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patient information booklet on

Inflammatory Bowel Disease

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intro

INTRODUCTION

Inflammatory bowel disease (IBD) is a condition in which the bowel becomes inflamed (irritated and swollen) and ulcerated (patchy breakdown of the inner lining). Two predominant types exist: Crohn's disease and Ulcerative Colitis. Although they are distinct diseases, they share many similarities. Both are chronic illnesses comprised of flare-ups (relapses) and periods of well being (remissions). Both, usually first affect people aged 20 to 40 years, but may present for the first time in children and the elderly. Ulcerative Colitis affects only the inner lining of the large bowel, known as the colon, (hence the term colitis). Crohn's disease, named after the American gastroenterologist Burrill Bernard Crohn, can affect any part of the gut from the mouth to the anus but most commonly affects the colon or small bowel and may involve the full thickness of the bowel wall.

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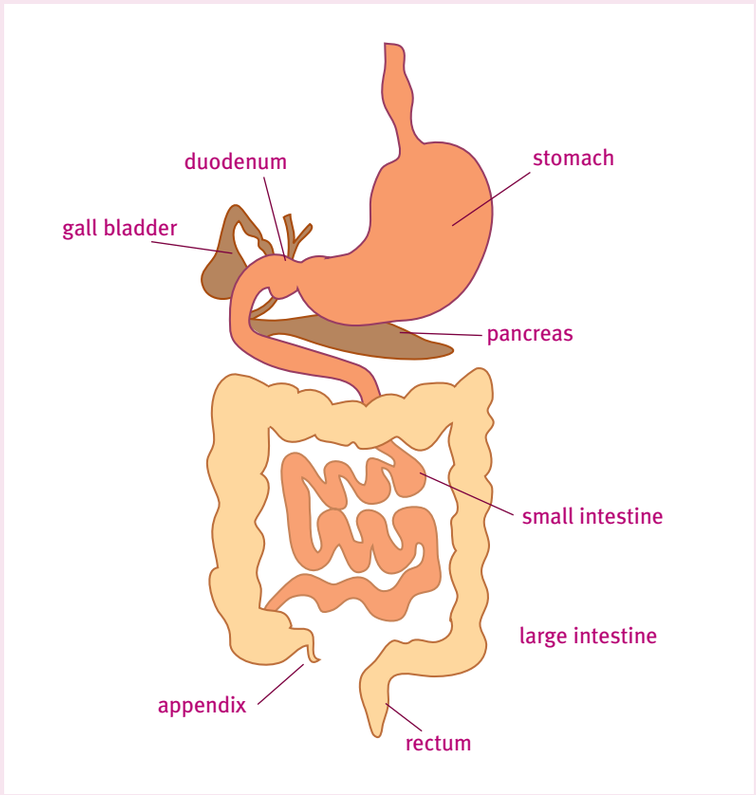
THE GUT OR GASTROINTESTINAL TRACT

The gut or gastrointestinal tract (see diagram) is a hollow tube that runs from the mouth to the anus and is approximately eight metres long. Its function is the digestion and absorption of nutrients, and storage and expulsion of undigested waste. The main parts are the gullet (oesophagus), the stomach, small bowel/intestine (duodenum, jejunum and ileum), large bowel (colon) and back passage (rectum). As mentioned, Crohn's disease can affect any part of the gastrointestinal tract from the mouth to the anus. The commonest sites affected in Crohn's disease are the lower small bowel (ileum) and the colon. The upper small bowel (duodenum and jejunum) is sometimes involved in Crohn's but it is rare for the oesophagus or stomach to be affected. Ulcerative Colitis only affects the large bowel (colon and rectum).



SYMPTOMS

Both types of inflammatory bowel disease may have similar symptoms, depending on the site and severity of inflammation. During your first consultation, the physician will ask about the common symptoms.

ULCERATIVE COLITIS SYMPTOMS

Ulcerative Colitis patients generally have few symptoms when the disease is in remission but when the disease flares up the following symptoms occur:

- *Frequent passage of blood, mucus and some loose stool often associated with urgency (requiring the toilet suddenly and without warning).*
- *Diarrhoea which may be severe*
- *Abdominal pain*
- *Tiredness* and *lack of energy.*

More rarely, there may be:

- *Weight loss*
- *Loss of appetite*
- *Fever.*

CROHN'S DISEASE SYMPTOMS

Crohn's disease is also characterised by periods of remission and flare-ups but the symptoms and pattern of disease are more varied compared to Ulcerative Colitis because Crohn's can affect any part of the gastrointestinal tract.

