

The National Association for Colitis and Crohn's Disease (NACC) offers a number of services to its members and to people who have Ulcerative Colitis (UC) and Crohn's Disease, together known as Inflammatory Bowel Disease (IBD), which include the following:

NACC Groups

NACC has approximately 70 Groups that are run by volunteers. They hold meetings at which specialists – gastroenterologists, dietitians, complementary therapists etc - give talks and answer questions. The meetings provide an opportunity to meet others with IBD and share experiences. Groups also undertake fundraising activities for research into IBD and for local projects, help to raise awareness of IBD and organise social activities.

Smilie's Network is a special Group for families who have a child or young person with IBD. They arrange activities for both children and parents.

NACC-in-Contact

NACC-in-Contact is a supportive-listening telephone service run by trained volunteers who have personal experience of Crohn's or UC. 'Contacts' are available to talk with patients or family members about living with IBD.

The service uses a local-rate telephone number: **0845 130 3344** and operates on weekdays between 1.00pm – 3.30pm and 6.30pm – 9.00pm excluding Bank Holidays.

Parent to Parent

Volunteers who are parents of children with IBD have been trained to give confidential support and information by phone to other parents. This service is for parents of children and young people,

aged 21 and under. Call the Information Line for an appointment.

Information Services

The Information Services provide an Information Line based at the NACC Office in St Albans. It is run by trained Information Officers, who provide up-to-date information on all aspects of IBD. Information is provided from our wide range of literature and comprehensive library of resources. The officers respond empathically to a vast variety of enquiries which include straight forward ones about travel insurance to more complex medical information. They also respond to letters and emails, though due to pressure of work it is not usually possible to reply immediately.

The information line uses a local-rate telephone number: **0845 130 2233** (also on **01727 844296**) and operates on weekdays, 10am – 1pm. There is an answerphone at other times.

Website: www.nacc.org.uk

Our website provides general information about NACC, details of forthcoming events, our research awards and includes our information sheets and benefit guides, as well as information about other relevant organisations and links to a discussion forum for 16-29 year olds **IBD and Me** – www.ibdandme.org.uk and to books on IBD you can buy.

Newsletter

NACC News is a 16-page A4 publication issued to NACC members four times a year. It is one of the major benefits of being a member of the Association.

Can't Wait Card

When members join NACC or renew their membership they receive a small

laminated membership card. On the back of the card is a message: "Please help – our member has a medical condition which is not infectious and means that they need to use your toilet facilities urgently." This message with the NACC logo, is known as the 'Can't Wait' Card.

The card is intended to support you in the event that you need to ask to use the staff toilet facilities in a shop, garage etc in an emergency. The card does not guarantee that you will be allowed to use these facilities as companies are not willing to give such a commitment, but it may confirm that you have a genuine and urgent need. NACC encourages companies to allow access to toilets as part of a good 'customer care' policy and from time to time publicises the Can't Wait Card scheme to make retailers and staff aware of the need.

Welfare Fund

Anyone affected by IBD may apply for a personal grant from the Welfare Fund if they are on a low income and have a specific need arising from their IBD. Grants do not exceed £300 and a person may only receive one grant in a 12-month period. Examples of recent grants are: washing machine or dryer; installation of a telephone for emergencies; new clothing because of sudden change in weight; partial installation of a downstairs toilet; new bedding; special education or retraining costs; a convalescent holiday.

There is also a special fund for young people aged 15-25 in full or part-time education who have special needs arising from their IBD.

Further details of these grants and an application form are available from the NACC office.

Benefits

Guides on benefits are available from the NACC Office as well as on our website.

Overview of Welfare Benefits: a guide to any state benefits relevant to a person with IBD.

Claiming Disability Living Allowance – Adults under 65 – aims to help people with IBD fill out an application form for DLA. The guide also contains a sheet for health professionals and there are additional guides on making appeals, on completing renewals when your award is close to ending and what to do if your circumstances change, for example because your condition improves or gets worse.

Claiming DLA for Children – under 16 – a guide on claiming DLA benefits for children with IBD.

Claiming Attendance Allowance (AA) – a guide on claiming this allowance for adults over 65 who are not receiving DLA.

DLA/AA Appointment Scheme: A small number of NACC volunteers specially selected and trained are available on an appointment basis, to help people with IBD talk through any practical questions relating to DLA and AA. This service is supportive and gives general guidance, but not specific advice on an individual's circumstances. Appointments are available through the Information Service on **0845 130 2233**.

Involvement and Fundraising

Involvement

NACC considers it important for members and supporters to become actively involved in the work of the Association. The main reason is that we are a member organisation and the spirit of community, friendship and 'everyone pulling together' should be maintained and developed. It also means that our policies and the way in which they are implemented should be closely related to the wishes of people who have IBD and their families. An additional benefit of having volunteers in NACC is that support and fundraising activities become more cost-effective.

You can become involved by:

- attending Group meetings
- offering yourself as an Organising Team member
- offering to be a helper at events or activities
- commenting on articles and sharing experiences in NACC News
- helping to raise funds for NACC Research and other NACC activities
- offering to share your personal experiences with the various media

IBD Patient Panels

You can also be involved in an IBD Patient Panel. A panel is made up of a group of people with Inflammatory Bowel Disease who use the same hospital services and who believe that by talking to and working with their IBD NHS professionals they bring a patient perspective which will help improve services

What can they do?

- Provide feedback on existing services
- Provide suggestions for future developments
- Strengthen Business Case support for service expansion
- Meet good practice as suggested by National IBD Standards

NACC supports over 20 Patient Panels around the UK. For more details please contact:

peter.canham@nacc.org.uk or visit <http://www.patientpanels.org.uk/>

If you would like to volunteer in any way please contact our Volunteer team on **01727 734472**. For details about Groups please call **01727 734475**.

Fundraising

NACC services are given free. As membership subscriptions cover less than 15% of our running costs, we depend on the generosity of our supporters for the remaining 85%. How can you help?

- If you are a taxpayer, Gift Aiding your subscription and donations increases their value by 28p for every £1 given at no extra cost to you.
- Take part in the annual NACC Walks or a fundraising activity organised by your group.
- Organise your own fundraising event.
- Take part in a sponsored activity – a run, a cycle ride, a swim...
- Persuade organisations to fundraise in aid of NACC – schools, businesses, sports clubs, social clubs...
- Buy NACC Christmas cards and awareness-raising merchandise.
- Leave a gift to NACC in your Will.

Our Fundraising Team is here to help with tips and ideas, Fundraising Packs, and a wide range of support materials. Call **01727 734485**.

Research Fund

NACC's Research Fund contributes £300,000 a year towards medical research (to help improve treatment and search for a cure), and also funds research into how the quality of life of people living with IBD can be improved.

Committees comprising leading experts in the relevant fields decide the allocation of grant awards to researchers.

The National Association for Colitis and Crohn's Disease (NACC) is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom. The Association also provides a supportive listening service called NACC-in-Contact which is available to anyone affected by Inflammatory Bowel Disease.

Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. . Additional donations to help the work of the Association are always welcomed.

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