

## **Steroids for children with brain tumours**

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It is highly likely that your child will be given steroids at some point during the course of their treatment for a brain tumour.

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 ease related symptoms, such as headaches. In other words, steroids help to manage the symptoms of a brain tumour rather than treating the tumour itself.

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

### **In this fact sheet:**

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

**Our series of animations includes one on steroids in children. Watch/listen to them here: [thebraintumourcharity.org/jake](http://thebraintumourcharity.org/jake)**

## **What are steroids?**

Steroids are substances 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 in some way.

Sometimes our bodies do not produce enough steroids to reduce the swelling. This can be the case 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 my child be given steroids?**

### **After diagnosis**

When your child has a tumour in their brain it is not only the tumour itself that causes some of the symptoms they may have, but also the swelling surrounding the tumour. This swelling puts pressure on surrounding tissues that can cause symptoms such as headaches, sickness and seizures (fits).

To help reduce the swelling your child's 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 reduce quite quickly.

**Steroids are a treatment for the symptoms of a brain tumour, but not for treating the tumour itself.**

**Therefore, if your child's symptoms reduce after having steroids, it does not necessarily mean that the size of the tumour has reduced.**

### **Before or after treatment**

If your child is having radiotherapy or surgery as part of their treatment, they may be given steroids afterwards to help bring down swelling caused by these treatments.

If your child is having chemotherapy, a small amount of steroids may be given if they feel sick (have nausea). However, sometimes the steroid usually given in this instance (Dexamethasone) may not be able to be used, as it can reduce the amount of the chemotherapy drug that gets into the brain.

Your child's medical team will advise whether it can be given or not, if your child is very nauseated.

(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.)

## **How will my child take steroids?**

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

- Orally (as tablets or liquid medicine)
- By injection (into the vein or muscle)

The most common way for children to take steroids is in tablet form. The tablets are small and should not be too difficult for your child to swallow.

If your child does have difficulty swallowing the tablets, speak to your child's health team, who may be able to suggest some ways of helping them to overcome this difficulty. For example, getting your child to swallow tic tacs as practice for taking tablets.

They may also refer your child to a Speech and Language Therapist (SLT), who can help with swallowing difficulties.

## **How long will my child need to take steroids for?**

Generally, your child will only take steroids for a short while (a few days or weeks), but there are some cases when they'll need to take them for longer. Your child may need to take their steroids every day, or for a few days at a time.

Occasionally the body is unable to produce its own steroids, due to the effect of the tumour, surgery or radiotherapy. In this case, your child will need to have lifelong replacement of steroids in the way that the body produces them.

This is called 'physiological replacement', rather than the 'pharmacological treatment' that is used to control symptoms at diagnosis. In this case, the drug usually used is hydrocortisone.

You will be given instructions from your child's doctor about exactly when and for how long your child will need to take steroids.

**It is important that your child keeps taking steroids for as long as their doctor tells them to.**

After taking steroids for a few days, your child's body will start to produce less of its own steroids naturally.

When taking your child off steroids, their doctor is likely to reduce their dosage gradually. This gives your child's body time to start making steroids naturally again so they have the correct levels when their medication is finally stopped.

Stopping steroids suddenly can make your child unwell, so it is important to follow the doctor's advice.

**If your child is given a steroid card by their doctor, make sure they carry it with them at all times.**

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

A steroid card will usually be given to your child by their nurse or doctor if they are taking steroids for more than a week.

The doctor may also advise you that your child needs to carry this card for up to a year following completion of their steroid treatment.

## **What if I forget to give my child their steroids?**

You should, of course, make every effort to help your child remember to take their steroids when they are required to, but with everything going on, it is possible that you may forget.

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

Getting into a routine of when your child takes their steroids is also helpful.

**If your child does miss a dose,  
DON'T GIVE THEM A DOUBLE DOSE NEXT TIME.**

**Speak to your child's doctor to see what they advise. This is a good question to ask when your child is first put on steroids, so that you are prepared in case this happens.**

You may wish to buy your child a 'medical alert bracelet', so that medical professionals can get information about your child's medication, even if your child is unable to tell them.

