

**Patient
Information**

The Inflammatory Bowel Disease (IBD) Service

Introduction

This leaflet gives you information about the specialist team for Inflammatory Bowel Disease (IBD), the services available and the IBD Advice line.

What is IBD?

IBD is a general term for Ulcerative Colitis and Crohn's Disease. These conditions are chronic (lifelong) disorders of the digestive tract, with periods of remission (when you are well) and relapse or flares (when your symptoms return). In both conditions parts of the intestine (bowel) may become inflamed and ulcerated causing symptoms such as pain, diarrhoea (sometimes with blood), fatigue and weight loss.

The IBD Team

The IBD Team is made up of consultant gastroenterologists, registrars (doctors close to the end of their speciality training), an IBD Nurse Consultant, IBD specialist nurses and dedicated administration staff. The team work together holding regular meetings where complex cases are reviewed. You will be allocated a named consultant who will have responsibility for your care. You may see different members of the team from time to time.

The IBD specialist nurses

The IBD specialist nurses are experienced nurses who have a special interest in looking after patients with IBD. Working closely with you, they can help you to manage your disease.

They provide information, education and support about aspects of your illness or treatments. The IBD specialist nurses are trained to assess your condition and advise you on changes to your medication, lifestyle or diet. They may also refer you for further tests (scans, X-rays or endoscopic procedures). Some of the IBD specialist nurses are non-medical prescribers, which allow them to prescribe your medication.

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IBD Team

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Their role includes monitoring patients who are receiving medication which suppresses their immune system and those treated with a group of medications called biologics. Before starting these medications, you will be seen by one of the specialist nurses, in clinic, who will give you more information about the medication. Once established, and keeping well on the medication you will be seen in clinic annually.

The IBD nurses see patients for both urgent and follow-up appointments. There are regular clinics at Gloucestershire Royal Hospital and Cheltenham General Hospital.

It may be possible to have an appointment at one of our community hospitals with a consultant or registrar. These include the hospitals at Moreton-in-Marsh, Bourton-on-the-Water, Cirencester, Tewkesbury, Stroud, Dursley, Dilke and Lydney. These clinics run less often so you may have to travel to Cheltenham or Gloucester for your appointment.

Support during flares

People who have Crohn's Disease or Ulcerative Colitis can experience worsening of their symptoms or flares. The IBD Advice line aims to give you access to an IBD specialist nurse who can offer advice or liaise with your consultant about the changes in your condition. This may result in changes to your medication or referral for tests. In some instances, you will be offered an appointment to see the IBD specialist nurse, IBD Nurse Consultant, Gastroenterology consultant or registrar in our Rapid Access Clinic either at Gloucestershire Royal Hospital or Cheltenham General Hospital.

Patient Initiated Follow Up

When a patient with IBD is stable we sometimes offer a patient initiated follow up. This means that they do not have a routine follow-up appointment but can contact us via the advice line if they are unwell.

Patient Information

Admission to hospital

Occasionally, you may be admitted to hospital. The ward staff will inform the IBD specialist nurses that you are in hospital.

Contact information

Inflammatory Bowel Disease (IBD) Advice Line

The IBD specialist nurses run an advice line for patients to call with any concerns or questions about their illness.

Tel: 0300 422 2475

This number links directly to an answerphone. Please leave a message including your full name, telephone number, date of birth and your MRN number which can be found on any correspondence sent from the hospital. **Please leave a reason for your call.**

The IBD administration team listen to the messages once a day, in the morning (Monday to Friday) and pass the information to the IBD nurses. The nurses aim to call you back within 24 to 48 hours.

If you need urgent advice and cannot make contact with us (such as during the evenings or at weekends), please contact your GP, or NHS 111.

Further information

Crohn's and Colitis UK (CCUK)

This is a national charity providing information and support for patients, their families and employers or educational establishments. Information and advice can be accessed via:

Website: www.crohnsandcolitis.org.uk

Tel: 0300 222 5700

There is a CCUK group in Gloucestershire. Meetings are held twice a year where members of the medical team will talk about a topic related to IBD. (Registered charity number 1117148)

For more information:

Email: gloucestershire@groups.crohnsandcolitis.org.uk

Patient Information

Patient Advice Liaison Services (PALS)

If you have any concerns, complaints or compliments about the care you have received, please contact one of our PALS advisors.

Freephone: 0800 019 3282

Email: ghn-tr.pals.gloshospitals@nhs.net

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Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

These resources have been adapted with kind permission from the MAGIC Programme, supported by the Health Foundation

* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85