



Oxford University Hospitals
NHS Foundation Trust

OXFORDSHIRE IBD SERVICE

Information for patients



**Translational
Gastroenterology Unit**

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Gastroenterology Unit

Level 5, John Radcliffe Hospital
Headley Way
Oxford OX3 9DU

This leaflet tells you about the Oxford University Hospitals Inflammatory Bowel Disease (IBD) Service and how to access support services when you have ulcerative colitis or Crohn's disease (also known as IBD).

It is important that you are fully informed about your condition and involved in decisions about your care, and that you know how to get help when you need it.

IBD ADVICE LINE

This is a telephone and email service answered by IBD Nurses. You will find it most useful if you are clear about what you can expect from the service, so please read the information below carefully.

Telephone: **01865 228 772**

Email: **IBD.Advice@nhs.net**

- Messages picked up 8.00am - 3.00pm
- Open all working days (closed weekends and Bank Holidays)
- Messages returned within 24 to 48 hours of working days
- Please leave your
 - full name – hospital number (if you know it)
 - date of birth – a short message
- This is not an emergency line: if your situation is urgent please contact your emergency GP or go to A&E.
- The line is for clinical queries e.g. unexpected problems such as disease flares, symptoms or medication, not for routine follow-up or test results: we may direct you to other departments if more appropriate.
- If you have multiple or complex issues we may organise a clinic appointment or admission.
- Please be patient; we aim to reply within 24 to 48 hours of working days (see above).
- We will try to contact you up to three times and leave a message. If we still cannot reach you we will stop trying to contact you.
- If using our email address please read the message below:
All emails received by this Trust are subject to the Freedom of Information Act 2000 and therefore may be disclosed to a third party. Recipients should also be aware that in contacting the IBD team by email they are giving implicit consent for discussion electronically.

To request an outpatient appointment or changes to an existing appointment, please call the

IBD Appointments Team.

Tel: **01865 227 777**

Our patients can expect to receive a compassionate, skilled assessment and have any agreed follow-up completed. In return we appreciate polite and receptive communication. Please do contact us. We are here to help!

THE IBD TEAM

Over the years, a variety of specialist departments will help you manage your IBD.

Gastroenterologists

IBD Appointments Team: 01865 227 777

Gastroenterologists specialise in intestinal disorders. Our consultants will oversee your IBD care and make decisions with you according to your exact diagnosis and the extent, severity and stage of your disease.

IBD Nurses

Advice Line: 01865 228 772

IBD Nurses offer specialist advice and support about your illness and treatment, remotely or when you are in hospital. They may also prescribe medication and assess you in specialist clinics. You can contact them via the Advice Line.

Colorectal Surgeons

Secretarial Team: 01865 235 468

Patients with IBD sometimes require surgical treatment. We have a number of IBD Surgeons and our IBD Clinic runs alongside a surgical clinic, so it is possible to have a joint consultation if needed.

Hospital Pharmacist

Pharmacy at the JR: 01865 221 523

We have information sheets about IBD medications in our Outpatient Department. We will give you the relevant sheet when we first discuss a medication with you, but please ask at any time. Your GP can also access them online. We also have specialist Gastroenterology Pharmacists who manage important processes needed for many of our treatments (particularly biologics) so you are likely to meet them and can discuss medication issues with them.

Some medications can be prescribed within the Gastroenterology Clinic and the prescriptions taken to a community pharmacy. Please

do not ask the hospital doctor for medications you usually get from your GP. For help with costs, consider a Prepayment Certificate (season ticket). This is cost-effective if you have four or five different medications in a four month period.

Tel: 0845 8500030

Web: www.ppa.org.uk

Dietitians

There is usually a Dietitian in clinic to give advice on special diets and nutrition at the request of the clinic doctor or IBD Nurse. They also run group sessions for particular types of diet which we may advise you to consider. If you would like to see the Dietitian, please discuss this with us.

Research Nurses

From time to time we will offer you the chance to take part in clinical research, including trials of new treatments for IBD. You may see members of our research team in clinic or elsewhere in the unit.

Gastroenterology Ward Staff

Patients with IBD sometimes need to be admitted to hospital for intensive treatment, close monitoring or multiple tests, and possibly for surgery. We always try and admit our patients to our specialist Gastroenterology Ward (Ward 5F at the John Radcliffe Hospital), or to an appropriate surgical ward. The Ward Manager and an experienced team of nurses work closely with the Gastroenterologists, Junior Doctors, Dietitians, Pharmacists and IBD Nurses.

Gastroenterology Day Case Unit (DCU)

Administrator: 01865 221 171

If you need to come in for a day case procedure, such as a medication infusion, you are likely to come to the Day Case Unit (DCU) next door to the Gastroenterology Ward. You may recognise our IBD Nurses there.

