • Thinning of bones, muscle & skin • Increase in sugar levels in blood, occasionally diabetes
<p><i>The adrenal glands may become suppressed by long-term use of steroids. This reduces the body's ability to cope with stress caused by an operation or accident. It is important to wear or carry a steroid bracelet or card, so that doctors can give you extra steroids if needed. These are not anabolic steroids used by bodybuilders.</i></p>		

Drug	What they do	Possible side-effects
<p>Immunosuppressants azathioprine (Imuran) 6-mercaptopurine (6-MP)(Purinethol)</p> <p>ciclosporin</p>	<ul style="list-style-type: none"> • Suppress inflammation over longer periods of time • Used intravenously in acute attacks 	<ul style="list-style-type: none"> • Can reduce the number of red and white blood cells, so regular blood check ups are necessary • Nausea, a flu-like illness, diarrhoea, abdominal pain and inflammation of the pancreas • Increases skin's sensitivity to sun light • Diarrhoea, nausea, headache, • Difficulty sleeping, tingling of hands or feet, increased blood pressure • A range including nausea, headache, swollen gums, growth of facial hair, increased blood pressure
<p>Biologics Anti-TNF infliximab (Remicade)</p>	<ul style="list-style-type: none"> • Blocks an inflammatory agent in the blood – TNF-alpha – believed to cause chronic inflammation 	<ul style="list-style-type: none"> • Nausea • Headache • Reaction to infusion • Make infections worse

The following table describes drugs that may help to relieve symptoms:

Drug	What they do	Possible side-effects
Antidiarrhoeals codeine phosphate diphenoxylate (Lomotil) loperamide (Imodium, Arret)	<ul style="list-style-type: none"> • Reduce the contractions in the bowel, therefore reducing the number of stools • Absorb excess water from the bowel 	<ul style="list-style-type: none"> • Constipation • Nausea/indigestion • Codeine can cause drowsiness, also drug dependence if taken over a prolonged period
<p><i>If you are having an acute or severe flare up, it is best to check with your doctor before taking antidiarrhoeal drugs, as they can make your UC worse.</i></p>		
Analgesics (Pain killers) paracetamol	<ul style="list-style-type: none"> • Relieve pain 	<ul style="list-style-type: none"> • Constipation • Dizziness • Rashes
<p><i>Paracetamol is commonly used in people with UC, though some evidence suggests its use may precede a relapse. It may be better to avoid non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and diclofenac. Although they can be very effective for pain in the joints and spine, they can make UC symptoms worse or possibly trigger a flare up. Severe arthritis in IBD can be treated with a special type of anti-inflammatory called a cox-2 inhibitor. It is best to discuss this with your doctor.</i></p>		
Anaemia treatments Supplements of iron, folic acid and Vitamin B12	<ul style="list-style-type: none"> • Enable body to rebuild the red blood cells lost during bleeding or damaged as a side effect of another drug 	<ul style="list-style-type: none"> • Constipation • Dizziness • Rashes
Laxatives: osmotic (Movicol) bulking agent (Fybogel)	<ul style="list-style-type: none"> • Softens stool by increasing the amount of water in the large bowel • Considered safer than other laxatives, being slow acting and not absorbed into body • Contains husks that absorb water to bulk stools 	<ul style="list-style-type: none"> • Constipation • Dizziness • Rashes

What about surgery?

You may consider surgery if your quality of life has been affected by repeated flare ups and you have not responded well to medication. Or, if dysplasia (pre-cancerous changes) or cancer is found in your colon during a colonoscopy, surgery is generally recommended. In these situations you will usually have time to discuss the most suitable surgery for you. More rarely, people with severe UC which does not respond to intensive medical treatment, will need urgent surgery (within a few days) or emergency surgery (within a few hours).

The two operations most commonly carried out when you are able to decide on surgery in advance are:

Proctocolectomy with permanent ileostomy

In this operation the surgeon removes the whole colon, rectum and anal canal, and brings out the end of the lower small intestine onto the wall of the abdomen through a permanent opening, called a stoma (ileostomy). A bag is fitted on to the opening to collect the waste from the small intestine which would previously have gone into the colon and passed out as stools through the anus. The bag is emptied or changed when necessary.

• Restorative Proctocolectomy with ileoanal pouch

This procedure, commonly called pouch surgery, generally requires two operations. In the first main operation the surgeon removes the whole colon and the rectum, but leaves the anus. Then a pouch is made using the lower end of the small intestine (ileum), which is joined to the anus. Finally a looped section of the small intestine is brought out onto the wall of the abdomen through a temporary opening (ileostomy). This allows the waste from digestion to be collected in a stoma bag until the newly-formed pouch has had a chance to heal. This will generally take about three months. The second operation will then go ahead to close the temporary ileostomy.