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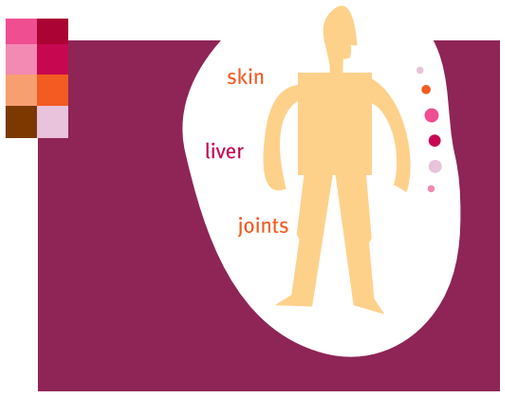

symptoms

CROHN'S DISEASE SYMPTOMS

The main symptoms of Crohn's disease are as follows:

- Diarrhoea, occasionally with bleeding.
- Abdominal pain - due to active inflammation or due to complications of Crohn's such as stricture formation (narrowing of bowel).
- Weight loss and poor absorption of nutrients (commoner in Crohn's disease than in Ulcerative Colitis).
- Bowel obstruction may occur due to swelling or strictures and this may cause abdominal pain, bloating and vomiting.
- Other complications include abscess formation (walled-off collections of pus), fistulae with discharge (abnormal channels or ducts between bowel and the skin or other organs such as bladder or vagina) and skin-tags around the anus.

Other symptoms of Ulcerative Colitis and Crohn's disease

In addition to the main symptoms mentioned above, inflammatory bowel disease may be associated with manifestations outside of the gastrointestinal tract. These are far less common than the symptoms mentioned above and can affect the following:

- *Joints: Inflammation of the large and small joints of the arms, legs, pelvis and spine, giving rise to pain, swelling and restriction of normal movement (arthritis and ankylosing spondylitis).*
- *Skin: Thickened, painful, red skin, especially on the shins (erythema nodosum).*
- *Eyes: Painful, red, gritty, watery eyes (iritis, conjunctivitis).*
- *Liver: Jaundice (yellow skin and eyes) and impaired digestion due to involvement of the liver and bile ducts (sclerosing cholangitis, chronic active hepatitis).*

doctor

WHAT HAPPENS WHEN YOU FIRST SEE THE DOCTOR?

History and Physical Examination

When the physician has asked about the symptoms mentioned in the last section, he/she will proceed to perform a general physical examination, in particular:

- Examination of the abdomen
- Examination of the rest of the body for any changes in the joints, eyes or skin
- In some instances, an examination of the anus (back passage) for skin tags, fistulae, abscesses, or bleeding.

WHAT INVESTIGATIONS OR TESTS WILL BE PERFORMED?

These may include the following:

- Stool specimen analysis to rule out any infective cause of diarrhoea
- Blood tests
- X Ray of the abdomen (useful in assessing the degree of inflammation in Crohn's disease and Ulcerative Colitis)
- Colonoscopy or Sigmoidoscopy (examination of the bowel with small flexible telescope)

COLONOSCOPY AND SIGMOIDOSCOPY

Colonoscopy and Sigmoidoscopy

Colonoscopy and sigmoidoscopy allow the doctor to look directly into the large bowel (colon) and may help distinguish between Crohn's disease and Ulcerative Colitis. This test is done as a day case and an overnight stay in hospital is usually not necessary.

The instrument used is called an endoscope and it is approximately the thickness of your thumb. It has a light, a camera and a device for obtaining samples of the lining of the bowel (biopsies) located at the end. The endoscope is passed carefully through the anus into the large bowel, allowing the doctor to see any abnormalities and obtain biopsies painlessly.

