

Inflammatory bowel disease (IBD)



Information for patients, relatives and carers

Introduction

A warm welcome to the Imperial College Healthcare NHS Trust Inflammatory Bowel Disease (IBD) Service.

Our aim is to support you as best as possible as you manage your condition. This information booklet provides an overview of the different healthcare teams that may be involved in your care at the Trust. It includes the contact details for the right healthcare professional for your care when needed.

We also encourage all patients to review the Crohn's and Colitis UK website. This contains in-depth details about all aspects of IBD care.



ontents		Page
•	What is IBD?	4
•	Overview of our IBD service	5
•	Helpful contact details	6-8
•	Trust pharmacies	9-10
•	Blood tests	11-12
•	Stool tests	12
•	What do I do if I have a flare?	13
•	Severe flares	14-15
•	Acute assessment units	15
•	Tips for preventing flares	16
•	Diet in IBD	17
•	Preparing for your outpatient appointment	18
•	Travel and vaccinations	19-20
•	IBD research at Imperial	21
•	External patient support groups	22
•	Hospital site maps	23-28
•	Useful definitions	29-32
•	How to make a comment about your visit	34

What is IBD?

Inflammatory bowel disease (IBD) is a term used to describe a group of long-term conditions in which the immune system does not work properly and starts attacking the lining of the gut. This causes inflammation. The exact cause of IBD is currently unknown. But genes, bacteria in the gut, and the environment (for example, diet, smoking, or stress) may play a role. In the UK, 1 in 123 people have IBD. This is more than half a million people.

The main types of IBD are ulcerative colitis, Crohn's disease, and IBD-unclassified (IBD-U). In ulcerative colitis, the inflammation most affects the large bowel. In Crohn's disease the inflammation can affect any part of the gut, from the mouth to the bottom. In patients with IBD-U, the inflammation resembles a mix of both ulcerative colitis and Crohn's disease.

IBD symptoms can **come** and **go**. Patients may experience 'flares' when their symptoms get worse, followed by periods of **remission** when they feel better.

Although there is currently no cure for IBD, many medicines are now available to help **control symptoms**, **treat flares**, and **maintain remission**. Some patients may also need surgery as part of their treatment, and support from a team of specialists including dietitians and specialist nurses. Together with your IBD team, you will be able to decide which treatment is right for you.

More information about IBD can be found from the Crohn's and Colitis UK website: www.crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis

Overview of our IBD service

Our IBD service consists of a **multidisciplinary team** of healthcare professionals located across three sites:

- St Mary's Hospital
- Hammersmith Hospital
- Charing Cross Hospital

At the forefront, our team of **specialist IBD nurses** will be your point of contact and will be closely involved in your care throughout your patient journey.

Our team of **gastroenterology specialist doctors** will oversee your care through outpatient clinic appointments. They will determine the most suitable medical treatments for managing your care needs in partnership with you. They will also perform endoscopic procedures for you as required.

Additional members of the multidisciplinary team that may be involved in your care include our IBD specialist **pharmacist**, **phlebotomists**, **dietitians**, **nutrition nurses**, **stoma nurses**, **secretaries**, **radiologists** and **surgeons**.



Helpful contact details

Your IBD nursing team

You can contact the IBD nursing helpline via:

Email: imperial.ibdnursing@nhs.net

Call: 020 3312 2385

The IBD nursing team deals with lots of requests. So, the phone line is not manned, and your call will go to voicemail. **But all voicemails and emails will be reviewed by the IBD nursing team**. They will aim to get back to you within 2 to 3 working days.

For any more urgent medical problems, please contact your GP or attend A&E.

Outpatient IBD clinics

Outpatient clinics with your IBD doctor or IBD specialist nurse are held either as a telephone or face-to-face consultation across the three hospital sites of the Trust.

