

Steroids

Steroids (sometimes called corticosteroids) occur naturally within your body, but they can also be created in a laboratory for medical purposes. One of their key functions in the treatment of brain tumours is to reduce inflammation/swelling and ease associated symptoms, such as headaches. Steroids can, therefore, help with symptom management rather than treating the tumour itself.

They are also used to protect the brain at the time of surgery. It's highly likely that you'll be given steroids at some point during the course of your treatment. The information here summarises when and why you might be given steroids.

In this fact sheet:

- What are steroids?
- Why do I need to take steroids?
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- What are the side-effects of steroids?

What are steroids?

Steroids are naturally occurring hormones that are produced by our bodies. They are made by the adrenal glands that sit just above each kidney, and control many functions in the body. These include the way we use fats, proteins and carbohydrates; the regulation of our immune system and the balance of salts and water in our bodies; and they help to reduce inflammation (swelling).

Steroids can also be made synthetically in the lab and used as drugs to help treat some symptoms of various illnesses. There are different types of these steroids, which all have different effects on the body. It is important to know that the steroids used with brain tumours are NOT anabolic steroids that are used by some athletes to build muscle.

Why do I need to take steroids?

There is only a fixed amount of space in the skull - as a result the presence of a brain tumour, and possible swelling around the tumour, can put pressure on surrounding tissues. (This swelling can be caused by the surgery or radiotherapy that you may be having as part of your treatment). The increased pressure in the brain can cause symptoms such as headaches, sickness and seizures (fits).

You may be given steroids to reduce the swelling in the brain (also known as cerebral oedema). Reduction of the swelling relieves the pressure on the brain and so relieves these symptoms.

You may also be given a low dosage of steroids if you are having chemotherapy or radiotherapy and experiencing nausea.

Steroids are also given to help manage symptoms when a tumour is advanced at the first point of diagnosis or if a tumour has come back.

The steroid most commonly used with brain tumours is dexamethasone, as this is useful in treating swelling in the brain. As steroids are fast-acting drugs, the effects caused by the tumour could reduce quite quickly.

It is important to be aware that steroids are not a treatment for the tumour itself, but for the symptoms - so a reduction in symptoms does not necessarily mean that the size of the tumour has reduced.

How are steroids taken?

There are different ways that steroids can be taken, including:

- Orally (as tablets or liquid medicine - colour and dosage will depend on which steroid you have been prescribed)
- By injection (as a clear fluid either to the vein or muscle).

As tablets, they should be taken with plenty of water or milk. They may need to be taken at set times of day. It is generally recommended that you don't take steroids later than 2pm. They are usually given in short courses (a few days or weeks). Make sure you know how long you should take them for.

They are only likely to be given by injection when you are in hospital.

Important points to remember

- **Keep taking your steroids for as long as your specialist tells you to.**
After taking steroids for a few days, your body will start to produce less of its own natural steroids. To allow for this, when taking you off steroids, your specialist is likely to reduce your dosage gradually to allow your body to start producing steroids naturally again. Stopping steroids suddenly can make you unwell, so please follow the advice of your specialist.
- **If you are given a steroid card, make sure you carry it with you at all times.**
A steroid card would usually be given to you by your nurse or doctor if you are taking steroids for more than a week. If you are given a steroid card, you must always carry it with you - it contains details of your steroid type and dosage, which is important information if you need to have medical treatment. Your doctor may advise you to carry it for up to a year after completion of your steroid treatment.

What if I forget to take my steroids?

You should, of course, make every effort to remember to take your steroids when you are required to. It might help to leave yourself a note or set an alarm to remind you. Getting into a routine of when you take your steroids is also helpful.

If you do miss a dose though, don't try to compensate by taking a double dose next time. Speak to your health team to see what they advise.

What are the side-effects of steroids?

As is generally the case with any medication, steroids affect different people in different ways and effects vary according to the exact type and dosage prescribed. You should talk to your health team about any side-effects you experience. **Please remember that you should never just stop taking steroids without your specialist advising you to do so.**

Some of the common side-effects are outlined below:

Increased appetite

It's fairly common to feel hungrier than usual when you are on steroids. Eating more can obviously lead to weight gain. If this happens, it may be helpful to eat filling, but low calorie foods, such as vegetables, or try serving smaller portions. Once you stop taking steroids, your appetite will return to normal. If you're concerned about weight gain, speak to your specialist who will be able to give advice about how to lose any weight gained.

In addition to weight gain, steroids can also cause the redistribution of body fat. This can lead to the build-up of fat at the back of the neck (resulting in a small hump), around the midriff, or on the face, making your features more rounded (sometimes referred to as 'moon face'). Steroids can also cause water retention which can add to these effects. However, both these effects should reduce quickly after you have finished your course of steroids.

Irritation to the stomach lining

If you are taking steroids in tablet form, you will need to take them with food or milk to prevent irritation to the stomach lining as they can cause stomach ulcers. You may experience

indigestion or heartburn after taking steroids tablets. If this happens, speak to your specialist who may be able to prescribe antacid medication.