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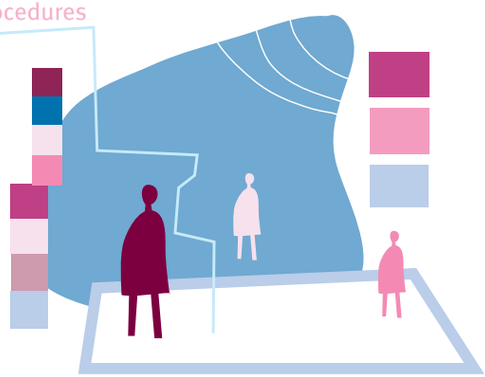

COLONOSCOPY AND SIGMOIDOSCOPY (cont.)

To optimise the view seen by the doctor, the bowel must be completely empty of faeces (motion/stool). Hence a laxative may be prescribed up to a day in advance or an enema may be administered prior to the procedure. Furthermore it is usually necessary for you to arrive in hospital, having fasted for 24 hours. In the examination room, you will be made comfortable on a special bed, resting on your left side. A sedative injection will usually be given before the procedure starts. The tube will then be passed through the anus into the rectum (back passage) with air being passed through to distend the bowel and allow a clearer picture of the bowel lining. This is mildly uncomfortable and you may feel a bloated sensation as if you need to go to the toilet. There is no risk of this however, as the bowel is empty of waste. You may also feel the need to pass wind, and although this may be a bit embarrassing, the nurses and doctors understand quite well why this should occur. The test takes approximately 20 minutes but may occasionally take longer.

Afterwards, you will be left in the recovery room for approximately half an hour and may eat again as soon as you are able. The doctor will be able to tell you most of the results immediately after the test although any biopsy results will take several days to process.

Virtual Colonoscopy (CT colonography)

This is a test where a computer recreates a 3-dimensional image of the colon from special CAT scan X-rays. This provides images similar to those obtained at colonoscopy. It is often used when, for whatever reason, the doctor is not able to get all the way around the large bowel with the endoscope.

Barium Studies

A barium enema involves the insertion of a small tube through the anus in order to pass a special liquid contrast medium (barium) into the large bowel. The barium shows up on x-ray and allows abnormalities of the bowel to be seen.

If Crohn's disease is suspected, you may also undergo a:

Barium follow-through

This is similar to a barium enema except the contrast medium is taken by mouth or delivered directly into the small bowel via a special tube passed into the small bowel via the mouth. Once again an x-ray is obtained to identify any abnormalities. This test is particularly useful to see the parts of the small bowel which cannot be accessed using the endoscope.

FOLLOW-UP TESTING IN INFLAMMATORY BOWEL DISEASE

Both Crohn's disease and Ulcerative Colitis are chronic diseases, which require regular life-long monitoring, even when the patient has no symptoms. To this end, regular visits to your doctor are required, particularly if long-term medications are being used. At each visit, an updated history of symptoms will be taken, a physical examination may be performed and some blood samples may be obtained. In patients with a long history of Ulcerative Colitis, a colonoscopy is usually recommended every few years as there is an increased cancer risk even if the patient remains well (see below). The risk of cancer development is less in Crohn's disease and screening colonoscopy is not advised at present.

In the case of acute attacks or flare-ups, some of the above diagnostic tests may be repeated to determine the activity and extent of the disease in order to guide treatment.

MEDICAL TREATMENT

The principles of treatment of both inflammatory bowel diseases are similar but there are some important differences. The medical treatments are as follows:

Drugs for Ulcerative Colitis

- Steroids, oral *(prednisolone)* or injected *(hydrocortisone)* may be used to alleviate acute attacks. These can be very effective but may be associated with side effects such as high blood pressure, salt and water retention, muscle weakness, stomach ulcers, osteoporosis (weakening of bones), high blood sugar, eye and skin changes and mood swings. Newer steroids, such as budesonide, have less side effects and may sometimes be helpful. Steroids can also be given as enemas (liquid or foam preparations given via the back passage) for treatment of disease involving the rectum and left side of the colon and this avoids many of the side effects of steroid tablets or injections, however if the right side of the bowel is affected then tablets or injections will be needed to get the disease under control. Once the patient has got over the acute attack, steroids are gradually withdrawn. It is important not to stop steroids abruptly as this can be dangerous.

