

For further information about steroids:

Cancerbacup

0808 800 1234

www.cancerbacup.org.uk

Cancer Help UK

www.cancerhelp.org.uk

Useful Contact details:

The British Brain and Spine Foundation

0808 808 1000

www.brainandspine.org.uk

Macmillan Cancer Relief

0808 808 2020

www.macmillan.org.uk

Brain Tumour Action

01506 436164

www.braintumouraction.org.uk

Brain Tumour UK

0845 4500 386

www.braintumouruk.org.uk

Samantha Dickson Research Trust

0845 130 9733

www.sdrtr.co.uk

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Understanding Steroids

A guide for patients with a brain tumour

This booklet was written by The Association of Neuro-oncology Nurses (ANON). Other multi-disciplinary team members, including Neurosurgeons, Oncologists, Pharmacists and Physiotherapists, have reviewed the content.

ANON are grateful to patients and carers who have also contributed to the content and wording of the booklet.

University College London Hospitals 
NHS Foundation Trust

This booklet has been approved for use at UCLH and within The North London Cancer Network by the North London Cancer Network Brain and CNS Tumour Board members

When should I ask for advice?

Whenever you have questions, concerns or symptoms.

Whom can I ask for advice?

You can ask your Specialist Nurse, Doctor, General Practitioner, Pharmacist, Dietician or Physiotherapist for information about various problems.

Please fill in the name and contact number of your:

Specialist Nurse:

GP/Hospital Doctor:

Physiotherapist/Dietician:

Steroid doses

The aim of steroid treatment is to reduce the symptoms of cerebral oedema, using a dose of steroids that will not give you too many side effects.

Steroids can be taken over a number of days, weeks or months. You may be prescribed a 'maintenance dose' or a 'reducing dose' of steroids.

Doses of Dexamethasone usually range from:
0.5 milligrams (mg) to 16mg per day

Tablets are available in two strengths:
0.5mg (500 micrograms) and 2mg

Dexamethasone may be prescribed at different times in the day, e.g. at breakfast and lunch. This is called a 'divided dose'.

Dexamethasone is usually taken in tablet form but is also available as an injection or syrup. **Prednisolone** is another steroid medication that is sometimes used to reduce cerebral oedema (swelling).

Steroid medication should never be stopped suddenly

Gradually reducing the steroid dose over time allows the Adrenal glands to take over the production of natural corticosteroids, which prevents the body from adversely reacting to the withdrawal of artificial steroids.

Your Doctor will advise on steroid reduction.

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How can steroids help when you have a brain tumour?

The symptoms that a person with a brain tumour may experience depend upon the position of the tumour in the brain. Symptoms may include weakness on one side of the body, memory problems or difficulty with speech and language. Symptoms are sometimes worse when there is **swelling** around the tumour; this swelling is also known as **cerebral oedema**.

Cerebral Oedema is an accumulation (collection) of fluid in the brain tissue surrounding the tumour. It can occur after any injury to the brain tissue.

Tumours inside the skull are growing in a confined space. The tumour and cerebral oedema create pressure inside the skull. This can cause you to experience symptoms; often the symptoms will be similar to the ones you had when the tumour was diagnosed.

Some people experience headaches and nausea (feeling sick) this indicates there may be some swelling around the tumour and pressure inside the skull.

Steroid medication reduces cerebral oedema (swelling) and can improve symptoms.

Safety Checklist:

- **Never stop taking steroids suddenly**
- **Make sure you do not run out of tablets**
- **Carry your steroid card with you at all times**
- **Inform your Doctor, Dentist, Pharmacist and Nurses that you have been treated with steroids**
- **If you are not able to take your tablets due to sickness, inform your Specialist Nurse or Doctor.**

The management chart in this booklet can be used to record your steroid dose, the effect of the steroids on your symptoms and any side effects you may experience.

Date:	Medication: Dose & Time:	Symptoms: How are you feeling?	Side Effects:	Comments or Instructions:	Discussed with:
17th Sept	2mg in the morning	Morning headache. Worsening right arm weakness	Feeling very hungry	Increase dose to 4mg	GP Review: 1 week
					Review:
					Review:

What are steroids?

Steroids are naturally occurring hormones. The steroids produced by the body are called **corticosteroids** and their actions are very complex.

Your body controls the amount of natural corticosteroid it needs to function normally, the adrenal glands produce corticosteroids in small quantities.

When you have cerebral oedema (swelling), the body requires more corticosteroid than can be produced naturally.

Your Doctor may prescribe an artificial corticosteroid (steroid medication) to reduce the swelling around your tumour and improve your symptoms. Steroid medication does not treat the tumour.

The steroid medication most commonly prescribed to treat cerebral oedema is **Dexamethasone**.

The steroids used to treat cerebral oedema (swelling) are different from anabolic steroids, which are used by some athletes to build muscle.