Greater chance of infection

If you notice any signs of infection (such as a temperature, redness, soreness) or wounds are taking longer than usual to heal, let your specialist know. If necessary, you'll be given antibiotics to help fight the infection.

Oral steroids may make you more vulnerable to viral infections, such as chickenpox, shingles and measles. You may become very ill if you develop these, even if you have been previously infected. You should avoid close contact with anyone who has these infections and seek medical advice if you are exposed, or if a member of your household develops one of these infections.

You should also have a flu jab, as flu can be more serious in people with lowered immunity.

Water retention

You may experience swelling around your hands and feet where your body is retaining fluid. To help reduce this, avoid standing in one place for too long or crossing your legs. It's also helpful to raise your feet when you sit or lie down. Following a low sodium (salt) diet can also help, but check with your specialist before making changes to your diet.

Changes to blood sugar levels

You may feel thirstier when taking steroids, or need to urinate more frequently, especially during the night. You may also notice that your urine has changed smell. If either of these happen, you should speak to your specialist promptly, as these symptoms could suggest that your blood sugar levels have temporarily heightened and you may have steroid-induced diabetes. This will usually resolve itself when your steroid dose is reduced or stopped. Occasionally, some people develop type-2 diabetes, which will need to be managed throughout life. This is more likely following longer term usage of steroids (longer than 3 months).

During your course of steroids, your blood sugar levels may be monitored via blood tests. This is particularly important if you already have diabetes.

Raised blood pressure (hypertension)

Some people taking steroids experience high blood pressure. This usually resolves when your medication is reduced or stops. During your course of steroids, your blood pressure will be monitored by your medical team.

Difficulty sleeping

Some people experience difficulty sleeping when they are taking steroids. Let your specialist know if this happens to you. They may suggest that you take the steroids early on in the day to minimise disruption to your sleep pattern. It is for this reason that it is generally recommended that you don't take steroids later than 2pm. **It's very important that you speak to your specialist before making any changes to your medication schedule.**

It may also be helpful to get into a routine before bedtime, perhaps having a warm drink and turning off the TV. In some cases you may be prescribed tablets to help you sleep.

Emotional effects

Side-effects on emotions are common with steroids. You may feel anxious, irritable and emotional and experience mood swings. As with any other side-effects, speak to your specialist about any such changes you are experiencing.

A small number of people can experience what is referred to as 'steroid-induced psychosis'. It is important to know that this usually only happens when given a high dose in hospital. It can range from mild to severe. It is usually characterised by rapid speech, increased energy levels and insomnia (four nights or more). Some people may also experience 'hyper-mania' with periods of hyper-activity alternating with periods of depression. During the hyper-active periods people can be more prone to making impulsive and rash decisions. If you are worried about your behaviour, or that of a relative, consult your health team. Treatment for emotional effects of steroids usually involves the reduction of the dose you have been prescribed.

Please remember that you should never just stop taking steroids (nor reduce the amount you are taking) without your specialist advising you to do so.

Menstrual changes

Women may find that their periods become irregular or stop.

Skin thinning

If you take steroids for a long time (i.e. for a period of more than a few months), you may find that your skin feels thinner and that it bruises more easily. This is an uncommon, temporary side-effect. It generally disappears once the dosage is lowered. However, if combined with weight gain it can result in stretchmarks.

Muscle wasting

With long-term use (more than a few months), your legs or shoulder muscles may feel weaker. When the steroids are stopped, some people experience muscle cramping for a short time.

Bone thinning

Taking steroids for a long time can cause bone thinning ('osteoporosis'). This means that bone fractures are more likely. If you are concerned about any of these effects, you should speak to your health team.

Other side-effects

Other side-effects with long-term use include acne, loss of sex drive, tiredness and eye effects, such as glaucoma or cataracts.

What if I have further questions?

If you have questions about your prescription, please speak to your health team. If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support and Information Team:

Call: 0808 800 0004

(free from landlines and most mobiles:
3, O2, Orange, T-mobile, EE, Virgin and Vodafone)

Email: support@thebraintumourcharity.org

Join our online forums at:
thebraintumourcharity.org/forums

About us

The Brain Tumour Charity makes every effort to ensure that we provide accurate, up-to-date and unbiased facts about brain tumours. We hope that these will add to the medical advice you have already been given. Please do continue to talk to your health team if you are worried about any medical issues.

We are the UK's pre-eminent brain tumour charity. We fund scientific and clinical research into brain tumours and offer information and support to those affected, whilst raising awareness and influencing policy.

We rely 100% on charitable donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us including fundraising, leaving a gift in your will or giving in memory, please visit us at thebraintumourcharity.org, call us on **01252 749043** or email fundraising@thebraintumourcharity.org

About this fact sheet

This fact sheet has been written and edited by The Brain Tumour Charity's Support and Information Team. The accuracy of medical information has been verified by a leading neuro-oncology health professionals. Our fact sheets have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence. If you would like a list of references for any of the fact sheets, or would like more information about how we produce them, please contact us.

The BRAIN TUMOUR CHARITY

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Your notes

**Saving lives through research,
information, awareness & policy**



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