



INFORMATION SHEET

TAKING MEDICINES

INTRODUCTION

If you have Crohn's Disease or Ulcerative Colitis – the two main forms of Inflammatory Bowel Disease (IBD) – you are likely to be prescribed medication as part of your treatment. This information sheet looks at some of the most common questions asked about IBD drugs and how to take them.

WHY ARE DRUGS USED IN IBD?

We do not yet know what causes IBD, so taking drugs will not cure your disease. They can however be very effective in treating your symptoms, and preventing the disease from progressing and causing complications.

Initially, the aim of drug treatment will be to reduce the inflammation in your gut to give you relief from symptoms and bring about remission (a period of good health). This is sometimes called induction therapy. Once your condition is under control, your doctor will usually continue to prescribe drugs to help maintain remission and prevent a relapse. This is called maintenance therapy, which is often needed on a long-term basis.

Drugs don't work the same way for everyone, so it is not always possible for your doctor to predict which treatment will suit you best. It is important to make sure you find a medication that works for you. For more information about the drugs used to treat IBD, see our individual information sheets on **Adalimumab, Aminosalicylates (5-ASAS), Azathioprine and Mercaptopurine, Biologic Drugs, Infliximab, Methotrexate, Steroids (corticosteroids), Vedolizumab** and **Other Treatments for IBD**.

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Taking medicines every day made me feel like I had some ammunition to fight the disease with. It's just a part of my routine now, like putting my wristwatch and glasses on.

”

Linda, age 57
diagnosed with Crohn's Disease in 1979

WHY MIGHT I NEED TO TAKE MORE THAN ONE DRUG?

Many people with IBD use more than one medication at a time to manage their condition. This is known as combination therapy, and may be used when the condition is severe or a fast response is needed. For example as azathioprine takes a few months to start working, steroids are sometimes given at the start of treatment to reduce symptoms quickly until the azathioprine can take effect.

Combination therapy is often used on a long-term basis to help certain medicines work more effectively. For example, some studies have shown that people who take an immunosuppressant such as azathioprine with their biologic drug are more likely to stay in remission than people who take a biologic alone. However, taking more than one medicine can also increase the risk of side effects, so it is important to discuss the risks and benefits with your IBD team.

WHAT DO I NEED TO KNOW BEFORE TAKING IBD DRUGS?

Before deciding to take any medication, it is important that you have all the facts you need to make an informed choice. For example it can be helpful to know:

- what the drug is and why it is being offered
- the potential benefits and risks, including side effects
- whether alternative treatments are available
- how it is administered (tablet, enema, injection or infusion) and whether you can choose the form you prefer
- how frequently it should be taken and whether there is an optimum time of day to take it
- how to store the medicine safely
- how long you need to take the drug for, and how to safely stop taking it
- how long it usually takes to start working
- whether the medicine contains any ingredients you are allergic to

If you are pregnant, breastfeeding or trying to conceive, it is also important you discuss this with your IBD team, as some medications may not be suitable for you. For more details see our information sheets **Pregnancy and IBD** and **Fertility and IBD**.

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When I reflect back, I think I would have benefitted from more information about certain drugs. I feel the more you know in advance, the more prepared you are to deal with any setbacks when they happen.

”

Angela, age 37
diagnosed with Crohn's Disease
in 2012

WHY DO SOME DRUGS HAVE SEVERAL NAMES?

Every drug has an approved generic or medical name, decided on by an expert committee. Many drugs are also known by a brand or trade name, chosen by the pharmaceutical company making and selling that drug as a medicine. So, for example, the drug adalimumab (generic name) is also known as Humira (brand name). Some drugs are sold in a generic form as well as in a branded form. If several companies market a drug, it will have several different brand names. For example, different brand names for mesalazine include Asacol, Salofalk and Pentasa.

DOES IT MATTER WHICH I HAVE?

As well as the main active ingredient (the generic drug), medicines usually contain inactive ingredients. These help to formulate the medicine – that is, to make it into its tablet, cream or liquid form. They can also be used, for example, to give tablets a particular colour or affect how long the tablets take to dissolve in the gut.

For most prescription medicines, such small differences are unlikely to create any problems. Whether you are prescribed the branded medicine or a generic version of a drug, your medicine should have the same therapeutic effect as long as your dose contains the same amount of active ingredient.

However, for a very small number of drugs, the differences in formulation may be more significant. For example, some of the different brands of mesalazine work in a slightly different way. For this reason your doctor may decide to prescribe a particular brand rather than the generic version.

