Neurology and Pharmacy directorate

Steroids for Myasthenia Gravis

Introduction

This leaflet provides information on a medicine called steroids when it is used to treat myasthenia gravis. After reading this leaflet you should have an idea about what to expect if you start taking steroids, for example, how well it works, and what side-effects you may experience.

What is myasthenia gravis?

Myasthenia gravis is an 'autoimmune disease'. This means that your immune system (the body's own defence system), which usually protects your body by fighting off infections such as the cold virus or measles, starts to attack a small part of your body by mistake. In people who have myasthenia gravis the immune system produces antibodies (a type of protein that circulates in the blood) which sticks to the muscle surface at the site were the nerves connect to the muscle fibres (the neuromuscular junction). These antibodies interfere with the transmission of chemical messages from the nerve branches to the muscle fibres. This results in fewer muscle fibres contracting and less power is therefore generated by the muscles. The symptoms of myasthenia gravis depend on which muscles are affected. For example, weakness of the muscles which move the eyes results in double vision, whilst weakness of the throat muscles may result in problems with swallowing.

What are steroids?

Steroids are a type of medicine called an ‘immunosuppressant’. They reduce the production of antibodies by 'damping down' the activity of the body’s immune system. This helps messages getting through from the nerves to the muscles and muscle strength improves. Other immunosuppressants that have been used to treat myasthenia gravis include; azathioprine, cyclophosphamide, ciclosporin, mycophenolate mofetil (MMF), and tacrolimus.

When are steroids prescribed?

In patients with mild myasthenia gravis, medicines called acetylcholinesterase inhibitors (e.g. pyridostigmine) are usually prescribed to increase muscle strength. They work by increasing the effect of the chemical messenger (acetylcholine) which transmits information from the nerves to the muscles. If the symptoms cannot be controlled using these drugs the next stage of treatment is some form of immunosuppressant to help increase muscle strength.
Steroids such as prednisolone are the immunosuppressant that is usually prescribed first. Some patients have other conditions, such as diabetes, where steroids are best avoided. In others, the myasthenic symptoms cannot be fully controlled with steroids without them causing side effects. In these patients another immunosuppressant (usually azathioprine) may be prescribed. Combining steroids with a second immunosuppressant often allows a smaller dose of steroids to be used, minimising side effects, such as osteoporosis.

**How quickly do steroids work?**

Symptoms usually start to improve 2-4 weeks after treatment is started. Maximum benefit is usually seen after 6-12 months of treatment.

**How well do steroids work?**

It is thought that for every 10 patients with myasthenia gravis who are treated with steroids, between 4-8 people will either go into remission or have such good symptom improvement that they have an almost normal daily life and muscle strength. How well you respond to steroids depends on how severe your myasthenia gravis is.

**When do I take steroids?**

Steroids are usually taken every day or every other day in the morning; after or with breakfast. Your doctor will advise.

**What dose should I take?**

This is different for every patient and may change throughout your treatment.

Steroids (prednisolone) are usually started at a low dose for example prednisolone 5-10mg each day and the dose gradually increased. This is because high doses of steroids at the start of treatment can make the muscles weaker. Therefore the dose is built up slowly. Once the recommended dose has been reached (prednisolone up to 80-100 mg every other day or up to 50 mg each day) it is usually held there for several months. After this, the dose is usually reduced over a number of months to the lowest dose that controls the symptom.

Ideally the dose of steroid should be reduced to prednisolone 5-10 mg every day. This is in order to lower the risk of side-effects. Unfortunately it is not always possible to lower the dose of steroid by this much and few patients are able to stop steroid treatment altogether.

**Note:** when you start treatment with corticosteroids you may find that your symptoms are worse in the beginning.

**What is the length of treatment?**

The length of treatment is different for each patient; however treatment is usually long-term (months or years). Some patient will need steroids permanently. If your symptoms are well controlled the doctor may decide to gradually lower the dose of your medicine to a dose that
will still keep the symptoms away. If symptoms return the doctor may decide to increase this
dose again.

**Stopping steroids**

Never stop taking steroids abruptly. Steroids are very similar to a hormone in that is made in
your body called cortisone. When you start taking steroids your body can stop making its
own. Your body will become used to the steroids level in your body and stopping them
suddenly may cause you to experience withdrawal symptoms. These effects include
weakness, tiredness, feeling sick, vomiting, diarrhoea, abdominal pain, low blood sugar and
low blood pressure which can cause dizziness, fainting or collapse.

Any dose reduction should be supervised by a doctor, undertaken slowly and over a number
of weeks or months. This will allow your body to start making its own corticosteroids and you
should not have any of these effects.

It is important to always tell your doctor or pharmacist if there is any reason you cannot take
your medication (e.g. sickness or diarrhoea)

**What should I do if I miss a dose?**

If you forget to take your medication in the morning, take it as soon as you remember the
same day.
If you forget to take your medicine, but do not remember until the next day. Take your
medicine as normal the next day. Do not take double the dose the next day.