Hammersmith Hospital

Location: Zone A, A Block, East Side

Call: 020 3313 1000



St Mary's Hospital

Location Main outpatients, 8 Winsland St

Call 020 3312 6666

Charing Cross Hospital

Location: Main outpatients, 1st floor

Call: 020 3311 1234

Endoscopy units

Hammersmith Hospital

Location: Endoscopy Unit A block, Ground floor

St Mary's Hospital

Location: Floor 2, QEQM Building

Charing Cross Hospital

Location: Endoscopy Unit First floor, West Wing

Hours: All units are open 08.00 to 18.00 daily

Call: 020 3312 6010

For all endoscopy enquiries, please call this number. Have your appointment letter and **hospital reference**

number or NHS number with you when calling.



Planned investigation unit (PIU)

Patients who have been prescribed certain medications such as biologic drugs or intravenous iron will be administered their drugs via intravenous infusion at the Hammersmith Hospital PIU,

A team of nurses and doctors manage the unit. You will receive an appointment to attend the unit for a few hours to receive the infusion. You will be medically monitored during this time.

If you wish to cancel or change your appointment, please inform the infusion unit by telephone and the IBD nursing team via the IBD nursing helpline.

Location: Christopher Booth Ward, Fourth floor, Zone F, Renal

building, Hammersmith Hospital

Call: 020 3313 6732 or 020 3313 6733

Trust pharmacies

The first prescriptions for your IBD treatment that are made by your IBD doctor will be issued by one of the Trust pharmacies. Your GP may then issue repeat prescriptions.

But the hospital pharmacy will continue issuing repeat prescriptions for advanced therapies such as biologic drugs or small molecule therapies. We cannot issue these at your local pharmacy.



Trust pharmacy locations

Hammersmith Hospital Lloyds Pharmacy

Location: Ground floor, A block

Hours: Monday to Friday: 08.00 to 18.30

Saturday and Sunday 10.00 to 13.30

Call: 020 8743 4360

Charing Cross Hospital Lloyds Pharmacy

Location: Ground floor, North wing

Hours: Monday to Friday: 08.45 to 18.30

Saturday: 09.00 to 13.00 Sunday: 10.00 to 14.00

Call: 020 8563 1448

St Mary's Hospital pharmacies

1) Main Outpatient Rowlands Pharmacy (weekdays only)

Location: Ground floor, Main Outpatients building

Hours: Monday to Friday: 09.00 to 18.00

Call 020 7402 2903

2) Lloyds Pharmacy (weekends or A&E prescriptions)

Location: Queen Elizabeth the Queen Mother QEQM building

Hours: Monday to Friday: 09.00 to 18.00

Saturday: 09.00 to 13.30 Sunday: 10.00 to 13.30,

Call 020 7402 2988

Homecare medications service

If you are on an advanced therapy that is administered subcutaneously (that is, under the skin), a homecare service provider will deliver your medications directly to your home. The nurse working with the homecare company will administer the medication. Alternatively, if you feel comfortable to do so, the homecare nurses can train you to administer the medication yourself. We will give you all the information you need about this before your treatment starts.

Blood tests

Appointments for blood tests are available Monday to Friday at the blood testing (phlebotomy) clinics located in the main outpatient departments at all three hospitals. Please note that blood tests at the Trust are by appointment only and only after blood tests have been requested by your clinical team. You can book blood test appointments online via the Trust website:



www.imperial.nhs.uk/our-services/blood-tests

If you cannot book online, please use these numbers to contact phlebotomy:

Charing Cross Hospital

Call: 020 3313 5338 (Hours: Monday to Friday 8.00-18.45)

Hammersmith Hospital

Call: 020 3313 2610 (Hours: Monday to Friday 8.00-18.45)

St Mary's Hospital

Call: 020 3312 1680 / 5935 (Hours: Monday to Friday 9.00-17.00)

How to access your blood test results

You can find your blood test results on the Patient Knows Best website: patientsknowbest.com. You'll need your NHS login. Blood test results from the Trust will be part of your personal healthcare record.

