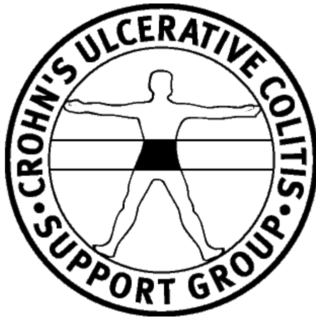

Crohn’s disease

CCSG Information pamphlet No. 1

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This booklet sets out to answer the questions most commonly asked about Crohn's disease. 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 Crohn's disease, 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.

Why Crohn's Disease?

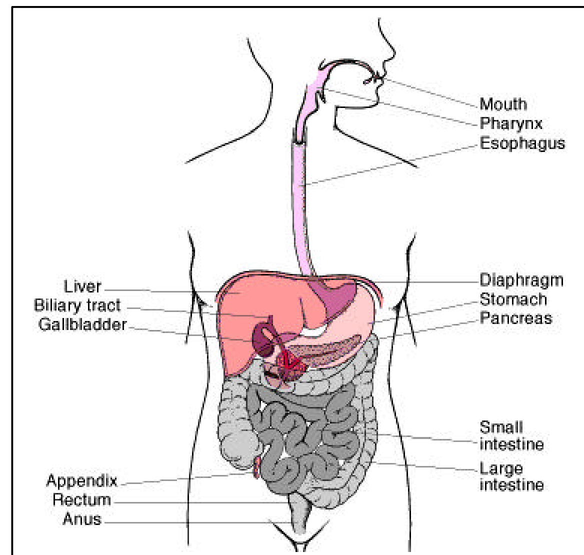
Although Crohn's Disease existed for possibly 300 years before it was named, it was only distinguished from other conditions with similar symptoms by a New York physician, Burrill Crohn, in 1932. Originally it was thought to involve only the lower small intestine, the ileum, and it is still called ileitis in the USA.

What is Crohn’s Disease?

Crohn's disease is an inflammatory bowel disease in which the wall of one or more segments of the gastrointestinal tract becomes thickened, inflamed and swollen (Figure 1). The thickening may lead to narrowing of the hollow digestive tube in that area. Intermittent patches of Crohn's inflammation may involve only a few centimetres of the intestine or may be much longer, over a meter or more. Any part of the gastrointestinal tract from the mouth to the anus can be affected and there may be more than one area of involvement at one time. The most common site of involvement is the last part of the ileum, but all or part of the colon or large intestine, may be affected, either alone or with the adjacent ileum. It affects all the layers of the bowel. Inflammation in or around the anus is also common. This may take the form of fissures (ulcerated cracks) in the skin of the anal canal, fistulae (small openings discharging pus) around the anus, or tags (swollen but often painless lumps) just outside the anus.

What is the gastrointestinal tract?

It is a continuous hollow tube stretching from the mouth to the anus. Its chief purpose is to digest and absorb the food and fluid eaten and thereby supply the rest of the body with energy sources for growth and repair. Food is conveyed from the mouth down the oesophagus to the stomach which dilutes and mixes the food. The main processes of digestion and absorption take place in the small intestine which consists of the duodenum, the jejunum and the ileum.



The gastrointestinal tract.

The jejunum which is about 3 metres long digests carbohydrates, while the ileum, which is about the same length, breaks down fats and

absorbs vitamin B12 and bile salts. Fluid waste passes from the ileum into the colon (about 1.5 meters long) where water is re-absorbed into the bloodstream and residual wastes become solid stools (faeces). These enter the lowest part of the large intestine, the rectum, and are then discharged via the anus.

What is meant by Crohn's being a 'chronic' disease?

An acute disease is one which runs a short sharp course like, for example, the ‘flu. A chronic disease can give trouble over a number of years, although there may be long periods of good health alternating with episodes of symptoms lasting for weeks or months. Crohn's disease frequently runs this kind of 'relapsing and remitting' course. Unfortunately, no doctor can predict when a relapse is likely to occur, nor can they guarantee that the future will be trouble-free, even when all visible evidence of Crohn's disease has disappeared following medical or surgical treatment.

What symptoms does Crohn's disease produce?

