CROHN'S & COLITIS UK

FIGHTING INFLAMMATORY BOWEL DISEASE **TOGETHER**

INFORMATION SHEET

STEROIDS (CORTICOSTEROIDS)

> "Once your IBD is under control (with steroids) life quickly returns to normal. You realise how much the steroids can help you to get your life back."
>
> Barry, age 41
> diagnosed with Intermediate Crohn's Colitis in 2009

INTRODUCTION

This information leaflet is designed to answer common questions you may have if you have been given steroids (corticosteroids) to treat your Crohn's Disease or Ulcerative Colitis (UC), the two main forms of Inflammatory Bowel Disease (IBD). It is not intended to replace specific advice from your own doctor or any other health professional. You can obtain further information from your doctor, pharmacist, the information leaflet supplied with your medication or from the website: **www.medicines.org.uk.**

WHY AM I BEING TREATED WITH THIS MEDICINE?

Some types of steroids, known as glucocorticoids, can be very effective medicines at healing inflamed parts of the bowel. The immune system is important for fighting infections, but sometimes immune cells attack the body's own tissues and trigger chronic inflammation (like that found in IBD). Steroids (glucocorticoids) are one of the oldest treatments used in IBD. They work by reducing the activity of cells in the immune system and blocking inflammation. Four out of five people with IBD are likely to be treated with steroids at some time for their condition. The steroids used in IBD should not be confused with anabolic steroids, which are sometimes used by body builders to increase muscle mass.

WHAT ARE STEROIDS?

Steroids are hormones (chemicals) that are produced naturally from cholesterol by the body's adrenal glands (which sit on top of your kidneys). These hormones have a number of important functions. They help regulate blood pressure and the breakdown of carbohydrates and proteins and help the body adjust to physical stress. In the treatment of IBD, steroid drugs are man-made versions of glucocorticoids, that reduce inflammation and allow the bowel to heal.

HOW EFFECTIVE ARE STEROIDS IN IBD?

Treatment for IBD has two main goals – to lessen the symptoms of active disease or a flare-up, and to maintain remission (a period of time where you have no symptoms and feel well).

Studies show that steroids help to control both active Crohn's Disease and active UC. But research shows steroids do not help to maintain remission. Steroids are therefore not used as long term maintenance therapy to prevent flare-ups. After achieving remission, you may need other medications, such as 5 amino-salicylates (5-ASA), azathioprine, or anti-TNF therapy in order to stay in remission. For more information, see our **drug information sheets**. Steroids do not prevent IBD flares following surgery.

While steroids are good at healing inflamed bowel, they are not recommended for long term treatment due to their lack of effect in preventing flare-ups and their side effects [see What are the possible side effects?] The aim for people with IBD is to reduce and stop steroids and move on to alternative treatments as soon as possible.

HOW ARE STEROIDS TAKEN?

There are several different types and formulations of steroids allowing these drugs to be taken in a variety of ways. The choice depends on the location of your IBD and severity of symptoms.

- Most commonly steroids are taken as tablets by mouth (orally).

- For severe flare-ups steroids are given intravenously (injected into a vein) to achieve the quickest response. This only takes place in hospital. You will then be switched to oral steroids.

- For IBD affecting the lower part of the colon and rectum, steroids can be given as topical treatments that apply drugs directly to an affected area by enemas or suppositories. Enemas use a specially designed applicator (containing the drug as a liquid or foam) that is inserted into the anus (back passage) and reaches into the colon. Suppositories are small 'bullet-like' capsules of drug inserted into the rectum via the anus. One of the main advantages of topical treatments is their ability to directly target inflamed area. This means other parts of the body are not so affected, reducing side effects.

WHAT DIFFERENT NAMES ARE USED FOR STEROID MEDICATIONS?

Steroids have different brand names according to the companies making them.

- Steroids taken orally include prednisolone (brand names Deltacortril®, Deltastab® and Dilacort®) prednisone, hydrocortisone (Plenadren®), methylprednisolone (Medrone®), and beclometasone dipropionate (Clipper®). Budesonide (Entocort and Budenofalk) is a newer type of oral steroid used in Crohn's Disease. The Budensonide Multi-Matrix system® (Cortiment® and Uceris®) allows budensonide to be released throughout the colon. It is mainly used for people with UC.
- Steroids given intravenously (by infusion into a vein) include hydrocortisone and methylprednisolone.
- Steroids delivered directly to the site of inflammation with suppositories, foam or liquid enemas include hydrocortisone(Colifoam®), prednisolone (Predfoam®) and budesonide (Budenofalk®).

