cicra

better lives for children with crohns and colitis

children with crohns and colitis

a guide for parents and carers

We are CICRA and we support children living with Crohn's and colitis, and their families.

We believe that all children deserve **a childhood unlimited by inflammatory bowel disease.**

CICRA was founded in 1978 to fund research into Crohn's, working towards better treatments and training of specialists. We continue to drive the development of paediatric gastroenterology in the UK.

We are working hard to find out what causes Crohn's, colitis and all forms of IBD, to help the many children and young people diagnosed each year, including a growing number under 5 years old.

We lead research into better treatments, support children and families with relevant information, work with health professionals to improve care and give children a voice to help everyone understand the impact these conditions have on childhood.

contents

what is inflammatory bowel disease (IBD)?

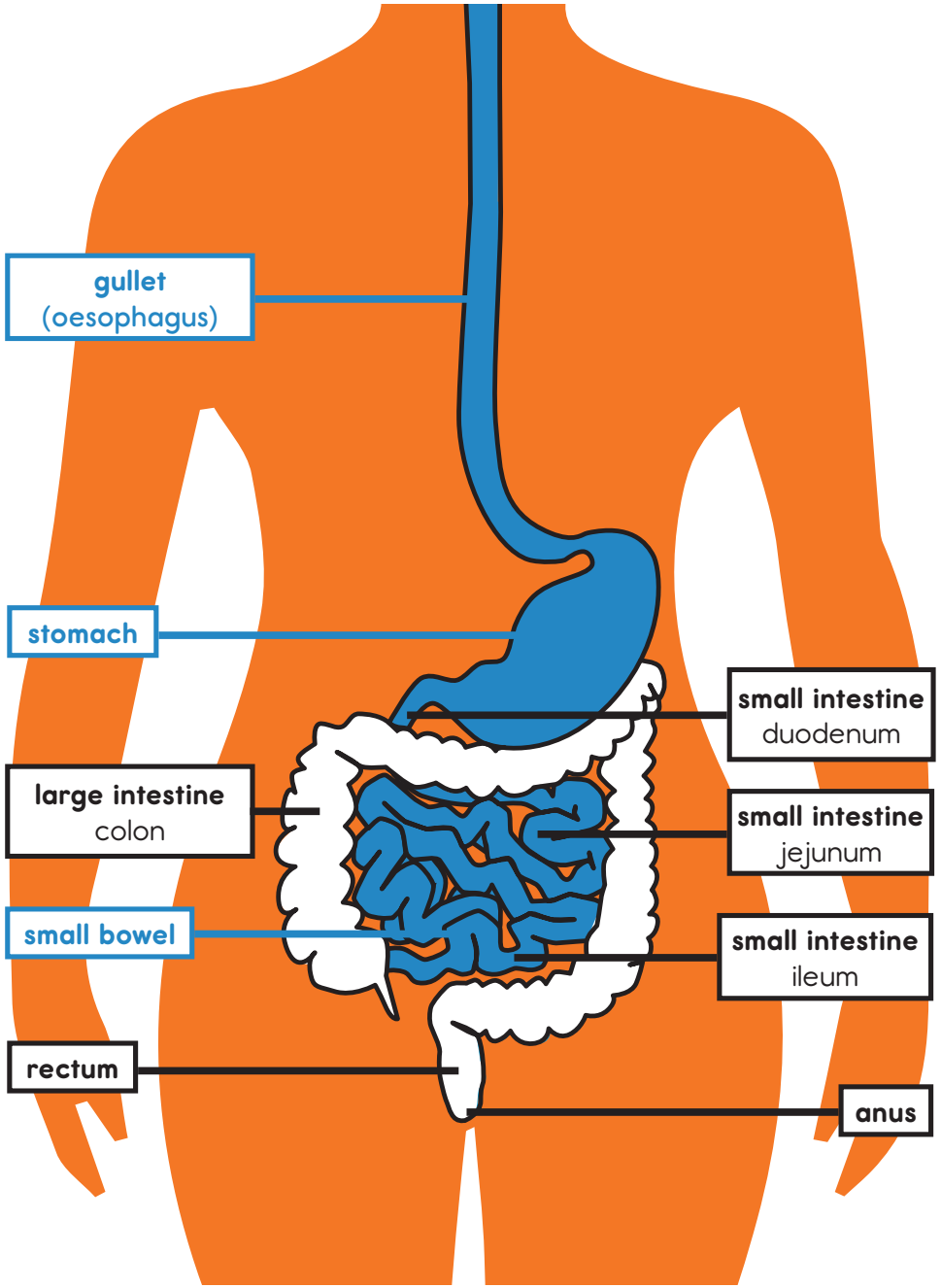
Crohn's disease and Ulcerative colitis are two of the most common diseases in a group of illnesses known collectively as inflammatory bowel disease (IBD). Although they are different diseases, they are difficult to tell apart, and indeed are often treated in a similar manner. When there is definite evidence of chronic inflammation but it is not possible, at least at first, to decide whether it is Crohn's disease or Ulcerative colitis it is referred to as IBDU (inflammatory bowel disease unclassified), previously known as 'Indeterminate Colitis'. In rare cases, it may remain 'indeterminate' for a considerable length of time. In some instances, results from subsequent tests may show changes resulting in a previous diagnosis being amended.