**What are the possible side-effects?**

Like all medicines steroids have a number of side-effects. In general it is thought that side-
effects are more likely to occur if you are taking high doses or if you are taking steroids for a
long time. It is important to remember that not all patients will experience side-effects and for
most myasthenia gravis patients the benefit of steroid treatment is far greater than the risk of
getting any of the side-effects listed below. The more common side-effects of steroids are:

- **Osteoporosis** - this is when bones become weak and fragile. Osteoporosis usually
  occurs when you take steroids for a long time (e.g. greater than three months). Your
doctor will monitor regularly and assess your risk of getting osteoporosis. You may
need to take medicines to help prevent osteoporosis (e.g. a bisphosphonate and
calcium supplements). Your doctor will advise.

- **Stomach or duodenal ulcers** – if you develop indigestion or stomach pains, contact
your doctor for advice. If you are at high risk of getting an ulcer your doctor may
prescribe a medicine to help prevent ulcers (e.g. a proton pump inhibitor such as
omeprazole).

- **Increased risk of infection** - steroids reduce the activity of the immune system. This
means that you are not able to fight infection in the same way. This is particularly
important if you have not had chicken pox before and you come into contact with
some one who has chicken pox. This is because if people who take
immunosuppressants get chicken pox or shingles they can get very severe infections
and they may need special treatment. If you take steroids, try to avoid people who
have chicken pox or shingles. If you come into contact with any one who has chicken pox or shingles contact your doctor as soon as possible.

- **Mood changes** - some patients may find that steroids make them feel better, but other patients may find that they suffer from a low mood. For some people who have depression or other mental health problems, steroid can sometimes make these conditions worse. It is thought that mood changes are more likely to occur within the first few weeks of treatment or at high doses.

- **Increased appetite and weight gain** - patients who take steroids for a long time can put on weight. This is because steroids may increase your appetite. It is important to maintain a healthy diet and weight. Patient may also find that their face becomes puffy. This is sometimes referred to as having a ‘moon face’.

- **High blood pressure** - your doctor should check your blood pressure on a regular basis.

- **Skin problems** - steroids can cause thinning of the skin, stretch marks, and poor healing. You may also find that you bruise more easily.

- **Cataracts and glaucoma** - are conditions which affect your eyes. Contact your doctor or optician if you feel your eye sight worsens.

- **Hair growth** - steroids may cause increased or darkened hair growth. Your hair usually returns to normal if treatment is stopped.

- **High blood sugar** - steroids may increase the amount of glucose in your blood. Sometimes they can also cause diabetes. Your doctor should monitor you regularly for this, especially if you have a family history of diabetes.

For a full list of side-effects with more detailed information, please see the leaflet that came with your medicine.

**Do I need any special tests while taking steroids?**

Your doctor will monitor you regularly throughout your treatment. This will involve routine blood pressure and blood tests to check how much glucose or potassium is in your blood. These may be done in clinic at the hospital or at your GP surgery. Your doctor may also send you for a bone scan to see if your bones have been affected by the medication.

**Can I take other medicines along with steroids?**

Steroids may be prescribed along with other drugs however it is important to discuss any new or old medications with your doctor before starting them. It is important that you do not take any anti-inflammatory pain killers (e.g. ibuprofen or diclofenac) unless this has been advised by your doctor. This is because this type of pain killer can increase your risk of having a stomach or duodenal ulcer.

Do not take ‘over-the-counter’ medications without discussing this first with your doctor or pharmacist.
Can I have immunisations while taking steroids?

You should not be immunised with ‘live’ vaccines such as ‘rubella’ (German measles) if you are taking steroids. However, in certain situations a live vaccine may be indicated (for example rubella immunisation in women of childbearing age). In this case your doctor will discuss the possible risks and benefits of the immunisation with you. Pneumovax® (a vaccine for pneumonia) and yearly flu vaccines are safe and recommended.

Steroid cards

Your will be given a steroid card by your doctor or pharmacist. You should carry this with you at all times. This is in order to make sure that if you need any emergency medical treatment that the doctor or nurse treating you knows you take steroids. You may need higher doses for a short time while you are ill.

What about pregnancy?

If you are planning on having a baby please seek the advice of your doctor well in advance so they can we discuss how best to manage your myasthenia gravis during your pregnancy. It is possible to take steroids during pregnancy, but the risks of doing so will have to be carefully balanced against the benefits. If you become pregnant while taking steroids contact your doctor immediately.

What about breastfeeding?

You may be able to breastfeed if you are taking steroids, but you will need to discuss this with your doctor.

Can I drink alcohol with steroids?

There is no particular reason for you to avoid alcohol completely; however you should not exceed the recommended daily units.

Useful websites/contacts

- Myasthenia Gravis Association
  - Address: The College Business Centre Uttoxeter New Road, Derby DE22 3WZ
  - Tel no: 01332 290219 or Free Phone 0800-919922
  - Wed address: www.mga-charity.org

For further information

- Medicines information patient helpline:
Tel: 0191 2823016. Available from 9:00 to 4:00 pm. Monday to Friday (excluding bank holidays). This helpline is available for patients of the Newcastle Upon Tyne Hospitals, to answer any questions they may have regarding their medicines.

- The Patient Advice and Liaison Service (PALS) can offer on-the-spot advice and information about the NHS. You can contact them on free hone 0800 032 02 02 or e-mail northoftynepals@nhct.nhs.uk.

- If you would like further information about health conditions and treatment options, you may wish to have a look at the NHS Choices website at www.nhs.uk. On this website there is an information prescription generator www.nhs.uk/ips which brings together a wealth of approved patient information from the NHS and charity partners which you may find helpful.

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