



University Hospital  
Southampton  
NHS Foundation Trust

# Inflammatory bowel disease service

Information for patients



## Your personal details and care information

Name: .....

Hospital number: .....

Diagnosis: .....

Area of the gut: .....

Date of diagnosis: .....

Doctor: .....

Nurse specialist: .....

Medication	Dose / frequency	Start date	Stop date

Investigation	Date	Result / comment

We've written this leaflet to explain about our inflammatory bowel disease (IBD) service. If you have ulcerative colitis, Crohn's disease or another IBD, you will be cared for by our IBD service team. We hope this leaflet will help to answer some of the questions you may have.

### Meet our IBD service team

Our IBD team are specialists in the digestive system. There are several different roles within the team:

**Gastroenterologists:** doctors who specialise in treating the digestive system.

**Colorectal surgeons:** doctors who specialise in bowel surgery.

**IBD nurse specialists:** nurses who specialise in caring for people with IBD.

**Specialist pharmacists:** pharmacists who specialise in medications used in IBD, with a particular interest in advanced therapies. They answer medication helpline queries, see patients in person and provide advice on treatments and side-effects.

**Dietitians:** experts in food and nutrition who can give practical dietary advice to people with IBD, bowel strictures, adhesions, stomas, nutritional deficiencies, food intolerances or difficulty maintaining their weight. If you would like to speak with one of our dietitians, please ask your doctor or IBD nurse specialist.

### Other specialists

Other specialists within the hospital may also be involved in your care, such as endoscopy staff, infusion staff, ward staff, stoma nurses, rheumatologists (joint specialists), dermatologists (skin specialists), ophthalmologists (eye specialists) and the IBD research team.

### Your GP

Your GP will receive a letter after each of your clinic appointments with us. We will keep them up-to-date with the details of your condition, any investigations you have had or require, and any treatments you are having.

## Ongoing care

All patients who have an IBD diagnosis have their care via a 'patient-initiated follow-up' service (also known as PIFU). This means that you can contact the IBD team via the helpline or My Medical Record when you need support and we will assess your situation and make a plan with you.

This does not replace any hospital appointments you have booked in but enables us to provide support when you need it most without needing to wait until a routine follow-up appointment.

## Telephone support

We operate a telephone helpline (**023 8120 5363**) which has an answerphone service to ensure your call is handled by the correct team. You will be asked for your contact details and hospital number, and whether your call concerns an administrative query, medication question, or a problem with your condition. Your message will be reviewed the next working day and a member of the most appropriate team will phone you back.

## Arranging and cancelling appointments

If your GP has asked for you to have an IBD clinic appointment, we'll send you a letter through the post with the details of your appointment. We can also send you text reminders if you would like us to. If you are expecting an appointment letter and have not received it or need to change your address, please call the secretary on telephone: **023 8120 4965**.

If your appointment is cancelled for any reason by you or by us, an alternative appointment slot should be offered to you. If you need an earlier appointment, please arrange this through the secretary.

If you are signed up to the IBD web portal, My Medical Record, you can also view and cancel appointments online.

## My Medical Record web portal

You can use our secure and confidential web portal called My Medical Record to help you keep track of your IBD care. The portal lets you access your hospital records and test results, record your symptoms and cancel clinic appointments if you need to. You can also use it to contact the IBD team or find out more about IBD.

Your IBD nurse or doctor will need to register you for My Medical Record. Speak to one of our team at the clinic or contact the IBD secretary on **023 8120 4965** if you would like to use this free service.

Once you are registered, you can log on at: **[mymedicalrecord.uhs.nhs.uk](https://mymedicalrecord.uhs.nhs.uk)**

## Home stool test

To assess inflammation levels within the bowel, we may ask you to do a stool test called a faecal calprotectin. In the past, this has always been sent off to our laboratory for testing and the results can take up to three weeks to come back. More recently, however, we have also been piloting a new home testing kit which uses a lateral flow device (similar to a Covid test) to give a result within 15 minutes, which can then be shared with the hospital team via an app and uploaded to your record. At present, this does not replace laboratory testing but may be done as well.

