

# Inflammatory Bowel Disease (IBD) Service

## Information for patients

---

Welcome to the IBD service in NHS Lothian. This leaflet outlines what to expect, who you may meet and how you may get in touch with us.

### Our goal

Our goal quite simply is to get you well and keep you well.

### Hospitals

People with inflammatory bowel disease (IBD), most commonly Ulcerative Colitis and Crohn's Disease, may be seen at one of the 3 hospitals in NHS Lothian.

- Western General Hospital
- Royal Infirmary of Edinburgh
- St John's Hospital

You may visit a different hospital at different times, but the surgical services are based mostly at the Western General. If you are well then visiting the hospital closest to you would be most common.

### Diagnosis

Whether you have had a very recent diagnosis or, this was made a number of years ago, you will have had some initial investigations. After this you will have met with one of our IBD team. Our team is made up of many different people with different skills and this is why you will see different people at different times. However, you are the most important member of the team, and it is very important that your voice is heard and that you play an active role in your care and treatment decisions.

Once the diagnosis has been made you will start some treatment. We always try to discuss the options with you and if you have any questions then please do make sure you ask these. In order to assess your disease, we may carry out a number of different tests to determine the best treatment for you. These include:

- Blood sampling / Stool testing
- Colonoscopy / Endoscopy
- Scans / X-rays / MRI.

If you would like to know more about any of these tests, then please ask a member of your IBD team.

## Follow up clinics

When you have been started on your treatment, we will arrange a follow up appointment for you. There are a number of follow up options such as a face to face clinic, a video consultation, or a telephone call. If you would prefer one of these options over another, please let us know and we will do our best to accommodate you.

At your appointment (whatever the type) you will see a member of our IBD team. Although your appointment will be under a consultant's name you will not always see the consultant. You may see one of the other doctors in the unit, such as a Gastrointestinal Registrar, or a Specialist Nurse. These different people are all part of the IBD team.

At these appointments we will ask how you have been, and we will often do some tests such as blood and stool tests to see how effective a treatment may be. These appointments are also a good opportunity for you to discuss what is important to you. You should think about any questions that you would like to ask the team before you come and write these down. You may have been given a personalised care plan, which can help you make the most of your visits.

We aim to offer personalised care as suggested by Crohn's & Colitis UK - personalised care for people living with Crohn's and Colitis is:

- **Personal:** It focuses on what matters to them, rather than what's the matter with them.
- **Holistic:** It recognises that a person with IBD is more than just a diagnosis, and instead addresses their physical, emotional well-being, and social care needs together as one.
- **Involves:** It actively involves them in decisions about their care. For example, in decisions about medications or surgical interventions.
- **Supports:** It empowers individuals to take an active role in their care by giving them the information, skills, and confidence to self-manage and live as well as possible.
- **Equal:** It treats people with IBD as an equal partner in decisions about their care, not doing things to them but with them.
- It **delivers good joined-up care**, where information and decisions are shared in a timely manner and include everyone involved in the person's care.

## A flare of your IBD

IBD is a condition that can get better and worse over time. A worsening of your symptoms is often called "a flare" or "relapse" of your IBD. When your symptoms are under control it is called a remission.

It is important to do a number of things if you have a flare. Your team should give you a copy of the flare card as part of your information just after diagnosis, and this gives you some simple advice on which treatments you can change before you speak to the team. You should get in touch with your IBD team using the number below. It is often better if you do this sooner rather than later. They will arrange for you to have your blood tests checked and hand in a stool sample. If this does not improve the situation, then they will suggest changes that you can make to improve your symptoms. The goal is to settle a flare as quickly as possible to ensure it impacts your life as little as possible.

## Supported self-management

The IBD team want to support you as much as possible but there are many things that you can do to help yourself. After your diagnosis you should meet with one of the specialist nurse team to discuss supported self-management. There are a number of different parts to this. Recognising a flare, getting your tests done, changing your treatment, and getting in touch with the IBD team is perhaps the most recognisable part of this but supported self-management is, however, much wider and also involves managing the way that IBD can influence your life in other ways. This includes being able to influence effects that it may have on your work, family life, mental health, travel, and social occasions. We will direct you to a number of resources that may be useful with many other areas. Please ask your team if you would like to discuss this more.

## Research

We are actively involved in all aspects of clinical research in IBD.

Your doctor or nurse specialist will let you know if you may be suitable to participate. Please ask if you would like further information.

## How to contact us

### IBD helpline

If you have problems with your IBD between your appointments, you should always ring us using the IBD helpline. The number is:

**0131 537 1272**

This is an answering machine service. Please note this is a Monday – Friday service.

### Changing appointments

If you need to change an appointment, please do get in touch using one of the numbers below. If you are unable to keep your appointment, please notify us as soon as possible using the relevant number below. This will enable the staff to arrange another date and time for you and give your appointment to someone else.

**Outpatient appointment:** 0131 537 1340

**Day Unit (Ward 75):** 0131 465 9023

**IBD Nurse Telephone clinic:** 0131 537 2724

**Drug Education appointment:** 0131 537 1873

## The IBD Team and their roles

### The IBD Nursing Team

The IBD Nursing Team is made up of the Senior Charge Nurse, Senior Clinical Nurse Specialists, and Clinical Nurse Specialists.

Their roles include:

- Education and support
- Medication education and starting new treatments
- Advice during a flare up of your condition
- Advice on side effects from medications.

### The IBD Medical Team

Gastroenterology doctors specialise in intestinal disorders such as IBD and are responsible for making decisions with you about your care and appropriate treatment options for you. You will be assigned to one of the Gastroenterology Consultants.

There are also usually 3 specialist gastrointestinal registrars who are part of IBD team who you may also meet from time to time.

### Other members of the IBD Team

There are also a number of other members of the IBD Team who you may meet. These include Specialist Pharmacists, Colorectal Surgeons, Dietitians, Endoscopy staff, staff on specialist Gastroenterology Ward 75, Radiologists, and Pathologists

**We work together as a multidisciplinary team to provide the highest standard of care to you with the resources we have.**