When will the Doctor prescribe steroids?

Steroids may be prescribed at different times:

- **When cerebral oedema (swelling) is seen on your brain scan**
- **Around the time of surgery**
Cerebral oedema can occur at the time of surgery. Steroids may be prescribed before or after surgery. Your steroid dose may be reduced and stopped over a period of days as the swelling reduces after surgery.
- **Around the time of Radiotherapy**
Radiotherapy treatment can cause cerebral oedema. Steroids may be prescribed during and/or after treatment.
- **Around the time of chemotherapy**
If you require further treatment with chemotherapy because of tumour growth, you may also have some cerebral oedema.
- **Any time you are experiencing problems which are thought to be caused by cerebral oedema.**

Inform your Specialist Nurse or Doctor if you think you have been exposed to shingles, measles or chicken pox; additional treatment may be required.

- **Changes in the skin including bruising, stretch marks and aches**
The side effects of steroids can cause changes in your appearance. If this is causing you distress, discuss this with your Nurse Specialist; a referral for counseling may be useful.
- **Interaction with anti-seizure medication**
Anti-seizure medication and steroid medications are often used together, although this can sometimes affect the way the medications work.

Your Doctor will be monitoring you for any adverse interactions.

This list contains the more frequently occurring side effects. For additional information, please read the information leaflet provided with the medication and discuss with your Pharmacist, Doctor or Specialist Nurse.

- **Weakness in the muscles of the upper arms and legs (thighs)**

You may notice that it is more difficult to perform daily activities such as climbing the stairs, or getting out of a chair. This weakness, caused by the steroids is called, 'proximal myopathy'. It is more likely to be a problem if you have been taking steroids for a number of weeks or months. A Physiotherapist can advise you of the types of activity and exercises that help in this situation.

- **Interruptions to the menstrual cycle**

Your menstrual cycle may become irregular. This usually returns to normal once steroids treatment has finished. It is not advisable to become pregnant when you are taking steroids. Please discuss any concerns regarding contraception or pregnancy with your Specialist Nurse or Doctor.

- **Increased risk of infection and delayed healing**

Steroids can affect your immune system and increase your risk of infection. Oral thrush (fungal infections), urine infections, and chest infections can occur.

Inform your Specialist Nurse or Doctor if you are experiencing:

A raised temperature, flu-like symptoms, delayed healing of cuts or wounds, pain or stinging when passing urine, persistent cough, or a sore mouth.

Avoid coming into contact with people who have a cold.

Discussed with:	Review:	Review:	Review:
Comments or Instructions:			
Side Effects:			
Symptoms: How are you feeling?			
Medication: Dose & Time:			
Date:			

What are the side effects of steroids?

The Specialist Nurse and your Doctor will discuss the side effects of steroids with you. The side effects experienced vary from person to person and are usually more noticeable when you are on a higher dose or when you have been taking steroids for a while.

Below is a list of the more common side effects and advice on how to cope with them.

- **Problems with sleeping (insomnia)**
To reduce the effects of insomnia take your tablets in the morning and early afternoon, if you are prescribed steroids twice a day.
- **Increased appetite leading to weight gain**
You may experience a craving for sweet foods and an increased appetite. Try to stick to a healthy balanced diet, although some weight gain may be unavoidable. Information about healthy eating is available from Cancerbacup. Ask to see a dietician if you are having difficulties managing your weight. Your appetite should return to normal after steroid treatment.
- **Changes in your mood**
Be aware that steroids may affect your mood. You may feel irritable, agitated, depressed or have mood swings. Your mood should return to normal when the steroid dose is reduced, or steroid treatment is finished. Additional help may be required to deal with these effects, discuss any concerns with your Specialist Nurse or Doctor.

- **Irritation of stomach lining**
You may experience heartburn or indigestion. Take your tablets with food or a glass of milk. Additional medication to protect your stomach lining may be prescribed. Tell your Specialist Nurse or Doctor if you are experiencing heartburn or indigestion.
- **Increased thirst and frequent urinating**
The body regulates sugar levels in the blood (blood sugar level) using insulin. Steroids can affect your blood sugar level, causing a type of diabetes to develop. The symptoms include increased thirst and passing urine more often; tell your specialist Nurse or Doctor if this is happening to you. A simple urine test can detect this type of diabetes. It may be possible to control your blood sugar level with your diet. Your Specialist Nurse or a Dietician can advise you. Occasionally, additional medication will be required to control your blood sugar level. Blood sugar levels usually return to normal after your steroid treatment finishes.
- **If you are Diabetic your blood sugars may be affected**
You will need to monitor your blood sugars closely. Your Doctor will make changes to your diabetic medication if needed.
- **Fluid retention**
If you experience fluid retention (puffiness or swelling) in your legs or a bloated feeling in your stomach, seek advice from your Specialist Nurse or Doctor.