Introduction
At Addenbrooke’s we look after more than 2000 patients with either crohn’s disease or ulcerative colitis which are the two main forms of IBD. This information sheet describes how you can access the service. For example if you have IBD, you may be feeling unwell with a flare-up of your symptoms, or you may have queries or concerns about your condition or treatment.

It will mainly be useful for people newly diagnosed with crohn’s disease or ulcerative colitis who are not so familiar with how things run but can also serve as a useful reminder for more established patients.

This fact sheet is not intended to describe the conditions themselves or how to treat them. There are many other sources of information which give more details on these topics. For example see the crohn’s and colitis UK website www.crohnsandcolitis.org.uk and the listing at the end of this booklet. You should note that IBD is different to IBS (irritable bowel syndrome) but patients with IBD can have IBS as well.

The IBD team
The IBD team at Addenbrooke’s is led by its consultant gastroenterologists and team of IBD specialist nurses. We have a team of other doctors working with us, and we work closely with the surgical service and paediatric IBD service as well as other colleagues across the Addenbrooke’s site, including our dedicated dieticians and pharmacist. We also work very closely with the local branch of the patient support group crohn’s and colitis UK (formerly NACC) and have an established patient panel. The latter consists of a number of patients with IBD we see in Cambridge who help to provide a patient’s perspective on our IBD service. If you are interested in becoming part of this panel or would like information please let your doctor or IBD know.

You should expect to meet your allocated consultant and one of the IBD nurses early in the course of your assessment or treatment so that you know who is in charge of your care. If this does not happen, please ask when attending clinic.

The consultants have a team of registrars and other doctors supporting them.

The IBD clinic
Most of our IBD patients have their first contact with the team in the outpatient clinic, having been referred by their GP. Patients with more severe symptoms may be admitted to hospital for inpatient treatment in the first instance. In clinic you are likely to be seen by a consultant or a ‘registrar’ (a middle-grade doctor undertaking specialist training under the supervision of a specific consultant).

The possibility of a diagnosis of crohn’s disease or ulcerative colitis may be raised at this first visit if you have typical signs and symptoms of these conditions. Alternatively a
diagnosis may be made later following special investigations (which may include blood and stool tests, scans, colonoscopy etc). The following information describes what is likely to happen during and following your clinic visits:

- All patients newly diagnosed with IBD will be assigned to a consultant team. After diagnosis, further follow up appointments in the outpatient clinic will be arranged. At these follow ups you might be seen by a doctor or by one of the IBD nurses.

- Following clinic review you may be started on some medication or recommended for specific dietary therapy. If the former you may be given a prescription in clinic or asked to collect a prescription from your GP surgery. If dietary therapy is recommended or a personal preference, you will be referred to one of the dietitians for further support and guidance with this. A report on your response will be communicated back to your referring doctor and/or IBD nurse.

- If a longer course of treatment is required, as is often the case for IBD (for example with drugs such as mesalazine or azathioprine), then you will need to get a ‘repeat prescription’ from your GP – who will have been informed of your treatment plan by letter from clinic following your appointment. You will need to liaise with your GP’s surgery to collect this in good time so that you do not run out of medication and risk having a relapse of your disease.

- In the clinic, following your appointment, we often do blood tests in order to monitor your disease and effects of treatment. You will be notified directly or via your GP if there are any problems with these with further action plan accordingly.

**Learning about your condition:**

- At the time of your clinic appointment you should get an explanation about IBD and can get more information from reputable sources such as the national patient support group Crohn’s and Colitis UK [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk) (see last page)

- Over time we do advise that you try to find out as much as possible about your condition in order to understand this better, manage the symptoms more effectively and reduce the risk of complications in the future. However, although there is a wealth of information available from many different media sources, not all sources are reputable or helpful, especially to newly diagnosed patients. This is why we recommend sticking to reputable sites.

- It is also important to bear in mind that a lot of the information regarding severe forms of IBD is unlikely to be relevant to the large majority of patients whose condition will be relatively easily controlled with simple medications and/or some dietary and other lifestyle changes. We have therefore suggested a list of good information sources at the end of this document.

- We advise that you contact the IBD helpline or discuss with your GP or your clinic doctor any further questions or concerns you might have about what you have read. Try not to worry unnecessarily about things that might never happen to you.