Stool tests

Most stool tests require samples of poo (stools) to be collected in blue-topped stool pots. You can get these from the outpatient clinic, your local pharmacy, or your GP surgery.



To be processed by the laboratory, **stool pots** will need to have:

- a Trust patient label containing the specific test request
- your hospital ID details

Patient labels can be printed off for you from phlebotomy, if your clinical team has requested the test. Once the label has been attached to your stool pot, you can submit it to the pathology lab. Ideally do this within 24 hours of collecting the sample.

Pathology lab locations:

Hammersmith Ground floor, Pathology Centre, Area G (near the hospital restaurant)

St. Mary's Second floor, Mint Wing Hospital

Charing Cross First floor, Laboratory block, East Wing Hospital

What do I do if I have a flare?

IBD is a relapsing and remitting disease which means that many patients experience symptoms that come and go.

Please contact the IBD nursing team if you experience a flare of your disease. You might be having symptoms such as:

- worsening abdominal pain
- bloody poo
- urgency
- increased bowel frequency compared to your normal baseline
- night-time diarrhoea



Either leave a voice message on the IBD helpline (020 3312 2385) or email imperial.ibdnursing@nhs.net. The IBD nursing team will aim to respond to you within 2 to 3 working days to advise on how to manage your symptoms. They may:

- give you advice about the current doses of your medications or start you on new treatments
- organise blood tests, stool tests or an endoscopy procedure to evaluate the severity of your flare
- or in more severe cases, ask you to come to the hospital (for example to the acute assessment unit) for further evaluation.

Severe flares

If you suspect you may be having a severe flare, then it is important to get medical help straight away. Please go directly to your local A&E or arrange to see your GP urgently. Do not wait for the IBD nursing team to reply, as this may take 2 to 3 working days.

Symptoms suggestive of a severe flare may include any of the following:

- opening your bowels more than five times than you normally open your bowels within a 24-hour period
- observing blood in your poo more than 50% of the time
- fever
- significant abdominal pain
- incontinence
- night-time symptoms
- lack of appetite
- weight loss

Please also leave a message on the IBD helpline via voicemail or email if you do see your GP or go to your local A&E. This will allow the IBD nursing team to reach out to you and track your progress and arrange follow-up care as needed.

Acute assessment units

Occasionally, patients with a flare of their condition may be asked by their medical team to come to one of the acute assessment units at the Trust for a clinical review and examination to determine further management.

These units are:

Same day emergency care (SDEC), St Mary's hospital

Location: Ground Floor Paterson Building, St Mary's

Hospital

Hours: Monday to Friday: 08.00 to 22.00

Saturday to Sunday: 08.00 to 20.00

Call: 020 3312 3196

Ambulatory emergency care (AEC), Charing Cross Hospital

Location: Ground floor, North block, Charing Cross Hospital

Hours: Monday to Friday: 08.00 to 22.00

Saturday to Sunday: 08.00 to 20.00

Call: 020 3313 0734

Hammersmith Hospital does not have an acute assessment area.

Tips for preventing flares

While the precise factors causing a flare are still unclear and it is not currently possible to predict when a flare might occur, the following measures can often help to prevent the onset of a flare:

- avoid stress
- sleep well and finding time to rest and relax
- take regular exercise
- avoid non-steroidal anti-inflammatory medications, like ibuprofen, diclofenac and naproxen
- eat a healthy balanced diet
- ensure you take your IBD medications regularly as prescribed
- avoid smoking especially if you have Crohn's disease. Find support for quitting smoking: www.nhs.uk/better-health/quitsmoking/



Diet in IBD

Patients often have questions about their diet. It's important that you do not starve yourself to artificially reduce your need to go to the toilet. Try to ensure you have a well-balanced healthy diet.

During a flare, eat small amounts regularly and drink plenty of fluids. Reducing your fibre intake can be helpful during a flare or in certain cases of Crohn's disease.

