

Inflammatory Bowel Disease (IBD) Service



Information for patients

This leaflet is about the King's Inflammatory Bowel Disease (IBD) service at Denmark Hill. It includes information on members of the team and how to contact us. There is information on how you can get urgent specialist advice about your condition or treatment (for example if you have IBD and are feeling unwell). There is also information about what you can expect after being diagnosed with IBD and about our IBD clinics.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

The Inflammatory Bowel Disease (IBD) team

The IBD team at King's, Denmark Hill is led by consultant gastroenterologists and two IBD specialist nurses. We have a team of other doctors working with us, and we work closely with the surgical service and paediatric IBD service. We also work with colleagues at the hospital, including specialist gastro dietitians and a gastrointestinal disease pharmacist.

You will meet your allocated consultant and one of the IBD nurses early in the course of your assessment or treatment so that you know who is in charge of your care. If this does not happen, please ask when attending clinic.

The IBD clinic

Our main IBD clinic runs on Wednesday mornings in the Venetian Building at Denmark Hill. This is next to the main car park, opposite the Golden Jubilee Wing, on the corner of Caldecot Road and Venetian Road.

The following information describes what you can expect during your clinic visits.

All patients newly diagnosed with IBD will be assigned to a named consultant. Your consultant is in charge of your care, but at each visit you may be seen by other members of the IBD team. This may be a specialist registrar, a middle-grade doctor undertaking specialist training in gastroenterology under the supervision of the consultant, or one of our IBD nurse specialists.

After diagnosis, we will arrange further follow-up appointments in the outpatient clinic. These appointments are an opportunity to monitor your IBD and to plan your care. It is important to tell us



about how you are coping with your condition and the impact it is having on work and daily life so that we can offer you the right support.

Regular monitoring tests (including stool and blood tests) are an important way for us to monitor your condition. You will be notified directly or via your GP if there are any problems with the results. There is more information on these tests on pages 6 and 7.

Following clinic review, you may be started on medication. You may be given a prescription in clinic to take to the outpatient pharmacy or asked to collect a prescription from your GP surgery.

If a longer course of treatment is required (more than two weeks), then you will need to get a repeat prescription from your GP. They will have been informed of your treatment plan by a letter from the clinic following your appointment. You will need to liaise with your GP's surgery to collect this in good time so that you do not run out of medication and risk having a relapse.

After each clinic visit we will write to your GP to explain how you are doing, what the plan is in terms of tests and any changes to your treatment. Please ask if you would like a copy of this letter.

IBD helpline

Telephone: **020 3299 1606** (Monday to Friday, 9am to 5pm)

Email: **kch-tr.IBDhelpline.nhs.net**

IBD is often unpredictable in terms of when symptoms recur. It is therefore important that you have access to advice and support between clinic visits. This is to prevent a more severe attack and perhaps save you having to come back to clinic. The sooner appropriate treatment is started, the better the outcome is.



- The helpline service is available for information and advice on IBD treatment or related issues between your normal clinic appointments.
- It is a voicemail service so it is important that you leave a message clearly. State your full name, hospital number (if known), and a contact number and best time to call. One of the nurses will call you back with advice usually within 24 hours. The helpline does not operate at the weekend.
- If your call is more urgent or the IBD nurses are not available, then contact your GP or emergency GP team. If necessary, they can speak with the gastroenterologist on call for further advice.

Specialist IBD clinics

Young person clinic

Patients previously diagnosed with IBD in childhood will transfer to adult care when they turn 16 (or shortly after).

The young person clinic is held on the last Monday of each month in the Venetian building. It is attended by members of both the paediatric and adult IBD teams.

Young patients, particularly those being moved from paediatric to adult services, are seen in this clinic. You will be seen by a consultant paediatrician or adult gastroenterologist. You will have access to the IBD nurses from paediatrics and adult teams and a specialist dietitian. The clinic enables both paediatric and adult teams to remain involved with your care while you make a gradual move to the adult team.



We encourage young people to take more control and responsibility for managing their own condition, and for their parents/carers to allow them to do so. We are aware that this process may take some time to adjust to and will vary among individuals. All patients are supported through this process.