There also may be more significant differences in formulation in biosimilar medications for biologic drugs. Infliximab (brand name Remicade) was the first biological drug to be used in IBD, and the patent expired in 2015, meaning other companies can now produce their own versions of the same drug. Two biosimilars are currently available for infliximab, called Inflectra and Remsima. However unlike

'chemical' drugs, biologic drugs are made by living cells, meaning their manufacturing process is much more complicated. Each manufacturer has its own unique cell line and process – so the final products can never be exactly identical because they are made using different cells. Hence we have biosimilars, which are similar but not identical to the original biological drug.

In order for a biosimilar to be approved for use, it has to meet strict standards to show it is as safe and effective as the original biologic drug. For more information on biosimilars see our information sheet **Biological Drugs**.

WHY DO DRUGS COME IN DIFFERENT FORMS?

Some of the drugs and medicines prescribed for IBD come in several different forms – for example as tablets, as granules, or as a liquid or foam. This is so that they can be taken in the way that helps them to work most effectively. This is usually orally (by mouth), but may be topically (applied directly to the body) or by injection. The best way will depend partly on which area of the gut is affected by your IBD, and partly on the nature of the drug itself.

Oral drugs

Many drugs used for IBD have a tablet, capsule or granule form, so can be swallowed by mouth. This is often a convenient way to take your medication and it is easy for a doctor to change dosage levels if necessary. However, anything taken by mouth will start to dissolve very quickly, so many of the tablets and capsules have a special 'gastro-resistant' coating. This makes sure the drug is released in the right part of the digestive system – usually the small intestine (small bowel) or large intestine (colon). This is why it is often important to swallow tablets or capsules whole and not to break or crush them.

Topical treatment

Taking a drug topically means applying it directly to the affected part of the body. This can mean that the drug works more efficiently. Topical treatment also tends to cause fewer side effects, as the drug does not significantly enter the bloodstream and so does not affect other parts of the body as much.

In IBD, topical treatment is usually most appropriate when the inflammation is in the rectum (a condition often known as proctitis) or near the end of the colon. One way of delivering topical treatment to inflammation in these areas is to use a suppository. This is a small bullet-shaped capsule of the drug in a waxy substance that will dissolve at body temperature. The suppository is inserted directly through the anus (back passage) into the rectum. As it dissolves, it releases the drugs in the right area.

Another way of getting a drug directly into the rectum and colon is to take it as an enema. These can come in a liquid or foam form, and are put into the rectum through the anus using a specially designed applicator. Foam enemas are often easier to retain than liquid enemas so can be particularly useful at the beginning of a flare-up, when the gut is most sensitive. Liquid enemas can usually travel further along the colon so will reach more of the inflammation, especially if taken just before lying down. Both steroids and aminosalicylates (5-ASAs) are sometimes given topically, using a suppository or enema.

If the inflammation is on the surface of the skin, an ointment or cream may be helpful. An immunosuppressant called tacrolimus is available in ointment form and may be used to treat perianal Crohn's.

Injections and infusions

Some medicines are injected subcutaneously (under the skin, usually in the thigh or stomach), intramuscularly (into a muscle) or intravenously (into a vein). This is because the digestive system would break down and destroy the drug if taken orally. Intravenous injections are often given through a drip in your arm using an infusion (a dilute form of the drug).

Biologics such as infliximab and adalimumab cannot be taken orally, so are always given by injection or infusion. Steroids and some immunosuppressants may be injected intravenously to get a quick response in people having a severe flare-up.



CAN OTHER MEDICINES AFFECT IBD DRUGS?

It is possible that other drugs might interact with your IBD medication. This could make your treatment less (or more) effective, or alter its side effects. For example allopurinol, a medication used to treat gout, can increase the harmful effects of azathioprine. So it is very important to tell your doctor and specialist IBD team about any other medicines, treatments or therapies you are taking. This includes medication for other conditions as well as any over-the-counter, herbal or complementary medicines. It may be a good idea to take a list of all your medicines, including dosages, to your appointments, to make sure you don't forget to mention something.



DOES IT MATTER IF I DON'T TAKE MY DRUGS?

Getting into a routine of remembering to take your medicines every day can be challenging. Initially when your drugs have an immediate effect on your symptoms, you may find it easy to remember to take your doses exactly as instructed. However once you feel better and your illness is on your mind less, you may be less focused on taking your medication and start to forget the odd dose. Or, you may be tempted to stop taking your medication altogether, thinking you don't need it now that you don't feel so ill. A lot of people get fed up with having to take pills every day, maybe even several times a day – or just feel they would rather do without such a regular reminder of their IBD.