WHAT IS THE NORMAL DOSAGE?

Your IBD team will advise you on the correct dose depending on the type of steroid prescribed, your condition and weight. For prednisolone, for example, people are usually started on 40 mgs (eight tablets a day) taken as a single dose in the morning. But there can be considerable variations in doses prescribed. Talk to your IBD team before making any changes to your dose or how you take it. People with severe flare-ups admitted to hospital normally receive methyl-prednisolone 60 mg over 24 hours or four infusions of hydrocortisone (100 mgs each dose) every day. Higher doses offer no greater benefits, but lower doses have been shown to be less effective.

HOW SHOULD ORAL STEROIDS BE TAKEN?

If your condition allows, oral steroids should be taken in the morning. This helps to reduce side effects and is less likely to affect your sleep. Budesonide tablets and granules, as well as any delayed release or enteric coated steroids, should be swallowed whole with a glass of water and taken around half an hour before food. This is important because chewing can destroy the way the drug is delivered.

> “It took me a few goes to reduce my steroid dose as the symptoms kept coming back and I had to return to the starting dose. But each time I was able to get telephone advice from my IBD nurse.”
>
> Lucy, age 45
> diagnosed with Crohn’s Disease in 2013

HOW LONG DO STEROIDS TAKE TO WORK?

Oral steroids normally improve symptoms within one to four weeks, while intravenous steroids take four to 10 days. Around one in five people shows no response to steroid treatment (this is known as being steroid refractory). If your condition is not improving, contact your IBD team.

There are many reasons why steroids may not work including people not taking them as prescribed and genetic differences. It could also be that your symptoms are not caused by active IBD, but by a separate problem, such as underlying infections (Cytomegalovirus, Clostridium difficile), or another condition, such as irritable bowel syndrome (IBS) or lactose intolerance. If your symptoms are definitely being caused by inflammation, but are not responding to steroids, then your IBD team might suggest alternative treatments, such as biologic therapy (infliximab, adalimumab or vedolizumab) or an immunosuppressant, such as azathioprine. For more information, see our drug information sheets.

HOW LONG SHOULD I BE ON STEROID TREATMENT FOR?

Steroids should ideally only be used for a short period of time to get over a flare-up or while long term treatments, such as azathioprine, become established.
If you are starting a course of steroids, then you should complete the full reducing course, which is generally prescribed for eight weeks. You should NOT stop on your own accord even if you are feeling better. If you have been using steroids for more than a few weeks (or a week in the case of prednisolone 40 mg per day or more) you will need to gradually reduce the dose before stopping completely. Your IBD team will carefully guide you on this.

WHY YOU SHOULD NOT SUDDENLY STOP TAKING STEROIDS

For steroid treatments lasting longer than a few days, it is VERY important not to miss a dose, and to only stop treatment under medical supervision. This is because after some days or weeks of taking steroids your body stops making enough of its own steroids to maintain important functions (such as blood pressure). A sudden withdrawal from medication may cause a sharp fall in blood pressure and affect blood sugar levels. You will need to - 'taper'(gradually reduce) the dose to give your adrenal glands time to start making their own steroids again. Generally, people will not need to 'taper' if they have taken steroids for less than three weeks, but you should always consult your IBD team before stopping treatment.

Unfortunately, sometimes when people reduce the dose of steroids their IBD symptoms return (known as steroid dependence). If this happens you can be offered other drugs, such as azathioprine, to help you come off steroids completely.

HOW ARE STEROIDS USED IN ACUTE SEVERE ULCERATIVE COLITIS?

Intravenous steroids are considered to be the main treatment for patients with severe UC, with studies showing they work in seven out of 10 patients who have been hospitalised. Steroids have revolutionised the treatment of severe UC. Responses to intravenous steroids take around two to four days (much quicker than oral treatments). Response is assessed around day three, allowing alternative drugs to be introduced (such as ciclosporin, infliximab or tacrolimus) or surgery to be performed if steroids are not working. Once flare-ups have been brought under control, people can be moved on to tablets, and in time (under the supervision of their IBD team) start to 'taper' the dose.

WHAT IS BUDESONIDE?

Budesonide is a steroid developed more recently with special features to reduce side effects. It has been designed to be broken down more completely by the liver, reducing the amount of steroid in the blood affecting the rest of the body. Budesonide is used for Crohn's Disease; while the Budesonide MMX® delivery system, a new type of tablet which extends the release of budesonide throughout the colon, is generally used for UC.

