

# **Ulcerative Colitis:** the real impact

A survey of patient members of the National  
Association for Colitis and Crohn's Disease

## Foreword

**Ulcerative colitis (UC) is a chronic inflammatory bowel disease that is estimated to affect between 60,000 and 120,000 people in the UK and up to 700,000 across Europe. It can occur at any age and affects men and women equally. It is most often diagnosed between the ages of 15 and 30 years.**

The symptoms of UC illustrate how distressing and embarrassing this condition can be. Inflammation and ulcers develop on the inside lining of the colon, resulting in pain, urgent and frequent diarrhoea and continual tiredness. These symptoms can prevent those affected from leading a normal life. There is currently no cure for ulcerative colitis, although a range of treatment options is available which can help to relieve symptoms, including new biologic treatments. Access to more treatment options is critical, especially to give an alternative to surgery.

This report summarises the findings of a recent survey of 1,000 National Association for Colitis and Crohn's Disease (NACC) members. The survey formed part of a larger pan-European survey of patient groups in seven countries conducted by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) involving 5,636 patients with inflammatory bowel disease (UC and Crohn's disease). There were 580 NACC responses to the survey, of which 281 members had UC. It is the UC responses that are covered in this report.

The aim of this survey was to develop a clearer picture of how ulcerative colitis is managed in the UK and across Europe and to gain a better understanding of how patients live with the disease and how it impacts on their daily life. The results show that although many patients are satisfied with current treatments, the majority report that their symptoms have a significant impact on everyday life in terms of leisure activities and/or work. Also, nearly all patients indicated they would try a new type of drug therapy as an alternative to surgery. The survey suggests that when it comes to talking about symptoms or asking about new treatment options, there is room for more open communication between patients and their doctors.

## Key findings

- Ulcerative colitis (UC) can cause a variety of distressing and sometimes embarrassing symptoms. The most common symptoms among the survey respondents included: diarrhoea, rectal bleeding, fatigue and painful stomach cramps. Flare-ups are frequent: 55% of respondents experience flare-ups every few months with some patients coping with monthly or even weekly recurrences.
- Overall, feedback on medications is positive, with 48% of respondents 'very satisfied' and 32% 'somewhat satisfied' with their current treatments.

***We need to encourage a positive on-going dialogue between health professionals and their patients***

NACC & EFCCA

The results from the survey will help inform our campaign for improved standards of care for all patients with ulcerative colitis, for example by increasing the number of Inflammatory Bowel Disease Nurse Specialists, educating patients about treatment options and encouraging a positive on-going dialogue between medical professionals and their patients.

NACC brings together people of all ages who have ulcerative colitis or Crohn's disease, as well as their families and the health professionals involved in their care. By joining NACC people with UC can benefit from the range of services we provide, including a network of local groups, a telephone support line and a comprehensive information service. NACC also invests £300,000 a year in research in the field of inflammatory bowel disease.

EFCCA's aim is to improve the well-being of patients with inflammatory bowel disease and their partners and families through: working with and for the 22 national member associations throughout Europe; facilitating the exchange of information and promoting cross-frontier activities; effecting regular contact with the European authorities, health professionals and organisations world-wide; and encouraging scientific research in the field of inflammatory bowel disease.

Please contact NACC now if you would like to become a member. If you would like to find out more about our work or wish to help us support the estimated one million people who are affected by inflammatory bowel disease in Europe, please click on [www.nacc.org.uk](http://www.nacc.org.uk) or [www.efcca.org](http://www.efcca.org). Thank you for your support.



Richard Driscoll  
Director, NACC

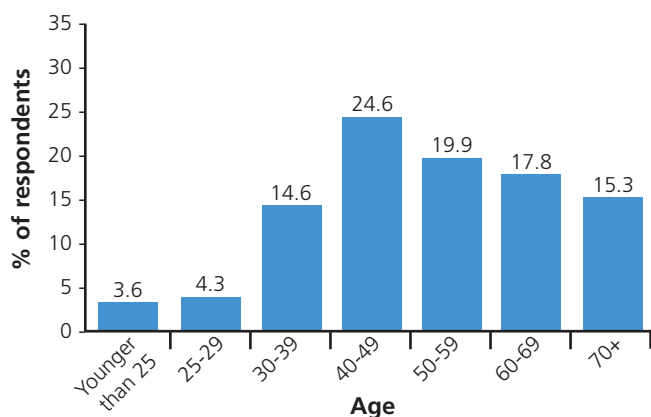


Rod Mitchell  
Chairman, EFCCA

- Despite this apparent satisfaction with current treatments, UC can interfere with many of the activities of daily life. 75% of respondents said that the condition affected their ability to enjoy leisure activities, such as dining out, sport and travel, and over half (56%) felt that it interfered with their ability to perform their job effectively.
- In many cases, surgery is not curative: half of those undergoing surgery experience a relapse and 38% suffer serious complications following surgery. The vast majority (92%) of participants would be willing to try a new type of drug therapy as an alternative to surgical intervention.

## Diagnosis and referral

The age figures recorded for the survey respondents show that people of all ages have UC, although the younger age groups are under-represented compared to the expected prevalence. This probably reflects the age distribution of the NACC membership.



- 15% of participants had a close family member who had also been diagnosed with an inflammatory bowel disease such as UC or Crohn's disease, supporting the likelihood of a genetic predisposition to the condition.
- The vast majority of patients with UC (80%) were diagnosed by a gastroenterologist, with just 8% being diagnosed by a family physician and 9% by other types of clinician. A similar proportion (84%) are currently being treated by a gastroenterologist.
- Waiting time for referral to a gastroenterologist varied: 68% were referred within one year of experiencing symptoms but 14% waited between two and four years and 10% waited for five years or more. These UK figures compare favourably with the pan-European survey that showed that almost twice as many patients (19%) across Europe waited for five years or more before seeing a gastroenterologist.