Find more detailed information about diet in IBD on the Crohn's and Colitis UK website:

crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/living-with-crohns-or-colitis/food



Preparing for your outpatient appointment

Please have a full list of your current medications available for review.

If the appointment is by telephone, please be in a place where you feel comfortable to discuss your symptoms.

It may also be useful to keep a summary of your disease history such as your diagnosis, date diagnosed, which part of your bowel is affected, current and previous medications (along with when and why they were stopped).



If you have results of any recent investigations such as blood tests arranged by your GP, then it would be helpful to bring a paper or digital copy of these to your appointment. Sometimes we may be unable to access these results from hospital computers.

If you have a question about your appointment, or would like to cancel or change your appointment, you can contact our appointments booking team.

Hours: Monday to Friday, 08:00-17:00

Call: 020 3313 5000.

Email: i.outpatientappointments@nhs.net.

Travel and vaccinations

Travel advice

In-depth advice for IBD patients who are planning to travel abroad can be found on the IBD passport

website: www.ibdpassport.com.

Vaccinations

Patients with IBD who are on advanced therapies which suppress the immune system should **avoid live vaccines**.

These vaccines contain a weakened form of the microorganism, which is generally safe for people with healthy immune systems. However, for those with weakened immune systems, such as patients on advanced therapies, there is a risk that the microorganism from a live vaccine could cause illness.

It is recommended:

- to wait at least three weeks after receiving a live vaccine before starting an advanced treatment
- to delay live vaccinations for 3 to 6 months after stopping advanced therapies.



It is important to consult with your IBD clinical team about this.

Non-live or inactivated vaccines

Non-live or inactivated vaccines, however, are safe to use in IBD patients.

We recommend GPs or local pharmacies arrange for IBD patients to receive inactivated vaccines against common infections before starting new advanced therapies. This reduces the risk of developing these infections while on these immunosuppressive therapies. These include vaccines for flu or influenza, pneumococcus and COVID-19. There's also a new inactivated version of the shingles vaccine, called Shingrix.

Find more information about vaccines in IBD on the IBD passport website: www.ibdpassport.com

IBD research at Imperial

Every medication you take for managing your IBD has been the result of years of research. The Trust and Imperial College London have formed an Academic Health Sciences Centre with a thriving pre-clinical and clinical research programme in IBD.

Research is critical for better understanding the mechanisms contributing to IBD and developing new, effective treatments to improve outcomes and quality of life of patients.

As we have a strong research programme at Imperial, you may be asked to provide additional samples for research when you have an endoscopy procedure or come to clinic. This could be blood, stool or tissue samples.



We are also a major centre in the UK for participating in Phase II and Phase III clinical trials for investigating new treatments in IBD. If you are considered suitable, we will offer you the opportunity to participate in research studies.

Or if you would like to be considered for a research study, please discuss this with your IBD consultant at your next appointment. They will evaluate if you would be eligible to participate.

Taking part in a research study does not affect the level of care you receive and is entirely voluntary. The research team works closely with the rest of the IBD team, and they will be kept informed of your progress in a study.

External patient support groups

crohnsandcolitis.org.uk



The Crohn's and Colitis UK charity website is an excellent patient resource for all aspects of IBD care. It's been created in conjunction with patients and clinicians.

We encourage all our patients to review this resource to get a better understanding of their condition and management.

gutscharity.org.uk



Guts UK is a charity for the whole digestive system.

