

Taking medicines for IBD

Introduction

Inflammatory Bowel Disease (IBD) is the name given to a group of conditions, of which Crohn's Disease and Ulcerative Colitis (UC) are the best known. In both conditions the bowels, also known as the intestines or gut, become swollen and inflamed. In Crohn's Disease any part of the gut from the mouth to the anus can be affected. In Ulcerative Colitis the colon (large bowel) is affected. IBD is a chronic or ongoing condition that can flare up, when symptoms are more active, or go into remission, when symptoms go away or significantly decrease.

If you have IBD, you may be on medication to reduce inflammation and to help keep you in remission. You may also take medicines to treat other symptoms, such as pain or diarrhoea. At present there is no cure for IBD, but drug treatment can be very effective. Generally it is easier to keep IBD under control with medication than to get it back under control after a flare-up. For this reason it is advisable not to stop taking your medication without speaking to your specialist nurse or doctor.

This information sheet looks at the main types of drugs you may be prescribed, why you need them, and how they should be taken. It explores concerns you may have about drug safety, potential side effects and possible interactions with other drugs you may be taking. It also looks at checks you may need and some precautions to take while on these medicines, as well as travelling with medicines.

For more details of all the medicines that may be used, including the newer biological drugs, see NACC's booklet *Drugs used in IBD* and individual Drug Treatment leaflets.

What medications are prescribed for IBD?

Drugs to reduce inflammation

The two main types are aminosalicylates, known as 5-ASAs, and steroids. These drugs reduce the active inflammation in the bowel and so give the damaged lining of the bowel time to heal.

The most common 5-ASAs are:

| Drug names | Brand names |
|----------------|-------------|
| sulphasalazine | Salazopyrin |
| mesalazine | Asacol |
| | Ipocol |
| | Mesren |
| | Mezavant XL |
| | Pentasa |
| | Salofalk |
| olsalazine | Dipentum |
| balsalazide | Colazide |

They are similar, but not identical, and you or your doctor may feel that one suits you better than another.

You may take 5-ASAs by mouth, as capsules, tablets or granules to be swallowed. They are specially designed to release the active ingredient in the part of the intestine that is inflamed. For this reason it is important to take capsules or tablets whole, without chewing them.

Alternatively, you can take these drugs topically. This means applying them directly to the affected part, by inserting suppositories or enemas through the anus.

The most common steroid used to treat IBD is prednisolone. An alternative is budesonide. Steroids are usually prescribed for acute flare-ups. They can be given by injection (in hospital), as tablets, or topically.

The dose has to be large enough to be effective, so it is usual to start with a relatively high dose. These drugs must be reduced gradually, generally over 8-12 weeks, until the inflammation is no longer active. It is important that you do not stop taking them suddenly, as the body's own natural steroids need time to return to their normal levels. Slowly reducing the dose also helps to give time for the tissues inside the bowel to heal and lessens the chances of a relapse.

If you take steroids regularly it may be a good idea to carry a 'steroid card' or medic-alert bracelet in case of emergencies or accidents. Bracelets can be obtained from The Medic Alert Foundation on 0800 581420 or see the website: www.medicalert.co.uk

Drugs to maintain remission

The 5-ASAs used to reduce inflammation may also be taken when you are in remission, to help prevent flare-ups, so you may take them indefinitely.

Steroids are not effective in preventing flare-ups, so are not used long-term. If your symptoms cannot be kept in check by 5-ASAs without steroids, then it is likely that your doctor will prescribe another type of drug, called an immunomodulator or immunosuppressant, to stop the inflammation. These include azathioprine, 6-mercaptopurine and methotrexate. Immunomodulators allow the steroid dose to be kept to a minimum or withdrawn altogether. These drugs act slowly and can take 6-12 weeks to work.

Research has shown that many people with IBD, in particular UC, who continue taking one of these drugs after their inflammation has become inactive, will have longer periods of remission. It is therefore likely that your doctor will advise you to continue taking one of these drugs even when you feel much better and believe that the inflammation has calmed down.

