

Neuro-oncology

Steroids

Information for patients, relatives and carers

Introduction

This leaflet provides guidance on taking or starting a steroid treatment and their potential side effects. The information in this leaflet is a guide only and does not replace the advice from your healthcare professional.

What are steroids?

Steroids are substances naturally produced in the body. Two adrenal glands - one on top of each kidney - produce these substances.

Steroids help control many different functions in our bodies, including:

- the way the body uses fats, proteins and carbohydrates
- regulating our immune system and the balance of salt and water in our bodies
- reducing inflammation

Sometimes you need more steroid than your body is producing naturally. If this is the case, a manufactured steroid drug is used. There are several types of steroids and they all have different effects on the body. The most common type of steroids used in our cancer treatment is **dexamethasone**.

Steroids can come as an injection or in tablet form.

- They are normally given as tablets. You should swallow them with plenty of water and you may need to take them at set times each day
- They are usually given in short courses

It is important you make sure you know the following when being started on a course of steroids:

- how long the course is supposed to last
- when you should stop taking them
- when to get a repeat prescription, if applicable

PLEASE NEVER STOP TAKING STEROIDS SUDDENLY AS THIS CAN HAVE FATAL CONSEQUENCES.

If you need or want to stop taking your steroids for any reason and you have not been given a plan for gradual weaning, please contact your doctor or clinical specialist nurse (CNS) for advice. They can help by slowly weaning you off them. If you run out of tablets, please urgently contact your GP or CNS for advice about a repeat prescription or if out of hours please contact your local out of hour's service urgently.

Common side effects of steroids

Always tell your doctor or nurse about any side effects you may experience, even if these are not bothering you. It is important to remember that each person's reaction to any drug is different. This means that you may get some of the side effects discussed but it is unlikely you would get all of them.

Tummy pain and/or indigestion

Steroids can irritate the stomach lining. We recommend you take medication, such as omeprazole, before taking your steroids. This medication belongs to a group of drugs called proton pump inhibitors (PPI) designed to reduce the amount of stomach acid produced and limit the irritation of the stomach lining. We strongly advise you to take your steroid tablets with food to help protect your stomach. Some steroid tablets have an extra coating to help reduce irritation.

Raised blood sugar levels

Steroids can raise your blood sugar levels if you are on high doses or have long-term treatment with steroids.

Common symptoms of raised blood sugar include:

- feeling thirsty
- needing to pass urine more often
- feeling tired

Please tell your doctor or nurse if you have any of these symptoms.

If you have diabetes, your blood sugar levels may become higher than usual. You may need your insulin or tablet dose adjusting. Your doctor can talk to you about this.

Increased chance of infection and delayed healing

This is more likely to happen if you are taking high-dose steroids or have been taking them for a long time.

It is important to tell your doctor if you notice any signs of infection, such as redness, soreness or a temperature. You should also tell them if cuts take longer than usual to heal.

Mood and behaviour changes

Steroids can affect your mood. You may feel anxious or restless, have mood swings or difficulty sleeping.

Taking your steroids early in the morning should help you to sleep better.

Increased appetite

Steroids can make you feel much hungrier than usual and can cause you to gain weight. Your appetite will go back to normal when you stop taking them.

Build-up of fluid

Your ankles and legs may swell because of fluid building up. This is caused by the steroids and is more common if you are taking them for a long time. If your ankles and legs do swell, it can sometimes help to put your legs up on a footstool or cushion. The swelling usually gets better after your steroid treatment ends.

Changes to your menstrual cycle (periods)

Women may find that their periods become irregular or stop. These will usually return to normal once the steroid treatment has finished.

Less common side effects of steroids

You can experience some less common side effects with steroid use. These usually develop because of long-term steroid treatment.

Eye changes

Steroids can cause eye problems, including an increased risk of eye infections.

You must tell your doctor or specialist nurse if you notice any changes to your eyes such as:

- blurred vision
- pain
- redness

Cushing's syndrome

Cushing's syndrome is a condition that can cause acne, puffiness of the face, facial hair in women and dark marks on the skin.

Talk to your doctor if you have any of these side effects. Cushing's symptoms can sometimes improve by lowering the dose of steroids, but this needs to be carefully considered by your doctor or specialist nurse.

Muscle wasting

Steroids can cause muscle wasting; you may find your legs feel weaker and it is harder to climb stairs or stand from sitting.

When you stop taking steroids you may experience muscle cramps for a short time.

Summary

If you experience any side effects, you should discuss them with your doctor or specialist nurse.

It is important to follow any instructions given to you about your steroid treatment and never stop them suddenly unless advised to do so by your doctor or specialist nurse.

If you are unsure about any part of your steroid treatment then please speak to your doctor or specialist nurse.

How to contact us

Imperial College Healthcare NHS Trust has a Macmillan navigator service, which can answer questions on behalf of the relevant CNS. Navigators will also refer you to the CNS teams and to other specialist clinical staff, as needed. The service is available Monday to Friday 08.00 – 17.00.

Telephone: **020 3313 0303**

Outside of these hours, please contact your GP or phone NHS 111.

Further sources of support and information

Macmillan Cancer Support Helpline: **0808 800 000** (Monday to Friday, 09.00 - 20.00)
www.macmillan.org.uk

Macmillan Cancer Information and Support Service at Charing Cross and Hammersmith hospitals

The information centre at Charing Cross Hospital and the Infopod at Hammersmith Hospital provide support, practical and signposting advice to anyone affected by cancer. These drop-in services are set in friendly, non-clinical environments in which people affected by cancer can discuss private and emotional needs.

The centre is located on the ground floor of Charing Cross Hospital, telephone: **020 3313 0171** and is open (except bank holidays):

- Monday, Tuesday, Wednesday and Thursday 08.00 - 17.00
- Friday 09.00 - 17.00 (volunteer only)

The Infopod is located on the ground floor of the Garry Weston Centre at Hammersmith Hospital, telephone: **020 3313 4248** and is open (except bank holidays):

- Monday and Tuesday 09.00-17.00
- Wednesday, Thursday, Friday 09.00-16.00

Maggie's Cancer Caring Centre

Maggie's is a cancer charity that provides the emotional, practical and social support that people with cancer may need. The centre combines striking buildings, calming spaces, professional experts offering professional support, and the ability to talk and share experiences with a community of people who have been through similar experiences. Designed by leading architects, Maggie's centres are warm, friendly and informal places full of light and open space with a big kitchen at their heart. Maggie's West London is located in the grounds of Charing Cross Hospital but is independent of our hospital. The centre is open Monday to Friday, 09.00-17.00. For more information, please call 020 7386 1750.

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information, visit our website: www.imperial.nhs.uk