



An Introduction to the Inflammatory Bowel Disease Service at Brighton and Sussex University Hospitals Trust



Our contact details

Outpatient appointments: 0300 303 8360

Endoscopy bookings: 0300 303 8517

X-ray appointments: 01273 664575

IBD helpline

24hr answer phone, Monday – Friday

Expect a response within one working day (Monday-Friday)

Telephone: 01273 664427

Email: ibdnursingservice@bsuh.nhs.uk

Patient Support Group

Crohn's and Colitis UK, Brighton and West Sussex Group

Telephone: 0845 434 8511

Email: bws@groups.crohnsandcolitis.org.uk

Web: <http://www.crohnsandcolitis.org.uk/get-involved/local-groups/Brighton+Group>

The Brighton & Sussex IBD Team

Consultant Gastroenterologists

Dr Mark Austin

Dr Fergus Chedgy

Dr Susi Green

Dr Neil Jackson

Dr Khaleel Jamil

Dr Ziva Mrevlje

Dr Nick Parnell

Dr Melissa Smith (IBD lead)

Dr Jeremy Tibble

IBD Surgeons

Mr Jeremy Clark

Miss Heena Patel

IBD Nurse Specialists

Emma Hills

Heidi Barkhordar

IBD Pharmacist

Anja St. Clair-Jones

Archana Parmar

Biologics Nurse

Kate Blake

The IBD Team

Gastroenterologists

Gastroenterologists are doctors who specialise in disorders of the intestines and liver. Our team has a special interest in Inflammatory Bowel Diseases (IBD). They will discuss with you the nature, extent and severity of your disease and decide, along with you, what would be the most appropriate way to investigate and treat your IBD. You will be allocated a named consultant but, whilst they will lead your treatment, you will not necessarily see them at each appointment.

IBD Nurse Specialists

IBD Nurse Specialists are senior nurses with special training in IBD. They form a central part of our team, offering support and information about IBD and its treatment and managing treatment in some cases. They run the IBD advice line and are often the best point of contact with the team. They see patients in the outpatient clinic and on the wards, run telephone clinics and administer some treatments, (for example infliximab).

IBD Surgeons

IBD sometimes requires surgical treatments and we work closely with our surgical colleagues, meeting each week to discuss relevant cases.

Dieticians

You may be referred to a dietician, who can give advice about dietary management of IBD and may also see you to discuss more general nutritional issues, or to help you to adapt your diet to improve your symptoms.

IBD Specialist Pharmacist

You may see, or have telephone appointments with, a pharmacist with a special interest in the management of IBD, if you are started on a treatment which requires close monitoring.

Clinic Appointments

Our service runs across two sites, so please always check carefully whether your appointment is at the Royal Sussex County or Princess Royal Hospital. After arriving at clinic, you will generally see one of the clinic nurses who will weigh you and let the team know you have arrived. You will be seen by one of the IBD team, any junior doctors in the clinic are training in IBD and work under close supervision of the consultants. If you wish to see a particular doctor, please tell the clinic nurses when you arrive, but please be aware that this may not always be possible. Sometimes there may be a delay in clinic, due to factors such as emergency appointments for sick patients, please be patient, but if you feel you have been forgotten, ask one of the clinic nurses. It is a good idea to bring something with you (e.g. a book) to keep you occupied.

Telephone Appointments

You may be offered a telephone clinic appointment, (where you talk to our team on the telephone, rather than coming up to the hospital). These are a convenient way to keep in touch for some patients.

The IBD advice line

The advice line is an answer phone and email service and not for emergencies. A specialist nurse will return your call/email as soon as possible, usually by the end of the next working day (Mon-Fri). To ensure your enquiry can be answered as promptly as possible, please leave your full name, hospital number or date of birth and a contact telephone number. In the rare event that the advice line is closed, you will be directed to alternative points of contact.

Telephone: 01273 664427

Email: ibdnursingservice@bsuh.nhs.uk

Tests and Procedures

You will probably have to undergo blood tests, x-rays, scans and/or endoscopy investigations to diagnose and monitor your IBD. Blood tests can generally be taken on the day of your clinic appointment, however, most other tests will be done a few days or weeks afterwards, the relevant department will send you the details. Please read these carefully and remember to check which hospital site your appointment is at. Test results will be reviewed by our team and discussed at your next appointment. If you have concerns about a test result, you can contact the IBD advice line.

Research

As part of an on-going attempt to improve our treatments for and understanding of IBD, our department is involved in many research projects. It is likely that you will be approached at some point, to enrol in one of these. Participation is entirely voluntary and your normal care will be unaffected, whether you decide to take part or not.

Contacting the Hospital

If you have a question about your disease, treatment or test results which cannot wait until your next appointment or if you wish to report a change in symptoms or other health concern, then please contact us via the IBD advice line. If you have become unwell and need to be seen in clinic urgently, this is also a good point of contact. If you wish to cancel or rearrange a routine appointment then please contact the appointment booking service on: **0300 303 8360**. It helps us if you have a record of your hospital number. It may also be useful to keep a summary of your disease history, including facts such as your diagnosis, date diagnosed, which part of your bowel is affected, current medications (including doses), previous medications (along with when and why they were stopped) and recent investigation results.

Second opinions

We are aware that decisions to have surgery or take strong medications are very difficult. In some instances, you may want to be absolutely sure that every option has been considered, and that the advice you have received is correct. We discuss all complex decisions, (particularly if they are about surgery), at a weekly team meeting. However, if you have particular concerns and would like to see a different consultant, to get another view on your treatment, then please just ask us. We will not be offended. The IBD helpline would be a good way to approach us about this, if you find it hard to mention to your usual consultant in clinic.

Help us to help you

Please attend all your appointments promptly and let us know with as much notice as possible if you are unable to attend. We cannot stress strongly enough the importance of taking your medication as prescribed. If it is giving you side effects or you have concerns about taking it, please tell us straight away so that we can discuss this. If you are pregnant or trying to conceive, then please tell your doctor, as it may affect decisions about investigations and treatments. We advise all our patients, but particularly those with Crohn's disease, to stop smoking, for help with quitting please ask.

If you need help or advice about things which are not covered in this leaflet then please contact the helpline so that we can advise you.

Further Information

Crohn's and Colitis UK (formerly known as NACC) is a national charity offering support and information to patients with IBD and their families. Their website contains a lot of helpful and reliable information, their contact details are:

Information service: 0845 130 2233

Email: info@crohnsandcolitis.org.uk

Website: www.crohnsandcolitis.org.uk

Getting involved

There is a strong network of people with IBD in the Brighton and Sussex area. The local Crohn's & Colitis UK group offers support and social contact for all people in Sussex living with IBD, not just Crohn's & Colitis UK members. The group is one of the best in the country in terms of offering support, and also holds informal get-togethers each month in Hove, Haywards Heath and Worthing where people living with IBD can meet, talk and share experiences. Contact details are on page 1 of this leaflet.

You could become a patient volunteer, to help with organising events such as our annual IBD Study Day, or support the team in a variety of roles. We also have a "patient panel" of a small number of patients who would like to help the IBD team to improve services here. They meet a few times a year to discuss new ideas for the IBD service and help us to make sure that our service remains patient-centred. Please let us know if you are interested.

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Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

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