**Access to the hospital:**

- Accessing the patient car park (multi-storey) can be stressful and it does get busy so try to leave plenty of time before your appointment.
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- There is a drop off area just outside the main outpatients entrance if somebody else can then take the car to the car park (you cannot park at the drop off zone). There are also ‘park and ride’ car parks at Trumpington or Babraham Road.

- Please note that access to the gastroenterology clinic (clinic 12) on level 3 can seem confusing as ‘level 2’ at Addenbrooke’s is the ground floor – and therefore level 3 is only one floor up.

Frequently asked questions relating to your follow up

What happens if I’m booked for a scan or an endoscopy?
If scans are ordered, you will be sent an appointment from the X ray department with details of the appointment and any preparation required before the test. If an endoscopy (either gastroscopy for the upper gut or colonoscopy for the lower bowel) is requested, you will either be able to book the appointment time at the time of your clinic appointment or you will be asked to telephone the endoscopy department a couple of days later on 01223 257080 to schedule this.

A follow up appointment in clinic will usually be arranged shortly afterwards to discuss the results.

Do I need to see a dietician?
This is not always necessary, but in some situations you may be referred to the dieticians for specific dietary advice to help control symptoms.

Why have I been referred to the pharmacist?
We may arrange for you to be seen by the pharmacist, for example if needing to start on immunosuppressant therapy where standard treatment has failed to control the inflammation. The pharmacist will explain about the drugs and the need for any blood test monitoring. Further follow up will then be arranged with a doctor of IBD nurse Specialist.

How will my GP know what is happening?
After each clinic visit we will write to your GP to explain how you are doing, what the plan is in terms of tests etc and any changes to your treatment. If you want a copy of this letter, please just ask.

The IBD telephone helpline: how should this be used?
IBD is often unpredictable in terms of when symptoms might recur. It is therefore important that you have access to advice and support in between clinic visits in order to prevent a more severe attack and perhaps save you having to come back to clinic. The sooner appropriate treatment is started, the better the outcome usually is.

- The IBD helpline number to call is 01223 257212. This service is available for information and advice on IBD treatment or related issues between your normal clinic appointments.

- It is a voicemail service so it is important that you leave a message clearly stating your full name, hospital number (if known) along with a contact number and best
time to call. One of the nurses will call you back with advice usually within 24 to 48 hours, although not at the weekends.

- If your call is more urgent or if it is clear the IBD nurses are not available, then contact your GP or emergency GP team: if necessary they can speak with the gastroenterologist on call for further advice.
- Please ask for a copy of our IBD telephone helpline leaflet if you have not already been given one.

If you are unsure about when you should call the helpline and are worried about “being a nuisance” it is important that you let us know if you experience any of the following:

- severe abdominal pain or persistent painful swelling of the abdomen
- vomiting for more than 24 hours
- diarrhoea not responding to your usual medication
- persistent bleeding from the back passage
- unexplained weight loss or fever (greater than 38°C)
- side effects or any unusual reactions from your medications

Additional clinics relating to IBD management

Paediatric IBD transition clinic

Patients previously diagnosed with IBD in childhood will transfer to adult care on reaching the age of 16 years of age (or shortly after).

The transition clinic is held around four times a year. Patients are reviewed by the consultant paediatrician, the paediatric IBD nurse, the adult consultant, the IBD nurse and the IBD nurse. An explanation of the differences in the way the clinics run is given and new contact details are issued in the event of problems prior to the next scheduled review.

We encourage the young patient to take more control and responsibility for managing their own condition, and for their parents/carers to allow them to do so. We are aware that this process may take some time to adjust to and will inevitably vary amongst individuals. All patients are supported through this process.

The joint medical/surgical IBD clinic

In cases where surgery is an option, you may be reviewed in a joint clinic by your consultant and a surgeon who specialises in operations on the bowel.

This does not mean that surgery is inevitable but sometimes it helps to have a combined review and give you a chance to explore other treatment options.

Importantly, surgery is only infrequently required for ulcerative colitis. It is considered where all medical options have failed, resulting in poor quality of life. It may also be considered in patients admitted to hospital with acute severe colitis. In Crohn’s disease, surgery usually only becomes an issue after some years, or in patients who develop an infected abscess that needs surgical drainage. If and when the need for surgery arises you will be given more detailed information and support at this time. It is better not to dwell too much on this aspect of management in the meantime but important that you are aware
of the possibilities. You can discuss this further with your doctor or IBD nurse if you have any specific at one of your clinic appointments.