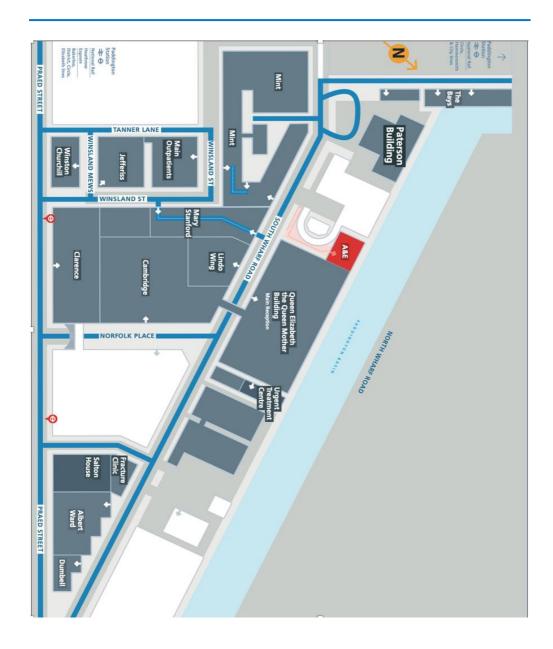
They work closely alongside with the British Society of Gastroenterology to develop evidence-based, expert patient information for patients covering a broad range of digestive diseases and symptoms, including IBD.

Hospital site maps

St Mary's Hospital

www.imperial.nhs.uk/ our-locations/ st-maryshospital

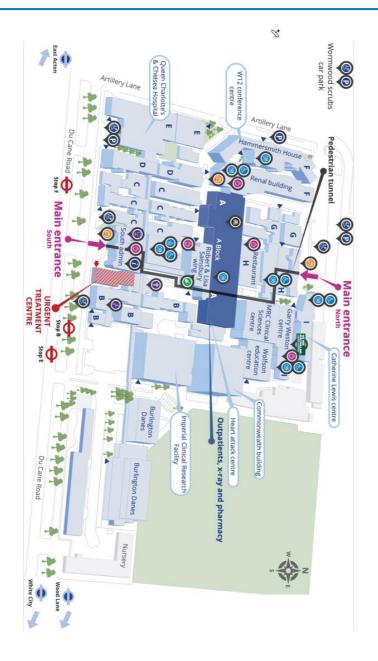




Hammersmith Hospital

www.imperial.nhs.uk/ our-locations/ hammersmith-hospital

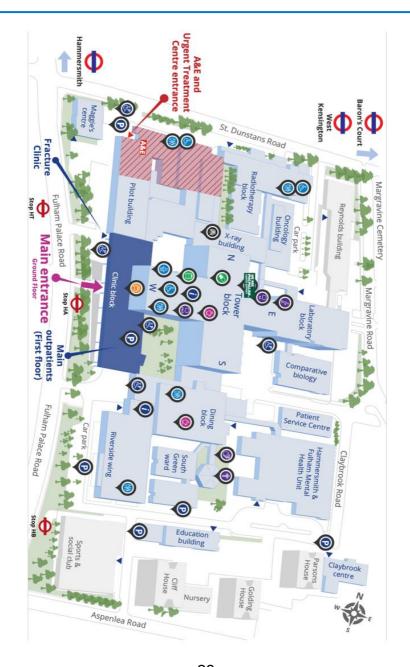




Charing Cross Hospital

www.imperial.nhs.uk/ our-locations/ charing-cross-hospital





Useful definitions

Below is a list of definitions for some medical terms you may hear or read about as a patient with IBD.

This list has been compiled from the Crohn's and Colitis UK website. See a longer definition list on their website: https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/understanding-crohns-and-colitis/medical-words

Biologic drugs – a type of medicine used to treat IBD. Biologics block particular proteins or chemical pathways involved in inflammation.

Biopsy – a small piece of tissue taken from a part of the body for examination under a microscope. These are often taken from the gut during an endoscopy to check for inflammation.

Colon – part of the large bowel. The colon absorbs water from undigested food waste to form poo.

Colonoscopy – a type of endoscopy that is used to examine the rectum, colon, and last part of the small bowel. A narrow tube with a camera in its tip, sometimes called a colonoscope, is inserted into the bottom.

