

Steroids for adults with brain tumours

It's very likely that you'll be given steroids at some point during the course of your treatment for a brain tumour.

Steroids are sometimes called corticosteroids. They are used to help reduce the swelling (inflammation) that can happen in the brain after surgery or other treatments for a brain tumour.

By reducing the swelling and therefore the pressure inside the skull, they also ease related symptoms, such as headaches.

In other words, steroids help to manage the symptoms of a brain tumour rather than treat the tumour itself.

In this fact sheet:

- What are steroids?
- When and why do I might I be given steroids?
- How are steroids taken?
- What are the possible side-effects of steroids?
- Answers to some commonly asked questions you may have about steroids

This fact sheet is relevant to brain tumours in adults - for fact sheets and other resources for children, please see www.thebraintumourcharity.org

What are steroids?

Steroids are hormones that are produced naturally in our bodies in small amounts.

They help to control various functions, such as inflammation (swelling) when our body is injured.

Sometimes our bodies don't produce enough steroids to reduce the swelling. This can happen if the brain is 'injured' by the growth of a tumour, or after surgery or other treatments for brain tumours.

Fortunately, steroids can also be created in a laboratory and given to reduce the swelling in these cases.

The steroids used are NOT anabolic steroids that are used by some athletes to build muscle.

When might I need to take steroids?

After diagnosis

When you have a tumour in your brain, it's not only the tumour itself that causes some of the symptoms you may have, but also the swelling surrounding the tumour. There is only a limited amount of space in the skull. This means that the swelling puts pressure on surrounding tissues and can cause symptoms such as headaches, sickness and seizures (fits).

To help reduce the swelling, your doctor may prescribe steroids (often a steroid called Dexamethasone). As steroids are fast-acting drugs, this could mean that some of the effects caused by the tumour get better quite quickly.

Before or after treatment

If you have radiotherapy or surgery as part of your treatment, you may be given steroids afterwards to help bring down swelling caused by these treatments.

If you have chemotherapy or radiotherapy, a small amount of steroids may be given if you feel sick (have nausea).

Sometimes the steroid usually given for nausea (Dexamethasone) can't be used. It can reduce the amount of the chemotherapy drug that gets into the brain.

Your medical team will advise whether it can be given or not.

If a tumour comes back

Steroids are also given to help manage symptoms if a tumour has come back after treatment or when a tumour is found to have already spread at first diagnosis.

Steroids treat the symptoms of a brain tumour, not the tumour itself.

Therefore, if your symptoms reduce after having steroids, it doesn't necessarily mean that the size of the tumour has reduced.

How do I take steroids?

Steroids can be taken in different ways , including:

- orally as tablets, or sometimes by liquid medicine
(the colour and dosage will depend on which steroid you are prescribed)
- by injection, into the vein or muscle
(they are only likely to be given by injection if you're in hospital and when you're unable to take tablets by mouth).

The most common way to take steroids is in tablet form.

They may need to be taken at set times of day. It's generally recommended that you don't take steroids later than 2.00pm. However, this may be necessary for people on very high doses e.g. in the run-up to an operation.

They are usually given in short courses (a few days or weeks). Make sure you know how long you should take them for.

The tablets are small and should not be too difficult to swallow. If you have difficulty swallowing the tablets, you could practice by swallowing tic tacs® . Speak to your health team if it's still a problem. They may refer you to a Speech and Language Therapist (SLT or SALT), who can help with swallowing difficulties.

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.

A steroid card is usually given to you by your nurse or doctor if you are taking steroids for more than a week.

A steroid card contains details of your steroid type and dosage, which is important information if you need medical treatment in an emergency.

The doctor may also advise you to carry this card for up to a year after the end of your steroid treatment.

Important points to remember

- Keep taking your steroids for as long as your doctor tells you to.
- If you are given a steroid card, make sure you carry it with you at all times.

What if I forget to take my steroids?

You should, of course, make every effort to remember to take your steroids when you're required to, but with everything going on, it's possible that you may forget.

It can help to set an alarm to remind you (and others who are likely to be with you), or leave yourself a note.

Getting into a routine of when you take your steroids is also helpful.

If you do miss a dose though, do NOT 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 with many medications, steroids affect different people in different ways. Their effect will also depend on the exact type and dosage of steroid prescribed for you.

You should talk to your doctor 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 of steroids are:

Increased appetite

It's fairly common to feel hungrier than usual when you're taking steroids. Eating more will obviously lead to weight gain. If this happens, it may be helpful to have filling but low calorie foods, such as vegetables. You could also try having smaller portions.

Some people, who have been taking steroids and gained weight prior to treatment, find they lose the weight during treatment. This is because chemotherapy, radiotherapy and the anaesthesia used in surgery can cause nausea, vomiting and loss of appetite.

Once you stop taking steroids, your appetite will return to normal and you should gradually lose the excess weight. If you're concerned about your weight gain, speak to your doctor for advice.

For further information, please see our [*Diet and brain tumours*](#) webpage and fact sheet.

As well as 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've finished your course of steroids.

Irritation to stomach lining

If you are taking steroids in tablet form, you'll need to take them with food or milk. This helps prevent irritation to the stomach lining, which can cause stomach ulcers.

You may have indigestion or heartburn after taking steroids tablets. You'll usually be given anti-acid medicine with the steroids to prevent this, but let your doctor know if you develop these symptoms.

Difficulty sleeping

Some people find it difficult to sleep when they're taking steroids. Let your specialist know if this happens.

