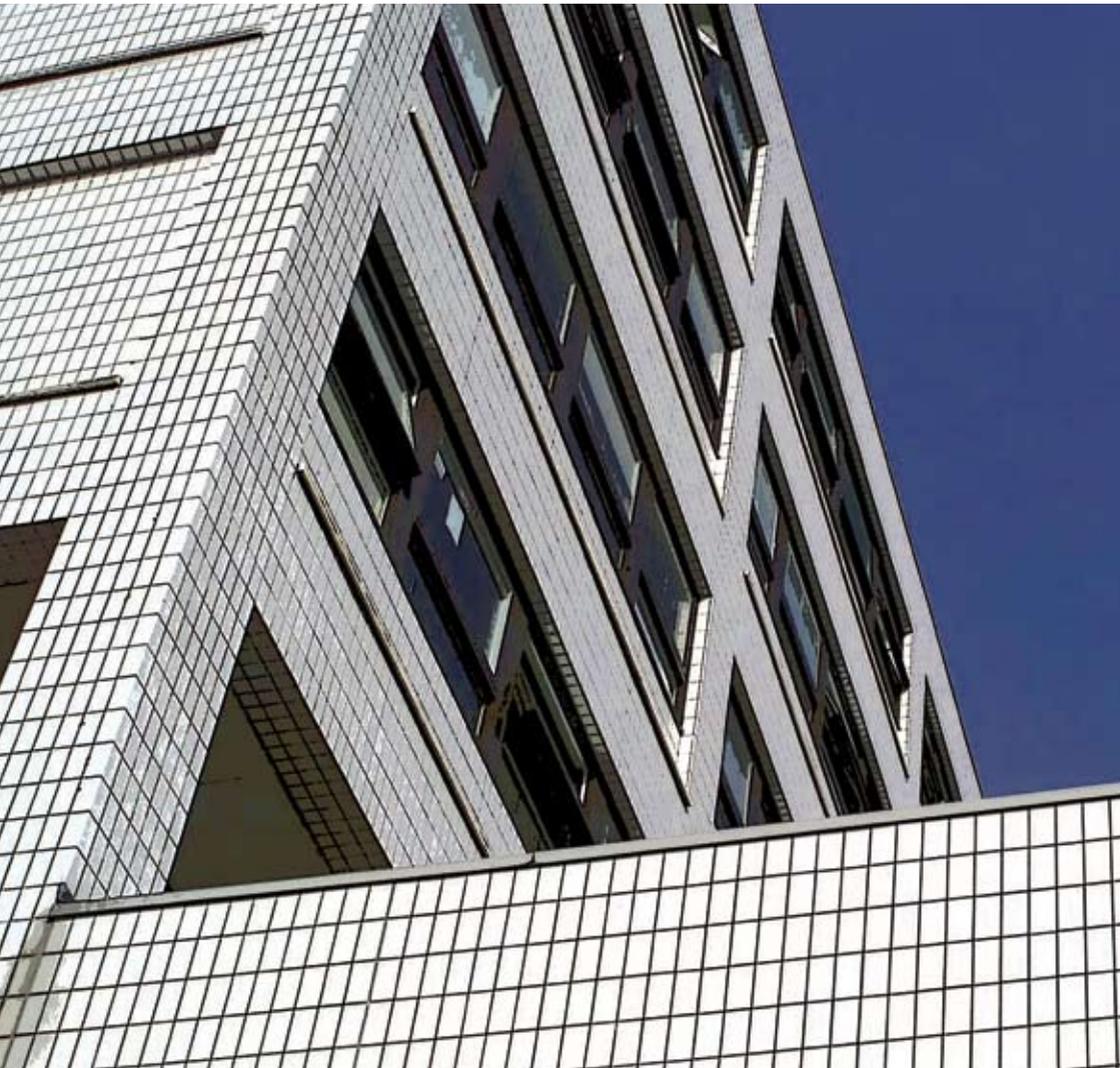


Oxford Radcliffe Hospitals **NHS**  
NHS Trust

Gastroenterology Unit, John Radcliffe Hospital

# The Oxford IBD Service

Information for patients



# The Oxford Inflammatory Bowel Disease (IBD) Service

## **Consultant Gastroenterologists**

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Gastroenterology Unit

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## **IBD Nurse Specialist**

Sister Lydia White

## **Table of contents**

The IBD Team	page 3
The role of your General Practitioner	page 6
Relapses and changes in your condition	page 7
Outpatient appointment	page 7
Telephone appointments	page 8
Tests and procedures	page 8
Research	page 9
Further information	page 9
Contacting the Hospital	page 10

## Information for patients

This leaflet tells you about the IBD Service and how to access the support services you need after a diagnosis of ulcerative colitis or Crohn's disease (also known as 'inflammatory bowel disease' or IBD). There is information about key members of the IBD team, their roles, and how to contact them. If you have any questions please ask one of the team in clinic or call the IBD advice line:

### **IBD Advice Line**

For particular concerns related to your condition that your GP is unable to answer, you may contact the advice line.

