Department of gastroenterology

The Cambridge Crohn’s and colitis service

Introduction
At Addenbrooke’s we look after more than 3000 people with either Crohn’s disease or ulcerative colitis which are the two main forms of IBD (inflammatory bowel disease). This information sheet describes the service we deliver and how you can access it. 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 people already familiar with the service.

This information sheet is not intended to describe the conditions themselves or how to treat them. There are many sources of information which give details on these topics. For example 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 people with IBD can have IBS as well.

The IBD team
The IBD team at Addenbrooke’s is led by its consultant gastroenterologists and a 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 dietitians, psychologist and pharmacist. We also work closely with the local branch of the patient support group Crohn’s and Colitis UK and we are looking to re-establish our patient panel. The latter consists of a number of people 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 nurse 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 and you may see them in clinic.

The IBD clinic
The first contact with the team is usually in the outpatient clinic, having been referred by the GP. People with more severe presenting 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 people newly diagnosed with IBD will be assigned 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 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. If you sign up to the MyChart app then you will automatically receive test results that have been arranged within the hospital. Please ask a member of the team how to sign up to this (see section below for more details).

**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 disease related 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 advice line 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.
- 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 close to the hospital at Trumpington and Babraham Road and others a little further away but still easily accessible at Madingley Road, Milton Road and Newmarket 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.

Additional clinics relating to IBD management

Paediatric IBD transition clinic
Adolescents or young persons 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. The review takes place in one clinic (usually the adult clinic) with the consultant paediatric gastroenterologist, the paediatric IBD nurse, the adult consultant gastroenterologist and the adult services 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 adolescents 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 young persons 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 but may be considered where all available and reasonably evidence based medical options have failed, resulting in poor quality of life. It may also be considered in patients admitted to hospital with acute severe colitis where there is considered to be a high risk of complications including risk to life if surgery is delayed in the event of failure to respond to medical therapy in the expected time period.

In Crohn’s disease, surgery may be required to manage infective complications such as abscesses that require surgical drainage in addition to medical treatment with antibiotics.
Also in the event that the now multiple medical treatment options fail to bring about disease remission, or to remove the most active part of diseased bowel where medicines have failed to settle it completely, or whereby areas of the bowel have become tight/ narrow causing partial or full obstruction. If and when the need for surgery arises you will be given more detailed information and support at this time. You can discuss this further with your doctor or IBD nurse if you have any specific concerns at one of your clinic appointments.

**IBD psychology clinic**

A diagnosis of IBD can carry a lot of uncertainty, such as around outcomes, disease pattern, treatment effectiveness and disease flares. In addition, some of the symptoms themselves can be distressing and stressful to manage. It is therefore quite normal at times to feel anxious, worried or low in mood. Having good coping mechanisms, such as a reliable support network, will help but it may also be beneficial to talk to our dedicated IBD psychologist. Our psychologist can work with you to help you manage the emotional impact of diagnosis, living with inflammatory bowel disease, with the stressors and demands of treatment, or with concerns about the future.

Education, employment, personal relationships and social and family life may all be disrupted by the unpredictable nature of IBD. A frequent and urgent need for the toilet, constipation, the invisible symptoms of pain and fatigue and fears before and after surgery can severely affect how you feel about yourself and your confidence in living your life. You may feel that your problems are unrelated to your condition but have noticed that they impact on your feelings of being able to cope or manage your IBD. The aim of psychological therapy is to help people to increase their understanding of their problems so that they are able to make changes if they wish to improve their quality of life.

We may offer this service to you in clinic, or if you feel you might benefit from it, please do ask at your next clinic appointment. For some people, there may be a more appropriate service elsewhere, for instance if you live too far away to attend appointments at Addenbrooke’s or when it would be helpful to have full mental health team support. On these occasions, we will discuss this with you in clinic, or at your first psychology appointment, and we will support you in accessing the alternative service.

**IBD dietitian clinic**

As part of the IBD team we have a gastroenterology specialist dietitian who runs dietitian-led clinics. It is not necessary for everyone to see a dietitian but in some situations you may be referred for specific dietary advice to help manage symptoms. Typical referral reasons include: losing weight unintentionally and you need support preventing further weight loss or regaining lost weight; you have a ‘flare’ of your symptoms and require possible dietary changes or an exclusive liquid diet to try and promote remission (for people with Crohn’s disease); you require pre-surgery nutritional optimisation.

**IBD research in Cambridge**

The IBD department in Cambridge is also part of a world-leading research team dedicate to finding better treatments and improving understanding of IBD. Our patients are often invited to be involved with clinical trials and studies. You might be invited to take part in one of these trials.
Please ask in clinic or look on the noticeboards to see if there are any trials currently running that might be suitable for you or register your interest to be contacted in the event of taking part in any future trials that may be suitable.

Frequently asked questions

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.

Why have I been referred to the pharmacist?