The surgical IBD clinic

This clinic runs monthly and may be attended by one of the IBD nurses who is familiar with your care. You will see a surgeon who specialises in operations on the bowel. This does not mean that surgery is inevitable but provides a chance to assess this further and discuss the options.

IBD Obstetric (Pregnancy) clinic

This is held in the Fetal Medicine Research Institute, Windsor Walk (close to Denmark Hill train station). Patients are seen jointly in this clinic by a consultant obstetrician and by one of the IBD team consultant gastroenterologists. We will plan your obstetric and IBD care jointly and see you as regularly as needed during your pregnancy. Your named IBD consultant will remain in charge of your IBD care during this period.

Biologic Multi-Disciplinary Meeting (MDM)

Patients with more severe ulcerative colitis or Crohn's disease may be considered for biologic (antibody) therapies. These patients are discussed in our Biologic MDM, which is attended by members of the IBD team. Each patient's case is carefully considered to ensure that use is appropriate, screening tests are complete and that appropriate monitoring is undertaken. The outcome of these discussions and recommendations for treatment are sent to your GP by letter. Patients are contacted directly to explain their treatment plan.



IBD research at King's

The IBD department is often involved with clinical trials to improve the management and treatment of IBD. You might be invited to take part in one of these trials or you might like to ask about new treatments in clinic.

IBD trials look at patients who are in remission (symptom free) or relapse (have active symptoms). Either way, the requirement is usually that medication doses have been stable and no new treatment has been commenced prior to trial entry. Therefore, if you have a recurrence of IBD symptoms and might be interested in a trial, it would be better to contact the IBD helpline as soon as you have symptoms to see if you would be suitable for any current trial.

Our gastroenterology research nurses may contact you about trials or other studies that may be suitable. They attend the Wednesday IBD clinic and can provide information and guide you through any research you choose to participate in.

Please ask in clinic or look on the noticeboards to see if there are any trials currently running that might be suitable for you.

Frequently asked questions

Where should I go for blood tests?

Forms will be printed out for collection at the clinic reception desk for blood tests ordered in the IBD clinic. Your doctor or nurse may ask you to have these tests done by the research nurses in the clinic. Otherwise you will be directed to the blood tests (phlebotomy) department in the main hospital. This is located on Ground Floor, Golden Jubilee Wing, Denmark Hill.



My doctor has requested a stool (faecal calprotectin) test. How should I collect this and where can I drop it off?

- You will be provided with:
 1. A transparent plastic collection pot with a small spoon attached to the lid.
 2. A sticky label with a barcode (supplying your details and those of the test) to attach to the pot.
 3. A clear plastic specimen bag.
- It is important that the bowel motion you take the sample from has not been in the toilet bowl as this could affect the result. Instead you can catch the sample using folded pieces of toilet paper or a clean disposable container.
- Using the blue-topped sample pot, unscrew the lid and use the attached spoon to collect a sample of the motion. A sample about 2cm wide (the size of a small walnut) is required.
- Carefully transfer the sample into the pot and screw the lid on tightly.
- Write the date you collected the sample on the pot. This is important because if the sample is too old (more than seven days) by the time it reaches the laboratory it cannot be tested.
- Place the pot in the clear specimen bag and seal the bag.
- Return the bag with the stool sample to a pathology drop-off point in the hospital. We recommend dropping samples off to the clinic staff in the Venetian building, where the IBD clinic is held. This is open Monday to Friday, between 9am and 5pm.

We recommend that you bring a fresh stool sample to each IBD clinic appointment unless otherwise advised by your doctor. This will mean that your doctor or nurse can request a stool test at the time of your appointment, the label can be attached to the pot and the



sample can be dropped off immediately.

A limited number of postal kits are available for return of samples. Please ask your doctor or nurse regarding availability.

What do I do if I have a 'flare-up' between clinic appointments?