Drugs to reduce the possible long-term effects of the disease

You are at a slightly increased risk of bowel cancer if you have had IBD in

your colon (large bowel) for more than 8-10 years. There is evidence to suggest that taking 5-ASA medication regularly, besides maintaining remission, may also significantly reduce the risk of colorectal cancer. For more details see NACC's information sheet *Is there a risk of cancer in IBD?*

Drugs to relieve particular symptoms of IBD

These include:

- anti-diarrhoeals – to help lessen diarrhoea
- bulking agents – to help with difficulty in passing stools
- analgesics – to help reduce pain
- treatments for anaemia – when you have an iron deficiency
- supplements – when you need extra vitamins and minerals

These medicines are prescribed when you have particular symptoms of IBD that are causing you difficulty or distress. Non-steroidal anti-inflammatory drugs for pain relief, such as ibuprofen and diclofenac, are best avoided as they may make your IBD symptoms worse or possibly trigger a flare-up.

If you are on steroids it is important to take calcium and vitamin D supplements, as these drugs can affect the bones.

Some of the medicines will not need to be taken all the time, and you may decide yourself when you need them. It is important that you discuss with your doctor how much and how often you can take these medicines, and what to do if they are not proving helpful.

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 (MHRA). The MHRA gives permission and sets strict safety criteria for all clinical trials in the UK. The Agency demands high standards from medicines manufacturers and will only issue a licence when it is satisfied that a medicine

meets the required safety and quality standards.

The MHRA continues to review the safety of drugs after licensing. As part of this process, it has introduced a Yellow Card scheme to encourage people to report any suspected side effects from medicines. As a medicine becomes more widely used in the general population, other side effects can appear. You can report online at www.yellowcard.gov.uk. Alternatively, you can obtain the yellow card form from pharmacies or from the Yellow Card hotline on freephone 0808 100 3352.

No medicine is completely free of risk as all drugs have side effects. These may be very minor, but they may also be serious. Different people respond to medicines differently and some people get no side effects. The main question to ask yourself is whether the advantages of taking the medicine outweigh the disadvantages.

For more information on the regulation and monitoring of medicines see *Medicines & Medical Devices Regulation: What you need to know* available to download from the MHRA website at www.mhra.gov.uk or telephone 020 7084 2000 for a copy.

Can other medicines affect IBD drugs?

Besides taking drugs for your IBD, you may be taking drugs for other conditions, or over-the-counter medicines, herbal or homeopathic remedies, or other alternative or complementary treatment. There can be interactions between your IBD drugs and any of these other treatments, which may make the drug less effective, produce a more intense effect or cause unexpected side effects. For this reason it is important to tell your doctor about all medication you are taking, as well as any alternative or complementary treatment, and any other medical condition you may have.

Do I need to take any special precautions while on medication for IBD?

Steroids and immunosuppressant drugs, mentioned on pages 1 and 2, reduce the effectiveness of the immune system. The body can still fight infections if you are taking these drugs; however you may be

slightly more likely to pick up infections, such as cold and flu. It is best, therefore, to avoid people with infections. You may also be more prone to catching potentially severe infections such as chickenpox or shingles, measles and pneumococcal disease (infection caused by bacteria that can affect the lungs and bloodstream and cause serious pneumonia). If you are not already immune you can be vaccinated against some of these infections.

Certain vaccinations and immunisations may be unsafe to take together with immunosuppressants. This means you should avoid 'live' vaccines such as polio, yellow fever, rubella (German measles), MMR (measles, mumps and rubella) and BCG (tuberculosis) while on these drugs. An 'inactivated' polio vaccine can be given instead of the 'live' one. Pneumovax and yearly flu vaccines, including Swine Flu (H1N1) vaccine, are safe, as they are not live vaccines. The Chief Medical Officer recommends the flu vaccine for people on immunosuppressants. Close relatives and family members may take live vaccines without any risk to you.

Immunosuppressants also increase the skin's sensitivity to sunlight, so it is very important to use sunscreens and protective clothing and avoid sunlamps or sunbeds.