Crohn's disease is characterised by inflammation of one or more areas of the digestive tract, with normal areas of gut between. It can occur anywhere from the mouth to the anus but most ommonly in the large and small intestine. This inflammation may lead to ulceration, abscesses and strictures in the bowel. It is a chronic (long lasting) condition which tends to wax and wane over a period of months or years. So far there is no cure, but treatment should produce symptom-free remission.

Oral Crohn's, affecting the mouth and lips, occurs frequently in children and may occur with or without any involvement of the digestive tract.

Ulcerative colitis is inflammation of the colon (large bowel) causing ulceration and bleeding. It may affect only the rectum or may spread along the whole length of the colon (universal or total colitis). It is characterised by periodic relapses where the symptoms recur and periods of remission where the patient is symptom free.

Allergic colitis is an inflammatory disorder of the colon which occurs mainly in pre-school children. It is caused by an allergic reaction to food; most usually cow's milk, egg, soya and/ or wheat. It is nearly always associated with other conditions such as asthma, eczema and hayfever but may also occur in other children who have minor immunodeficiency states.



what are the symptoms of IBD?

With Crohn's disease the symptoms are extremely variable including severe abdominal pain (sometimes mistaken for appendicitis), vomiting, nausea, persistent diarrhoea (possibly with blood and/or mucus), constipation, dramatic weight loss and mouth ulceration. Sometimes the symptoms may not suggest bowel disease at all with the child feeling lethargic with a loss of appetite, joint pains, skin rash or just growth failure.

With Ulcerative colitis, the symptoms are usually more acute with severe abdominal pain, persistent diarrhoea, usually with blood and mucus (slime) in the stools.

With allergic colitis, the symptoms are usually less marked than in Crohn's disease or Ulcerative colitis and consist mainly of loose stools with flecks of blood often associated with abdominal pain. In addition to the colitic symptoms there may be allergic reactions in other systems such as eczema and asthma.

what causes IBD?

We simply do not know but it is probably due to a combination of factors. Damage to the intestine is caused by an overreaction of the body's own immune system but what causes this to happen still remains a mystery. However, we are quite sure that it is nobody's fault. It is not due to poor diet, nor to inadequate care and it is not cancer. Crohn's disease and Ulcerative colitis are strictly speaking not hereditary; however, sometimes more than one member of the same family may be affected. This could be the result of genetic susceptibility to the condition or perhaps the result of people sharing the same environment. If a family member has bowel symptoms their GP should be told of the family history of inflammatory bowel disease. Stress does not cause inflammatory bowel disease but, as with other chronic conditions, stressful situations can have a temporary worsening effect.

who gets IBD?

Crohn's disease and Ulcerative colitis can appear at any time and do not discriminate. They can affect people of any age, ethnicity, sex or background. When Dr Crohn first published his findings of what was referred to then as Regional Ileitis, the most common time for this to appear was between the ages of 20 and 30, but for no known reason, since the early 1970's there has been a dramatic increase in the incidence of inflammatory bowel diseaase in children of all ages.

what tests are needed to diagnose IBD?

As some of the symptoms mimic other less serious disorders, diagnosis is very difficult and often another diagnosis may have been made at first. Because of this and the vague and sometimes intermittent nature of the symptoms, special examinations are necessary to give the doctors a clear picture of exactly what is happening. In inflammatory bowel disease, blood changes occur which are known as inflammatory markers, for which a standard screening test is a single blood sample for a full blood count, ESR, CRP and serum albumen. In some centres a white cell scan is carried out (see CICRA's booklet 'what do the doctors mean?' for more details).