While studies show budesonide is less effective than conventional oral steroids at treating flare-ups, it has the advantage of causing fewer side effects. Bone loss is reduced with budesonide, but not completely eliminated. Like other steroids, budesonide is not effective at maintaining remission in IBD longterm, and is not used in severe IBD.

WILL I NEED TO TAKE ANY SPECIAL PRECUATIONS WHILE BE ING TREATED WITH STEROIDS?

- If you take a course of steroids you may be given a blue 'steroid card' providing details of the prescriber, drug, dosage and duration of treatment. This should be carried with you at all times and given to any health professional treating you. Also, consider wearing a Medic Alert Bracelet. If you were to become unconscious health staff would immediately be aware your steroid treatment needed to be continued and that the dose might need to be increased temporarily.

- If you become ill, require surgery or have an infection, the dose of steroids may need to be increased. This is because your body needs more steroids when exposed to physical stress. Your body's requirement for extra steroids when unwell can persist for many months after a course of steroid treatment, especially if the course is prolonged or has to be repeated.

- Because steroids damp down your immune response, you should avoid people with chickenpox, shingles and measles. You could become seriously ill from these conditions. Tell your doctor promptly if you have come into contact with anyone who has these conditions as you may be able to have a protective injection.

- Also, even mild infections, such as a cold or sore throat, may develop into a more serious illness. Contact your doctor if you have not been able to shake off an infection.

ARE THERE ALTERNATIVES TO STEROIDS?

Enteral nutrition (a special liquid only diet) can be used as an alternative to steroids to induce remission. People on this diet do not need to eat ordinary food or drink because the liquid diet provides them with all the necessary nutrients they need. [For more information see our booklet: **Food and IBD: Your Guide.**] This approach can be especially helpful for children when there are concerns steroids could affect growth. In adults, studies show steroids work better at inducing remission than enteral therapy, but liquid diets or supplements may be used to support nutrition. If you prefer to try the liquid diet approach discuss this with your IBD team.

For people with IBD affecting the colon who cannot tolerate steroids (or wish to avoid them) 5 amino-salicylates (5-ASA) can be considered in some circumstances, but are generally less powerful. For people who can not come off steroids (because their symptoms return when they stop treatment) biological treatments or immunosuppressants can be considered. For more information, see our **drug information sheets.**

WHAT 'CHECKS' WILL I NEED FOR LONG TERM STEROID TREATMENT?

- Blood pressure and weight should be measured regularly, and children will need growth checks.
- You may be offered blood tests to check your potassium level and for raised blood sugar and triglycerides after starting steroid treatment and then every few months.
- You should visit an optometrist every six to 12 months to check for glaucoma (a condition increasing pressure within the eye that can damage the optic nerve) and cataracts.
- People taking steroids long term will be monitored for adrenal suppression.

"The side effects I've experienced include heart palpitations, being ratty and the dreaded moon face. The sleepless nights were annoying, but nothing that I couldn't handle."

Rachel, age 25
diagnosed with Crohn's Disease in 2015

WHAT SPECIAL INFORMATION SHOULD YOU GIVE YOUR DOCTOR?

Make sure you tell doctors and nurses treating you about any of the following:

- Infections. Oral steroids can both make infections more severe and mask symptoms of infections. Also let them know if you have had Tuberculosis (TB) in the past or been in contact with someone with TB.
- Liver problems. Levels of steroids in the blood may be increased if your liver is not working properly.
- Psychiatric disturbances. If you have a pre-existing mental illness (including psychosis, severe depression or bipolar disorder) or a predisposition to mental health problems (such as a family history of depression).
- If you have wounds from recent surgery or are going to have surgery soon. Steroids can delay healing.
- Pre-existing conditions, including heart failure, a recent heart attack, high blood pressure, diabetes, epilepsy, glaucoma, an underactive thyroid, osteoporosis, obesity or peptic ulcers. Steroids can make some conditions worse so your medical team may need to monitor your condition more closely. In patients with diabetes, for example, steroids can increase blood sugar levels leading to the need to adjust medications.

WHAT ARE THE POSSIBLE SIDE EFFECTS?

Although steroids are produced naturally by the body, steroid medications can cause unwanted side effects. Studies suggest around one in two people taking steroids experience side effects. Side effects can be minimized by using the lowest effective dose of steroids for the minimum period, and sometimes by taking the medication in the morning.

The side effects of steroids can be divided into three main categories. Early effects due to the body being exposed to higher than natural levels of steroids; effects due to prolonged use; and effects due to coming off steroids.