Colorectal Surgical Ward staff

The Colorectal Ward is at the Churchill Hospital. If you need planned surgery at any time we will probably care for you on this ward. If you come in as an urgent case the Surgical Emergency Unit (SEU) at the John Radcliffe Hospital will care for you. The medical team may come to see you while you are in hospital.

Additional hospital support

IBD can become complex, so we may refer you to specialties such as Rheumatology (joints), Ophthalmology (eyes) or Dermatology (skin).

You may also meet other specialist teams.

- **Total Parental Nutrition (TPN) Team**

Intravenous nutrition for those unable to digest enough food through their digestive system.

Tel: 01865 740 378

- **Stoma Care Nurses**

Information and support before and after surgery; education about appliances and how to care for a stoma.

John Radcliffe: 01865 221 839

Churchill: 01865 235 367

Only a small number of IBD patients are likely to need these interventions, but if they do become necessary the relevant team will be able to support you for as long as necessary – even when you have left the hospital.

TESTS AND PROCEDURES

At times you will need to have investigations such as blood tests, X-rays, scans or endoscopies to diagnose IBD and to monitor your progress. Blood tests are generally taken at a clinic appointment but other investigations require specialist equipment and staff, so are arranged separately.

If you need a test, you will receive an appointment and instructions by post. Please contact the department concerned if you have any questions.

Endoscopy:

Tel: 01865 223 010

Email: endoscopy@ouh.nhs.uk

Radiology reception:

Tel: 01865 231 750

Email: JRRadiologyAppointmentsCoordinators@oxnet.nhs.uk

MRI/MRE:

Tel: 01865 221 144

CT:

Tel: 01865 228 944

When you receive an appointment for a test or investigation, please call us and arrange an appointment with the IBD Team for around two weeks afterwards, as we will need to discuss the results with you.

IBD Appointments Team:

Tel: 01865 227 777

This is not necessary for blood tests: we will send your blood test results in a letter up to two weeks after your clinic appointment. If you have concerns, please contact the secretary of the doctor you saw in clinic: the doctor will contact you if they have any urgent concerns.

Oxfordshire GPs can also access blood results via a joint system called 'Casenotes'.

We cannot give any test results via the IBD Advice Line.

IBD Clinics

IBD Appointments Team:

01865 227777 / GastroOPD@ouh.nhs.uk

We have a range of specialist clinics which you may attend at some point while under our care.

Please attend your appointments, or let us know in good time if you cannot attend so we can offer them to other patients. To change or cancel an appointment, please call the IBD Appointments Team. Sometimes we have to cancel appointments: if you have any concerns about this please call us to discuss it.

Please bring a list of your medication with you to your clinic appointments, and any questions you wish to ask.

MAIN IBD CLINICS

Our clinics are run by our specialist nurses. Please report to Reception and one of our nurses will weigh you while you wait to see the clinic doctor.

The doctor may examine you, and will discuss and plan your treatment with you. There is an IBD Consultant in every clinic for the doctors to refer to if needed.

Follow-up

- The doctor will give you a white form: take this to Reception before you leave to arrange your next appointment.
- If you need a blood test, take a numbered ticket from the dispenser outside the Phlebotomists' room
- If the doctor has given you an endoscopy request form, please go to the Endoscopy Department to arrange an appointment.
- If you are on biological therapies, the doctor will give you a purple slip. Put this in the labelled tray as you leave so that important information is passed on to the staff managing the therapies, such as the Pharmacy team.

Our main IBD Clinic (including the Biologics Clinic) is at the John Radcliffe Hospital (JR) on Friday afternoon in the Outpatients Blue Area, and our Urgent IBD Clinic is on Wednesday afternoon.

Our main IBD Clinic at the Horton General Hospital is on Monday.

Transition Clinic

We run a clinic for young patients who are about to move from children's to adults' care. Young people are ready to move at different ages, normally around 16, and we aim to move them while they are in clinical remission. A paediatric IBD specialist and adult IBD specialist work together with the patient, their parents or friends, as appropriate.

Young Adult Clinic

The Young Adult Clinic is for patients aged 16 to 24 and offers a chance to become familiar with the Adult IBD Team. Parents and carers are welcome to attend, but take a 'back seat' role and may be asked to leave the room for part of the consultation.

New Diagnosis Clinic

After your initial diagnosis, an IBD Nurse will see you to discuss your condition and treatment and answer your questions. If you did not have an appointment like this when you were diagnosed, your doctor can arrange for you to see the IBD Nurse at any time.