Depending on the site of involvement, the intestinal inflammation of Crohn's disease usually produces abdominal pain and diarrhoea. Sometimes narrowing of the ileum causes some obstruction to onward passage of wastes, with episodes of vomiting, nausea, bloating and constipation. Bleeding may accompany diarrhoea in patients with Crohn's disease of the colon or rectum. Patients with active Crohn's disease commonly feel tired and lethargic, and they may have a fever. Anaemia often contributes to the tiredness, but may be reversed partly or completely by iron supplementation. Correction of deficiencies in folic acid and vitamin B12, if present, may also help. Sometimes the anaemia, like the fever, just reflects the presence of an inflamed intestine, and will only improve when the Crohn's disease itself settles spontaneously or with medical or surgical treatment.

Disease around the anus is frequent and may be painless unless a local abscess develops. Discharge from fistulae may however be sufficient to stain the underwear, in which case a local dressing or pad should be worn, once the area has been inspected by a doctor.

Can Crohn's disease affect other parts of the body?

Yes. A small proportion of patients with Crohn's disease suffer episodes of inflammation affecting the eyes, skin, limb joints or spine. A few other patients develop inflammation in the liver, but this is usually recognised by blood tests rather than symptoms. Patients may have crops of painful mouth ulcers which are identical to the ulcers commonly experienced by healthy people and do not necessarily imply the presence of Crohn's disease in the mouth.

Is Crohn's disease only a disease of young people?

No. Crohn's can start at any age although it is rare at the extremes of life. It most commonly appears for the first time between the ages of 15 and 40, a time of life when people normally expect good health to cope with the challenges of studying, starting a career or a family. It is equally common in men and women.

Why do patients with Crohn's disease lose weight?

The active phases of Crohn's disease are usually accompanied by a diminished appetite, and also patients may be frightened to eat for fear of worsening their pain or diarrhoea. Sometimes weight loss is a result of gross failure to absorb nutrients because of extensive inflammation of the small intestine. In addition, severe inflammation causes the body to burn more energy and may accelerate weight loss.

How is Crohn's disease diagnosed?

Crohn's disease may be suspected in a patient, particularly a young adult, who develops diarrhoea, abdominal pain and weight loss which lasts for weeks or months. Routine blood tests may show anaemia and other general evidence of inflammation. Further tests will include an x-ray examination (barium meal and follow-through) in which a barium sulphate suspension is given as a drink, or occasionally by a tube put down through the mouth. Pictures of the stomach and small intestine can be

obtained using this procedure. Alternatively, a barium enema may be preferred, in which a similar suspension is introduced by tube into the rectum. In this way the colon will show up on an x-ray. The anus and rectum will be examined with a short telescope (a sigmoidoscope) and sometimes a small fragment (biopsy) will be taken from the lining layer (mucosa) of the rectum, to be examined under the microscope. Sigmoidoscopy and biopsy are minor procedures, though initially embarrassing and uncomfortable.

The x-ray appearances may provide sufficient evidence to confirm Crohn's disease, though typical findings on biopsy of the rectal mucosa may give further help. Sometimes it is difficult to distinguish Crohn's disease of the colon from other chronic inflammatory disorders of the large intestine, particularly ulcerative colitis (Information Leaflet No. 2). In such cases it may be necessary to perform a more extensive inspection of the colon using a flexible telescope (a colonoscope) passed through the back passage, usually after a mild sedative has been injected into a vein.

Occasionally the diagnosis of Crohn's disease is only confirmed when a segment of diseased intestine is removed at an exploratory operation and subsequently examined by a pathologist.

Why should x-ray and other examinations need to be repeated?

Specialists looking after Crohn's patients will aim to avoid repeated x-ray examinations, but from time to time these may be necessary to reassess the changes in the small and large intestine, particularly after an operation has changed the previous anatomy.

Is Crohn's disease hereditary?

No, not in the same sense as a characteristic like colour blindness or a disease like haemophilia. However there seems to be some inherited contribution to the development of the disease in that a minority of patients have one or more close relatives with Crohn's disease. If you have the disorder there is a 10-25% chance that a further family member (child/parent/sibling) will also have or develop Crohn’s disease.

What causes Crohn's disease?

Despite a great deal of research, the cause of Crohn's disease remains uncertain. It is not an infectious illness in that it cannot be passed from patients to previously healthy individuals. However, something infective, perhaps a virus or bacterium, may play a part in its development. It is thought that some individuals have a genetic predisposition to Crohn’s disease and that some sort of “trigger”, such as and infectious agent, initiates the disease process later in life. Environmental factors also appear to play a role.

Is Crohn's disease a psychosomatic illness?

