



Understanding steroids

For brain tumours



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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 called cerebral oedema. Cerebral oedema is an accumulation (collection) 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 indicates that there may be some swelling around the tumour and pressure inside the skull. Steroid medication reduces cerebral oedema (swelling) and can improve symptoms.

What are steroids?

Steroids are naturally occurring hormones. The steroids produced by the body are called corticosteroids. 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 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 cerebral oedema (swelling) is seen on your brain scan. If you present with any new symptoms you might be started on a dose of steroids followed by a CT scan or MRI scan that will confirm the presence of cerebral oedema.

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

This 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

When you experience symptoms

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 and stick to a healthy balanced diet, although some weight gain may be unavoidable. Information about healthy eating is available from www.macmillan.org.uk/Cancerinformation/Cancerinformation.aspx 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

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 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 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 blood sugar level. It may be possible to control this by altering your diet, ask for advice. 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. 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 steroid 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 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 or wounds, pain or stinging when passing urine, persistent cough, or a sore mouth. You will also need to avoid coming into contact with people who have a cold.

- if you think you have been exposed to shingles, measles or chicken pox; additional treatment may be required.

- experience 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 Specialists Nurse, a referral for counselling may be useful.

- experience 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 leaflet provided with the medication and discuss 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 mg and 16 mg per day

Tablets are available in two strengths:

0.5 mg (milligram) tablet and a 2 mg (milligram) tablet

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; 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 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 and specialist nurse will advise on steroid reduction.

For further information about steroids:

Cancer Research UK

Website: www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/cancer-drugs/steroids

Macmillan Cancer Support

Website: www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Supportivetherapies/Steroids.aspx

Other useful contacts

Brain Tumour Support

Brain Tumour Support
Unit One
Thornbury Office Park
Midland Way
Thornbury
South Gloucestershire, BS35 2BS

Support Services Line: 01454 422701
Website: www.braintumoursupport.co.uk

Macmillan Cancer Support

Call: 0808 808 00 00

Website: www.macmillan.org.uk

Any questions about cancer, need support or just someone to talk to, call free, Monday to Friday, 9am to 8pm (interpretation service available).

Within the Macmillan website is the [cancerbackup/macmillan](http://www.macmillan.org.uk/cancerbackup/macmillan) information and support line for cancer information:
www.macmillan.org.uk/Cancerinformation/Cancerinformation.aspx

Helpline call free on 0808 808 00 00.

Our cancer support specialists are available Monday to Friday, 9am-8pm. Calls from landlines and mobiles (3, O2, Orange, T-mobile, Virgin and Vodafone) are free.

Cancer Research

www.cancerresearchuk.org

Marie Curie

For more information for patients and carers call 0800 716 146.
(freephone)

Website: www.mariecurie.org.uk

The Brain Tumour Charity

Call: 01252 749990

Email: enquiries@thebraintumourcharity.org

Support & Info Line: 0808 800 0004

Email: support@thebraintumourcharity.org

Website: www.thebraintumourcharity.org

Epilepsy Society

The National Society For Epilepsy

www.epilepsysociety.org.uk

Helpline: 01494 601 400

NSE switchboard: 01494 601 300

Epilepsy Action (British Epilepsy Association)

Epilepsy Helpline: 0808 800 5050 (freephone in the UK)

Website: www.epilepsy.org

Braintrust

Email for help and support: hello@braintrust.org.uk

Call: 01983 292 405

Website: www.braintrust.org.uk/index.php

DVLA

www.dft.gov.uk/dvla

Medical Enquiries

If you contact the DVLA by telephone, you will be greeted by an interactive voice system. Staffed telephone enquiry hours are Monday to Friday 8am to 5.30pm, and Saturday 8am to 1pm. Outside these times you will be able to listen to a variety of messages covering the most commonly asked question on driver and vehicle licensing and vehicle registration.

If you are a car or motorcycle licence holder, call: 0300 790 6806

If you hold a bus or lorry licence call: 0300 790 6807

Address: Drivers Medical Group, DVLA, Swansea, SA99 1TU

Email: eftd@dvla.gsi.gov.uk

Directgov

www.direct.gov.uk/en/index.htm

Driving licence information: www.direct.gov.uk/en/Motoring/DriverLicensing/index.htm

This booklet was adapted from The Association of Neurooncology Nurses (ANON). Other multi-disciplinary team members, including neurosurgeons, oncologists, pharmacists and physiotherapists have reviewed the content.

Space for your notes:

For more information contact

Yeovil Hospital reception
01935 475122

Sarah Levy - Brain Tumour Nurse Specialist
01935 384485 mobile 0755731843.

Macmillan Unit at Yeovil Hospital
01935 384553

If you would like this leaflet in another format or in a different language, please ask a member of staff.

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