Use of steroids in neurological conditions

Information for patients
Pharmacy
The information in this leaflet is about a group of medicines called steroids, which includes medicines such as prednisolone, methylprednisolone and dexamethasone. Please read it along with the manufacturer's patient information leaflet supplied with your medicine.

What is my medicine and how does it work?

'Steroids' is the term commonly used to describe corticosteroids, which are hormones produced naturally in the body that help to keep us healthy. Steroids can be used as a medicine to treat several neurological conditions, including:

- Inflammatory conditions of peripheral nerves, such as chronic inflammatory demyelinating polyneuropathy (CIDP)
- Myasthenia gravis
- Bell's palsy
- Vasculitis
- Temporal arteritis
- Relapses of multiple sclerosis
- Some types of headache (cluster headaches)

Steroids treat these conditions by damping down the effects of the immune system, which can be overactive and start to cause damage to nerves, skin, muscle or combinations of these. Your doctor will decide which steroid and whether tablet or injection treatment is suitable for your condition.

Is this medication suitable for me?

To ensure steroids are suitable for you it is important for your medical team to know other medical conditions you have and what other medicines you take. This also includes any medicines you buy, including any herbal, vitamin or other complementary medicines.
What are the potential side effects?

As with all treatments any potential side effects need to be weighed against the benefit of treating your condition. Your medical team will aim to use the lowest possible dose of steroid to reduce the chances of side effects. The manufacturer’s information leaflet that comes with your medication lists possible side effects but not everybody gets these effects. This leaflet describes some of the more common effects and ones it is important for you to know about.

Potential effects from taking steroids short term (up to several weeks)

- Increases in blood sugar levels (see 'Steroids and diabetes')
- Mood changes such as feeling tearful or restless ('high'). Rarely some people become agitated or confused.
- Disturbed sleep or unable to sleep which can be minimised by not taking tablets before bedtime, unless specifically prescribed this way.
- Increased risk of infection (see 'Steroids and infections')
- Increased appetite
- Fluid retention causing ankle swelling
- Stomach or intestine problems such as indigestion and, rarely, ulcers or bleeding. You may be offered another medicine to reduce stomach acid and the chances of these problems happening.
- Cramps and spasms
- Avascular necrosis (see 'Steroids and bone health')

Potential effects from taking steroid for longer than several weeks

As a general rule, the chances of developing the effects from short-term use become higher. Your medical team will try to reduce the dose of steroid you need to take as quickly as they can and they may discuss
other treatments to help to do this. Other medicines that can be used include azathioprine, mycophenolate, methotrexate, cyclophosphamide, ciclosporin, immunoglobulin and rituximab. These medicines work in a different way to steroids; your medical team will discuss them with you if appropriate.

Other effects from longer term use of steroids can be:

- Eyes - visual changes from cataracts, or increased pressure in the eye (glaucoma)
- Raised blood pressure (hypertension)
- Skin changes such as thinning, bruising, sweating or stretch marks, and acne
- Muscle weakness
- Hair growth, especially on the face
- Weight gain and a round or 'moon-shaped' face
- Reduced bone strength (see 'Steroids and bone health')
- Your body being less able to naturally produce steroids, so steroid treatment should not be stopped suddenly.

**Steroids and bone health**

Steroids can reduce the strength of bones and increase the risk of osteoporosis. Your medical team may discuss strategies and treatments to help maintain the strength of your bones, especially if you are likely to need steroid treatment for longer than 3 months. You may also need to have scans of your bones and your medical team can discuss this further with you. Rarely, taking steroids has been associated with a condition called avascular necrosis where blood flow to joint bones is disturbed, most commonly the hip, and results in damage to the joint. Report immediately any pain or stiffness in your joints, especially the hips.
**Steroids and diabetes**

Steroids can increase sugar levels in the blood. If you have diabetes you will need to keep a close eye on your blood sugar levels, especially around the time of your evening meal. You may need to check your blood sugar levels more often at this time of day. Seek advice from your GP or diabetes team if your blood sugar becomes high as you may need to alter some of your medication. If you are not diabetic but notice that you are feeling thirsty and passing urine more often, especially at night, this may mean your blood sugar levels are increasing. If you experience these symptoms please seek medical advice.

**Steroids and infections**

Taking medicines that reduce the effectiveness of the immune system can mean a higher risk of getting infections. Seek medical advice immediately if you develop a fever or symptoms of infection. If you have never had chickenpox you should avoid close contact with people who have chickenpox or shingles. If you do come into contact with somebody who has chickenpox or shingles, seek medical advice urgently. If you need to have any vaccinations you should always check as some may not be suitable to have when taking steroids. However it is recommended that you have the flu vaccination every year, and get vaccinated against bacteria called pneumococcus.

**How do I take steroids?**

The dose of steroid you need to take and for how long is very individual to you and your condition. It is not always possible to know in advance how long you will need steroid treatment. There are several important things to remember:

- Be sure you know the plan for your steroid treatment and how to take it. For most conditions, except myasthenia gravis, it is usual to
start with higher doses and then reduce the dose as you respond to treatment.

- Ask somebody to write down your treatment plan if you are unsure. If you are being discharged from hospital you should receive a copy of your discharge letter which will include information about your treatment. The hospital pharmacy can also provide you with more detailed information that explains when you have to change doses and what dose you need to take each day.
- Make sure you have a further appointment with the neurology team for review of your condition and the steroid dose.
- **Do not run out of or suddenly stop taking steroids without medical advice**, especially if you have taken them for longer than 3 weeks. Discuss with the hospital pharmacy team or your local community pharmacy if you do not think you have enough supplies.
- Discuss with the neurology team if you are having problems taking the tablets. Higher strength tablets can be supplied to reduce the number of tablets you need to take.
- Make sure you have been given a blue 'Steroid Treatment Card' from the pharmacy and carry this around with you to show every time you have a medical appointment.

**What if I take more medicine than I should?**

Seek medical advice as soon as possible.

**What if I miss a dose?**

Take the dose as soon as possible unless it is almost time to take your next dose, then continue as normal. Do not take an extra dose to make up for the missed one.
What should I do if I have another illness whilst on steroids?

You may need a higher dose of steroid to cope with the stress of illness or surgery. Talk to your doctors urgently in case of any illness. If you need an operation you should inform your surgeon and anaesthetist that you are taking steroids.

What should I do if I have diarrhoea or vomiting?

Discuss urgently with your GP or hospital team because you may not absorb the oral steroid and you may need injections instead, especially if you have been on steroids for a long time.

Can I have steroids in pregnancy or while breastfeeding?

If you are pregnant or are planning on becoming pregnant or are breastfeeding you should discuss this with your medical team.

How do I get a repeat prescription?

You will probably need to get prescriptions from your neurologist when you first start treatment. As your condition becomes controlled your GP should be able to provide repeat prescriptions if you need ongoing steroid treatment. However, it is important that you continue to get reviewed regularly by your neurologist to ensure it is appropriate for you to continue taking steroids.

Who do I contact if I have any questions?

Do not hesitate to contact your doctor, nurse or pharmacist if you require more information or advice.
The hospital switchboard number is:

- **0114 243 4343**

If you have questions about your medicines the hospital's Medicines Advice lines are

- **0114 271 3296** (Royal Hallamshire), and
- **0114 271 4371** (Northern General)

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