## Tests

As part of your diagnosis and treatment, your doctor or nurse may arrange for you to have some tests. These may range from simple blood, stool and urine tests to camera tests to look inside the bowel (known as endoscopies).

There are several different kinds of endoscopy:

**colonoscopy:** a camera test to look inside the whole of the large bowel

**flexible sigmoidoscopy:** a camera test to look at the lower end of the bowel

**gastroscopy:** a camera test that goes through the mouth to look inside the stomach.

We may also need to take some scans such as ultrasounds, X-rays and bone scans.

If you need any of these tests or scans, your doctor or nurse will explain why and give you further information about them.

## Research

Research is needed to advance our understanding of IBD and allow new treatments to be developed. At UHS we have an active research programme and there are many research studies in which IBD patients can participate. These include studies in nutrition, genetics, new medicines, biosimilars and quality of life surveys.

Some of our studies are solely questionnaire-based, some may involve collecting extra samples during routine procedures, and sometimes you may be invited to participate in a clinical trial where you can receive a treatment that is not yet available more widely.

If you would like to know more about the research studies we are currently running and how you can take part, you can contact the research team directly via telephone: **023 8120 3713**, mobile: **07769 234251** or email: **ibdresearch@uhs.nhs.uk**.

If you attend the hospital as an outpatient, you may recognise the research nurses and clinical trials assistants by their grey uniforms.

## Patient panel

The patient panel is a group of patients, consultants, nurse specialists and other members of the multi-disciplinary team. They meet approximately every six weeks at the hospital or on Microsoft Teams (online video conference) to discuss the IBD service and how it can be improved for patients. If you have a suggestion for the panel or would like to get involved, email **ibd@uhs.nhs.uk** or speak to your doctor or nurse at your appointment.

## Useful links

### **www.crohnsandcolitis.org.uk**

Information about inflammatory bowel disease including support, fundraising and research.

### **www.ibdpassport.com**

Travel advice for people with IBD including travelling with medications, food advice, vaccinations, healthcare abroad and insurance.

### **www.citizensadvice.org.uk**

Information about services in your area.

### **www.nhs.uk/better-health**

For information and support on quitting smoking, losing weight, drinking less and getting active.

### **www.italk.org.uk** or **www.steps2wellbeing.co.uk**

Free psychological therapy services for anyone suffering with anxiety or depression in the Hampshire and Dorset areas.

### **Dorset and West Hampshire Crohn's and Colitis Support Group**

Dorset and West Hampshire Crohn's and Colitis Support Group is Southampton's nearest support group for IBD sufferers and their families.

The support group's purpose is to raise awareness of and support those suffering with inflammatory bowel disease. Throughout the year they have regular social gatherings and fundraising events.

Email: **dorset@groups.crohnsandcolitis.org.uk**

Facebook: **facebook.com/crohnsandcolitisdorsetgroup/**

X: **@CrohnsColitisDO**

## **IBD helpline**

**023 8120 5363**

For queries and problems relating to your IBD e.g. flare up, drug reactions, test results, travel advice etc. This is an answerphone service.

## **IBD Secretary**

**023 8120 4965**

In order to cancel or rebook an appointment, update your contact details or sign up to My Medical Record.

## **My Medical Record**

**[mymedicalrecord.uhs.nhs.uk](https://mymedicalrecord.uhs.nhs.uk)**

You can message your IBD nursing team through My Medical Record.

## **IBD Research Team**

**023 8120 3713 / 07769 234251**

If you are interested in our research or are already on a study, please contact the research team directly.

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **[patientsupporthub@uhs.nhs.uk](mailto:patientsupporthub@uhs.nhs.uk)**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **[www.uhs.nhs.uk/additionalsupport](https://www.uhs.nhs.uk/additionalsupport)**

**[www.uhs.nhs.uk](https://www.uhs.nhs.uk)**

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