



# Corticosteroids to treat immune-mediated neurological conditions: information for families

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Corticosteroids are hormonal substances that are produced naturally in the body by the adrenal glands (which are just above each kidney) and by the reproductive organs. There are many different types of corticosteroids and they have different effects on the body. This information sheet from Great Ormond Street Hospital (GOSH) explains about the use of corticosteroids to treat immune-mediated neurological conditions, how they are given and some of the possible side effects. Each person reacts differently to medicines, so your child will not necessarily suffer from the side effects mentioned. If you have any questions or concerns, please speak to your doctor, nurse or pharmacist.

Common types of corticosteroids used for reducing inflammation are: prednisolone, dexamethasone and intravenous methylprednisolone. These are different to the anabolic steroids used by athletes to enhance their performance.

## How are they given?

Corticosteroids are usually given by mouth in a variety of forms. Most types of corticosteroid are available in tablet form – some in a soluble format or others that are coated to stop them breaking down in the stomach too quickly (gastro-resistant). Dexamethasone and prednisolone are also available in an oral liquid solution. Sometimes steroids are given intravenously (this is methylprednisolone).

Oral corticosteroids are best taken at the same time each day with food (usually in the morning), as directed by the doctor, nurse or pharmacist.

## Who should not take corticosteroids?

People with the following conditions should discuss taking corticosteroids with their doctor:

- Hypersensitivity to corticosteroids or any of their ingredients

## What are the side effects?

If your child is given a short course of corticosteroids, they are unlikely to suffer many side effects. Most side effects will stop when the course of treatment has finished.

- **Changes in behaviour:** You may notice that your child becomes irritable and has mood swings. They may revert to earlier childhood behaviour, for example, temper tantrums. This effect is usually temporary but please discuss any concerns with your doctor or nurse who will be able to offer advice and support.
- **Weight gain:** Your child may have an increased appetite, which means they will feel hungrier than usual and therefore

might eat more leading to weight gain. Keeping to a well-balanced diet may help. Another reason for weight gain is increased fluid retention.

- **Irritation of the stomach lining:** These medicines are best taken with meals or after food to reduce any stomach irritation. Medications to protect the stomach lining are often given together with the steroids.

These side effects tend to occur only after long-term use or with high doses.

- **Weight gain:** Your child's face may appear more chubby than usual, particularly after long-term steroid treatment. If the weight gain has been considerable, your child may develop stretch marks, especially on their tummy and thighs.
- **High blood pressure (BP):** Your child may complain of having a headache or feeling dizzy (twice weekly BP checks are recommended for children on long term steroids).
- **Alteration in blood sugar level:** Corticosteroids may cause a temporary increase in blood sugar levels. Some signs of a raised blood sugar level are thirst and needing to pass more urine than usual.
- **Effect on growth and/or thinning of bones:** If taken over a long period of time or at a high dose, your child's growth may be affected and/or your child's bones may become thinner.

Your child will be monitored closely throughout treatment to manage any side effects but discuss with your doctor or nurse if you have any concerns.

## Interactions with other medicines

Some medicines can react with corticosteroids altering how well they work. Always check with your doctor or pharmacist before giving your child any other medicine, including medicines on

prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines.

## Important

- Keep medicines in a safe place where children cannot reach them.
- Keep the corticosteroid tablets at room temperature, away from bright light or direct sunlight and away from heat.
- If your doctor decides that your child should stop taking corticosteroids or the medicine passes its expiry date, please return it to your pharmacist. Do not flush it down the toilet or throw it away.
- If you forget to give your child a dose and it is within a few hours of when the dose was due, give it as soon as you remember. Otherwise, do not give this dose but wait until the next dose is due. Do not give a double dose.
- Your child should NOT have any live vaccinations such as MMR, oral polio, chicken pox or BCG while taking corticosteroids. Inactivated or killed vaccines such as influenza/flu, meningitis C, pneumococcal, hepatitis, Hib, tetanus, diphtheria, whooping cough/pertussis and the killed version of the polio immunisation are permitted if the patient is stable under treatment.
- If your child is on corticosteroids and has not had chicken-pox but comes into contact with someone who has chicken pox or shingles (either face to face or longer than 15 minutes in the same room), you should report to your doctor immediately as your child may be at risk of developing a more severe form of the infection and may need special treatment with immunoglobulin. If your child gets chicken pox or shingles you should also report to your doctor immediately for aciclovir to be given. If you are unsure whether your child has had chicken pox

prior to starting corticosteroids, their immunity should be checked with a simple blood test at that time and the result entered on the parent-held monitoring card.

- Your child may be at an increased risk of infection while they are on corticosteroids. If your child has a mild illness (such as a head cold) with little or no temperature, diarrhoea or vomiting then no change in dose is necessary. If your child has a temperature and is more unwell then you should see your family doctor (GP) or take them to your local Accident and Emergency (A&E) department.
- You will be given a corticosteroid card if your child is on corticosteroids for more than two weeks. Your or your child

should always carry this card and show it to any healthcare professional treating them.

- A medical alert necklace or bracelet carries the same information as the corticosteroid card and should always be worn. Please ask your doctor or nurse for details and an application form. You can also visit their website at [www.medicalert.org.uk](http://www.medicalert.org.uk).
- If your child has been on corticosteroids for more than a few weeks and becomes unwell after stopping treatment or needs to have an operation, their natural production of steroids (which helps a child respond to a stressful situation) will be reduced. They may need a short course of a different type of corticosteroid to cover this period.

## Useful numbers

- GOSH Switchboard 020 7405 9200
- Pharmacy medicines information 020 7829 8608 (Monday to Friday from 9am to 5pm)
- Clinical Nurse Specialist for Neuroimmunology 020 7405 9200 5051 or 0460

## Disclaimer

Please read this information sheet from GOSH alongside the patient information leaflet (PIL) provided by the manufacturer. If you do not have a copy of the manufacturer's patient information leaflet please talk to your pharmacist. A few products do not have a marketing authorisation (licence) as a medicine and therefore there is no PIL.

For children in particular, there may be conflicts of information between the manufacturer's patient information leaflet (PIL) and guidance provided by GOSH and other healthcare providers. For example, some manufacturers may recommend, in the patient information leaflet, that a medicine is not given to children aged under 12 years. In most cases, this is because the manufacturer will recruit adults to clinical trials in the first instance and therefore the initial marketing authorisation (licence) only covers adults and older children.

For new medicines, the manufacturer then has to recruit children and newborns into trials (unless the medicine is not going to be used in children and newborns) and subsequently amend the PIL with the approved information. Older medicines may have been used effectively for many years in children without problems but the manufacturer has not been required to collect data and amend the licence. This does not mean that it is unsafe for children and young people to be prescribed such a medicine 'off-licence/off-label'.

However, if you are concerned about any conflicts of information, please discuss with your doctor, nurse or pharmacist.