



Parents Need To Talk!

Mums and Dads of children with Colitis and Crohn's Disease benefit from new NACC telephone service – Parent To Parent

4th June 2008. St Albans, Herts. What would you do if you were told that your child has a serious medical condition that you had never heard of before; that there is no cure; a possibility that your child will need surgery and you are left with more questions than answers?

Sadly, this scenario can be all too common amongst the parents of children with the inflammatory bowel diseases, Colitis and Crohn's disease. Faced with a seriously sick child and a bewildering diagnosis, parents can find themselves isolated and searching for answers to their many questions.

Happily, this is where the patient support charity The National Association for Colitis and Crohn's Disease (NACC) can step-in. NACC's new **Parent to Parent** service is being launched to support worried, sometimes frightened parents by providing them with the experienced listening ear of a parent who has been similarly affected.

Endorsed by BBC *Fame Academy's* voice coach and NACC Ambassador, Carrie Grant, who herself has Crohn's Disease, **Parent to Parent** is being launched to coincide with Colitis & Crohn's Week (14th – 22nd June) will focus on inflammatory bowel disease and families. This new confidential service, staffed by a team of trained parent volunteers will help parents feel that they are not so alone with their child's condition and point them in the right direction for more information and support.

A teacher from Liphook, Hampshire, Snezzy Floyer is one of NACC's first **Parent to Parent** volunteers. Snezzy's son Simon was fifteen when he first experienced symptoms of Crohn's disease which took over a year to diagnose. Simon lost three stone as a result of his symptoms which included pain, diarrhoea and almost resulted in the removal of a quarter of his bowel.

Snezzy recalls feeling a huge mix of emotions, "When Simon was ill and asked me to help him feel better, I felt guilty that as his Mum I was unable to do anything to solve the problem and take his pain and fear away. Mums are supposed to be able to put things right, but when there is a serious

health problem, you suddenly realise that you are helpless and that you have to rely on others who may or may not be able to help. Somehow, you hope that doctors and consultants will be able to 'fix' things, but these things can take a very long time. I grieved for the loss of Simon's previously good health and had to fight hard to hold on to my teaching job due to his unpredictable disease flare-ups. He was often seriously ill and either needed me to take care of him at home or stay at hospital with him when he was admitted.

Added to all this, I had, initially felt totally uninformed by Simon's doctors who found it difficult to recognise the illness, and our original consultants seemed to keep changing their minds as to whether or not Simon needed an operation or further treatment with medication. It was only after Simon was hospitalised that we saw a new consultant who managed to help and advise us. All the uncertainty and lack of information left me feeling powerless until I discovered NACC."

Snezy explains, "**Parent to Parent** is exactly what Mums and Dads need when they are going through the often traumatic experience of establishing how and why their child is so seriously ill. **Parent to Parent** is a telephone service available through the NACC Information Helpline (Tel: 0845 130 2233) that is open to all parents, whether they are NACC members or not. The trained volunteers offer a sympathetic, experienced ear and give worried parents as much time as they need to ask questions. Sometimes parents are so upset and worried that they do not know where to start when talking to their doctors. We can clarify information but most importantly we can help them feel supported."

Snezy concludes, "I truly wish that I had known about the NACC and this excellent new service when Simon was first diagnosed. When you talk to other Mum's in the same situation you can begin to feel normal again."

Richard Driscoll, NACC Director, explains, "Parents of a child with a chronic illness such as Colitis and Crohn's disease are often confused and distressed. Now, through this new NACC Service they will have the chance to talk to another parent whom they know has 'been there' and can really understand."

The Parent to Parent service is open to any parent with a child of school age or under the care of a paediatric department. If parents want to get in touch with the Parent to Parent service, please call the NACC Information Service on 0845 130 2233 and a telephone appointment will be made with the Volunteers. NACC is also providing more information on www.nacc.org.uk/parentonline.

ENDS

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

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Editor's Notes

1. Background Information on NACC

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. 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. The 70 local NACC Groups across the UK enable members to meet other people who have these illnesses and share information and experiences.

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 in the first year, £10 thereafter. NACC is now offering free membership to 16-18 year olds.

2. People living with Ulcerative Colitis

Who is affected?

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.

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?

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

3. People Living with 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 **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 and 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.

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, particularly young people, 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. 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.

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.

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