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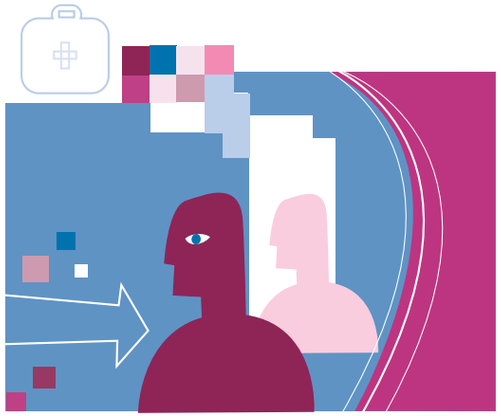

MEDICAL TREATMENT (cont.)

- 5-ASA drugs such as mesalazine *(Asacolon, Pentasa),* olsalazine *(Dipentum),* and sulphasalazine *(Salazopyrin)* are also used to treat inflammation. These may be taken in tablet, suppository or enema form, the latter being useful in the many cases affecting the rectum (back passage) and left side of the colon. These drugs are often used during attacks and as regular maintenance medication to try and prevent flare-ups.

- *Azathioprine* is an immunosuppressant drug which may be used in place of steroids for patients requiring ongoing steroids or frequent courses of steroids. Azathioprine has particular side effects such as allergic reactions, inflammation of the pancreas gland (pancreatitis) and a reduction in white cells in the blood which can predispose to infection. Regular blood tests are needed to monitor for these side effects.

- *Ciclosporin* is a strong immunosuppressant drug which is given intravenously in patients with severe Ulcerative Colitis which is not responding to intravenous steroids. Patients on this drug are at increased risk of developing infections. Other side effects include high blood pressure and impairment of kidney function. Levels of the drug have to be closely monitored.

- Infliximab (Anti-TNF-alpha) is sometimes used in place of Ciclosporin to treat patients with severe colitis not responding to intravenous steroids.

drugs

DRUGS

Drugs for Crohn's Disease
The medications used for Crohn's disease depend to some degree on the site of disease.

- *Steroids* are used as for Ulcerative Colitis.

- *Mesalazine, sulphasalazine* and *olsalazine* are used for Crohn's disease of the large bowel. Slow release *mesalazine* is used for Crohn's involving the small bowel and pH-dependent release *mesalazine* for localisation in the lower small bowel.

- *Metronidazole,* an antibiotic, may be used for acute attacks in patients, particularly for disease involving the anus and back passage.

- *Azathioprine* is also used in Crohn's patients to try to prevent disease flare-ups and to avoid the long-term use of steroids.

- *Methotrexate* is sometimes given to patients not responding to, or intolerant of Azathioprine. It is given as a once weekly intramuscular injection. As with all immunosuppressants, it can predispose to the development of infections. It can also cause bone marrow suppression leading to a reduction in circulating blood cells. Less common side effects include lung and liver damage. Patients receiving Methotrexate are given folic acid tablets to reduce the risk of side effects.

- Infliximab is used to treat severe Crohn's disease, especially fistulating disease, not responding to steroids, azathioprine or 5-ASA agents. It is usually given as an intravenous infusion at week 0, week 2 and week 6 then potentially every 8 weeks. Infliximab can predispose to the development of serious infections, in particular TB. As it is a relatively new drug the long-term side effects are not yet known; it has been suggested that it may increase the risk of some forms of cancer. Patients being considered for this treatment will be screened for TB and will be continued on Azathioprine or Methotrexate.

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- Humira is a new drug, similar to Infliximab, which has just been licensed for the treatment of Crohn's disease. It is given as an subcutaneous injection (under the skin) every 2 weeks. Patients may give the injections to themselves at home.

Importance of compliance with medications.
It is very important to take the medications as prescribed by your doctor. Even if you are well, it is important to continue taking the medication if this is what the doctor suggests because the aim is to try and keep the disease in remission and prevent flare-ups

SURGICAL TREATMENT

Surgical treatment may be used in inflammatory bowel disease for a number of reasons.

Surgical Treatment for Ulcerative Colitis

Most patients with Ulcerative Colitis will never need to have an operation. However, surgery may be required in the following circumstances:

- Failure of response to medical treatment using the medications described above
- Acute deterioration of symptoms where there is a danger of perforation (rupture) of the bowel
- The development of cancer or pre-cancerous tissue change.