The following operation is much less common, being only suitable for a small number of people with UC:

- **Colectomy with ileorectal anastomosis**

In this operation the surgeon removes the colon and joins the end of the ileum (the lower part of the small intestine) to the rectum. It avoids the need for a stoma, so it may be useful for people who could not cope with a stoma or who are unsuitable for pouch surgery. However, this operation is only suitable if there is little or no inflammation in the rectum or if there is no long-term risk of developing cancer in the rectum.

If you need emergency surgery, you are likely to have the following operation:

- **Colectomy with ileostomy**

In this procedure the surgeon removes the colon, but leaves the rectum. This allows for the possibility of pouch surgery (see above). As in the proctocolectomy, the lower end of the small intestine is brought out onto the abdomen wall to form an ileostomy to collect the waste from digestion. The upper end of the rectum is either closed or brought out to the surface to form another stoma. This is called a mucous fistula and is needed because the rectum may still produce mucus for a while. After recovering from this surgery, you can then decide whether to opt for pouch surgery or a permanent ileostomy, which may depend on your individual medical condition.

For more details about surgery see our publication: *Surgery for UC*.

Do I need to change my diet?

There has been extensive research into diet as a possible cause or trigger of UC, but so far there are not any clear answers. Researchers suggest that certain foods may alter the balance of bacteria that live in the colon in huge numbers. If so, it may be that eating foods and supplements that encourage the growth of 'good' bacteria could improve UC, but further

research is needed. The most important thing is to eat a nutritious and balanced diet to maintain your weight and strength, and to take sufficient fluids to stop you getting dehydrated (see our information sheet: *Dehydration*). You may, however, find that certain foods affect your symptoms. For example, when you have a flare up, you may find that bland, soft foods cause less discomfort than raw vegetables, spicy or high-fibre foods. Some people find that their condition improves if they cut out milk products from their diet. This may be due to some people with UC being sensitive to milk protein rather than the effects of milk on inflammation in the gut. If you have IBS symptoms, it may help to avoid high fibre foods, particularly cereals high in bran. (See the National Institute for Health and Clinical Excellence Guidelines for Irritable Bowel Syndrome at: www.nice.org.uk and The Gut Trust listed under *Other Useful Organisations* at the end.)

You may sometimes need nutritional supplements to replace the loss of vitamins and minerals. This can happen when you have a poor appetite, do not eat enough or when you have ongoing diarrhoea. Before taking any supplements or making any changes to your diet, always check with your doctor or a qualified dietitian.

For more information about diet see our booklet: *Food and IBD*.

What about pregnancy and UC?

If you have UC your chances of conceiving are not usually affected by the disease. However, if you have pouch surgery your fertility may be affected. Also, men taking sulphasalazine may have reduced fertility whilst on the drug, but alternative medication is available. Most women with UC can expect a normal pregnancy and the delivery and development of a healthy baby. However, if your disease is active when you conceive, or flares up during pregnancy, there may be an increased risk of miscarriage or premature birth. So doctors usually recommend that you avoid pregnancy when your disease is very active.

The contraceptive pill is safe and effective unless you have severe diarrhoea, in which case you may wish to use other contraceptive methods. You can continue taking most drugs through pregnancy, including steroids, aminosalicylates and azathioprine. It is important to keep UC under control during pregnancy by continuing treatment, as active disease can harm the growing baby.

For more details see our information sheets: *Fertility and IBD and Pregnancy in IBD*.

Does UC run in families?

UC tends to run in families, so we know that genes are involved. Studies have shown that about two out of 10 people with UC have a close relative with either Ulcerative Colitis or Crohn's Disease. However, genes are only part of the picture and research suggests that environmental triggers play an important role too. So, if you have children, studies have shown that they are more likely not to get IBD.

How does UC affect children and young people?

UC is rare in children under the age of five. About one out of 10 people with IBD are diagnosed before the age of 18. In young people with UC symptoms first appear more commonly around the age of 12. The symptoms are the same as in adults, though they tend to be more severe. This may be because UC tends to be more extensive in children – the whole colon is affected in about eight out of 10 children with UC. Inflammation of the bowel can affect how well a child grows and delay puberty, but most generally catch up in the end. Steroid treatment can also affect growth, but this improves as soon as the steroids are stopped. Your child may at times need additional vitamin and mineral supplements to help their growth. Very occasionally doctors recommend surgery to remove the bowel when a child fails to grow enough.

Children and young people may have particular problems due to loss of time from school, a sense of being 'different' from other young people, and difficulty in the development of independence. We have a booklet for parents: *IBD in Children: a parent's guide*, an information sheet for schools:

Children and young people with IBD: a guide for schools, and a leaflet for young people: IBD concerns for young people. If you have any concerns it is best to talk to your child's specialist doctor or nurse.

What about complementary and alternative approaches?