There is no good evidence that Crohn's disease is caused by stress or worry, or even that adverse 'life events' bring about flare-ups of the disease. Naturally, symptoms are going to be more difficult to cope with when patients are anxious or depressed for other reasons. Moreover general ill-health, frequency and urgency of bowel action and nagging abdominal pains may sometimes lead to a short temper, anxiety and despondency, as well as stressed relations within the family. These emotional upsets result from the disease; they do not cause it.

Is Crohn's disease influenced by diet?

The role of diet is fully discussed in a separate booklet (Information Leaflet No. 3 - *Nutrition & Diet*). Suffice it to say that no item of the normal Western diet and no food additives have been found to cause Crohn's disease. There is thus no logical reason for specific exclusion diets.

In general, patients with Crohn's disease will benefit from the high nutritional content of a varied and ample diet. This should approach as near as possible to a normal diet, though individuals may wish to avoid specific foods (e.g. nuts) which they know from personal experience will worsen their symptoms.

Will Crohn's disease be worsened by activity or work?

No, activity and work do not worsen Crohn's disease. Sometimes admission to hospital and rest in bed are needed during acute flare-ups

of the disease, and at times patients not ill enough to need hospital care will nonetheless feel too unwell to cope with work. However, most patients with Crohn's disease should be encouraged to pursue their normal work and leisure activities, including sports, and not to become over-concerned about themselves or overprotected by their families. Patients should be masters of the disease, not its servants.

How will Crohn's disease affect a patient's future?

Many Crohn's patients never have more than mild and rare symptoms of diarrhoea and pain, and most patients with the disease lead full, useful lives, able to enjoy family life and gainful employment. At the other extreme a few have continuous and severe symptoms in spite of intensive medical and surgical treatment. Formerly some of these really ill patients wasted away from malnutrition, but nowadays they can be helped by nutritional support with liquid feeds given either through a fine tube passed down the gullet into the stomach, or directly into a vein.

Can Crohn's disease be cured?

Unfortunately, no known treatment, either medical or surgical, can be guaranteed completely and permanently to eliminate Crohn's disease. However, medical treatment is frequently effective in settling down flare-ups of the disease for long periods, and surgery often brings prolonged relief of symptoms for those who are not managed with medical treatment.

Why are steroid drugs used in Crohn's disease?

Flare-ups of Crohn's disease usually improve substantially when treated with corticosteroid drugs (e.g. prednisone) which restore appetite and abolish fever, pain and diarrhoea by diminishing the inflammation in the diseased intestinal wall or elsewhere, e.g. in the eyes, skin or joints. Unfortunately the large doses of steroids which so effectively cause symptoms to subside also sometimes cause unwanted side effects, such as excess weight gain, "mooning" of the face, mood swings or a rise in blood pressure and diabetes. Dosage will therefore usually be reduced 'stepwise' to a low level, or treatment stopped altogether, over weeks or months. There is little evidence that long continued treatment with corticosteroids prevents relapse of Crohn's disease, but some patients are kept reasonably well on a low dose. However, long-term treatment may increase the risk of osteoporosis (bone thinning) but this can be detected and treated . Side effects may be reduced if such patients take their tablets every other day. Steroids given locally in the form of liquid enemas, foam or suppositories are useful in the treatment of Crohn's disease of the lower colon, rectum, and anus.

What other drugs are useful in Crohn's disease?

Diarrhoea may be controlled effectively with tablets such as codeine phosphate or loperamide (Imodium®) but these do not act against the disease itself.

Sulphasalazine (e.g. Salazopyrin®) and mesalazine (e.g. Pentasa® and Asacol®) have some anti-inflammatory effect in Crohn's disease and are without the long-term hazards of steroid drugs. However, sulphasalazine does not suit some patients, in whom it causes nausea, indigestion or a skin rash. A newer steroid budesonide (Entocort®) is now available which has been shown to be nearly as effective as prednisone in patients with ileal Crohn’s disease, but with much fewer side effects.

Antibiotics have an uncertain role in the treatment of Crohn's disease except when there is an obvious infection such as an abscess in association with disease around the anus.

Supplements of iron, folic acid and vitamin D as tablets, and vitamin B12 by injection, are given as appropriate. Occasionally zinc, potassium, calcium or magnesium are given if deficiencies of these minerals arise.

Why is Crohn's disease not always treated by an operation?