Some drugs, such as methotrexate, can interact with alcohol and affect your liver, so it may be better to limit the amount of alcohol you drink. The general recommendation from the Department of Health is a limit of 2-3 units a day for women and 3-4 units a day for men.

If you want to start a family or become pregnant, it is important to discuss your medication with your doctor, as some drugs can affect fertility, or should be avoided or used with caution in pregnancy. Research shows that generally the disease itself is more likely to affect a growing baby rather than the medicines prescribed. However some medicines must definitely be avoided in pregnancy: in particular, a man or a woman who wishes to try for a baby, must **not** be taking methotrexate or have been taking it in the last three months.

Many IBD medicines can be taken while breastfeeding. However, some drugs pass into breast milk and can potentially affect the baby's immune system. For this reason it is always best to check with your doctor before breastfeeding.

For more information see NACC's leaflets on *Fertility and IBD* and *Pregnancy in IBD*.

Will I need any special checks while on medication for IBD?

Before treatment you will usually have blood tests and liver and kidney tests to check your suitability for a particular medicine. You are likely to have ongoing regular tests; the type and frequency will depend on which medicine(s) you are taking. It would be a good idea to discuss what checks you need with your doctor or specialist nurse. See NACC's individual Drug Information leaflets for more details.

Do I need to take my medicine exactly as prescribed?

It is usually important to take the full dose. Some medicines must also be taken in particular ways if they are to be effective. Some need to be taken at particular times of the day, some work best when your stomach is empty, but others need to be taken with food.

It can be difficult remembering to take your medicine, especially when you are feeling well. Try to make taking it a part of your daily routine, such as at mealtimes or when brushing your teeth. NACC's information sheet *Staying well with IBD* has a number of useful tips to help remind you.

However, if any part of your lifestyle, such as school, work, sport, your meal-times, makes it difficult for you to follow the instructions, discuss this with your doctor. It may be that some compromise or alteration in the dose is possible.

I am worried about the amount of medicine I am taking

You may be worried about becoming dependent on the medicines or you may find that you cannot stick to the prescribed dose, especially if you believe that the medicines are making you feel worse.

Your concerns are natural and are best discussed with your doctor. It may be possible to adjust the dose of your medicine to a level you find acceptable. If you are taking 5-ASAs, you may be able to change to a once a day high dose drug, which some people find easier. It may be that some of your fears are unfounded and that your doctor can reassure you. You do not necessarily have to wait until your next appointment, as you could try to talk to your specialist nurse (if you have one) or consultant by telephone.

I am worried about side effects

You may feel that the side effects from taking a particular medicine are too distressing and unpleasant to tolerate. You may then be tempted to stop taking it, in the hope that the inflammation will stop without treatment. This can sometimes happen, but the risk you are taking is that the inside of the bowel may become more seriously damaged if the inflammation is left untreated. However, a small number of people are intolerant of some drugs.

There may be other options and it would be best to discuss your concerns with your doctor. Different makes of medicine may be very similar in how effectively they control inflammation and one particular make may suit you better than another. For example there are different makes of mesalazine (see list on page 1).

Many people experience side effects when taking steroids, such as a more rounded face, increased appetite, difficulty sleeping, or mood swings, but these usually disappear when the dose is reduced or stopped. It may help to lessen the side effects if you take the whole dose before 11 am, because this follows the natural rhythm of steroids in the body. You may be able to take one of the newer preparations. These have a special coating, which means there may be fewer side effects as less of the steroid enters the bloodstream.

Is there any alternative to treating an acute flare-up with drugs?

Some hospitals offer dietary treatment using liquid feeds to rest the bowel and let the

inflammation clear up. This treatment is more commonly used in Crohn's Disease.

Research is ongoing into alternative treatment options, such as leucocytapheresis (a process in which blood is pumped out from one arm, passes through a special cylinder to remove inflammatory cells and is infused back into the body through the other arm). Others include prebiotic and probiotic bacterial therapy, but so far the evidence for the effectiveness of these treatments is limited. For the present steroids are still thought to be the simplest and most effective way of treating sudden flare-ups. However, for some people steroids become ineffective over time and a newer type of drug, a biologic, such as infliximab or adalimumab, may be an option. See NACC's leaflets: *Infliximab* and *Adalimumab*.

