Understanding steroids
How can steroids help when you have a brain tumour?

Information for patients
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 down one the 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 called cerebral oedema.

Cerebral oedema an increase in the amount of fluid in the brain tissue surrounding the tumour. It can occur after any injury to 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 may indicate that there is some swelling around the tumour and pressure inside the skull.

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

When you have cerebral oedema (swelling), the body needs 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 medications do 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 steroids be prescribed?
*Steroids may be prescribed at different times:*

- When the 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. You may have chemotherapy as part of your initial treatment and/or at a later date if the tumour is growing.

• At any time you are experiencing problems which are thought to be caused by cerebral oedema.

What are the side-effects of steroids?

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 with advice on how to cope with them.

Problems with sleeping (insomnia).
To reduce the effects of insomnia take your tablets in the morning. If you are prescribed steroids twice a day take them in the morning and early afternoon.

Increased appetite leading to weight gain
You may experience cravings for sweet food 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 Macmillan Cancer Support (see page 10 for contact details). Ask to see a dietitian if you are having difficulties managing your weight. Your appetite should return to normal after steroid treatment has been stopped.
Changes in your mood
Steroids can affect your mood. You may feel irritable, agitated, depressed or have mood swings. This should return to normal when the dose is reduced, or steroid treatment finishes. Additional help may be required to deal with these effects, discuss any concerns you have with your specialist nurse or doctor.

Irritation of the 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 need to pass urine more often
The body regulates sugar levels in the blood 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; inform your specialist nurse or doctor if this is happening to you. A simple urine test can detect changes in the blood sugar level and it may be possible to control this by altering your diet. Occasionally medication is required to control the blood sugar. Blood sugar levels usually return to normal after 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.

Muscle weakness in 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. The steroids cause this weakness, it 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. Please speak to a member of your healthcare team if you experience this as a physiotherapist can advise you on the types of activity and exercises that help in this situation.

Interruptions to your menstrual cycle
Your menstrual cycle may become irregular. This usually returns to normal once steroid treatment has finished. It is not advisable to become pregnant when you are taking steroids. Please discuss any concerns you have regarding contraception or pregnancy with you 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 infection), urine infections, and chest infections can occur.

Inform your specialist nurse or doctor if you experience;
- a raised temperature
- flu-like symptoms
- delayed healing of cuts and wounds
- pain or stinging when passing urine
• persistent cough, or sore mouth.
• Try to avoid coming into contact people who have a cold.

Inform your specialist nurse or doctor if you think you have been exposed to shingles, measles or chicken pox as additional treatment may be required.

**Changes in the skin including bruising, stretch marks and acne**

The side-effects of steroids can cause changes in your appearance. If this is causing you distress talk to your specialist nurse.

**Interaction with anti-seizure medication**

Anti-seizure medication and steroid medication 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 leaflets provided with the medication and discuss any concerns with your pharmacist, doctor or specialist nurse.

**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 vary between: 0.5 milligrams (mg) and 16mg per day

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

Dexamethasone may be prescribed at different times of the day, for example, at breakfast and lunch time. This is called a divided dose.

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

Steroid medication is not usually stopped suddenly.

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

Your doctor and specialist nurse will advise you on steroid reduction.

Who can I ask for advice?

You can ask a specialist nurse, doctor, your GP, or pharmacist for advice about your steroid treatment. A dietitian or physiotherapist can also provide additional advice about managing side-effects.
Please fill in the name and contact number of your:

Specialist nurse: ..............................................................................................
Tel: ....................................................................................................................

Hospital doctor: ................................................................................................
Tel: ....................................................................................................................

GP: ...................................................................................................................
Tel: ....................................................................................................................

Physiotherapist: ...............................................................................................
Tel: ....................................................................................................................

Dietitian: .........................................................................................................
Tel: ....................................................................................................................
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 if you have been treated with steroids.
• If you are not able to take your tablets due to sickness inform your specialist nurse or doctor.

Please take this booklet with you to hospital or GP appointments.

Further information about steroids

Cancer Research UK
Website: www.cancerresearchuk.org

Useful contact details

Macmillan Cancer Support
89 Albert Embankment,
London SE1 7UQ

Freephone 0808 808 2020, 9am to 6pm Monday to Friday
A textphone service for deaf and hard of hearing people on 0808 808 0121.

Website: www.macmillan.org.uk
Email: cancerline@macmillan.org.uk
They offer information and emotional support.
Leeds Cancer Support

Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of support, in a welcoming environment for you, your family and friends.

We can be found in the information lounges in Bexley Wing and also in the purpose built Robert Ogden Macmillan Centre.

The Sir Robert Ogden Macmillan Centre

The Centre is on the St James’s Hospital site and offers a variety of support services including counselling, support groups and complementary therapies. These therapies include Reiki, relaxation and visualisation, hand and foot massage and many others. You can also just drop in for a coffee and a chat at any time. The centre is open from 10.00am - 4.00pm Monday to Friday.

Contact numbers for Leeds Cancer Support

Information Centre Level 1 Outpatients Department

Open from 10.00am - 4.00pm. Tel: (0113) 206 8816

Information Lounge Level -2 Radiotherapy Department

Open from 8.30am - 6.00pm Tel: (0113) 206 7603

Sir Robert Ogden Macmillan Centre

Open from 10.00am - 4.00pm. Tel: (0113 206 6498)

All the above services can also be contacted by email on: leedsth-tr.cancersupport@nhs.net