



Lack of awareness and understanding present serious challenges for people living with Colitis and Crohn's

NACC Colitis & Crohn's Week 20th – 28th June 2009

8th June 2009. Two important surveys commissioned by the National Association for Colitis and Crohn's Disease (NACC) reveal that the general public is largely unaware of the life-long and painful inflammatory bowel diseases – Ulcerative Colitis and Crohn's disease – causing serious challenges at both school, college and work for people living with these chronic conditions.

Supported by *Emmerdale* actor Jeff Hordley, who was diagnosed with Crohn's in 1996, NACC is launching the new initiative *Rising to the Challenge of Colitis and Crohn's Disease* to improve levels of understanding amongst the general public. Through the 2009 campaign, NACC aims to improve the 'learning and earning' conditions for the estimated 244,000 people affected by Colitis and Crohn's in the UK.

The NACC / Ipsos MORI survey¹ of 2,023 adults shows that Ulcerative Colitis and the collective term, Inflammatory Bowel Disease (IBD) are less well known than many other chronic medical conditions. For example, compared with diabetes at 95% and MS at 84% awareness, only 41% of the public are aware of Ulcerative Colitis and awareness of IBD stands at just 64%.

NACC Chief Executive, Richard Driscoll, explains, "The major issue is that despite IBD affecting 1 in 250 of the population, making IBD fairly common, many young people with the symptoms of urgent diarrhoea, pain and severe fatigue have their lives made even tougher as a result of 40% of the public having little or no understanding of the severity of their Colitis and Crohn's symptoms¹.

This finding was further supported by an extensive survey² of over 3,000 NACC members which reveals that around 70% believe their teachers, lecturers and employers do not appreciate the true impact of their Colitis and Crohn's symptoms.

Richard continues, "Understandable embarrassment makes it difficult to talk about these chronic bowel diseases. Over 2,000 (almost 70%) of NACC survey responders admitted to being embarrassed by their condition and a third (34%) said that they hid their disease. A greater

awareness and understanding of the symptoms of Colitis and Crohn's amongst the general public is clearly called for.

The challenge for NACC's *Rising to the Challenge of Colitis and Crohn's Disease* initiative is twofold: firstly NACC members need to put aside embarrassment and come forward to talk about their experience of living with Colitis and Crohn's. Secondly, employers, schools, colleges and universities need to take advantage of the new information now available on the NACC website (www.nacc.org.uk). It is vital that they offer greater support to their students and staff who have Colitis and Crohn's Disease so that they can be helped to reach their full academic and work potential.

Richard concludes, "There are often easy measures that schools, universities or employers can take to make life easier for students and staff who have Colitis and Crohn's. Simply ensuring that they have quick access to toilets, for example by moving an employee to a desk which is closer, can make a big difference to how confident and comfortable the person feels at work. Flexibility over important hospital appointments is also essential. The key to making better arrangements is more open communication and better information."

Talking about his own experiences, Jeff Hordley, explains, "Having lost my mum to Crohn's when I was nine, I was devastated when I was diagnosed with Crohn's and thought that it was a death sentence. However, my doctors were excellent and they explained that I would do well after a major operation to remove parts of my bowel. At the time of the operation, I was a student actor and probably well placed to talk openly about my condition. I personally find that people are more supportive and understanding if they know about my condition."

Most NACC members agree with Jeff. The NACC survey shows that better communication does make a difference. Three quarters or 74% of the 3,010 NACC members in the survey consider that they cope better with their disease when they have discussed their symptoms with those around them. **ENDS**

References:

1. **Ipsos MORI NACC Public Awareness Survey (J35902)**
2. **NACC Members' Survey – May 2009**

Notes to Editors

Backgrounders on Ulcerative Colitis, Crohn's disease and NACC available at www.nacc.org.uk/content/media.asp