These are understandable feelings. However IBD cannot be cured, and many studies have shown that maintenance therapy (continuing to take medication even when you are well) does reduce the chance of a flare-up. Repeated flares not only cause ongoing, troublesome symptoms, but increase the risk of irreversible damage to the intestines which may lead to complications such as narrowing (strictures), or abscesses. Continuing your maintenance therapy can also mean that you are less likely to need to move on to taking additional or stronger drugs. If you stop your treatment and experience a flare-up, there is a chance that your medication may not work as well, or at all, when you restart it. In this case, stronger drugs or even surgery may be necessary to control the inflammation.

It is very important to be honest with your IBD team about whether you are taking your medicines, as failing to keep them informed could have a negative effect on your care. They will understand your concerns and may be able to discuss alternatives. If you would like to stop or reduce treatment, this may be possible on advice from your doctor if your condition is mild and limited to a small part of your digestive system, and an endoscopy shows disease healing.

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I dispense all my tablets for the week into a pill dispenser with the days of the week on. They live on my bedside table so they're the first thing I see upon waking and the last thing before I go to bed, so I don't forget. I also set alarms on my phone to remind me.

”

Sharon, age 37
diagnosed with Ulcerative Colitis
in 2005

If you do miss taking a dose, the Patient Information Leaflet that comes with your medication should tell you what to do. If you can't find this, check with your doctor or nurse.

It is important to take your medicines at the same time each day. If you are prone to forgetting things like taking tablets, try making it part of your daily routine, for example taking them with a meal, if your medication can be taken with food.

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CAN I ALTER THE DOSE MYSELF?

It is important that you do not stop taking any prescribed treatment without discussion with your IBD team, even if your symptoms improve. It is also important to take the full dose to get the full effect.

Additionally, some medicines must be taken in particular ways – for example, at particular times of day, on an empty stomach, or with or after food. If your lifestyle makes it difficult for you to do this, try discussing it with your doctor. It may be that some compromise or alteration in the dose is possible. For example if you are taking 5-ASAs, you may be able to change to taking the full dose just once a day, which some people find easier.

Your medication can be prescribed by your gastroenterologist, your GP or your IBD nurse. You may be feeling that as someone who has lived with an ongoing medical condition for some time, perhaps years, you are now quite an expert on what works for you. As a result, you may feel you would like to take a more active part in your treatment and be able to adjust your own medication when your symptoms begin to get worse or better. If so, discuss this with your doctor or IBD specialists. You may find that they are happy to include this idea in a plan for what to do in the event of a flare-up.

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HOW SAFE ARE IBD DRUGS?

Before drugs are licensed in the UK, they go through rigorous research and clinical trials on thousands of people. This process can take many years. Drugs are licensed by the Government's Medicines and Healthcare Products Regulatory Agency. The MHRA is responsible for regulating all medicines and medical devices in the UK, ensuring they work and are acceptably safe. It gives permission and sets strict safety criteria for all clinical trials in the UK. It demands very high standards from medicines manufacturers, and will only issue a licence when it is satisfied that a medicine meets all its safety and quality requirements.

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WHAT SHOULD I DO IF I AM WORRIED ABOUT SIDE EFFECTS?

As well as potential benefits, every drug has the potential to cause unwanted side effects, though not everybody will get them. These may be mild and stop once your body has adjusted to the drug, or they may be more severe and mean you have to stop taking the drug and seek medical attention.

“
I’m particularly susceptible to side effects. If you really are struggling, don’t feel you have to carry on. You have options.”

Shelley, age 33
diagnosed with Ulcerative Colitis
in 2005

It is worth talking to your doctor or IBD nurse about any worries you have about side effects or the amount of medicine you are taking. They may be able to reassure you or suggest changes that you find helpful. Sometimes a change in brand or form of drug would suit you better. With some drugs, taking them at a different time of day can make a difference – for example taking steroids before 11am can help reduce side effects as this follows the natural rhythm of steroids in the body.

The MHRA has a Yellow Card scheme to encourage people to report any suspected side effects they experience from medicines. See **Other Organisations** for contact details.

DO I NEED TO TAKE ANY SPECIAL PRECAUTIONS WHEN TAKING IBD DRUGS?

Certain medications used to treat IBD require you to take extra care with some aspects of your lifestyle. For example, people taking drugs that weaken the immune system, such as steroids, immunosuppressants or biological drugs, must take extra care to avoid infections.

