



Living With Crohn's Disease

The Real Impact

May 2006

People Living With Crohn's Disease - The Figures

- The following estimates are taken from the Inflammatory Bowel Disease Guidelines published by the British Society of Gastroenterology in September 2004. Unfortunately at present there is no national database of people who have Crohn's Disease.
- Between **30,000 and 60,000 people** in the United Kingdom live with this life long and potentially life threatening condition. (Over 13,000 of these are members of NACC.)
- Between **3,000 and 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.
- NACC, which provides support to people with Colitis and Crohn's of all ages, works closely with CICRA (The Crohn's in Childhood Research Association) which offers support and information to children and their families who are similarly affected.

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 may also be fed by means of special liquid feeds to rest the bowel. Those with severe disease may be offered monoclonal antibody-based treatments. Surgery may be required to remove narrowed or damaged parts of the intestine.

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.
- 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. 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 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.
- The possibility that food might be the cause of Crohn's Disease has an understandable appeal, but no specific dietary cause has been found. Some patients find that their symptoms improve if they omit certain foods, and some manage their condition in this way. Liquid diets are sometimes used in treatment as an alternative to drugs particularly in children.

- An overview of research into IBD, including that funded by NACC, is available on the NACC website <http://www.nacc.org.uk/content/research>

In March 2006, NACC awarded £208,229 to new research projects into Crohn's Disease and Ulcerative Colitis. Since 1984, members have raised over £4 million and more than 100 research awards have been made to hospitals and universities throughout the United Kingdom.

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

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