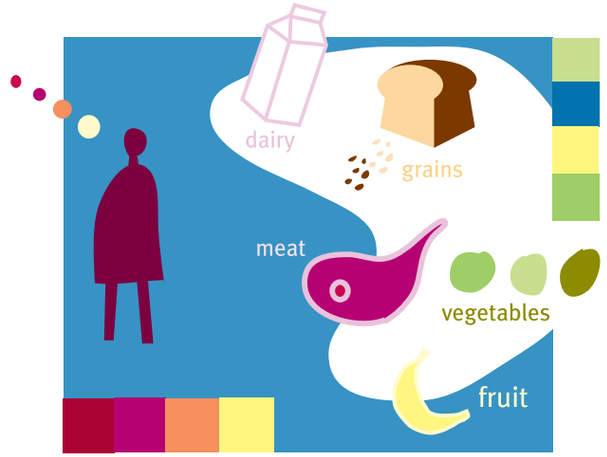
Surgery usually involves removal of all of the colon and rectum *(proctocolectomy)*. In some cases a special pouch will be created out of the remaining small bowel to function as an artificial rectum (back passage). This operation is usually done in two stages to allow the pouch to heal. The small bowel is brought out to the abdomen as a temporary spout (ileostomy) that empties into a bag and is reconnected to the pouch at a later date. Such patients will have approximately 5 bowel motions per day, which is usually acceptable to most patients. If this is not possible or unsatisfactory, an ileostomy is made. The ileostomy bag lies flat on the abdomen. There are specialist nurses who will give advice on care of an ileostomy. The formation of an ileostomy should not interfere with normal daily living.

It should be remembered that even though surgery is only ever performed if absolutely necessary, removal of the large bowel is a "cure" for Ulcerative Colitis and patients often experience a greatly improved quality of life after surgery.

Surgical Treatment for Crohn's Disease

Patients with Crohn's disease are more likely to require surgery to:

- Remove parts of the large or small bowel which are very diseased
- Deal with narrowings (strictures) or fistulas of the bowel
- Drain abscesses (sometimes under CAT scan or ultrasound scan guidance).



diet

NUTRITION AND DIET IN INFLAMMATORY BOWEL DISEASE

A key component in the treatment of IBD is a healthy diet. A balanced diet of foods from all food groups (grains, dairy, fruits and vegetables, meat and alternatives) is recommended to ensure an adequate supply of carbohydrates, proteins and fats. This balanced diet gives the body the nutrients needed for daily growth, and allows the body to repair damage and fight illness.

The patient will generally know best which foods they tolerate and which foods they must avoid. However, in general many patients find fatty, spicy and raw foods more difficult to digest.

Diet and nutrition problems arise in Crohn's disease more commonly than in Ulcerative Colitis and usually consist of the following:

- Iron, vitamin B12 and protein deficiency due to reduced absorption if the small bowel is affected

- Increased nutritional requirements due to fever, infection and inflammation.

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meals should not be missed

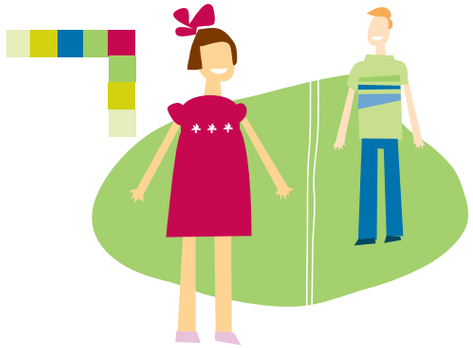
Some people with IBD feel “full” easily, especially if there is bowel inflammation or narrowing. In this case, eating more frequent but smaller meals is often helpful. Nutritional supplements between meals can improve low energy levels and supply needed nutrients. It is very important to note that meals should not be missed.

If the disease is severe, the person may be advised to take additional nutritional supplements (along with medications) to restore the balance of nutrients and to help prevent weight loss. In rare cases, patients may be unable to eat sufficiently or to eat at all, although this is usually only temporary. In these instances, feeding can be achieved using a narrow feeding tube passed through the nostril and into the stomach (enteral nutrition), An alternative is total parenteral nutrition (TPN), in which nutrition is given intravenously. Enteral nutrition is sometimes used as a treatment, together with standard medications, as it gives the bowel a chance to rest and may relieve pain.

