



Royal Berkshire
NHS Foundation Trust

The Inflammatory Bowel Disease (IBD) Service at the Royal Berkshire Hospital

This booklet tells you about the IBD Service and how to access the support services that you need following a diagnosis of Ulcerative Colitis or Crohns Disease, also known as Inflammatory Bowel Disease or IBD. The booklet also contains information about key members of the IBD team, their clinical roles and how to contact them.

Some background information

Gastroenterologists specialise in conditions of the digestive tract system including inflammatory bowel conditions such as Crohns disease and Ulcerative Colitis. People with IBD sometimes go for long periods without any symptoms or with very mild symptoms, known as remission. Remission can be followed by periods where symptoms flare up and become particularly troublesome. You will be under the care of a gastroenterologist consultant and you may attend one of our four main IBD clinics in the Outpatients Department (level 2 South Block) at the Royal Berkshire Hospital.

Clinics

Our four main IBD clinics take place in the Outpatients Department (level 2 South Block) at the Royal Berkshire Hospital. These clinics are currently held on a Monday morning, Monday afternoon and Friday morning; and you are seen by either a consultant, a member of their team, or an IBD clinical nurse specialist. All gastroenterology doctors and clinical nurse specialists report on your case back to your consultant and can readily obtain advice from the consultant during your appointment if necessary. We will discuss your condition with you and formulate a care plan to meet your treatment needs.

Regrettably there may be occasions when the IBD clinics are delayed and you have to wait; this may be due to factors such as staffing, technical issues, last minute emergency bookings (which take priority), or clinical commitments. We will try our best to minimise delays, but if there is one at the time of your appointment please be patient and

considerate of our staff who will be doing their best to resolve any problems. We will try to ensure that you are kept up to date on the length of your appointment delay by displaying up-to-date information in the clinic waiting rooms.

Investigations

You may need to undergo blood tests, x-rays, scans and possible endoscopy investigations such as a flexible sigmoidoscopy or colonoscopy to diagnose your IBD and to monitor your progress (relevant information booklets will be given to you if endoscopy investigations are required). After you have had your tests we may then need to see you in clinic to discuss the results with you, or alternatively we may write to your GP who will be able to follow up your care.

Clinical nurse specialists

The clinical nurse specialists can offer advice about any aspect of your condition and treatment and are the first point of contact if you are having a flare-up of your IBD or if your symptoms persist for more than 10 days after treatment has been started. There is a flare-up hotline (number at back of this booklet) which allows us to identify those patients who are unwell or have urgent queries. We aim to respond as quickly as possible.

If you need to update your personal details or rebook an IBD outpatient clinic appointment then you can contact the Gastroenterology Team on 0118 322 8391, or alternatively you can also contact Patient Services on 0845 900 7000.

If you are unable to attend your clinic appointment please inform us as early as possible so that it can be offered to another patient.

If you have a flare-up of your IBD condition that requires medical treatment outside of office hours you should access your GP surgery's emergency service, or visit your nearest Accident and Emergency Department for assessment and monitoring.

If you are admitted to hospital due to your IBD the IBD nurses will visit you on the wards. We cover Sidmouth Ward regularly, but this will be

influenced by staffing levels and our other clinical commitments. If you have an urgent query then please ask the nurse looking after you to contact the IBD nurses and request a visit, particularly if you are admitted to somewhere other than Sidmouth Ward.

Telephone consultations

Telephone clinics will be offered to patients who are stable and have not had any recent flares-ups. Telephone clinics will be alternated with an 'at clinic' appointment the next time - many patients find this alternating system very useful as, for example, it means they might not have to take so much time off work, pay public transport costs getting to the hospital or car parking charges if bringing a car.

Colorectal surgeons

Patients with IBD sometimes require surgery if medical treatment has failed to manage their symptoms. If surgery is required then you will be referred to the colorectal surgical team for assessment.

Multi Disciplinary Team (MDT) Meeting

On the first and third Monday morning of every month we hold an MDT meeting to discuss patients with complex care needs or who have been admitted to the hospital. This meeting is attended by the consultant gastroenterologists, specialist nurses, surgeons and a radiologist. By using a multi disciplinary approach we can discuss your care in more detail to ensure you get the best possible care.

Dietitian

We have a hospital dietitian attached to our gastroenterology team who can advise you on weight loss/gain, nutrition and special diets as part of your treatment. If you feel that you would benefit from seeing a dietitian then please inform us at your clinic appointment, and we can refer you.

