# Information on taking Steroids for Inflammatory Bowel Disease

#### What are steroids?

Steroids are hormones which are chemical messengers that are produced naturally by the body. Steroids that play a role in controlling inflammation are referred to as corticosteroids. Corticosteroids are different from the anabolic steroids sometimes taken by athletes to enhance their performance.

This leaflet aims to tell you more about steroids.

## What are steroids used for?

Steroids can be used to treat many conditions where inflammation is involved, for example asthma and arthritis as well as inflammatory bowel diseases (IBD) for example Crohn's disease and ulcerative colitis.

## How do they work?

Steroids work by blocking the hormone produced by the body called prostaglandins; these are responsible for triggering the inflammatory response in the body. If steroids are taken at high dosages or for long periods of time, they temporarily depress the body's immune system whose job it is to recognize and protect the body from bacteria, viruses and other foreign substances.

## How are they taken?

Steroids can be taken by a variety of different routes depending upon the severity of inflammation present. The most common route is orally (by mouth) in tablet or soluble form. Occasionally they are given intravenously (direct into a vein) and very rarely given rectally (into the bottom).

Steroids are best taken in the morning, at the same time each day, with food. If you have been told by your doctor to give the steroids twice a day, it's best to give the second dose by late afternoon as it may disrupt sleep if given any later.

## How long will they take to work?

A reduction in symptoms should be seen within 2-4 days from commencing treatment.

# Are there any side effects?

Remember all medicines affect people in different ways, and someone taking steroids may not experience all or any of the side effects mentioned here. However, the possible side effects of any medication need to be balanced against the risk of problems if the disease is not treated properly.

## Common side effects

- Irritation of the stomach lining, to try and reduce any stomach irritation steroids are best taken with food. If taken at high dosages or for long periods of time another medication is prescribed to try and prevent stomach irritation from occurring.
- Weight gain, which can be due to an increase in appetite or retention of fluid.
   It is advisable to try and keep to a well-balanced diet. Dietary advice is available from the children's gastroenterology specialist nurses or children's dietitians.
- Changes in behaviour; may become irritable with mood swings or revert to earlier childhood behaviour with temper tantrums or bed wetting.
- May make the skin and hair more greasy, causing acne, especially to the face.

## Less common side effects

(These side effects tend to occur with long term use or high doses)

- Effects of weight gain, face may appear chubbier; stretch marks may develop especially on the stomach and thighs.
- High blood pressure which gives symptoms of headaches or feeling dizzy.
- Increase in blood sugars levels, which give symptoms of increased thirst and need to pass urine much more frequently.
- Effects on growth (height in particular).
- Thinning of bones, a calcium supplement may be prescribed if steroids are given over a long period of time.

If experiencing any of these symptoms or if there are any concerns or worries, please contact a member of the children's gastroenterology team or the children's assessment unit (CAU), contact details can be found at the bottom of this leaflet.

#### How will the treatment be monitored?

Close monitoring of weight, height, blood pressure and urine testing will be carried out at the clinic appointment.

Frequent blood tests will be taken to monitor the reduction of inflammation, the frequency of blood tests will depend upon the response the steroids have in reducing the inflammation.

If your child requires an extended course of steroids or multiple steroid treatments an additional blood test will be taken before the steroids are stopped. This will be to check if it

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is safe to stop the steroids. If this blood test is required, your children's

## **Vaccinations**

Please discuss any vaccinations required with a member of the children's gastroenterology team before administration as the immune system is suppressed and on occasions can cause a severe reaction. No 'live' vaccines must be given.

However, it is recommended that the annual influenza vaccine (flu vaccine) is given. It must be given as an injection and **NOT** the nasal spray as this is 'live'. This can be arranged through the family doctor.

It is also advisable if long term steroid treatment is required to be immunised against pneumococcal infection, this is now part of the routine childhood immunisation program, but older children may not have received it.

## Chicken pox and measles

Because the immune system is suppressed chicken pox and measles can be more severe, therefore should the child be in contact or contract either infection contact a member of the children's gastroenterology team or CAU immediately for advice.

## Infections

There may be a higher risk of infection whilst on steroid treatment, if the child should develop a fever or become unwell contact a member of the children's gastroenterology team or CAU for advice.

## Missed doses

It is very important not to miss a dose because the body may depend on the amount of steroids being taken. A sudden withdrawal may cause a sharp fall in blood pressure, causing the body to go into shock which can in **very rare** causes be fatal. Therefore it is important to ensure that a good supply of tablets and that the medication is not stopped suddenly or changed without first discussing it with a member of the children's gastroenterology team. When it is time to stop the treatment the steroids will be reduced slowly allowing the body time to adjust to the decreasing dose.

If vomiting occurs after giving a dose of steroids or if a dose is forgotten contact a member of the children's gastroenterology team or CAU immediately.

## Steroid cards

A steroid card will be issued by the pharmacist on start of the treatment, it is very important to read the information on the card and show to any doctor, nurse, dentist or pharmacist especially if any other medication or treatment is required.

# Pregnancy and breast feeding

It is advisable to use a reliable form of contraception because taking steroids during pregnancy or breast feeding may have an effect on the baby. If a pregnancy should occur whilst on steroids, continue taking the medication but discuss this with a member of the children's gastroenterology team as soon as possible. There are many considerations for the use of steroids during pregnancy and breast feeding as they may have effects on the

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baby. If appropriate, contraception may be discussed with your doctor or nurse. If your child becomes pregnant, continue taking the steroid tablets but discuss with your doctor as soon as possible.

# **General points**

- Keep all medicines in a safe place where children cannot reach them.
- When on steroids the skin may be more sensitive to sunlight, therefore it is important to minimise the exposure to strong sunlight and use a high protection factor sunscreen (SPF 30 or above).
- If the medication is no longer required or the date has expired, please return to the pharmacist. Do not flush down the toilet or throw them away.

# How to contact a member of the children's gastroenterology team if you have any queries or concerns:

The members of the children's gastroenterology team are normally available Monday – Friday between 09.00 – 17.00 hours on the following numbers

Children's Gastroenterology Specialist Nurse 01603 286320

Paediatric Consultant (via secretaries) 01603 289936 or 287174

Specialist Paediatric Registrar (via secretary) 01603 289936

Paediatric Dietitian 01603 287011

If a member of the children's gastroenterology team is unavailable please contact the Children's assessment unit (CAU) 01603 289774



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