These bracelets are clearly visible and can hold information about their medication and treatment and come in a range of different designs. For example, the ID band company has a range of designs for children:

***theidbandco.com***

## **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 your child.

**Please remember that your child should NOT stop taking steroids without advice from their doctor.**

You should talk to your child's doctor about any side-effects they experience.

Some of the common side-effects of steroids are:

### **Increased appetite**

It is fairly common to feel hungrier than usual when you are taking steroids. Eating more will obviously lead your child to gain weight. If this happens, it can be very distressing for your child.

It may be helpful to give them filling, but low calorie, foods, such as vegetables. You could also try serving smaller portions.

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

Once your child stops taking steroids, their appetite will return to normal and they should gradually lose the excess weight. Teenagers sometimes find it more difficult to lose the weight they have gained. This too can cause them much anxiety.

If you are concerned about your child's weight gain, speak to their doctor for advice.

**For further information, please see our *Diet and brain tumours* webpage and fact sheet.**

## **Difficulty sleeping**

Some children may find it difficult to sleep when they are taking steroids. Let your child's doctor know if this happens. They may prescribe medication that helps to calm your child before bedtime.

Alternatively, they may suggest that your child takes the steroids early in the day to minimise disruption to their sleep pattern.

**Be sure to speak to your child's doctor before making any changes to their medication schedule.**

It can be helpful to get into a routine before bedtime, perhaps giving your child a warm drink and switching off the TV, computer, iPad etc to help them calm down and relax.

## **Irritation to stomach lining**

If your child is taking steroids in tablet form, they will need to take them with food or milk to help prevent irritation to the stomach lining, that can cause stomach ulcers.

Your child may have indigestion or heartburn after taking steroids tablets. Your child will usually be given anti-acid medicine with the steroids to prevent this, but let your doctor know if your child develops these symptoms.

## **Candidal infection in the mouth (oral thrush)**

This can often happen with steroid treatment. Keeping a close eye on your child's mouth can help in spotting this early and getting it treated by your child's doctors.

## **Changes to blood sugar levels**

**If your child feels thirstier, or needs to wee, more often, you should speak to your child's doctor promptly as these symptoms could suggest that your child's blood sugar levels have temporarily risen.**

If their blood sugar level remains high, some children may need to have insulin for a time. However, their blood sugar level will usually go back to normal once the steroid treatment is completed.

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## **Water retention**

Your child's hands and feet may swell, because their body is not getting rid of fluid. To help reduce the swelling, encourage your child not to stand in one place for too long and to avoid crossing their legs.

It is also useful if they raise their feet when they sit or lie down.

Following a low salt (sodium) diet can also help, but check with your child's doctor before making any changes to their diet.

## **Skin thinning**

If your child is taking steroids for a long time (i.e. for more than a few months), their skin may feel thinner and they may bruise more easily. It can be quite shocking to see your child with more vivid bruises from normal childhood rough and tumble.

Skin thinning is an uncommon, temporary side-effect of steroids. Speak to your child's doctor, who may lower the dose of steroids. It generally disappears once the dosage is lowered.

## **Muscle wasting**

With long-term use of steroids (more than a few months), your child's legs may feel weaker.

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

## **Greater chance of infection**

Steroids can make your child more likely to catch infections as they restrict the way their immune system reacts to viruses and bacteria. You may be able to help your child avoid infections by encouraging good hygiene, such as hand washing and being extra vigilant.

Let your child's doctor know if you notice any signs of infection in your child, such as:

- Temperature above 37°C
- Redness or soreness
- Wounds taking longer than usual to heal

If necessary, they will be given antibiotics to help fight the infection.

It can be particularly worrying when childhood diseases, such as chickenpox and mumps, are going around their school.

## **Inoculations**

Chickenpox is often more severe in children who are having steroid treatment due to their reduced immune response. Most treatment centres will test newly diagnosed patients to see if they are immune to chickenpox. You can ask your child's health team for the results or, if it hasn't been done, if it needs to be.