The problem with Crohn's disease is that although it may appear to be confined to one or two segments of the intestine such as the lower ileum, other areas of intestine which at the time

of an operation appear to be healthy may subsequently become involved with the disease. Often the disease does not recur after surgery, but over the years some sort of recurrence does affect a third to a half of the patients who have had all actively involved intestine removed. In addition, recurrence is most common at the site where 2 sections of healthy bowel have been joined. This means that some patients may need two or more operations where further lengths of small or large intestine are removed. As an end result, a few patients can suffer diarrhoea and nutritional problems not due to Crohn's disease itself, but to lack of a sufficient length of normal intestine for adequate function. Hence doctors try to achieve a balance between the benefits and the possible problems of surgical treatment and they steer their patients away from surgery unless there are positive reasons for it as outlined in the next section.

When do patients with Crohn's disease need surgery, and what operations are involved?

Troublesome problems around the anus such as abscesses or fistulae may have to be dealt with by local surgical procedures.

More major surgery involves removal of severely inflamed segments of small or large intestine and restoration of the continuity of the 'tube' by joining healthy intestine to healthy intestine. This kind of operation is called a resection, and such treatment is valuable in patients whose symptoms do not settle on medical treatment, and in particular in those with obstructive symptoms due to a narrowed ileum or colon. Patients with a fistula (false passage) connecting the diseased intestine with the skin on the front of the abdomen or connecting with an internal organ such as the bladder or another piece of bowel, will also benefit from a surgical approach.

Occasionally when the large intestine is seriously diseased and especially if there is also severe anal inflammation with distressing diarrhoea, pains and general ill-health, all or part of the large intestine including the rectum and anus needs to be removed. It is then impossible to restore continuity and the cut end of the intestine is brought out through the abdominal wall as a permanent spout-like opening: an '-ostomy'. If all of the colon has to be resected, the '-ostomy' or stoma is constructed from the ileum and is termed an ileostomy. More rarely, when the upper part of the colon is healthy and is not removed, it is brought out as a colostomy. Wastes are discharged into a plastic bag which fits securely and discreetly over the stoma. Patients adapt quickly to life with a stoma, particularly as they will have been restored from chronic ill-health to good health. In some districts a nurse with special training (stoma therapist) is available to help them. Ostomy Societies throughout New Zealand are available for help and support.

See Information Leaflet No. 9 - *Surgery in IBD*, for more detailed information.

What special problems do children with Crohn's disease have?

While in adults, the decreased intake of food associated with active Crohn's disease leads to weight loss, in children it may also slow down growth and delay sexual development. Thus great emphasis is placed on restoring the child's food intake towards normal levels, either with supplements taken by mouth or occasionally with feeding into a vein. Prolonged steroid treatment can also retard growth. With children and adolescents there is therefore rather greater enthusiasm than in adults for operations which remove areas of active Crohn's disease and allow normal growth to take place unhindered. It is important to promote growth, as once this ceases in the late teenage years, lost potential height cannot be regained.

Children and young people may also have special problems due to loss of time from school, a sense of being "different" from other young people, and difficulty in development of independence. (For more information see Information Leaflet No. 7 - *IBD in Children and Adolescents*).

What about pregnancy and Crohn's disease?

This is dealt with in greater detail in another booklet (Information leaflet No. 4 - *Sexuality, Fertility and Pregnancy*). Briefly, however,

women with active Crohn's disease are a little less likely than healthy women to become pregnant, partly because intercourse may be uncomfortable and therefore less frequent, and partly because of reduced fertility, perhaps due to irregular ovulation or to local damage to the fallopian tubes by the adjacent inflamed bowel.

Pregnancy should be avoided when the disease is very active. The contraceptive pill is safe and effective unless diarrhoea is severe. If Crohn's disease is mild or inactive, there is no reason why women should not become pregnant. Pregnancy should be a planned event and discussed with your specialist as to best timing. Once pregnant women can continue on most treatments, including steroids and azathioprine. Inflammation is not particularly likely to flare up during pregnancy and may even improve. Crohn's disease is most unlikely to cause a miscarriage or to put the baby at risk, though the mother needs to pay special attention to her nutrition and to the taking of regular iron and vitamins during pregnancy.

Is Crohn's disease really a form of bowel cancer?

No. There is no resemblance between Crohn's disease and cancer of the intestine. Crohn's disease is a form of chronic inflammation; cancer is a progressive and uncontrolled overgrowth of cells.

Is any research done on Crohn's disease?

Yes. An enormous amount of research has been and is being done on the causes and treatment of Crohn's disease and other chronic inflammatory disorders of the intestine such as ulcerative colitis. A disease which frustrates patients provides a constant challenge to doctors, and little by little the pieces of the puzzle will be put together so that more effective treatment, and in time a cure, will be found.