They may suggest taking the steroids early in the day to minimise disruption to your sleep pattern. This is why it's generally recommended that you don't take steroids later than 2.00pm.

It's very important to speak to your specialist before making any changes to your medication schedule.

It can be helpful to get into a routine before bedtime, perhaps having a warm drink and switching off the TV, computer, iPad etc to help you relax. In some cases, you may be prescribed tablets to help you sleep.

Greater chance of infection

Steroids can make you more likely to catch viral infections, such as chickenpox, shingles and measles. This is because they restrict the way your immune system reacts to viruses and bacteria.

You may become very ill if you catch these, even if you've previously been 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 gets one of these infections.

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

Let your doctor know if you notice any signs of infection, such as:

- temperature above 37°C
- redness or soreness
- wounds taking longer than usual to heal.

If necessary, you'll be given antibiotics to help fight the infection.

Candidal infection in the mouth (oral thrush)

This can often happen with steroid treatment. Keeping a close eye on your mouth can help you spot this early and get it treated by your doctors.

Water retention

Your hands and feet may swell because your body is not getting rid of fluid. To help reduce the swelling, 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 salt (low sodium) diet can also help, but check with your doctor before making any changes to your diet.

Changes to blood sugar levels

Speak to your doctor without delay if you:

- feel thirstier than usual
- need to wee more often, especially at night
- notice your wee has changed smell.

These symptoms could suggest that your blood sugar levels have temporarily risen and you may have steroid-induced diabetes.

This will usually clear up by 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 will be monitored using 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.

Menstrual changes

Women may find that their periods become irregular or stop.

Emotional effects

Emotional effects are common with steroids. You may feel anxious, irritable, more emotional and experience mood swings while taking steroids and for a while after stopping.

As with any other side-effects, speak to your specialist if you are experiencing any of these changes.

Treatment for emotional effects of steroids usually involves the reduction of the dose you've been prescribed.

A small number of people can experience what is referred to as steroid-induced psychosis. It's important to know that this usually only happens when given a high dose in hospital.

It can range from mild to severe and is usually characterised by rapid speech, increased energy levels and insomnia (for 4 nights or more). Some people may have 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're worried about your behaviour, or that of a relative, talk to your health team.

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

Side-effects from long-term use of steroids

Skin thinning

If you take steroids for a long time (more than a few months), your skin may feel thinner and you may bruise more easily.

Skin thinning is an uncommon, temporary side-effect of steroids, but when combined with weight gain, it can result in stretchmarks.

Speak to your doctor, who may lower the dose of steroids. Skin thinning generally disappears once the dosage is lowered.

Muscle wasting

With long-term use of steroids, your legs and shoulder muscles may feel weaker.

When the steroids are stopped, some people may have muscle cramps for a short time.

Effects on the eyes

If you have to use steroids for a long time, it can lead to increased pressure in the eyes (known as ocular hypertension). This high pressure can damage parts of the eye that are vital for vision, such as the optic nerve.

Often the person is not aware of this increased pressure, as there are no early symptoms. If left untreated, it can result in glaucoma. Glaucoma is a gradual, but permanent, loss of vision beginning at the outer field of vision (peripheral vision) .

For this reason, it is important to go to the opticians regularly, to monitor for any signs of these side-effects.

Increased eye infections and delayed healing of the surface of the eye are also common side-effects of steroids.

Bone thinning

Taking steroids for a long time can cause bone thinning, often known as osteoporosis. This means that bone fractures are more likely. If you're 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 and tiredness.

Coping with side-effects

- Discuss any difficulties with your health team
They may have useful suggestions, for example, changing the timings of doses to encourage a more peaceful night's sleep.
- Join our closed Facebook group
This is a closed group where people affected by brain tumours can discuss issues with people going through the same thing. The group is very supportive and people often have useful suggestions based on their own experience.

thebraintumourcharity.org/facebook/supportgroups

Or contact our Information and Support Line - 0808 800 0004 or support@thebraintumourcharity.org

What if I have further questions or need other support?

You can contact our Information and Support Team in the following ways:

- Call 0808 800 0004 (free from landlines and most mobiles including 3, O2, EE, Virgin and Vodafone)
- Email: support@thebraintumourcharity.org
- Live Chat: Get in touch with us online via thebraintumourcharity.org/live-chat
- Join one or more of our closed Facebook groups: bit.ly/FBSupportGroups
- Website: thebraintumourcharity.org/getsupport

Disclaimer

This resource contains information and general advice. It should not be used as a substitute for personalised advice from a qualified specialist professional. We strive to make sure that the content is accurate and up-to-date, but information can change over time.

Patients must seek advice from their medical teams before beginning or refraining from taking any medication or treatment.

The Brain Tumour Charity does not accept any liability to any person arising from the use of this resource.

About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard – an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology.

Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you have already been given. Please do continue to talk to your medical team if you are worried about any medical issues.

If you would like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on **0808 800 0004** or support@thebraintumourcharity.org

About us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research worldwide, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We wouldn't be able to make the progress we have without the incredible input we receive from you, our community.

Whether it's reviewing our information resources, campaigning for change, reviewing research proposals or attending cheque presentations, everything you do helps to make the difference.

To find out more about the different ways you can get involved, please visit thebraintumourcharity.org/volunteering

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 leaving a gift in your will or fundraising through an event, please get in touch: Visit thebraintumourcharity.org/get-involved, call us on 01252 749043 or email fundraising@thebraintumourcharity.org

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Your notes



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