The BRAIN TUMOUR CHARITY

Steroids for children

Steroids (sometimes called corticosteroids) occur naturally within our bodies, 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 your child will be given steroids at some point during the course of their treatment.

The information on this fact sheet summarises when and why your child might be given steroids.

In this fact sheet:

- When and why your child might be given steroids
- Important points to remember
- How steroids are taken
- Answers to some common questions you may have about 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 making the effects of the tumour wider reaching. This pressure 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. This does not mean, however, that the size of tumour itself has been reduced.

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 after treatment.

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. Also, if your child is having chemotherapy, a low dosage of steroids may be given if they experience nausea.

Important points to remember

- **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. To allow for this, when taking your child off steroids, their doctor is likely to reduce their dosage gradually. This will mean that the body will have the opportunity to begin producing steroids naturally again and will have the correct levels when their medication is final stopped completely.

  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 would usually be given to your child by their nurse or doctor if they are taking steroids for more than a week. If your child is given a steroid card, they must always carry it with them – it contains details of their steroid type and dosage, which is important information if they need medical treatment in an emergency. 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.

  You may also 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. Medical alert bracelets are widely available and come in a range of different designs. For children there are a range of designs from the ID band company: theidbandco.com

How will my child take steroids?

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

- Orally (as tablets or liquid medicine)
- By injection (to 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.

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

Continued overleaf >

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. It might help to leave yourself a note or set an alarm to remind you. Getting into a routine of when your child takes their steroids is also helpful. If your child does miss a dose, don't try to compensate by giving them a double dose next time. Speak to your child's doctor 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 according to the exact type and dosage prescribed. You should talk to your child's doctor about any side-effects they experience. Please remember that your child should not just stop taking steroids without advice from their doctor.

Some of the common side-effects of steroids are:

Increased appetite
It's 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 may be helpful to give them filling, but low calorie, foods, such as vegetables. You could also try serving smaller portions. Once your child stops taking steroids, their appetite will return to normal and the excess weight should gradually be lost, although teenagers may find it more difficult to lose weight gained. If you are concerned about your child's weight gain, speak to their doctor for advice.

Difficulty sleeping
Some children may experience difficulty sleeping 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 on 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 may be helpful for you to get into a routine before bedtime, perhaps giving your child a warm drink and switching off the TV to encourage calmness and relaxation.

Irritation to stomach lining
If your child is taking steroids in tablet form, they will need to take them with food or milk to prevent irritation to the stomach lining, which can cause stomach ulcers. Your child may experience indigestion or heartburn after taking steroids tablets. If this happens, speak to their doctor who may be able to prescribe some anti-acid medication.

Candidal infection in the mouth (oral thrush)
This can often accompany steroid treatment. Keeping a close eye on your child's mouth can be valuable in spotting this early and getting it treated by your child's doctors.

Changes to blood sugar levels
Your child may feel thirstier when taking steroids, or may need to urinate more frequently. If this happens, you should speak to your child's doctor promptly as these symptoms could suggest that your child's blood sugar levels have temporarily heightened. During the course of steroids, your child's blood sugar levels will be monitored via blood tests.

Emotional effects
Side-effects on emotions are common with steroids. Your child may experience anxiety, irritability and feeling emotional while taking steroids and for a little while after stopping. You may find that they display behaviours that are characteristic of an earlier stage in their childhood (for example, temper tantrums) or you may notice that they experience '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.

Water retention
Your child may experience swelling of their hands and feet where their body is retaining fluid. To help reduce this, try to encourage your child not to stand in one place for too long and to avoid crossing their legs. It's also helpful for them to raise their feet when they sit or lie down. Following a low sodium (salt) 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 a period of 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 more vividly display the bruises from normal childhood rough and tumble. Skin thinning is an uncommon, temporary side-effect 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 have muscle cramps for a short time.

Greater chance of infection
Steroids can increase your child's chance of catching infections. This can be particularly worrying when childhood diseases, such chickenpox and mumps, are going around their class at school. You may be able to help your child avoid infection by encouraging good hygiene, such as hand washing and being extra vigilant. If you notice any signs of infection in your child, such as a temperature above 37°C, redness, soreness or wounds taking longer than usual to heal, let your child's doctor know. If necessary, they'll be given antibiotics to help fight the infection.

Inoculations
Chickenpox is often more severe in children who are having steroid treatment due to their reduced immune response. If a bout of chickenpox is going around at your child's school and you are worried, you can ask your doctor to arrange for your child to have a blood test to check their immunity against chickenpox. If their immunity is shown to be low, they may be given an injection for extra protection. Although injections to protect against chickenpox are not part of the normal UK schedule of inoculations for children, if your child is having steroid treatment, their siblings can be offered an injection to protect against chickenpox. This minimises the risk of them catching it and passing it on.

As your child's immune system may be lower when they are taking steroids, they should not be given 'live' vaccines (injections that contain a small amount of a living bacteria or virus that has been weakened in the laboratory), including the MMR (measles, mumps and rubella) injection and the BCG injection (which protects against tuberculosis).

Continued overleaf >

Effects on growth
If your child is taking a high dose of steroids for a long time, their growth may be affected. Your child's health team will keep a check on them throughout the course of the steroid treatment to ensure that any such effects are minimised.

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 them to reduce swelling and relieve pressure on their brain. You may find the following practical suggestions helpful:

- **Allow your child to burn off excess energy**
  For example, by encouraging them to run about in the garden or park. This can help to reduce 'bad' 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 fact that the steroids are able to have an affect on their mood to aid their understanding and make mood swings slightly easier to cope with.
- **Be aware of potential effects of mood swings on siblings**
  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 how old siblings are, to explain to them that medication can have an effect on mood to help them to understand their sibling's moods.
- **Discuss difficulties with your child's health team**
  They may have useful suggestions, i.e. changing the timings of doses to encourage a more peaceful night's sleep.

Disclaimers
Patients must seek advice from their medical teams before beginning or refraining from taking any medication. The Brain Tumour Charity provides the details of other organisations for information only. Inclusion in this fact sheet does not constitute a recommendation or endorsement.

What if I have further questions?

If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support and Information Team, which includes a dedicated Children and Families Worker:

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 doctor if you are worried about any medical issues. We are the UK's leading brain tumour charity. We fund scientific and clinical research into brain tumours and offer support and information 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 and is supported by the Children's Cancer and Leukaemia Group (CCLG). The accuracy of medical information has been verified by a leading neuro-oncology professional.

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

Steroids for children

Your notes

Saving lives through research, information, awareness & policy

The Information Standard
Certified member

The Helplines Association
Member

Registered office:
Hartshead House
61-65 Victoria Road
Farnborough
Hampshire
GU14 7PA
thebraintumourcharity.org

Registered Charity 1150054 (England and Wales) SC042096 (Scotland).

© The Brain Tumour Charity
Version 1, September2013. Review date, by September 2015.