For further advice on diet you should consult your doctor, specialist nurse or dietician.

PSYCHOLOGICAL MEASURES

- *Relaxation exercises,* or other measures to relieve stress may be beneficial.
- *Psychotherapy* may be useful in reduction of symptoms but is never curative if used alone.



INFLAMMATORY BOWEL DISEASE IN CHILDHOOD

Both Crohn’s disease and Ulcerative Colitis are relatively rare in childhood but the incidence increases as the teenage years approach. The unpredictable course of both diseases is similar to that of adulthood, with Crohn’s disease in particular tending to be most active for the first few years, after which the relapses become less severe and less frequent.

Despite their illness, most children with inflammatory bowel disease do well. There will be occasions where absence from school will be unavoidable, but these will usually alternate with long stretches of remission between flare-ups when a normal life can be led. Hospitalisation is rare. It is also advisable to speak with the child’s teacher regarding the illness. Medical certificates and notes are always available from the doctor. Furthermore, the child’s choice of career should not be limited by their illness.

Having a child with inflammatory bowel disease is sure to cause anxiety for the parents. It is important therefore to discuss your concerns with a physician in order to understand the illness sufficiently to avoid transmitting your anxieties to your child. Your child will feel better if you explain their illness to them in age appropriate language. The amount you can tell them will obviously vary with age, but some attempt at explanation is better than no explanation at all. Your doctor and clinical nurse specialist will be able to help if necessary.

It has been found in the past that up to 30% of children with Crohn’s disease experience a slower growth rate and a delay in onset of puberty when compared to the general population. This is much less common in Ulcerative Colitis sufferers and may be due to long-term steroid use or small bowel malabsorption in Crohn’s disease. It is important to adopt a suitably healthy diet and to take dietary supplements if necessary. Patients will usually be able to pinpoint the foods that make their diarrhoea and abdominal pain worse and can therefore avoid these. Further dietary advice is available elsewhere in this booklet.

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ANSWERS TO FREQUENTLY ASKED QUESTIONS

What causes inflammatory bowel disease?

The actual cause of inflammatory bowel disease is unknown but a number of clues exist. Genetic factors play a role; different races have different incidence rates of IBD and clusters of IBD occur in families. Other possible causes include viral or bacterial infection, and factors related to the immune system. There is no link with the MMR (mumps, measles, rubella) vaccine and present medical guidelines suggest that young children should receive the MMR vaccine as normal. Psychological factors may precipitate an acute attack in known sufferers but have never been shown to cause the disease. It is notable that the incidence of Crohn's disease is on the increase in industrialised nations.

What is the long-term outlook (prognosis) for patients with inflammatory bowel disease?

The long-term outcome of inflammatory bowel disease is very variable and each patient will differ from the next. It is therefore not usually possible to comment until each individual patient has been observed for a number of years. Many patients do very well, only suffering intermittent minor problems. Normal life expectancy is not affected in either Crohn's disease or Ulcerative Colitis. However, inflammatory bowel disease is a chronic illness characterised by acute phases in which the disease flares up and periods of remission during which the disease causes few problems. By seeking regular check-ups and by taking the prescribed medication (even if a few flare-ups must be endured) you will prolong the periods of remission and minimise the acute flare-ups.

Is there any cancer risk associated with inflammatory bowel disease?

Patients who have had Ulcerative Colitis for 10 years or more, particularly where the entire colon is affected, have an increased risk of developing bowel cancer. For this reason, regular colonoscopies should be performed to screen against tumours and pre cancerous change. There is a smaller increased risk of bowel cancer in patients with Crohn's disease involving the large bowel. Your doctor will advise you as to how often colonoscopy need be performed.

What effects will inflammatory bowel disease have on my career and leisure activities?

In general, inflammatory bowel disease should have little negative effect on either of the above. However when acute attacks occur, patients will need to take time off work and it is therefore useful when employers are flexible with regard to sick leave. Furthermore sedentary jobs are often more suitable than physically taxing ones, particularly for patients who are prone to frequent flare-ups. Sufferers are not discouraged from playing sports of any kind, however rest from physical exertion is recommended during acute flare-ups.