We may arrange for you to be seen by the pharmacist if, for example, you need to start on an immunosuppressant. The pharmacist will explain about the drug and the need for any blood test monitoring. Further follow up will then be arranged with a doctor or 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, and any changes to your treatment. If you want a copy of this letter, please just ask.

The IBD telephone advice-line: 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 advice-line 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 non-urgent voicemail service so it is important that you leave a message clearly stating your full name and hospital number (if known) along with a contact number on which you will be available for a call back. One of our administrative team will listen to your message within one working day. The team member will then call you back to advise on appropriate action, which may include booking you into a telephone clinic to speak with one of the nurses and in that event we would aim for this to be within one to two working days.

- You will appreciate that the telephone clinic can be much in demand and it is appropriate that use of consultations are for those with clinical need. There may also be times when
If your call is more urgent or if it is clear the IBD nurses are not available, contact your GP or emergency GP team: if necessary they can speak with the gastroenterologist on call for further advice. If a clinical emergency you should contact NHS 111 or attend A&E.

If you are unsure about when you should call the advice-line 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 rectum (back passage)
- unexplained weight loss or fever (greater than 38°C)
- side effects or any unusual reactions from your medications

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

- Contact the IBD nurses via the IBD advice line (see ‘IBD telephone advice-line’ above for details).
- Send a message via the MyChart patient portal (see section below ‘what is MyChart’).
- Contact your GP surgery. If they are unable to advise they can contact a member of the team on your behalf.
- Contact the Crohn’s and Colitis UK dedicated advice line and a member of the team will advise or signpost you to the most appropriate person or team that can give you further advice.

What is MyChart?

This is the electronic patient portal at Addenbrooke’s and the Rosie hospitals which allows you to securely access parts of your health record held within the hospital’s Epic electronic patient record system. Once the activation code has been received with simple instructions on how to set this up you will have access to a number of functions including:

- ability to view and change appointments
- update personal details
- receive copies of clinic reports
- obtain test results
- ability to send messages to your IBD team requesting advice on aspects of your management or to address concerns you might have about a particular treatment or symptoms you are experiencing.

We would advise you keep these to simple questions and answers. If the problem appears more complex or the message overly detailed your team might advise a telephone call or clinic visit would be necessary to better sort out the problem. MyChart is designed to improve communication between you and your clinical teams and enable you to be more involved and
informed about your care by having access to your information. If you are interested in signing up then please speak to the clinic receptionist on attending for your appointment or contact a member of your clinical team for further details.

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 GPs 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 and ensure you request a repeat prescription in good time.
- 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 advice-line 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 steroids (prednisolone) or immunosuppressants such as azathioprine which **always** require medical supervision.
- Where possible, avoid taking anti-inflammatory painkillers (known as ‘NSAIDs’ – such as aspirin, ibuprofen, Nurofen, 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 is more effective than alcohol gel).
- 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 early from family, friends and employers 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 the 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. Ensure you complete the full course of treatment as instructed and do not stop simply when symptoms resolve.

Do I need to change my diet when in remission?
During remission you should aim to follow a healthy, balanced diet which contains fruit and vegetables, carbohydrate and protein with some dairy (to help with calcium intake) and small amounts of fats. Heavily processed foods for example: fizzy drinks, confectionary, convenience style foods and fast-food should be limited. When in remission there are no special diets or foods to avoid. If you have ongoing bowel symptoms despite being in remission, we sometimes use exclusion diets to identify possible food intolerances triggering ‘functional’ type symptoms.

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, kidneys 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 letterhead, or alternatively via the hospital contact centre 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; 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. So if this has happened more than twice, especially if you are experiencing problems and importantly if you are taking immunosuppressant medication or biologic medication, please let us know by contacting the IBD advice-line on 01223 257212 or by contacting the IBD administrator on 01223 217990. You can also send a message via MyChart.

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.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.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 has 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 advice line (01223 257212)** or ask in clinic. The IBD nurses can also provide you with information on many aspects of living with IBD, for example

- pregnancy, contraception and related issues
- applying for insurance
The Cambridge Crohn’s and Colitis Service

- employment related issues
- school, college, university issues
- help with quitting smoking and advice on travel (for specific advice on travel contact www.ibdpassport.com)

Please do ask either when you are in clinic or by contacting the IBD advice line.

Similarly there is a selection of leaflets/booklets provided by the various pharmaceutical companies 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.

There is also more specific information provided by the many pharmaceutical companies relating to medications and drug monitoring requirements that you will be given if and when the time arises. Many companies also provide additional support services that can help you manage your medications and condition more effectively. Some also provide nurse support where this might be indicated that should complement and not be instead of that provided by your hospital team.

We are 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 or audio, please contact interpreting services on telephone: 01223 256998, or email: interpreting@addenbrookes.nhs.uk For Large Print information please contact the patient information team: patient.information@addenbrookes.nhs.uk

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