If your child has a definite contact with chickenpox i.e. sits/plays with someone, who develops chickenpox, in the 72 hours (3 days) before the spots come out, they may be given antibiotics or an injection of antibodies against chickenpox. Let your child's health team know as soon as there has been contact.

Their brothers and sister can also be offered immunisation to protect against chickenpox. This reduces the risk of them catching it and passing it on to your child. Discuss this with the team looking after your child.

As your child's immune system may be lower when they are taking steroids, they should not be given 'live' vaccines. These are injections that contain a small amount of a living bacteria or virus that has been made weaker in the laboratory.

Examples include:

- MMR (measles, mumps and rubella)
- BCG (which protects against tuberculosis).

## **Effects on growth**

If your child is taking a high dose of steroids for a long time, it can affect their growth. Your child's health team will keep a check on them throughout the course of the steroid treatment to make sure that any such effects are minimised.

## **Effects on the eyes**

If your child has 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 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' - a gradual, but



permanent, loss of vision beginning at the outer field of vision ('peripheral vision').

For this reason, it is important to take your child 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 a common side-effect of steroid usage.

## **Emotional effects**

Emotional effects are common with steroids. Your child may feel anxious, irritable and more emotional while taking steroids and for a while after stopping.

You may find that they display behaviours of a younger child (for example, temper tantrums) or you may notice that they show 'hyper' moods and find it difficult to relax and sit still.

Some parents feel guilty for feeling frustrated or getting cross with their child, but it is important to recognise that this is a very difficult time and such feelings are natural.

As with all side-effects, speak to your child's doctor about any such changes in your child. They may be able to involve a psychologist to help you and your child develop ways of coping with this.

## **Coping with emotional and behavioural effects**

The emotional and behavioural side-effects that steroids may cause can be difficult to cope with, but it is important that your child takes the steroids to reduce swelling and relieve pressure on their brain.

You may find the following practical suggestions helpful:

- **Let your child burn off excess energy**

For example, by running about in the garden or park. This can help to reduce 'difficult' behaviour caused by having too much energy (hyperactivity) and boredom.

- **Keep a diary of your child's mood swings**

This may help you to see if there is a pattern and help with planning certain activities, for example, family outings.

It may also be helpful to talk to your child about the effect on their moods that steroids can have - it may help them understand why they feel like this and make their mood swings slightly easier to cope with.

- **Be aware of the effects that mood swings may have on brothers and sisters**

For example, they may be on the receiving end of emotions such as anger and aggression. It may be a good idea to keep an eye out for this, and, depending on the age of their brothers and sisters, explain to them that medication can have an effect on mood. This will help them to understand.

- **Discuss any difficulties with your child's health team**

They may have useful suggestions, for example, changing the timings of doses to encourage a more peaceful night's sleep.

- **Join our Parents Facebook group**

This is a closed group where parents of children with 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](https://thebraintumourcharity.org/facebook/supportgroups)***

or contact our Information and Support Line 0808 800 0004 or ***[support@thebraintumourcharity.org](mailto: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](mailto:support@thebraintumourcharity.org)
- Live Chat: Get in touch with us online via [thebraintumourcharity.org/live-chat](https://thebraintumourcharity.org/live-chat)
- Join one or more of our closed Facebook groups: [bit.ly/FBSupportGroups](https://bit.ly/FBSupportGroups)
- Website: [thebraintumourcharity.org/getsupport](https://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](mailto: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.

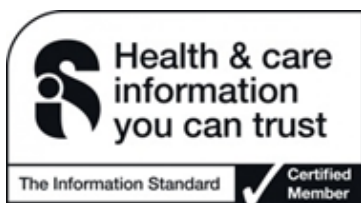
Whether it's reviewing our information resources, campaigning for change, reviewing research proposals or attending cheque presentations, everything you do helps to make the difference.

To find out more about the different ways you can get involved, please visit [thebraintumourcharity.org/volunteering](http://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](http://thebraintumourcharity.org/get-involved), call us on 01252 749043 or email [fundraising@thebraintumourcharity.org](mailto:fundraising@thebraintumourcharity.org)

## **Steroids for children with brain tumours**

### **Your notes**



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