

The Guy's and St Thomas' IBD Service

This leaflet contains information about the Guy's and St Thomas' IBD Service. It outlines how to access the support services you need after a diagnosis of ulcerative colitis or Crohn's disease (also known as inflammatory bowel disease or IBD).

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Who are the members of the IBD Service?

Consultant gastroenterologists

Dr Simon Anderson
Dr Peter Irving
Dr Nick Powell
Dr Jeremy Sanderson

IBD nurse specialists

Julie Duncan
Marlene Sastrillo
Theresa Bedwell
Cordella Brown-Clarke
Johanna Bidewell-Sullivan

IBD research nurses

Anna Stanton
Emma Lee

IBD pharmacists

Sonal Mashari

Gastroenterologists

Gastroenterologists are doctors who specialise in disorders of the intestines (bowels) and liver. Our team has a special interest in inflammatory bowel disease (IBD). We will discuss your condition with you 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. They will be responsible for your overall care and be kept up to date with your progress, but you will not necessarily see them at each appointment.

The consultants are supported by a team of registrars and fellows. These are all doctors who are undergoing

specialist training in gastroenterology. Many of them are specifically training to be experts in IBD, and are doing research in the IBD unit. If needed, after you have seen the registrar or fellow, one of the consultants may also review you.

IBD nurse specialists

IBD nurse specialists are senior nurses with specialist training in IBD. They offer support and information about IBD and its treatment, and manage treatment in some cases. They run the IBD Advice Line (see page 7) and are often your best point of contact with the team for any advice you may need. They see patients in the outpatient clinic and on the wards, run telephone clinics, and give some treatments (for example infliximab).

IBD research nurses

As a leading IBD centre, we often have access to new and innovative drugs or treatments for IBD. We have a team of research nurses who work closely with our doctors for those patients who are involved in research studies and clinical trials.

IBD surgeons

IBD sometimes requires surgical treatment. We work closely with our surgical colleagues, meeting each week to discuss relevant cases.

Dietitians

You may be referred to a dietitian, 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

If you are having a treatment that needs monitoring closely, you may see or have telephone appointments with a pharmacist with a special interest in IBD.

If you need an urgent prescription after a clinic appointment, or medicine that can only be prescribed by the hospital, we will give you a prescription to take to the hospital pharmacy.

All other prescriptions should be provided by your GP. The hospital doctor or nurses will not be able to supply medicines you usually get from your GP.

IBD team meetings

The IBD team, which includes all the people outlined above, holds weekly team meetings to discuss patients' progress. This helps to ensure that you receive the best care from all members of the IBD team.

Where do I go for my clinic appointments and what do they involve?

Our service runs at two different hospitals, so please always check carefully whether your appointment is at Guy's Hospital or St Thomas' 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. Then one of the IBD team will see you.

Please be aware that it may not be possible for you to see a specific doctor, but if necessary they can be consulted. Sometimes there may be a delay in the clinic, for example if a sick patient has required an emergency appointment. 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 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 to the hospital). These are a convenient way to keep in touch for some patients. Appointments for telephone clinics are made in the same way as outpatient department appointments. We will send you a letter detailing the date and time of your appointment and we will call you at that time. Please make sure we have up-to-date contact details on file (including your mobile number) and that you can make yourself available at the time of the appointment.

Tests and procedures

We will probably have to carry out blood tests, X-rays, scans and/or endoscopy investigations (where a thin tube with a camera is inserted through your mouth or bottom) to diagnose and monitor your IBD. We may carry out blood tests in clinic, but most other tests will be

done after your clinic appointment. The relevant department will send you the details. Please read these carefully and remember to check whether the appointment is at Guy's or St Thomas'. We will review any test results and discuss them with you at your next appointment. If you have concerns about a test result you can contact the IBD Advice Line.

Research

Our department is part of King's College London and we have a strong commitment to research of all aspects of IBD. We are involved in many research projects and drug trials. It is likely that we will be approach you at some point to see if you would like to take part in one of these. It is entirely up to you whether you take part. Your normal care will not be affected whether you take part or not.

How do I contact the IBD service?

If you have a question about your disease, treatment or test results that cannot wait until your next appointment, or if you wish to report a change in symptoms or other health concern, 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.

IBD Advice Line

t: 020 7188 2487 (for receiving voicemails only)

e: ibdhelpline@gstt.nhs.uk

If you wish to cancel or rearrange a routine appointment, please contact the appointment booking service on 020 7188 8874.

The Advice Line is a voicemail and email service and is not for emergencies. A specialist IBD nurse will return your call/email as soon as possible, usually by the end of the next working day. The IBD nurses work Monday to Friday, so if you call on Friday afternoons you are unlikely to receive a response until Monday. To ensure your enquiry can be answered as promptly as possible please leave your full name, hospital number (if you have it) 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. If you need immediate medical attention, contact your GP or local A&E department.

It helps us if you have a record of your hospital number.

How can I get involved in the IBD service?

We sometimes ask our patients to help us develop certain parts of our service or research programme. If you are interested in being involved in future projects, please let one of the team know.

Where can I get further information about IBD?

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 information

t: 01727 734 470 (information service, Mon–Wed / Fri 9am–5pm, Thurs 9am–1pm)

e: info@crohnsandcolitis.org.uk

w: www.crohnsandcolitis.org.uk

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 (this includes telephone appointments). **It is also very important that you take 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, please tell your doctor as this 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.

[illegible]

Contact details

Stoma care team

For particular concerns related to your stoma that your GP is unable to answer, you may contact the stoma care service.

t: 020 7188 6469 (9am–3pm Monday–Friday)

IBD Advice Line

t: 020 7188 2487 (for receiving voicemails only)

e: ibdhelpline@gstt.nhs.uk

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS)

e: pals@gstt.nhs.uk

t: 020 7188 3514 (complaints)

e: complaints2@gstt.nhs.uk

Language support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

t: 0800 731 0319 **e:** members@gstt.nhs.uk

w: www.guysandstthomas.nhs.uk/membership

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