**Telephone: 01865 228772**

**email:** [lydia.white@orh.nhs.uk](mailto:lydia.white@orh.nhs.uk)

Monday to Friday 8:30a.m. to 4:30p.m.

*The advice line is an answer-phone service and not for emergencies. A specialist nurse or doctor will return your call as soon as possible.*

## The IBD Team

### **Gastroenterologists**

Gastroenterologists specialise in intestinal disorders such as ulcerative colitis and Crohn's disease. Two Consultants head a team of Gastroenterology doctors who are responsible for making decisions with you about your care. They will discuss treatment options with you, taking into account your individual situation, such as the exact diagnosis, and the extent, severity and stage of disease.

### **IBD Nurse Specialist**

You may see the specialist nurse who can offer you support and further information about any aspect of your illness and treatment. This could be at a clinic appointment, during a stay in hospital, or by phone or email. The IBD nurse may also be contacted on the IBD advice line (see previous page).

## **Surgeons**

Patients with IBD sometimes require surgical treatment if, for example, medical treatment fails to control symptoms. We try to ensure that our Gastroenterology clinics run at the same time as the surgical clinics. If you require an appointment with both teams, please tell the appointments coordinator when booking.

## **Dietitians**

There is always a dietitian in clinic who, at the request of the clinic doctor or IBD Specialist Nurse, can give you advice on special diets and nutrition. If you feel that it would be helpful to see the dietitian, please tell us when we see you in clinic.

## **Hospital Pharmacist**

Information sheets on medicines used for IBD are available in Outpatients - please ask us for these. Your GP can also access them via the internet (OxWeb). Please ask the clinic nurse or doctor to contact our Gastroenterology Pharmacist, Sarah Cripps, if you would like to discuss any issues related to medicines.

If you need an urgent prescription after a clinic appointment (to start within 14 days), or medicine that can only be prescribed by the hospital, we will give you a prescription to take to a community pharmacy. Please do not ask the hospital doctor for medicines you usually get from your GP. You can obtain a Prepayment Certificate (season ticket) to help with your prescription charges by calling 0845 8500030, or via the internet at [www.ppa.org.uk](http://www.ppa.org.uk). This is cost-effective if you require five or more medicines in a four month period.

## **Clinic Nurses**

The outpatient clinic nurses, led by Sarah Mutlow, ensure the smooth running of the clinic for all specialities, including IBD. After reporting at reception, please let one of the nurses know you have arrived. The clinic nurses generally try to make sure that you see the same doctor on each visit. There is always a Consultant Gastroenterologist in clinic and if you wish to see a particular doctor, please ask the nurse. Junior

doctors in the clinic have a particular interest in IBD and can readily obtain advice from the Consultant.

### **Gastroenterology Ward Staff**

Patients with IBD sometimes need to be admitted to hospital for intensive treatment, close monitoring, multiple tests, and possibly for surgery. We try to admit IBD patients to our specialist Gastroenterology ward (Ward 5F), or to an appropriate surgical ward (Ward 5A). Sisters Luisa Goddard and Naomi Hart lead a highly experienced team of nurses who work closely with the Gastroenterologists, junior doctors, dieticians, pharmacist and IBD Nurse Specialist.

### **Colorectal Surgical Ward**

Ward 5A is the colorectal surgical ward at the John Radcliffe and is managed by Sister Elisabeth Clarke. If you need surgery at any point you are most likely to be cared for on this ward although this is not always the case. There are three other surgical wards in the surgical unit which also have experience of caring for patients with bowel operations.

*Please note that in the summer of 2008 some of the surgical unit will transfer to new facilities at the Churchill hospital so these details may change.*

### **Specialist Consultants**

Sometimes IBD occurs in areas outside the intestine and the doctor may refer you to specialists in these areas:

- Dr Roger Chapman: *Consultant Gastroenterologist. Specialist in liver related conditions such as Primary Sclerosing Cholangitis (PSC).*
- Dr John Salmon: *Consultant Ophthalmologist. Specialist in eye conditions.*
- Professor Paul Wordsworth: *Consultant Rheumatologist. Specialist in joint conditions*
- Dr Sue Burge: *Consultant Dermatologist. Specialist in skin conditions*

- Dr Chris Bass: *Consultant Liaison Psychiatrist. Specialist in the psychological features of medical disorders.*
- Dr Chris Conlon: *Consultant Infectious Diseases specialist.*

## **Additional Hospital Support**

At different stages in disease some people need the support of other specialist teams.

The **TPN (Total Parental Nutrition) Team** arrange and monitor giving nutrition into a vein if a person becomes unable to digest enough food through their digestive system.

The **Stoma Care Nurses** (01865 221839) give information and support before and after surgery whilst also providing education about appliances and how to care for stoma.

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.

## **The Role of your General Practitioner (GP)**

Your GP is kept informed of our involvement in your care. We always send a letter to your GP after a clinic appointment. This letter contains information about your condition, about any investigations or monitoring required, and advice on any routine, non-urgent treatment you may need. We will also send you a copy of this letter. **If you have any queries about what is said in the letter, please contact your GP.**

Please note that all GP surgeries in Oxfordshire now provide support for people who wish to quit smoking. As smoking greatly worsens the outlook for people with Crohn's disease, we advise smokers to stop.