- You can call the IBD helpline on **020 3299 1606** (Monday to Friday, 9am to 5pm) or email **kch-tr.IBDhelpline.nhs.net**.
- If you have ulcerative colitis and are experiencing a mild flare-up, your GP can help. In South East London we have an agreed shared care pathway that guides GPs on managing patients with ulcerative colitis between hospital appointments.
- If you have Crohn's disease that you suspect is not responding to your usual medication, or if you are having a severe flare-up of ulcerative colitis, you should contact the IBD team (call or email the helpline) for specialist advice.

How can I reduce my chance of having a flare-up?

- Take your medication as prescribed and make sure you get repeat supplies in good time.
- Do not stop taking your medication just because you feel better, as it is the medication that is keeping you well. Take the course of treatment as prescribed.
- Prompt and appropriate action can often prevent a flare-up getting worse. If your symptoms are flaring up over a period of 48 hours (two days) or more you can either contact your GP or the IBD helpline for further advice.
- Where possible, avoid taking anti-inflammatory painkillers (such as aspirin, ibuprofen, Neurofen® or Voltarol®) as these can trigger relapses. Take paracetamol instead with or without codeine if stronger pain relief is required. Codeine can lead to constipation so take with caution.



- Avoid situations which are likely to lead to stomach/bowel infections. Make sure you store, prepare and cook food appropriately. Take appropriate precautions during exotic foreign travel. More detailed information about travel advice can be obtained from the IBD nurses, GP practice or go to the Crohn's and Colitis UK website at **crohnsandcolitis.org.uk**. Maintain good hand hygiene if family members are affected by gastroenteritis.
- Many patients report worsening of their IBD in relation to periods of increased stress. Try to keep stress to a minimum. You might find practicing stress management techniques and seeking support from family, friends and employers early on helpful.
- We can arrange more formal psychological support following review in clinic if you need further support.

What do I do if I don't receive a follow-up appointment?

- All patients with IBD need to be followed up in the clinic unless alternative arrangements for review are in place.
- If an appointment you are expecting does not come through, or has been repeatedly cancelled, please contact the IBD administrator through the IBD helpline (**020 3299 1606**) or your consultant's secretary. You can find the number of your secretary on your clinic letterhead, or you can call the hospital switchboard on **020 3299 3000**

Where can I get more information about IBD?

We encourage you to learn as much as possible about your condition to help you manage the symptoms more effectively and to reduce the risk of complications in the future. You will be given an explanation about your condition and treatment in clinic. Your doctor or IBD nurse may also provide you with written information in the clinic and can direct you to useful online information.



We advise you to contact the IBD helpline or discuss with your GP or clinic doctor any further questions or concerns you might have about what you have read.

Below are a number of recommended sources that you might find helpful:

- Crohn's and Colitis UK is an information and support resource for IBD patients and their families or carers. We recommend that you join the group. It can be particularly helpful for newly diagnosed patients, but will also benefit those who have had IBD for longer. The group have also produced an introductory pack for newly diagnosed patients. Please ask for a copy in clinic.
www.crohnsandcolitisuk.org.uk
- For paediatric or adolescent issues, you can contact the Crohn's in Childhood Research Association (CICRA) at **www.cicra.org**
- The Crohn's and Colitis Foundation of America also have a good website: **www.ccfa.org**
- **www.ibdpassport.com** provides evidence-based travel advice for patients with IBD.
- The IBD nurses can also give you lots of other information on living with IBD, for example:
 - pregnancy, contraception and related issues
 - applying for insurance
 - employment-related issues
 - prescriptions
 - help with quitting smoking
 - travel advice
 - supporting health reports.

Please ask either when you are in clinic or by contacting the helpline.



There is also a selection of leaflets and booklets provided by various drug manufacturers which you might find helpful. These may be on display in clinic but if not then please ask to see what is available during your appointment.

Please get in touch if you have any questions about what you have read.

How to find us

The IBD clinic is located in the Venetian Building at Denmark Hill. This is next to the main car park, opposite the Golden Jubilee Wing, on the corner of Caldecot Road and Venetian Road.

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.



PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: **020 3299 3601**

Email: **kch-tr.palsdh@nhs.net**

You can also contact us by using our online form at

www.kch.nhs.uk/contact/pals

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.