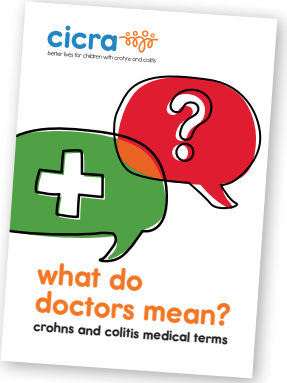
Ultrasound of the abdomen (like an antenatal scan in pregnancy) is sometimes used.

Endoscopy is a painless, but sometimes slightly uncomfortable procedure, carried out by looking at the gastrointestinal tract with a flexible lighted tube. A sigmoidoscopy is an examination of the lowest part of the bowel (rectum) and no preparation is needed. Before colonoscopy (to see all of the large bowel) a laxative is given to clear the bowel completely and just prior to the procedure a mild sedative given. The tube is then passed into the intestine via the anus so that the doctor can see the lining of the bowel. Sometimes a colonoscopy will be performed under a general anaesthetic.

Alternatively, a similar tube can be passed through the mouth – gastroscopy (to see the lining of the oesophagus, stomach and duodenum). This test is also used to exclude conditions which might mimic Crohn's disease, such as coeliac disease or duodenal ulcer. During endoscopy examinations a tiny sample (biopsy) of tissue is taken for examination under the microscope.

With a barium meal and follow through a flavoured chalk-like drink is given so that the radiologist can watch the progress of the liquid through the stomach and intestines on the x-ray screen. With a barium enema, the bowel is cleared and a chalk-like liquid gently poured into the rectum. This then flows backwards to give an x-ray picture of the large intestine.

A single x-ray of the abdomen is not a routine test. However, it might be needed, for example, to demonstrate constipation or to see whether, in a case of colitis, the bowel is dangerously distended.



what is the treatment for Crohn's disease?

As Crohn's disease is so variable, there is no one set treatment. In general, a plan of treatment is made for each patient individually. There are several ways of getting the condition under control. In children the first approach may be enteral feeding to bring about a remission. This liquid nutrition can either be drunk or passed to the stomach via a very fine nasogastric tube. Such tubes are easy to insert and can be worn at home, at school, work or even to play sports. However, drugs (including steroids) may be needed to suppress the inflammation and bring about remission. To try and maintain this remission a less powerful drug may be necessary for a long period. If the disease has caused severe weight loss, extra nutrients may be given straight into the blood stream (TPN – total parenteral nutrition). Unfortunately, there is no knowing how long remission will last and no way of preventing a further attack. Some patients will experience a relapse quite soon into remission but in others the remission may last for years.

At some stage surgery may become necessary if, for example, a narrowed segment of bowel causes an obstruction, or the symptoms are not responding to either enteral feeding or a drug regime. An operation may mean a small part of the bowel being removed (resection) and the healthy parts joined together. In some cases, the bowel will need to be brought out on to the surface of the abdomen creating a stoma either temporarily or permanently. If growth is retarded and puberty delayed, surgery may be performed to bring about remission to coincide with what would be a natural growth spurt.

what is the treatment for Ulcerative colitis?

An acute attack of Ulcerative colitis is usually treated with a combination of drugs including steroids taken by mouth, plus drugs in the form of an enema into the rectum. This is followed by a prolonged or indefinite period of maintenance treatment with a much less powerful drug. In severe cases an urgent operation may be necessary to remove all or part of the colon (colectomy or sub-total colectomy.)

Patients who have had severe Ulcerative colitis for many years are at slightly increased risk of cancer of the colon. In this case, regular colonoscopy is advised to detect pre-cancerous changes early. Total colectomy, if necessary, completely cures Ulcerative colitis but the patient is left with a permanent ileostomy (an artificial opening on the stomach).

what is the treatment for allergic colitis?

The majority of children will recover when the foods to which they are sensitive are removed from their diet. This should only be done in conjunction with a paediatric dietitian. In addition, they may require adjunctive treatment with sodium chromoglycate or sulphasalazine.