Telephone Clinic

If you are not on biological therapy, and have not had a flare for a year or two, a telephone review with the IBD Nurses may be appropriate for you. The Telephone Clinic is rarely delayed and longer term issues, such as surveillance colonoscopy, can still be discussed. The service has had positive feedback from patients.

Virtual Clinic

If you are on biological therapy, and have had a blood test to measure the level of the drug in your system, you may receive a phone call from an IBD Nurse asking how you are. The IBD Nurse will then meet with the Consultant and Pharmacist to decide if changes to the dose or timing of your biologic medication are needed. We will call you about any recommendations, and send you a copy of any letters sent to your GP. Please ask the nurses for a leaflet about the Virtual Clinic.

Primary Sclerosing Cholangitis (PSC) Clinic

Four percent of patients with ulcerative colitis or Crohn's disease can suffer from certain conditions of the liver. A liver specialist runs the PSC Clinic alongside the Urgent IBD Clinic, to co-ordinate and reduce the number of appointments needed with different specialists.

Surveillance Clinic

This is a multidisciplinary discussion about the appropriateness and timing of surveillance for selected patients with IBD. This is based on the extent (usually total colitis) and duration of their disease (usually after eight years), as well as other factors such as the presence of a liver condition, primary sclerosing cholangitis. It does not involve patients directly, but is a decision-making forum available to specialists who see patients in clinic.

RESEARCH

As well as caring for patients, we carry out research into the causes, treatment and consequences of IBD.

www.expmedndm.ox.ac.uk/tgu/gastroenterology

If you are under our care, at some point we will approach you about taking part in research. We may ask you to be part of our Cohort Study (below), ask to take samples during endoscopy, or ask you to be involved in trials of drugs relevant to your particular condition.

Oxford IBD Cohort Study

The Oxford IBD Cohort Study has established a detailed database of over 3000 patients with IBD under our care. This is one of the largest in the world. We ask permission to collect, store and use some samples of blood, DNA, stool, urine, bile or tissue. We approach patients who are waiting for an appointment to discuss this in a consulting room, and any involvement can take place during routine clinical care, with minimal disruption. Ideally we would like to include every patient, to allow us to monitor the pattern of IBD, and determine the effects of factors such as genes, proteins and the state of the immune system on the response to treatment. We want to involve patients who are willing to collect information on their day to day symptoms and outcomes.

RESEARCH (continued)

Specific drug trials

New treatments are badly needed for IBD. Our Clinical Trials Facility has access to therapies which are only accessible through clinical trials, long before they are available for general use. These have already gone through a long process of initial testing and ethical approval before they are offered to patients.

Your doctor may offer you the chance to take part in a trial, give you a leaflet about it and put you in touch with our Clinical Trials Facility team to discuss this in further detail.

Clinical Trials Facility:

Tel: 01865 231 618

Email: CTF.ResearchNurses@nhs.net

All new drugs have to be compared with dummy treatment ('placebo'), but the odds of receiving the new drug are two or more times greater than receiving placebo, and you will be closely supported by the Research Nurses and the medical team.

We are also a Genomic Medicine Centre, and you may be eligible to take part in the 100,000 Genomes Project. Please ask us for more information about this.

Participation in research is entirely voluntary and your normal care remains unaffected whether you take part or not. If you have any concerns about who has approached you, or how you have been approached, please do let us know.

YOU AND YOUR IBD

Everyone with IBD is different and treatment differs from person to person. A diagnosis of IBD can be confusing, but we are here to help you learn about your condition and how it affects you.

IBD typically goes through periods of remission (when you might feel completely well), and relapses (when symptoms return). Please keep your identifying details to hand (below): this is particularly important during a relapse, when you may need to contact us for advice.

Identification details we hold:

FURTHER INFORMATION

Travel: www.ibdpassport.com

Relationships: www.myibdportal.org/sexual-relationships-and-ibd

We have a number of leaflets about IBD and the medications used to treat it, including leaflets produced by Crohn's and colitis UK (CCUK), a national charity. The UKCC local group raises awareness and funds for local and national needs.

They are always keen to involve more people in their activities, so please do contact them:

Crohn's and Colitis UK Oxfordshire

Tel: 0845 130 6836

Email: oxfordshire@groups.crohnsandcolitis.org.uk

www.groups.crohnsandcolitis.org.uk/Oxfordshire

www.facebook.com/crohnsandcolitisoxon

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.



Authors: Lydia White, Rodica Nedescu, Charlotte Mullin,
Kate Griffiths, Penny Love, Professor Travis,
Professor Satsangi, Dr Brain, Dr Palmer, Dr Walsh
Gastroenterology Unit

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