**IBD research in Cambridge**

The IBD department is often involved with clinical trials to improve the management and treatment of IBD. You might be invited to take part in one of these trials or you might like to ask about new treatments in clinic.

IBD trials look at patients who are in remission (symptom free) or relapse (have active symptoms). Either way the requirement is usually that medication doses have been stable and no new treatment has been commenced prior to trial entry. Therefore, if you have a recurrence of IBD symptoms and might be interested in a trial, it would be better to contact the IBD helpline on **01223 257212** as soon as you have symptoms to see if you would be suitable for any current trial.

**Please ask in clinic or look on the notice boards to see if there are any trials currently running that might be suitable for you.**

We also run a major IBD genetics research programme in Cambridge. This has been highly successful and our department has an international reputation in this field. The hope is that by better understanding why people develop IBD we will be in a better position to develop new treatments and possibly even cures. You may be asked if you’d be willing to contribute samples to help with this research. If you would like more information, please see our website [www.ibdgenetics.org](http://www.ibdgenetics.org)

**Some frequently asked questions are listed below and may answer some of your own queries**

**What do I do if I have a ‘flare-up’ between clinic appointments?**

- **See ‘IBD telephone helpline’ above**
- Alternatively, you might find it more convenient to email. However, do bear in mind that sensitive information can be intercepted and we cannot always guarantee that emails will be answered swiftly. This method is best reserved for administration queries rather than treatment advice in the first instance.
- **Before** using email as a method of contact you will need to complete a consent form giving your permission to receive advice on treatment or sensitive information regarding your case. This will need to be done at a face to face visit, for example when you are in clinic, so please ask for a form if you feel you would like to communicate in this way.

**Who is in charge of my treatment?**

Treatment of your IBD will usually be shared between your nominated hospital consultant and your GP.

IBD is relatively uncommon and therefore some GP’s will defer a lot of the decision making about your care to the hospital IBD team. Others will be perfectly able and happy to deal with much of it through your GP surgery.

If you are unhappy with the care you are receiving from your hospital consultant or team, you are entitled to a second opinion. The IBD nurses or your GP will be able to explain how
to do this if you do not want to ask the doctor or of course speak with a doctor if for some reason you are unhappy with the IBD nurse.

**How can I reduce my chance of having a flare-up?**

- Take your medication as prescribed and make sure you get repeat supplies in good time.
- **Do not** stop just because you feel better as it is the medication that is keeping you well: take the course of treatment as prescribed.
- Prompt and appropriate action can often prevent a flare-up getting worse. If your symptoms are flaring over a period of 48 hours or more you can either contact your GP or the IBD helpline for further advice.
- Once you are more familiar with the treatment options and have seen how we tend to adjust these, you may be willing to manage some of the treatment adjustments yourself, but if in doubt ask. Such self-management can apply to restarting oral mesalazine (for example Asacol or Pentasa) or topical enema or suppository medications, but **not** oral steroid (prednisolone) **or** immune suppressants such as azathioprine which **always** require medical supervision.
- Where possible, avoid taking anti-inflammatory painkillers (known as ‘NSAID’s’ - such as aspirin, ibuprofen, Neurofen, Naproxen or Voltarol) as these can trigger relapses. Take paracetamol instead or paracetamol/codeine combination if stronger pain relief is required although codeine can lead to constipation and so should be taken with caution.
- Avoid situations which are likely to lead to gastrointestinal infections, ie store, prepare and cook food appropriately. Take appropriate precautions during exotic foreign travel (more detailed information regarding travel advice can be obtained from the IBD nurses, GP practice or go to www.crohnsandcolitis.org.uk or www.ibdpassport.com). Maintain good hand hygiene if family members are affected by gastroenteritis (soap and water rather than alcohol gel is more effective).
- Many patients report worsening of their IBD in relation to periods of increased stress. Therefore, minimising exposure where possible, practicing stress management techniques and seeking support from family and friends and also employers early can often be very helpful.
- **Very occasionally** patients may need more formal psychological support which can be arranged following review in clinic if this is required.