Hospital pharmacist

Our gastroenterologist pharmacist is Lindsay Yap. She can advise you on any issues related to your medicines. If you need an urgent prescription following a clinic appointment then we shall issue you with a prescription that you can take to the hospital pharmacy. They will usually dispense enough medication for 14 days and after this your GP will then be able to prescribe the remaining amount. Please do not ask the hospital consultant or IBD nurses for medications that you usually get from your GP; the hospital pharmacy will not process repeat prescriptions. If you are not entitled to free prescriptions you may want to purchase a pre-payment certificate to help with the cost of your prescriptions. This is cost effective if you require four or more medicines in a three month period or more than twelve medicines in a twelve month period. For further information contact 0845 8500030 or visit www.nhs.bsa.nhs.uk/1127.aspx.

Sidmouth Ward

Patients with IBD sometimes need to be admitted for intensive treatment, close monitoring, multiple tests and possible surgery. We try to admit patients to our gastroenterology ward which is Sidmouth Ward (located on level 2 Battle block) or to an appropriate surgical ward. Abbyrose Andrews is the sister who manages Sidmouth Ward. She leads a team of highly experienced nurses who work closely with the gastroenterologists, colorectal surgeons, junior doctors, dietitians, pharmacists and IBD clinical nurse specialists.

Psychological support

Being diagnosed with Crohns Disease or Ulcerative Colitis can be stressful and overwhelming and it may be helpful to talk to a clinical psychologist . There is a designated specialist clinical psychologist available to patients diagnosed with IBD in Reading. Your consultant or nurse can refer you directly.

Specialist consultants

Sometimes IBD affects areas outside of the intestine such as the eyes, skin, liver and joints. In these instances you may be referred to a consultant who specialises in one of these areas.

- Consultant hepatologists specialise in liver problems such as Primary Sclerosing Cholangitis.
- Consultant rheumatologists specialise in problems in the joints.
- Consultant dermatologists specialise in problems on the skin.
- Consultant ophthalmologists specialise in problems with the eyes.

Stoma nurses

If surgery resulting in a temporary or permanent stoma is required the stoma clinical nurse specialists will give you information and support prior to and after surgery about appliances and how to care for a stoma. The relevant team will also be able to support you for as long as necessary, including providing support following your discharge from hospital.

The role of your GP

We send a letter to your GP after each clinic appointment to keep them informed of our involvement in your care. Your clinic letter has detailed information about your IBD and any investigations or monitoring required, as well as advice on any routine or non-urgent treatment that you may need. You will receive a copy of the clinic letter for your personal records.

All GP surgeries now provide a smoking cessation service for those who wish to stop smoking. Aside from family history and ethnic background, smoking is the most important risk factor for Crohns Disease. Smokers are twice as likely to develop the condition compared with non-smokers. Furthermore, people with Crohns Disease who smoke usually experience more severe symptoms compared with those who have the condition but do not smoke.

Research

We are currently striving to offer better treatments and improve our understanding of IBD; therefore, from time to time you may be offered the opportunity to participate in clinical research, including trials of new treatment for IBD. Participation in clinical research is entirely voluntary. If you decide not to participate this will not affect the care you receive. Please ask if you would like to know more about our clinical trials or if you wish to participate in a particular trial.

Working together

As well as involving you in decisions when deciding on your treatment we also welcome any comments, criticism or ideas that you may wish to make about your treatment at any time. We believe that by working together we will continue to improve the IBD Service at the Royal Berkshire Hospital.

IBD Team Consultants

Dr Jon Simmons
Dr Dana Brooks
Dr Des DeSilva
Dr Caroline Green
Dr Kate Evans
Dr Nishant Patodi

IBD Clinical Nurse Specialists

Rebecca Merrick
Neil Whitehouse

Email: IBD.nurses@royalberkshire.nhs.uk
Telephone: 0118 322 8914

Gastroenterology Team

For any enquiries or appointments please call 0118 322 8391.

Endoscopy Department:

For any enquiries about your procedure please call: 0118 322 7459

IBD Flare-up Advice Line: 0118 322 8914

Please clearly state your full name, date of birth, hospital/NHS number and contact number, along with a brief description of your problem. The advice line is open Monday to Friday (excluding Bank Holidays). Messages are collected at 10am every morning so messages left after this time will be dealt with on the following day.

Do not email with urgent queries please use the telephone advise line.

Please note that we are not able to routinely offer test results over the phone/email or deal with appointment enquiries. If you have a problem with your appointment please contact Patient Services on 0845 900 7000 or 0118 322 8391.

Useful contacts

Crohns and Colitis UK www.crohnsandcolitis.org.uk/

For more information about the Trust visit www.royalberkshire.nhs.uk

This document can be made available in other languages and formats upon request.

Written by: Jessica Aparo, Inflammatory Bowel Disease Clinical Nurse Specialist, Department of Gastroenterology

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