

Inflammatory bowel disease service

Information for patients



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.

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

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

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 pharmacists, 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.

If you have any questions or problems with your IBD, speak to one of your IBD nurse specialists or use our flare helpline or routine helpline (see back cover). If you have other medical concerns not directly related to your IBD, it is best to see your GP.

Outpatient appointments

Your GP may ask for you to have an outpatient appointment at the IBD clinic at the hospital.

At your appointment, you'll meet one of our specialist IBD doctors or nurses. They will discuss your condition with you and make a plan for your treatment.

Our clinics can be very busy and appointments may sometimes be delayed. The doctor you see at your appointment may not always be the one named on your appointment letter. If there is a particular doctor you would like to see, please tell us when you are called through to be weighed before your appointment.

Further appointments

You may need to come back in for follow-up appointments every few months. We will also need to see you in person at least once a year if you are taking medications such as infliximab, adalimumab or vedolizumab.

If you have a flare-up of symptoms in between appointments, please use our flare helpline. We may invite you in for an earlier appointment.

If your IBD becomes stable you can opt to use our telephone clinic (see below).

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 booking office on telephone: **023 8120 6073**.

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 booking office.

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

Virtual clinic

The virtual clinic is a telephone clinic we offer to people whose IBD has been stable for a year or more. It is not compulsory but often people prefer the convenience of not having to come into the hospital for a clinic appointment.

If you are on our virtual clinic, we will send you a blood test form and a questionnaire to fill out once a year. The blood tests can be done either at the hospital or at your GP surgery. The questionnaire will show whether you should get in touch with us to discuss your condition further. In some cases you may need to come back in to the hospital for your next outpatient appointment.

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.

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 us through the routine helpline on **023 8120 5362** if you would like to use this free service.

Once you are registered, you can log on at:
mymedicalrecord.uhs.nhs.uk

IBD open days

We hold regular open days at the hospital for patients and their families to find out more about our IBD service. Previous topics for IBD open days have included travel, research, pregnancy, diet, surgery and legal rights. You can find information about the next IBD open day on the hospital website and in patient waiting areas.

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 University Hospital Southampton 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 the clinic.

Research

At UHS we have an active research programme and there are lots of research studies for IBD patients to take part in.

If you would like to know more about the research studies we run and how you can take part, you can contact the IBD research team directly:

Tel: **023 8120 3713**

Mob: **07769 234251**

Email: **ibdresearch@uhs.nhs.uk**

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.radar.org.uk

Information about the RADAR key national scheme, which offers access to more than 6000 locked public toilets for disabled people in the UK.

www.solenthealthyliving.nhs.uk

For information and support on quitting smoking.

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/**

Twitter: **@CrohnsColitisDO**

Donating to the IBD service

If you would like to give a charitable donation to the work of the IBD nurses or research team to help fund future developments of our service, you can do this through the Southampton Hospital Charity:

By card or bank transfer

You can visit the charity office in person (in the corridor between main pharmacy and security at the entrance of Southampton General Hospital), or call the charity team on **023 8120 8881**.

Specify that you would like your donation to go to the IBD nurses (**ref 0399**) or IBD research team (**ref 0384**).

By cheque

You can hand your cheque in at the charity office or post it to:

Southampton Hospital Charity, Mail point 135, Southampton General Hospital, Southampton, SO16 6YD

Cheques should be made payable to Southampton Hospital Charity, with **Gastro Nurses 0399** or **IBD Research Team 0384** written on the back.

Flare helpline

023 8120 5363

Use this number for **urgent** queries and problems relating to your IBD, such as flare ups or drug reactions.

Leave your name, hospital number and contact details and your call will be returned the next working day.

Routine helpline

023 8120 5362

Use this number for **non-urgent** queries or concerns relating to your IBD, such as travel advice, medication enquiries, test results or mild symptoms.

Leave your name, hospital number and contact details and your call will be returned within three working days.

If you need a translation of this document, an interpreter or a version in large print, Braille or on audiotape, please telephone 023 8120 4688 for help.

www.uhs.nhs.uk