Most children get better with either enteral feeding, drugs given over a period of time or a simple operation. Should an ileostomy become necessary, either temporary or permanent, then help will be given by a specialist nurse, called a stoma therapist. Most children who have to undergo this surgery go on to live a full and active life.

what about drugs and their possible side effects?

Drugs used in the treatment of Crohn's disease and Ulcerative colitis are powerful because these are serious illnesses. Further details can be found by contacting CICRA to ask about drugs used in the treatment of inflammatory bowel disease.

Most drugs have side effects, but the doctors have to balance these against the benefits of the treatment. However, there are ways of minimising side effects such as giving steroids on alternate days and doctors do take all this into consideration. Drugs given to maintain remission are less powerful and are as safe as possible.

is diet important?

Poor appetite and inflammation in the bowel lead to rapid weight loss and it is important to counteract this. There is no special diet that will help all patients but generally a well-balanced diet containing essential nutrients should be encouraged. When unwell, children often feel as if they have just eaten a big meal so a normal size meal will probably be refused. Gentle encouragement with small amounts may help. If a particular food upsets the child, then it should be omitted from the diet. However, it is dangerous to try dietary manipulations without the supervision of a doctor or dietitian as avoiding too many foods will lead to further malnutrition. Sometimes a liquid (elemental) diet will be needed to supplement the food taken.

what about growth and puberty?

A number of children with Crohn's disease have a notable delay in height and pubertal development. The cause is due to a combination of factors including the inflammatory process itself, loss of nutrients, steroid treatment and perhaps hormonal changes. Monitoring by careful measurement and clinical examination of the stages of puberty are important. Fusion of the bones in the wrist also indicates pubertal changes and x-rays of the wrist are taken to assess the bone age. If the bone age is less than the actual age of the child there is time to catch up in both height and sexual development. Referral to an Endocrinologist (a doctor who specialises in growth and development) may be suggested. Follow-up studies of children with inflammatory bowel disease have shown that even though puberty may be delayed by several years most teenagers eventually reach maturity and function normally. Some youngsters continue to grow in height into their twenties, long after the onset of puberty, and long after their peers have stopped growing. Many reach their normal height in this way.

how can I help my child cope with this disease?

A prolonged illness of any sort, particularly when the future outlook is uncertain puts enormous stress on the whole family and there is no doubt that a calm, positive attitude to the problem is of tremendous benefit. If possible you should talk openly with your child and answer any questions as honestly as possible. It is important for you to become as well informed as you can. Ask questions of your child's doctor and encourage your child to ask questions. CICRA publishes leaflets on special subjects including guides for Primary and Secondary schools, and a Teacher's Guide and these are available by contacting the CICRA office. Some of the symptoms of inflammatory bowel disease such as severe pain or bloody stools can be very frightening to a child but your knowledge of these symptoms can have a reassuring effect on the child. After a period of relatively good health your child may suffer a setback and may become depressed – quite understandably – at the realisation that the disease is not going to go away. Changes in mood and personality may also result from some treatments. You can help by reassuring your child that this setback is probably temporary and by making sure that they receive prompt medical attention. It may be that you will need to spend more time with your sick child than with other children. This can cause resentment and feelings of jealousy. Even though inflammatory bowel disease in a child does tend to become a family problem try, if possible, to avoid making the illness the centre of family life.

Another member of the medical team who may be able to help your child come to terms with having a long term illness and prevent the natural anxieties is a Child and Adolescent Psychotherapist or Psychiatrist. It is also helpful to speak to other parents who have faced similar problems. If you are not in touch with others but would like to be, a call to the CICRA office where there are parents and others who have been through similar problems may be of help.

In summary there will be times when the symptoms of inflammatory bowel disease will be very distressing and although the temptation may be to protect and spoil them it will not help the child cope with having a chronic illness or help them learn to take control of their own condition as they get older. With good treatment they should feel well most of the time and should be encouraged to lead as normal a life as possible. In time they will know whether there are any limitations on their lifestyle and adjust to these accordingly. Within the CICRA membership are adults who suffered from Crohns Disease or Ulcerative Colitis as children and who are leading a very normal life, many with healthy children of their own.

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get in touch

020 8949 6209 | support@cicra.org | www.cicra.org

find us on social media

@CICRAcharity

Crohn's in Childhood Research Association
Pat Shaw House, 13-19 Ventnor Road, Sutton, Surrey SM2 6AQ
Registered charity in England and Wales no. 278212 and in Scotland no. SC040700

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