People taking drugs that weaken the immune system should also avoid live vaccines. See our information sheet **Travel and IBD** for a list of live vaccines that are given in the UK. People with a weakened immune system may also be at risk of infection if the people they live with have had live vaccines – but this is only a low risk and only the case for a small number of vaccines:

- Chicken pox and shingles (also known as varicella). Only a risk if the person vaccinated develops a rash. The rash should be covered and face-to-face contact avoided until the rash is dry and crusted.
- Rotavirus (given to babies only). Practice good hygiene after contact with babies for two weeks following vaccination, in particular washing hands after changing a nappy and before food preparation.
- Nasal spray flu (given to children only). Only a risk to those who are severely immunocompromised – speak to your doctor if you are concerned.

Azathioprine and mercaptopurine increase the skin’s sensitivity to sunlight, and so people taking these medications are advised to use sunblock and cover their skin when out in strong sunshine.

The Patient Information Leaflet that comes with your medication will tell you whether you need to take any special precautions. For more information you can also refer to our individual drug treatment sheets.

HOW SHOULD I TRANSPORT MY MEDICINES?

If you are travelling abroad, the government advises you to keep your drugs in their original packaging, along with the Patient Information Leaflet, to show at customs. You may also need to show customs your letter from your GP or consultant.

When you are travelling, it is important to be aware of the temperature which your medication needs to be stored. Biologics such as adalimumab and golimumab

that have to be kept refrigerated could be stored in a small cool bag, obtainable from chemists. If you are travelling to a hot country, certain other medications may also need to be kept cool. For example, the waxy coating on suppositories may begin to melt in the heat.

Our information sheet **Travel and IBD** has more details on taking and storing medications away from home.

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My hospital has two IBD nurses who explain things to me clearly about new treatments, or what routes they feel I might have to explore. I have also found that Crohn’s and Colitis UK and the Crohn’s and Colitis UK Facebook forum has helped me process new information.
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Emily, age 23
diagnosed with Ulcerative Colitis in 2014

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WHO CAN I TALK TO ABOUT MY TREATMENT?

Many hospitals have a specialist IBD nurse for information and support. It can be very helpful to build a good relationship with your healthcare team, so that you can ask about your options and discuss any concerns and worries. Talking openly about your feelings and symptoms will help them understand your needs more fully and make sure they are providing the right treatment.

You can also talk to your local pharmacist, who has professional knowledge and should also be able to answer any questions you have about medicines. Many pharmacists have a private consulting room if you do not feel comfortable discussing your prescription over the counter.

All medicines come with a Patient Information Leaflet. These are produced by the manufacturer and approved by the MHRA. They include instructions on how to take the medicine and information on possible side effects. Copies of Patient Information Leaflets can be found on the Electronic Medicines Compendium website. The Association of the British Pharmaceutical Industry has details of companies that make prescription drugs. For companies that make over-the-counter drugs, (drugs you can buy without a prescription) go to the Proprietary Association of Great Britain website. See our list of **Other Organisations** for contact details.

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HELP AND SUPPORT FROM CROHN’S AND COLITIS UK

We offer more than 45 publications on many aspects of Crohn’s Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease. You may be interested in our comprehensive booklets on each disease, and other topics such as **Food and IBD**. We also publish information sheets on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships, school and employment.

All publications are available to download from **www.crohnsandcolitis.org.uk**. The complete list is here: **www.crohnsandcolitis.org.uk/about-inflammatorybowel-disease/quick-list**.

Health professionals can order some publications in bulk by using our online ordering system, available from the webpage above.

If you would like a printed copy of a booklet or information sheet, please contact our helpline.

Our helpline is a confidential service providing information and support to anyone affected by Inflammatory Bowel Disease.

TAKING MEDICINES

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- help you to find support from others living with the condition.

Call us on **0300 222 5700** or email **info@crohnsandcolitis.org.uk**

See our website for LiveChat: **www.crohnsandcolitis.org.uk/livechat**

OTHER ORGANISATIONS

- **The Medicines and Healthcare products Regulatory Agency**
www.mhra.gov.uk
- **The Electronic Medicines Compendium**
www.medicines.org.uk
- **Association of the British Pharmaceutical Industry**
www.abpi.org.uk
- **Proprietary Association of Great Britain**
www.pagb.co.uk
- **NHS Choices**
www.nhs.uk

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at publications@crohnsandcolitis.org.uk. You can also write to us at Crohn's and Colitis UK, 45 Grosvenor Road, St Albans, AL1 3AW or contact us through the **Information Line: 0300 222 5700**.

ABOUT CROHN'S & COLITIS UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 35,000 members and 50 Local Networks throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how, call **01727 734465** or visit www.crohnsandcolitis.org.uk

