



NACC Colitis & Crohn's Week 2004

Campaign Theme:

“The Painful Truth about Colitis and Crohn’s Disease”

“The pain is worse than childbirth. You face a lifetime of agony and on top of that you are continually rushing to the toilet!” These are the words of one National Association for Colitis & Crohn’s Disease (NACC) member who is typical of many people facing the challenges of life with Ulcerative Colitis or Crohn’s Disease – known collectively as Inflammatory Bowel Disease (IBD). As something that affects us all at times, pain is a subject that most people can understand and empathise with. However, there has been relatively little research into the pain that IBD patients experience.

This year, with the help of Carrie Grant from Fame Academy who has herself spoken about the intense pain of her Crohn’s Disease, NACC will be highlighting this issue during **Colitis & Crohn’s Week (19th – 27th June, 2004)**. NACC will ask everyone touched by the campaign to think of the worst pain that they have personally suffered and then imagine living with pain for months or years on end. In this way NACC proposes to highlight the debilitating impact that pain and the other serious symptoms can have on the daily lives of the estimated 180,000 people suffering with IBD - people who are also trying hard to get on with their lives and jobs and who need everyone’s understanding and support.

NACC has a team of excellent spokespeople who are willing to speak out and share their personal experiences of Colitis or Crohn’s Disease with local journalists all around the country. Some of these spokespeople will take part in a Survey of 5,000 NACC members, which will provide much-needed evidence that pain is a real, often under-estimated issue for people living with the challenge of IBD and will create the necessary platform for raising awareness amongst the public and health professionals.

Richard Driscoll, Director of NACC explains, “The Survey results will be presented during Colitis & Crohn’s Week, but are expected to show that a significant proportion of responders consider their daily experience of pain to be around 7+ , on a scale of 1 to 10.”

Richard continues, “It is clear from NACC’s earlier research that the pain experienced by IBD patients is individual and each person deals with their pain in a different way. For example one patient reported that he has to “keep on the go” to deal with his pain, while another takes to her bed during particularly bad patches. Serious pain symptoms can often be linked to a disease flare-up which may result in hospitalisation and the administration of powerful morphine-based pain killers and steroids.

Forthcoming guidelines from the leading IBD medical body, the British Society of Gastroenterology, acknowledge the fact that abdominal pain in IBD is common but under-researched. NACC members also highlight the fact that their pain is multi-faceted and that it is often experienced in their joints and their backs as well as their bowels. Therefore NACC will be encouraging further research into the pain experienced by IBD patients.”

Please help NACC raise awareness of IBD and of pain as one of the serious symptoms so that we can increase levels of understanding for the 180,000 people in the UK who live with these distressing conditions.

**Please contact the National Association for Colitis and Crohn’s Disease (NACC)
Daytime Information Line 0845 130 2233 Evening Support Line 0845 130 3344
Or visit the Website on www.nacc.org.uk**

ENDS

Editor's Notes

- **What is IBD?**

Ulcerative Colitis and Crohn's Disease are life-long, potentially life-threatening conditions that are often first diagnosed in teenagers and young adults. Together the two conditions are known as Inflammatory Bowel Disease (IBD) and affect around 180,000 people in the UK with over 8,000 new cases diagnosed every year. IBD is an inflammation of the bowel and alimentary canal with bouts of painful and bloody diarrhoea, which can cause patients to be house-bound for many weeks. For some people, the disease requires frequent hospitalisation and major surgery.

- **IBD Treatment & Pain Relief**

Patients frequently require more than one drug to bring their IBD under control and some may need four medicines at the same time while their disease stabilises. Serious hospital pain relief will be morphine-based.

- **NACC provides Support and Information**

NACC provides a valuable support network and information resource for people and families living with IBD. The 70 NACC Groups across the UK enable members to share information and experiences. An evening support line offers people the chance to talk to a trained volunteer who has personal experience of IBD. Membership 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.

- **For more local IBD Case Studies or Medical Interviews** please contact Sarah Rogers on 01428 604444.

For more press information on NACC Colitis and Crohn's Week 2004 please contact:

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