Can I alter the dose of my medicines myself?

Healthcare professionals usually encourage people to be directly involved in decision-making about their own care. Having an open, co-operative relationship with your doctor helps both of you to understand your needs and come to a decision about treatment. As you become experienced with living with an ongoing medical condition, you are likely to become an expert on what medication and dose works for you. You may feel confident about adjusting your medication when your symptoms begin to get worse or better. Generally it is a good idea to plan ahead with your doctor about how to adjust your medication at these times. If you have any doubt at any time as to what is the right thing to do, it is best to speak to your specialist nurse or doctor.

What about travelling with my medicines?

It is a good idea to take sufficient medication for the whole time you plan to be away from home, as well as extra in case of delays. It is also useful to take along a copy of your prescription in case you need extra supplies. For more information, particularly about taking medicines abroad, see NACC's leaflet *Travel and IBD*.

Where can I get further information?

All medicines come with a Patient Information Leaflet. These are produced by the manufacturer and approved by the MHRA. You can find details of companies that make prescription medicines on the Association of British Pharmaceutical Industry website: www.abpi.org.uk or telephone: 0870 890 4333.

For details of companies that make over-the-counter medicines, that is, medicines you can buy without a prescription, you can go to the Proprietary Association of Great Britain (PAGB) website: www.pagb.co.uk or telephone: 020 7242 8331.

Your local pharmacist with a professional knowledge of medicines should be able to answer any questions you have about medicines.

NHS Direct is available 24 hours a day all year round on 0845 4647 (England and Wales) or 08454 24 24 24 (Scotland) to help with queries you may have about medicines.

Useful websites:

www.askaboutmedicines.org

Set up to improve communication between people and health professionals and includes useful tips on questions to ask health professionals.

www.chic.org.uk

Consumer Health Information Centre
General information about health, over-the-counter medicines, storing and using medicines safely.

www.emc.medicines.org.uk

electronic Medicines Compendium
Up-to-date information about medicines.

www.hsis.org

Health Supplements Information Service
Information on food supplements.

www.medguides.org.uk – Medicines Guide
Regularly updated information on medicines.

www.medicinechestonline.com

Medicine Chest Online
Information on medicines and food supplements.

www.netdoctor.co.uk

A-Z of prescription and over-the-counter medicines.

www.nhsdirect.nhs.uk

For health and medicine advice.

Useful books:

A-Z of Medicinal Drugs: a family guide to over-the-counter and prescription medicines. 2003. Oxford Paperback Reference. Market House.

BMA New Guide to Medicines and Drugs 7th Edition. 2007. Dorling Kindersley. London.

Guide to Over-the-counter Drugs, Vitamins, and Natural Medicines. Time-Life. 1998. USA.

Booklet:

Finding and using information about health and medicines: A guide for patients, medicine users and carers. 3rd Edition 2007. Call ABPI on 01795 427614 for a copy or download from www.abpi.org.uk or www.askaboutmedicines.org.

Further help

If you have any further queries or would like copies of NACC publications mentioned please call the **NACC Information line** on **0845 130 2233** or email: nacc@nacc.org.uk
Leaflets can also be downloaded from the NACC website: www.nacc.org.uk

NACC-in-Contact on 0845 130 3344 is open weekday afternoons 1-3.30pm and evenings 6.30-9pm (except Bank Holidays). A supportive listening service run by trained volunteers who have IBD or a relative with IBD.

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NACC publications are research based and produced in consultation with patients, NACC medical advisers and other health or associated professionals.

This Information Sheet is intended for guidance only and NACC cannot accept responsibility as advisers in this field.

We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based can be obtained from NACC at the address below. Please send your comments to Helen Terry at NACC, 4 Beaumont House, St Albans, Herts AL1 5HH – or email h.terry@nacc.org.uk.

The National Association for Colitis and Crohn's Disease (NACC) is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 a year. Additional donations to help the work of the Association are always welcomed.