**What do I do when the medication prescribed from clinic runs out?**

It should be clear following your consultation whether your treatment should stop or continue as longer term maintenance. If not, or if you are unsure what you have been told, please ask. You can do this by contacting the IBD helpline or by contacting your GP’s surgery who will have a letter regarding this. Otherwise it may be on the copy of the clinic letter that you receive.

The initial prescription may be given in clinic but subsequent repeat prescriptions should be obtained from your GP – please contact your GP’s surgery to arrange these.
I do not like the idea of using suppositories or enemas – are there any alternatives?

Suppositories and enemas are often used in combination with oral tablets for maximum benefit. For many patients, particularly those with ulcerative colitis where the inflammation affects the lower colon and rectum, using suppositories or enemas provides a very effective means of getting a high concentration of medication exactly where it needs to be – without having to take high doses by mouth.

This leads to a faster resolution of symptoms such as urgency and bleeding compared to taking medication by mouth.

- Using such medications just before bedtime, for example after a hot bath or shower, may make them easier to manage. KY lubricating gel or a little water should be applied to the applicator or suppository prior to insertion.
- If your bottom is sore it might help to use a little local anaesthetic gel, such as instillagel, before insertion of the enemas or suppositories.
- Standing the enema bottle in a jug of warm water for a few minutes before insertion or in the case of suppositories “moulding” them in your hand for a few minutes prior to insertion can make administration easier and improve retention.

Why do I need blood tests and what do they tell the doctor?

We will often ask for blood tests to be done at the GP surgery between visits, in order to monitor activity of your IBD or check up on the treatments we have given. This is to make sure that the treatments are not causing any unwanted problems to other areas of the body, such as liver, kidney and bone marrow.

Most of the medications we prescribe for so called maintenance treatment are relatively safe long term so long as blood tests are carried out at regular intervals and that you attend clinic or are under regular review by your own GP.

What do I do if I do not receive a follow up appointment?

All patients with IBD need to be followed up in the clinic unless alternative arrangements for review are in place.

If an appointment you are expecting does not come through, please contact clinic 12 on 01223 217452 or your consultant’s secretary. You can find the number on the clinic letter head, or alternatively via the hospital switchboard on 01223 245151.

This may be especially necessary if your next appointment has not been booked pending a special test/scan/endoscopy. You can usually expect to get an appointment following a procedure your doctor or nurse has requested around two weeks later. However, it may be a little time after this depending on the availability and so if there appears to be a long delay you can always contact the IBD helpline to discuss but definitive treatment may still need to be commenced in clinic and your appointment can be expedited accordingly.

What do I do if my appointment keeps getting cancelled?

From time to time it is necessary for appointments to be cancelled and rescheduled for reasons which are unavoidable. This can be at short notice and is done by computer so it is not possible for us to know if your appointment has been repeatedly cancelled. Therefore if this has happened more than twice, especially if you are experiencing problems, please let
Where can I get more information about IBD?

It is important to gather information relating to your particular case so that you understand how best to manage the symptoms and live day to day with IBD. Listed below are a number of recommended sources that you should find helpful. Please let us know if you have any questions as a result of viewing information from any of the listed sources.

- [www.crohnsandcolitisuk.org.uk](http://www.crohnsandcolitisuk.org.uk) Crohn’s and colitis UK (formally NACC) is an information and support resource for IBD patients and their families or carers and we would recommend that you join the group. It can be particularly helpful for newly diagnosed patients, but will also benefit those who have had IBD for longer. The group have also produced an introductory pack for newly diagnosed patients. Please ask for a copy in clinic. Membership is free up to the age of 18.

- The Crohn’s and Colitis Foundation of America also have a good website: [www.ccfa.org](http://www.ccfa.org)

- [www.crohns.org.uk](http://www.crohns.org.uk) The IBD nurses have a selection of books which you might find useful. If you would like to borrow one of these then please contact the IBD helpline (01223 257212) or ask in clinic.

- The IBD nurses can also give you lots of other information on living with IBD, for example on pregnancy, contraception and related issues, applying for insurance, employment related issues, help with quitting smoking, travel advice, support in health reports and many other things. Please do ask either when you are in clinic or by contacting the helpline.

- Similarly there is a selection of leaflets/booklets provided by the various drug manufacturers which you might find helpful. These may be on display in clinic but if not then please ask to see what is available during your appointment.

- For specific advice on travel contact [www.ibdpassport.com](http://www.ibdpassport.com)

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:
If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

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