- Early effects include insomnia, cosmetic effects (acne, moon face, growth of facial hair, and stretch marks), retention of salt (which can lead to ankle swelling and raised blood pressure), mood disturbance, indigestion and glucose intolerance.

- Effects due to long term use include increased susceptibility to infections, appetite stimulation (which can cause weight gain), cataracts, osteoporosis, problems with blood supply to the top of the thigh bone, and myopathy (muscle weakness).

- Effects due to coming off steroids include adrenal insufficiency (where your body is not producing enough steroids). Here symptoms include fatigue, loss of appetite and weight loss, abdominal pain, nausea and vomiting, headache, joint pains, dizziness and fever.

- In babies, children and adolescents steroids can affect growth. Studies also suggest around one in 11 IBD patients are allergic to one or more steroid medications.

This is not a complete list of side effects of steroids, for more information see the Patient Information Leaflet provided with your medication, or visit **www.medicines.org.uk/emc/**. Overall, it is best to let your doctor or IBD nurse know about any new symptoms you develop while on steroids whenever they occur. Your IBD team should also be able to help with any queries and concerns.

> “Always speak to your IBD nurse if you have any concerns or side effects. They see lots of people with IBD and have lots of valuable experience.”
>
> Barry, age 41
> diagnosed with Indeterminate Crohn’s Colitis in 2015

WHEN SHOULD I SEEK MEDICAL HELP?

People taking steroids can on rare occasions require urgent medical attention. You should contact your doctor:

- If you experience mental health problems, feel depressed, high, or your moods go up and down. Contact your doctor if you feel confused, irritable, anxious, have suicidal thoughts or difficulties sleeping.

- If you have been vomiting and you are unable to take your tablets, or have diarrhoea, or have missed a dose.

- If you experience an allergic reaction including a rash, itching, difficulty breathing or swelling of the face, lips, throat or tongue.

- If you develop pain in the hip or groin.

SHOULD I BE DOING ANYTHING TO PROTECT MY BONES FROM OSTEOPOROSIS?

Steroids can affect bones by decreasing the rate at which the bone-building cells work, which accelerates bone loss. How seriously the bones are affected usually depends on the dose and length of steroid treatment. Guidelines recommend anyone prescribed steroids should take Vitamin D and calcium supplements to help their bones. They also state that bisphosphonate drugs (which slow down the cells which break down bone) should be considered for anyone over 65 years who has been taking steroids for longer than three months and younger people with low bone density (DEXA) scores. Bisphosphonates can cause skeletal abnormalities in foetuses, making it important for women of child-bearing years taking these drugs to avoid becoming pregnant. Older people using steroids could take the opportunity to get their bone density measured. Steroids taken rectally (in enemas or suppositories) and budesonide are less likely to cause bone weakness than steroids taken by mouth or intravenously.

To help maintain healthy bones you can introduce a number of life style changes including stopping smoking, increasing weight bearing exercise (jogging and brisk walking) and limiting alcohol intakes. For more details see our information sheet **Bones and IBD**.

DO STEROIDS AFFECT PREGNANCY AND FERTILITY?

Tell your doctor if you are thinking of becoming pregnant or find you are pregnant, and you are taking steroids. Because they are an effective treatment, many experts now feel steroids can be taken during pregnancy as there may be a greater risk to the baby if the woman does not take effective treatment and is unwell from her IBD. Studies suggest active IBD at the time of conception and delivery may increase adverse outcomes, including spontaneous abortion and pre-term delivery, making it important to have effective treatment for active IBD.

Guidelines consider steroids taken during pregnancy to be of low risk to babies. While steroids can cross the placenta to reach the baby they rapidly become converted to less active chemicals.

Experts prefer prednisone, prednisolone, and methylprednisolone since they are more efficiently broken down by the placenta than dexamethasone or betamethasone. Maternal prednisolone doses of up to 40 mg daily are considered unlikely to affect the baby.

While some studies have shown a small increase in the risk of cleft lip and palate in babies born to women taking steroids in the first three months of pregnancy, other studies have not reported this finding. Palate formation is complete by week 12 so there are no risks of cleft lip and/or palate after this. Less is known about budesonide, but a small study of eight pregnant women did not find an increased risk of adverse outcomes.

There have been isolated reports of babies born with adrenal suppression when mothers took steroids late in pregnancy. So if you are taking steroids at the time of delivery be sure to let your health care team know as your baby may need a tapering course of steroids after birth.

