



**NACC Colitis & Crohn's Week 2004**

## **“The Painful Truth about Colitis and Crohn's Disease”**

**8th June 2004, St Albans, Herts.** A new survey of people with the serious bowel conditions Colitis and Crohn's Disease, collectively known as Inflammatory Bowel Disease (IBD) reveals a largely hidden burden of severe pain. Organised by the National Association for Colitis & Crohn's Disease (NACC) to coincide with Colitis & Crohn's Week and supported by *Fame Academy's* Carrie Grant, who herself has Crohn's Disease, the survey provides a dramatic insight into the lives of the estimated 180,000 people living with IBD in the UK.

The 2,000 NACC members who took part in the NACC Survey were asked to describe and rank their current pain levels. Two-thirds of members experienced pain in their abdomen (66%), joints (38%) or back (31%) and often this was linked to a flare-up of their disease, but a significant and worrying 39% stated that they experience pain either constantly or on a daily basis. The intensity of their pain was significant too: 61% of those who suffered abdominal pain expressed their usual level of pain as worse than five on a Pain Scale of one to ten (where ten is the worst pain). Respondents described their pain as 'aching' (51%), 'stabbing' (46%), 'nauseating' (39%) 'deep-seated' (34%) and 'constant' (29%).

A third of responders stated that their pain seriously interferes with their daily life especially their ability to work and socialise, and 19% said that their sleep is badly affected at least once a week and for many, every night by their pain. Since Colitis and Crohn's disease are distressing bowel diseases which can 'flare-up' unexpectedly, a combination of the pain and debilitating bouts of diarrhoea can result in interrupted education, reduced work opportunities and restricted social lives for sufferers.

Patients have to live with the knowledge that painful flare-ups can occur at any time with 72% of responders having experienced more than one disease flare-up in the last two years. Typical medical management of disease flare-ups requires hospitalisation, powerful drugs and morphine-based pain killers to bring the patient's bowel inflammation and pain under control. Complications of Colitis and Crohn's disease can require surgical intervention and this was confirmed by 679 or 34% of responders stating that they had undergone surgery for strictureplasty (stretching of damaged, narrowed bowel) or to remove sections of the bowel.

Describing her own personal experiences of pain, Carrie Grant says, "There have been times where the hospital has administered pain killing drugs and after two hours the pain is back in full force. You know you still have two hours before they can give you your next injection and you are in agony. It's where you learn to live and cope minute by minute."

Launching the "Painful Truth of Colitis & Crohn's Disease" campaign, Richard Driscoll, Director of NACC, explains, "Pain is one of the most debilitating and yet largely hidden symptoms of IBD. When you hear someone describe their IBD pain as "worse than childbirth" and say that "their life is riddled with agony and the continual rushes to the toilet", it reminds us all just how serious these illnesses are. People try hard to get on with their family lives, jobs or education despite their symptoms and they really do need everyone around them to have a greater understanding and to offer support."

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. This Survey has highlighted the fact that IBD pain is multi-faceted and that it is often experienced in patients' joints and backs as well as their bowels. It is therefore proposed that NACC will encourage further research into the pain experienced by IBD patients as well as supporting patients through the charity's Information Line. **Please contact the National Association for Colitis and Crohn's Disease (NACC) on the Daytime Information Line 0845 130 2233 or the Evening Support Line 0845 130 3344 or visit [www.nacc.org.uk](http://www.nacc.org.uk) ENDS**

NB. NACC has local Patient Case Studies available for interview. Plus, we have the population figures for the number of people affected by IBD in your readership area – please call 01428 604444 for more information.

## ***Editor's Notes***

- **What is Inflammatory Bowel Disease?**  
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 sometimes known as Inflammatory Bowel Disease (IBD) and affect around 180,000 people in the UK with over 8,000 new cases diagnosed every year.
- **What are the main symptoms of Inflammatory Bowel Disease?**  
IBD causes parts of the small and large intestines to become inflamed, swollen and ulcerated. The most common symptoms are persistent, non-infectious, painful, bloody diarrhoea, unexplained weight loss and continual exhaustion. Most patients have periods when the symptoms flare-up and periods of remission when they subside.
- **IBD Treatment**  
Patients frequently require more than one drug to bring their IBD under control and some may need several medicines at the same time while their disease stabilises. For some people the disease can lead to repeated admissions to hospital and major surgery.
- **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 of NACC is open to anyone who has Colitis or Crohn's Disease, their friends and families, health professionals and anyone who wished to support the charity.
- **For local IBD Case Studies or Medical Interviews** please contact Sarah Rogers or Polly Tipton on 01428 604444.

For more press information on NACC Colitis and Crohn's Week 2003 please contact:  
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