C-reactive protein (CRP) – a protein in the blood that is often measured to check for active inflammation.

Dietitian – a healthcare professional who is qualified to assess and treat dietary and nutritional problems.

Endoscopy – a general name for a test that uses a long, thin, flexible tube called an endoscope with a small camera on the end to

look closely at the lining of your gut. An endoscopy is done by an endoscopist, a specially trained doctor, surgeon, or nurse

Enema – a liquid or foam inserted into the large bowel through the bottom using an applicator.

Faecal calprotectin – calprotectin is a protein that is found in poo when there is inflammation of the gut. Increased levels of faecal calprotectin can be a sign of active inflammation in the gut.

Flexible sigmoidoscopy – an examination of the rectum and the lower colon. A specialist inserts a short, flexible tube with a camera in its tip, called a sigmoidoscope, into your bottom

Flare – a relapse or worsening of a medical condition in which symptoms are more troublesome. In IBD, periods of active inflammation and symptoms are referred to as flares.

Gastroenterologist – a doctor who is specially trained in the diagnosis and treatment of gut disorders, including IBD.

Gastroscopy – an examination of the throat, stomach and small bowel. It is also known as an upper gastrointestinal (GI) endoscopy. Gastroscopy uses a slim tube with a camera in its tip, usually called a gastroscope, which is inserted through the mouth.

Histology – the study of tissues and cells under a microscope.

Immune system – the body's defence system. This is made up of different types of tissues and cells that protect the body by recognising and attacking infectious or other harmful organisms that may cause illness.

Inflammation – the way the body responds to irritation, infection or injury. White blood cells and other immune cells collect in affected areas, causing reddening, swelling and pain.

Induction treatment – treatment to ease the inflammation in your gut and get your Crohn's or Colitis under control.

Infusion – a procedure to inject a medicine or other liquid into the bloodstream at a steady rate over a period of time. The fluid flows from a sterile bag through plastic tubing and a small needle into a vein.

Intravenous (IV) – into a vein.

Irritable bowel syndrome (IBS) – irritable bowel syndrome is sometimes confused with inflammatory bowel disease (IBD) but is a different condition. Some of the typical symptoms of IBS, such as diarrhoea and tummy pain, can be very similar to those of IBD. But IBS does not cause inflammation or bleeding.

Large bowel – the part of the bowel that comes after the small bowel in the digestion process. It includes the colon, rectum and anal canal. It is where nutrients are absorbed, and poo is formed.

Maintenance therapy – treatment that usually involves one or more medicines that are taken long-term to keep an illness under control.

Phlebotomist – a healthcare professional trained to take blood samples for testing.

Radiologist – a doctor who specialises in interpreting X-ray, ultrasound, MRI and other types of imaging or scanning examinations

Rectum – the last part of the large bowel.

Relapse – symptoms becoming worse after a period of improvement. Often called a 'flare-up'.

Remission – a period of good health, free of active disease, with few or no symptoms

Small bowel – the section of the bowel that digests food and absorbs nutrients after they have passed through the stomach. The small bowel is divided into three parts: the upper region – called the duodenum; the middle region – the jejunum; and the lower region - the ileum. Also called the small intestine.

Steroids – a group of hormones used as a medical treatment to control IBD. These include prednisolone, budesonide, beclomethasone, and hydrocortisone. Also known as corticosteroids.

Stoma – an opening on the wall of your tummy made during surgery that brings your bowel to the outside. If you have a stoma, the contents of your gut do not travel all the way through your bowel to come out of your bottom. Instead, they come out of the stoma into a bag you wear on your tummy.

Suppository – a small waxy bullet-shaped capsule that is inserted into the bottom. This allows the medicine to act directly on the affected area.

Terminal ileum – the last part of the small bowel before it joins the large bowel

How do I make a comment about my visit?

We aim to provide the best possible service, and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: 020 3312 1337 / 1349

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

© Imperial College Healthcare NHS Trust