## Relapses and changes in your condition

IBD typically goes through periods of remission (when you might feel completely well), and relapses (when symptoms return). If you have a relapse, please contact your GP first. Your GP will be able to contact the hospital on-call Gastroenterology Specialist Registrar, Consultant Gastroenterologist, or IBD Nurse Specialist for advice.

However, if symptoms persist for more than 10 days after treatment has been started then you should telephone for an earlier appointment (01865 220959), or ask advice from the IBD Nurse Specialist (Tel: 01865 228772). Dr Travis' secretary (Tel: 01865 228753) or Dr Keshav's secretary (Tel: 01865 228751) can also arrange an urgent appointment for you to see a doctor.

If you experience a flare up of your bowel condition that requires medical attention out of hours, you should call your GP emergency service.

## Outpatient appointments

Each time you attend the IBD clinic you will be seen by a doctor or nurse with specialist knowledge of Crohn's disease and ulcerative colitis. They will discuss your condition with you and will plan your treatment accordingly.

The main gastroenterology clinics are held at the John Radcliffe Hospital on Tuesday or Friday afternoons, and on Thursday morning. There may be (and regrettably often is) some delay due to factors such as last minute bookings. Please be patient. If you feel that you may have been 'forgotten', by all means ask the clinic nurse.

## Telephone appointments

Telephone clinics (where you talk to the IBD Nurse Specialist or a doctor on the telephone) are offered to patients who are in a stable condition – many patients find this a more convenient way to have their follow-up.

**If you are unable to attend your outpatients or telephone appointment please call our appointments coordinator on: 01865 220959 so that we can use the time for another patient.**

## Tests and procedures

You will probably have to undergo blood tests, x-rays, scans, and/or endoscopy investigations to diagnose IBD and to monitor your progress. Occasionally an internal examination or **sigmoidoscopy** may be necessary in clinic. This is carried out in a separate room, with a nurse attending. If you are uncomfortable about this for any reason, please let us know. Most tests will be arranged for a few days or weeks after the clinic appointment. The relevant department will send you an appointment for these outpatient investigations.

After you've had your tests it is likely that we will need to see you in clinic so that we can discuss your results with you. When you know the date of the test or investigation we suggest that you telephone our appointments' co-ordinator, Lesley, on (01865) 220959 to ask for an appointment about 2 weeks after the test - if you don't already have one.

The exception to this is blood tests. Your GP will usually have access to results and if they are abnormal you or your GP will be contacted directly.

## Research

From time to time you may be offered the opportunity to participate in clinical research, including trials of new treatments for IBD. Currently available treatments do not always work, and we are constantly striving to offer better treatments and to improve our understanding of IBD. Participation in research is entirely voluntary and your normal care remains unaffected whether you take part or not.

**Please ask if you want to be involved in our research or if you would like more information about specific trials.**

## Further information

In the Outpatients clinic there are also a variety of leaflets about IBD and the medications used to treat it. These leaflets include some produced by the National Association of Colitis and Crohn's disease (**NACC**). NACC is a national charity offering information booklets, quarterly newsletters along with national and local support. The NACC website is: [www.nacc.org.uk](http://www.nacc.org.uk); telephone contact number: 0845 130 2233.

The Oxfordshire NACC Group actively work to raise awareness and funds for NACC and specific local service needs. Tim Airstone currently chairs the group with Karen Einig as secretary. Please contact them on 0845 130 6836 if you would be interested in receiving their newsletters or being involved in events.

In addition to general advice about healthy living, we stress the importance of **not smoking**. We also remind you to be meticulous about taking your prescribed medications, to follow dietary advice, and have regular tests as advised by the specialist team.

Everyone is different and optimal treatment will differ from person to person. Please discuss any questions or worries you may have with either your Gastroenterologist, IBD Nurse Specialist, or GP.

# Contacting the Hospital

When contacting the advice line, clinic appointments office or other hospital departments, it may be useful to have your hospital number available. The main information we have about you is printed on a patient sticky label:

*Patient sticky label  
Name, Hospital Number,  
Date of Birth and Address*

It would also help to have ready details on:

- Diagnosis, such as the date you were diagnosed, and anything specific you know about your condition, such as where about in the gut you are affected. (Table 1)
- Medications you are taking, and the doses. (It is also helpful to know what medication you have taken in the past, especially if you have had any bad reactions). (Table 2)
- Investigations or tests you have had, particularly recent ones. (Table 3)

You may wish to document the details above in this booklet:

**Table 1:**

<b>Diagnosis</b>	<b>Date diagnosed</b>	<b>Distribution (Where in the gut)</b>



If you require this document in another language, large print, Braille or audio version, please call **01865 221473** stating your requirements. When we receive your call we may transfer you to an interpreter. This can take some time, so please be patient.

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