## Attitudes towards treatments

- Patients with UC may be treated with a variety of therapies. The most commonly prescribed treatments were: anti-inflammatories/5-ASA therapies (68%), steroids (29%) and immunomodulators (22%). Fewer than 1% were receiving cyclosporine or biologics. (Biologics were not licensed for UC at the time of the survey although one has subsequently been licensed by the European Medicines Agency.) 13% of respondents were currently receiving no treatment.
- Feedback on current treatments was varied: 48% of patients were very satisfied with current treatment and a further 32% were somewhat satisfied. 11% were dissatisfied and the remainder made no statement.
- More specifically, 45% of those who had taken steroids said that their quality of life was greatly improved and 33% somewhat improved in the months following treatment. Among patients taking immunomodulators, the proportions were 39% and 28% respectively.

***Just under half of patients were very satisfied with their current treatment or felt their symptoms had greatly improved as a result***

## Past and present medications

Treatment	% who had previously received	% currently receiving
Immunomodulators	23.5	22.4
Steroids	61.9	28.8
5-ASA therapies	52.7	68.0
Antibiotics	7.1	2.8
Cyclosporine	4.6	0.4
Biologics	0.4	0.4
Surgery	9.3	-
Don't Know	5.3	0.4
No treatment	5.3	13.5

- In the UK, around one in 10 (9%) of UC patients had undergone surgery to treat their condition, compared with the European average of 14%. Across Europe, 88% of patients rated their quality of life as having improved greatly or to some extent following surgery while in the UK, this figure was lower, at 76%.
- The number of patients reporting problems after surgery was higher in the UK than in Europe. In the UK, 50% of those undergoing surgery subsequently experienced a recurrence of symptoms and 38% reported serious complications following surgery. In Europe as a whole, the picture is slightly different with 43% experiencing a recurrence and 32% reporting complications. It is not possible to determine whether this is due to a difference in the survey sample or the result of differences in therapeutic approaches or effectiveness in the UK as compared to the rest of Europe.
- Understandably, the majority of patients are keen to avoid surgery if possible: 92% would be willing to try a new type of drug therapy as an alternative to surgical intervention.
- Just 17% of those surveyed said that their physician had talked about newly developed treatments for UC, but this may be because for a long time there were no new treatment options available. If patients have concerns about their current treatment, they should take the initiative and raise the subject with their doctor.

### ***92% of patients would try a new drug therapy rather than undergo surgery***

***In the UK, 50% of those undergoing surgery report a recurrence of symptoms and 38% report having serious complications***

## Impact on everyday life

- UC can cause a variety of distressing and sometimes embarrassing symptoms. The symptoms most commonly reported among the survey respondents included: persistent or recurrent diarrhoea (87%), rectal bleeding (85%), fatigue (79%) and painful stomach cramps (72%). Other common symptoms included joint pain (54%), weight loss (49%), loss of appetite (40%) and soreness in the anal area (30%).
- Flare-ups are frequent: 55% reported flare-ups every few months, while an unfortunate 9% experienced weekly problems and a further 9% reported monthly flare-ups.
- UC can have a significant impact on many of the activities of everyday life. 29% of respondents felt that their symptoms greatly affected leisure activities such as dining out, travel and sports, and a further 46% felt that these activities were affected to some extent. 17% reported that UC interfered with their ability to do their job greatly, with a further 39% somewhat affected.
- The survey results suggest that there may be some barriers to open discussion between patients and their doctors. In the UK, 32% of respondents said doctors enquire about the way in which symptoms impact on their quality of life compared with 42% in the pan-European survey. It appears that British patients are equally reticent in this respect – in the UK, just 38% initiate discussions with their doctors on this topic compared with a pan European average of 52%.
- Reassuringly, when doctors do discuss the impact of symptoms on quality of life, the majority (63%) make modifications to treatment in an attempt to reduce this impact.

***Up to 120,000 people in the UK have Ulcerative Colitis at any one time***

***UC has a major impact on everyday life – almost half of patients said it affected their leisure activities, and almost 40% their ability to do their job***

## ***My story – Anna Grandidge***



I knew nothing about ulcerative colitis when I was diagnosed 13 years ago, but now am something of an expert patient. When I was diagnosed I realised I had been suffering symptoms like severe stomach pains, the embarrassment of having to rush off to the toilet at a second's notice, and blood and mucus when I went to the toilet, for years.

My family and friends didn't know the extent of my suffering as I put a brave face on it. I had no idea that there was something really wrong with me and didn't want to make a fuss. After being diagnosed I had to give up my A Levels, as I had missed so much school, and my plan to go to University three years later, as I was still struggling to deal with the illness and didn't feel comfortable moving away to cope on my own without my family near me.

My family and friends have been a great support since being diagnosed and have helped me come to terms with the illness, encouraging me to talk about how I am feeling, particularly if I am having a bad day with the symptoms. I now have a great career as an HR Manager and I talk a lot more about my condition, rather than keeping things to myself as I did when I was 17.

***“ I had no idea that there was something really wrong with me and didn't want to make a fuss ”***



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Registered charity no 282732

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The EFCCA survey and this report for NACC  
have been undertaken with the assistance  
of educational grants from Schering-Plough