



## Living with Ulcerative Colitis *The Hidden Facts* May 2006

### Who is affected?

- Unfortunately 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 **60,000 and 120,000 people** in the United Kingdom live with this life-long and potentially life-threatening condition. (Over 14,000 of these are members of NACC.)
- Between **6,000 and 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.
- 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?

- 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.

### **What causes Ulcerative Colitis?**

- Unfortunately the cause has not yet been identified. However, Ulcerative Colitis is not a form of cancer and is neither contagious nor infectious.

### **Recent research - Who? Why?**

- Research is focusing on why some families have a greater predisposition to Inflammatory Bowel Disease (both Ulcerative Colitis and the related Crohn's Disease) 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 are over-reacting to some stimulus or that their immune system fails to control the level of inflammation after responding to the stimulus.
- Both Ulcerative Colitis and Crohn's Disease are more common among relatives than in the general population. There are some families in which Ulcerative Colitis affects one person and Crohn's Disease another, suggesting that the two disorders share an inherited susceptibility. Recent research has 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.
- The role of nicotine has attracted some publicity, because it has been found to protect against bowel inflammation for some patients. This was discovered by a research team in Cardiff under Professor Rhodes, when they realised that some patients first experienced Ulcerative Colitis after giving up smoking. Doctors do not advise these people to take up smoking again because of the other harmful effects on health, but at Cardiff they have been undertaking tests to see whether nicotine patches could be an alternative to the use of steroids. Some early results have been encouraging, but the idea is not yet sufficiently proven to be

recommended as a normal treatment, and it is likely that this approach would only benefit some patients.

- The possibility that food might be a cause of Ulcerative Colitis has understandable appeal, but no specific dietary cause has been found. NACC is currently funding a study in Dundee to test whether a low-sulphur diet might be an effective treatment, based on earlier research which showed that dietary sulphate was converted to the potentially damaging sulphide by bacteria in the colon.
- An overview of research into IBD is available from the NACC website on <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 and is seeking to raise a further 120,000 by October 2006 to enable an important genetic study to proceed.

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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