How do I take suppositories or enemas?

Use a pair of thin rubber gloves to insert a suppository. Lubricate the suppository with petroleum jelly and then, using the first finger, insert the suppository into the back passage (rectum) as far as it will go. The longer it is kept in, the more effective it will be. Enemas usually come with a nozzle attached. Again, lubricate the nozzle with petroleum jelly and insert it slowly about three inches into the rectum, while gently squeezing out the contents. The enema should be retained for as long as possible. More detailed instructions will be available with each brand of suppository or enema.

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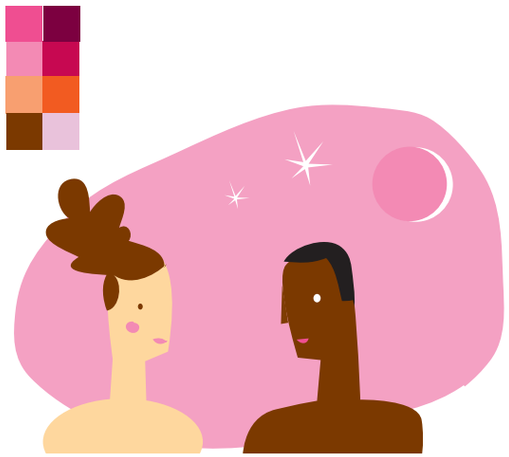
Can I go on holiday?

Patients who wish to go abroad on holiday should, in most cases, be able to do so without difficulty, providing they seek advice from their GP before travelling. It is advisable to take an E111 Form in addition to travel insurance. This is available from your local Health Authority. Medication should always be carried in your hand luggage in case of delays. Always carry a copy of your prescription when travelling abroad.

If travelling by air, ask for an aisle seat near the toilets in order to alleviate the stress of a possible 'accident'. It is wise to avoid remote destinations where medical advice may be difficult to obtain, and places where travellers' diarrhoea is common. Patients who go to such areas are advised to eat only well cooked foods and drink only bottled water. All patients should bring an adequate supply of medication to last the duration of their stay, allowing for delays. Crohn's disease patients on long-term metronidazole should avoid alcohol and direct exposure to sunshine (on holiday and at home). The Irish Society for Colitis and Crohn's Disease is part of a European Association with links to other patient support groups. Contact details may be obtained directly from the Irish Society (telephone 01-8721416).



What effects will inflammatory bowel disease have on sex, pregnancy and family planning?

Although inflammatory bowel disease should not interfere with any of the above, patients should bear a few points in mind:

- In Crohn's disease, anal fistulae may interfere with sexual activity. In such cases, medical advice should be sought.
- In acute flare-ups of either disease, menstruation may be temporarily affected.
- During flare-ups, particularly if diarrhoea is a problem, the oral contraceptive pill may be less effective and other barrier methods of contraception should be used.
- There is no evidence to suggest that either Ulcerative Colitis or Crohn's disease will be adversely affected by pregnancy. However, if you are planning a family or become pregnant, you should always discuss this with your doctor and it is best to try and conceive during disease remission, in other words when you are well.
- Acute flare-ups during pregnancy can be safely treated with corticosteroids or aminosalicylates without harming the foetus or embryo.
- Azathioprine has been used safely during pregnancy, however it is advisable to discuss treatment with your doctor.
- Although Infliximab has been used during pregnancy, experience with this drug in pregnancy is limited.

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HELP GROUPS CURRENTLY AVAILABLE

Ireland:
Irish Society for Crohn's and Colitis (ISCC),
Carmichael Centre,
North Brunswick St.,
Dublin 7.
Tel: 01 872 1416
Fax: 01 873 5737
Website www.iscc.ie

UK:
National Association for Colitis and Crohn's Disease (NACC),
4 Beaumont House,
Sutton Road,
St. Albans,
Herts AL1 5HH,
UK.

Tel: (44) 1727830038.
Fax: (44) 1727844296.

Website www.nacc.org.uk

Crohn's Childhood,
48 Ewell Downs Road,
Ewell KT17 3BN,
Epsom,
Surrey,
UK.

Other useful websites:
Crohn's and Colitis Foundation of America
www.ccfa.org
American Academy of Family Physicians
www.aafp.org

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