It is quite common for people with UC to turn to complementary and alternative medicine (CAM) to help control symptoms. These include herbal, traditional Chinese or Ayurvedic medicine, homeopathy, acupuncture, aromatherapy and reflexology. However, there are few reliable scientific studies to show the effectiveness of these therapies, which are generally unregulated. Sometimes people may think such therapies work when possibly, given the unpredictable course of the condition, symptoms have gone into remission coincidentally.

There have been several small scientific studies of CAM for Ulcerative Colitis, which have shown some benefits in mild to moderate UC. These have included research trials of acupuncture, aloe vera, boswellia serrata, bovine colostrum enemas, curcumin (turmeric), nicotine patches, omega-3 fatty acids (such as fish oil), probiotics and wheatgrass juice. While these therapies may help to improve UC, the trials have been limited and more evidence is needed about their effectiveness, so doctors do not usually recommend them.

There is also the issue of safety. Like all drugs, herbal medicines have the potential to be toxic and may interact with other drugs. The World Health Organisation (WHO) has been concerned about the extent of bad reactions to CAM, which have doubled over the past years. As a result the WHO has published a new set of guidelines for national health authorities. The Guidelines provide tips on what to look out for when using CAM and can be downloaded from:
www.who.int/medicines/library/trm/Consumer.pdf.

If you want to take a complementary or alternative product, it is best to talk to your doctor beforehand. It is also important not to stop any medication without discussing it first with your doctor.

How will UC affect my life?

UC is an unpredictable condition and people's experiences vary widely. Many people with UC can control their symptoms with medication and their lives are not likely to be much affected by UC. Others, with severe disease, may experience ongoing symptoms in spite of treatment and then UC is likely to have a greater impact.

Living with UC can have both a practical and an emotional impact. Symptoms of diarrhoea, pain or wind may make you worried about being in public places. Practical planning ahead can help you to overcome this, such as finding out where lavatories are located or taking along spare clothing. On the emotional side, living with a chronic, unpredictable condition can, not surprisingly, cause stress and sometimes depression, and may actually make your condition worse. We have an information sheet: *Staying well with IBD* which suggests ways to reduce stress. The Association also provides a supportive listening service called Crohn's and Colitis Support on 0845 130 3344. This is staffed by specially trained volunteers with personal experience of IBD. There may be times when you wish to see a counsellor and you could speak to your GP about this. There is also information on how to find a counsellor in our leaflet: *How can counselling help you?*

Managing your condition and receiving support can help in improving your quality of life. To help you cope with the day-to-day effects of UC on your life we have produced a booklet: *Living with IBD*, and information sheets: *Managing bloating and wind* and *Managing diarrhoea*, as well as the leaflet mentioned: *Staying well with IBD*. To help those around you – your family, friends, work colleagues and employers – to understand and support you, we have produced two leaflets: *When someone in your family has IBD and Ulcerative Colitis* and *Crohn's Disease: a guide for employers*.

Having UC, you may see your GP and specialist doctor or nurse regularly. This means that it is particularly important for you to build up a good relationship with them. Our information sheet: *Staying well with IBD* has some helpful suggestions on how to get the most from your time with health professionals. You may also find it useful to look at the IBD Standards. This is a document that we produced with other organisations, which sets out the quality of care and support for people with IBD that NHS services should aim for throughout the UK. You can see the document on the website: www.ibdstandards.org.uk or call our Information Line for a copy.

Further information

If you have any further questions or would like a copy of any of the publications mentioned, please contact our Information Line on 0845 130 2233 or email: info@crohnsandcolitis.org.uk. You can download the information sheets from our website: www.crohnsandcolitis.org.uk.

Other useful organisations

Bladder and Bowel Foundation www.bladderandbowelfoundation.org	0845 345 0165
Carers UK www.carersuk.org	0808 808 7777
Colostomy Association www.colostomyassociation.org.uk	0800 328 4257
Core – Fighting Gut and Liver Disease www.corecharity.org.uk	Freepost LON4268, London NW1 0YT
CICRA – children with crohn’s and colitis www.cicra.org	020 8949 6209
IA – The Ileostomy and Internal Pouch Support Group www.iasupport.org	0800 0184 724
NASS – National Ankylosing Spondylitis Society www.nass.co.uk	020 8948 9117

National Osteoporosis Society www.nos.org.uk	0845 450 0230
Ostomy Lifestyle www.ostomylifestyle.org.uk	0800 731 4264
PSC Support UK www.psc-support.demon.co.uk	01970 820 671
Steroid Aid Group	5 Wessex Court, Tennyson Road Worthing, West Sussex BN11 4BP
The Gut Trust (for IBS support and advice) www.thegutrust.org	0872 300 4537

Crohn's and Colitis UK

4 Beaumont House, Sutton Road, St. Albans, Hertfordshire AL1 5HH.

Information Service: 0845 130 2233
Administration: 01727 830038
Fax: 01727 862550
Crohn's and Colitis Support: 0845 130 3344

Email: info@crohnsandcolitis.org.uk

Website: www.crohnsandcolitis.org.uk

Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC)
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