



## Editor's Notes: Background Information on NACC, Ulcerative Colitis and Crohn's Disease

### NACC

NACC provides a valuable support network and information resource for people and families affected by Colitis and Crohn's disease as well as raising significant funds for research. Since 1984, NACC members have raised over £4.5 million and more than 100 research awards have been made to hospitals and universities throughout the United Kingdom. The 70 local NACC Groups across the UK enable members to meet other people who have these illnesses and share information and experiences.

NACC also campaigns for better healthcare services and seeks to raise awareness of these illnesses and their impact on people's lives. NACC is a partner in the UK national IBD Audit Project and has been leading the IBD Standards Group developing national standards for NHS IBD Services.

The NACC Information Line (daytime) 0845 130 2233 is available to members and non-members alike who have queries about all aspects of their disease. The NACC-in-Contact Line (afternoons and evenings) offers people a chance to speak to a trained volunteer who has Colitis or Crohn's Disease.

Membership of NACC is open to anyone who has Colitis or Crohn's Disease, their friends and families, health professionals and anyone who wishes to support the charity. Membership costs £12 per year and NACC offers free membership to 16-18 year olds.

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### Crohn's Disease

- The following estimates are taken from the Inflammatory Bowel Disease Guidelines published by the British Society of Gastroenterology in September 2004. At present there is no national database of people who have Crohn's Disease.
- Between **60,000 and 80,000 people** in the United Kingdom live with this life long and potentially life threatening condition. (Over 13,000 of these are members of NACC.)
- About **6,000 new cases** are diagnosed each year.
- Crohn's Disease affects men and women equally.
- The most common age for diagnosis is between 15 and 25. This will have a huge impact on a young person's life and may result in childhood and adolescence being severely disrupted. In some cases pubertal and physical growth may be delayed.
- In 1996, a study from South Glamorgan reported a doubling of the number of children diagnosed with Crohn's Disease between 1983 and 1993, and, in 1999, a study of children in Scotland has reported a 50% increase over 10 years in the incidence of Crohn's Disease in children aged 16 or under. A more recent study of South Wales incidence from 1996-2006 suggests this dramatic increase has now levelled off at these higher levels.

## What are the symptoms?

Crohn's Disease can affect anywhere from the mouth to the rectum but most commonly affects the small intestine. It causes inflammation, deep ulcers and scarring to the wall of the intestine and often occurs in patches with healthy tissue in between. There is no cure for Crohn's Disease at present.

The **main symptoms** of Crohn's Disease will usually include pain, urgent diarrhoea, severe tiredness and loss of weight. Crohn's Disease is quite often associated with other inflammatory conditions affecting the joints, skin and eyes. A good analogy is to imagine the worst bout of gastric flu that you have ever suffered recurring unexpectedly for the rest of your life.

## How is it treated?

Treatment is tailored to suit each patient but most will be treated with drugs, including steroids and immunosuppressants to reduce inflammation. Patients, particularly young people, may also be fed by means of special liquid feeds to rest the bowel. Those with severe disease may be considered for anti-TNF biological treatments.

Surgery may be required to remove narrowed or damaged parts of the intestine. Between 50% and 70% of patients with Crohn's Disease will undergo surgery within 5 years of diagnosis.

The condition is named after Dr Burril Crohn, one of the three doctors who first identified the disease in 1932.

## What causes Crohn's Disease?

- Sadly the cause has not yet been identified, but is probably due to a combination of genetic and environmental factors. Crohn's Disease is not a form of cancer and is neither contagious nor infectious.

## Recent Research – Who and Why?

- Research is focusing on why some families have a greater predisposition to inflammatory bowel disease (both Crohn's Disease and the related Ulcerative Colitis) than other families and on the process of inflammation which is created when the immune system responds to a foreign agent. It is possible that patients' immune systems are over-reacting to some stimulus or failing to control the level of inflammation after responding to the stimulus. A recent multi-centre study funded by the Wellcome Trust has just identified several new genes that predispose to Crohn's and that will provide a new focus for research.
- Both Crohn's Disease and Ulcerative Colitis are more common among close relatives of people who have IBD than in the general population. There are some families in which Crohn's Disease affects one person and Ulcerative Colitis another, suggesting that the two disorders share an inherited susceptibility. Family studies in London, Oxford, Paris and elsewhere have identified the location of two genes which pre-dispose to the conditions, but their function is not yet known. More research studies are due to report soon. It is likely that, at least for some patients, an inherited susceptibility interacts with unidentified environmental factor(s) to induce the disease. Particular genes may also help to determine the severity of the illness.
- There has been some publicity about the possibility that an organism called *Mycobacterium paratuberculosis* (MAP) may be a cause of Crohn's Disease. This is based on the work of Professor John Hermon-Taylor from St George's Hospital in London, who believes that MAP, which causes Johne's disease in cattle and sheep with symptoms very similar to Crohn's Disease, is transferred through milk and water systems to affect a proportion of the population. An expert review group set up by NACC reported that the evidence for MAP causing Crohn's Disease remains inconclusive. However, NACC supports the precautionary approach taken by DEFRA which has instituted a programme to reduce the prevalence of MAP in animal herds.

## Ulcerative Colitis

There is no national database of people who have Ulcerative Colitis. The following estimates are taken from the Inflammatory Bowel Disease Guidelines published by the British Society of Gastroenterology in September 2004.

- Between **120,000 and 160,000 people** in the United Kingdom live with this life-long and potentially life-threatening condition. (Over 14,000 of these are members of NACC.)
- About **12,000 new cases** are diagnosed each year. The most common age for diagnosis is between 15 and 35. This can have a huge impact on a young person's life and may result in childhood and adolescence being severely disrupted. In some cases this can delay pubertal and physical growth. The number of new cases each year has not risen recently, but the incidence is not decreasing. Ulcerative colitis affects men and women equally.

### What are the symptoms?

Ulcerative Colitis affects the colon (large intestine) or rectum and can cause a variety of distressing and sometimes embarrassing symptoms. Inflammation and ulcers develop on the inside lining of the colon resulting in pain, urgent and bloody diarrhoea, continual tiredness, weight loss and loss of appetite. A good analogy is to imagine the worst bout of gastric flu that you have ever suffered recurring unexpectedly for the rest of your life.

The condition varies as to how much of the colon is affected and the severity of the symptoms also fluctuates unpredictably over time. Patients are likely to experience flare-ups in between intervals of reduced symptoms or remission. Unfortunately, to date there is no cure for Ulcerative Colitis.

### How is it treated?

Most patients will be treated with drugs, including steroids, to control or reduce the inflammation. In severe cases some people need surgery to remove the affected part of the colon, if their symptoms do not respond to treatment with drugs. Lifetime surgery rates are about 20-30% and for patients who have chronic relapsing ulcerative colitis, about 50% need a colectomy though rates vary between countries and regions.

### What causes Ulcerative Colitis?

The cause has not yet been fully identified although the new study findings indicate a genetic predisposition. Ulcerative Colitis is not a form of cancer and is neither contagious nor infectious. An overview of research into IBD is available on [www.nacc.org.uk/content/research](http://www.nacc.org.uk/content/research)

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***NACC – Improving life for people affected by Colitis and Crohn's Disease***