In women taking steroids for other conditions (not IBD), an increase in maternal pregnancy complications (such as high blood pressure and diabetes) have occasionally been seen.

WHAT IS KNOWN ABOUT FATHERING A CHILD WHILST ON STEROIDS?

Much less is known about the effects of long-term steroids on male fertility and effects on their offspring. One study showed steroids can cause reversible decreases in sperm counts and motility, another found no link between steroid treatment and infertility.

WHAT ABOUT BREAST FEEDING AND STEROIDS?

Steroids are generally considered safe for use by breast feeding mothers. Although a small amount of the drug may pass to the baby, studies have found no harmful effects. Recommendations suggest that where possible women (especially those on high doses) should wait four hours after taking steroids before breast feeding.
High doses of steroids used in other conditions have occasionally led to temporary loss of the mother's milk supply.

CAN I TAKE OTHER MEDICINES ALONG WITH STEROIDS?

Before you take any new medicines, check with your IBD team or pharmacist whether there could be an interaction with steroids. This also applies to any over-the-counter medicines and any herbal, complementary or alternative medicines and treatments. You should tell any doctor or dentist treating you that you are taking steroids.

Some key drugs that interact with steroids include anticoagulants (such as warfarin), drugs for blood pressure, antiepileptics, antidiabetic drugs, antifungal drugs, bronchodilators (such as salbutamol) and diuretics.

Studies suggest taking steroids with aspirin and nonsteroidal anti inflammatory drugs (NSAIDs), such as ibuprofen, increases the risk of peptic ulcers. If you need both medications, ask your IBD team if you might benefit from taking proton pump inhibitors as well to help prevent ulcers.

CAN I HAVE IMMUNISATIONS WHILE ON STEROIDS?

If you are taking steroids it is recommended that you avoid live vaccines, such as polio, yellow fever, BCG (tuberculosis), rubella (German measles) and MMR (measles, mumps and rubella). As a rule you should avoid live vaccines from three weeks before starting steroids and then for three to six months after steroids have been discontinued. You should also avoid coming into contact with anyone who has recently received a live vaccine as there is a chance the infection could be passed to you.

When first diagnosed with IBD, your doctor should take an immunisation history, and if any gaps are identified, you should be offered 'catch up' vaccinations.

Once on steroids you will still be able to take inactivated vaccines, such as hepatitis A, and, typhoid (but not the oral active typhoid vaccine). Guidelines recommend an annual flu vaccination (with the inactivated vaccine) for people with IBD regardless of whether or not you are taking immunosuppressant drugs. It should be noted that the new nasal spray flu vaccine for children contains live forms of the flu virus and should not be used. Vaccines against pneumonia (such as Pneumovax®) should also be considered.

If vaccinations are required for travel sometimes a judgment needs to be made with your IBD team about whether the risks of the disease (you are being vaccinated against) outweigh the risks from live vaccination. It is important not to have any vaccinations during or after steroid treatment without consulting your IBD team. For more details see our information sheet: **Travel and IBD**.

CAN I DRINK WHILE TAKING STEROIDS?

Stomach problems may be more likely to occur if you drink alcohol while being treated with steroids. Talk to your IBD team about whether it is safe for you to drink alcohol while taking these medicines. For general health reasons it is best to keep within the Department of Health guideline limits.

WHO SHOULD I TALK TO IF I AM WORRIED?

If you are worried about side effects such as those described above, or have other questions about your steroid treatment, discuss them with your doctor or IBD team. They should be able to help you with queries such as exactly why it has been prescribed for you, what the correct dose and frequency is, what monitoring is in place, what you should do if new symptoms occur, and also what alternatives may be available.

You can find more information about other drugs used in the treatment of IBD from our other Drug Treatment Information leaflets. You can download all our information sheets and booklets for free from our website: **www.crohnsandcolitis.org.uk.**

FURTHER HELP

All our information sheets and booklets are available to download from our website: www.crohnsandcolitis.org.uk. If you would like a printed copy, please contact our Information Line – details below.

Crohn's and Colitis UK Information Line: 0300 222 5700, open Monday to Friday, 9 am to 5 pm, except Thursday open 9 am to 1 pm, and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn's and Colitis Support: 0121 737 9931, open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and is available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

Crohn's and Colitis UK Forum
This closed-group community on Facebook is for everyone affected by IBD. You can share your experiences and receive support from others at: www.facebook.com/groups/CCUKforum

Steroids Edition 1
Last Review - June 2016
Next full review planned - 2019

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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 28,000 members and 50 Local groups throughout the UK. Membership starts from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

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