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## Department of Neurosciences

# Living with a brain tumour: Taking steroids

This leaflet aims to answer commonly asked questions about steroids and explains how steroids are used to help people living with a brain tumour.

### What are steroids?

Corticosteroids (**steroids**) are a natural hormone produced by your body's adrenal glands. Steroids are vital in helping you to function normally in your daily activities. In people living with a brain tumour, additional steroids are often prescribed in tablet form. They help to reduce the swelling (**oedema**) and inflammation sometimes caused by brain tumours. This is known as an **anti-inflammatory** effect.

### Why do I need to take steroids?

Oedema is one of the body's natural responses to disease. If a tumour develops in the brain it is usually surrounded by oedema, which acts as a form of protective barrier between the tumour and brain tissue.

As there is limited space inside the skull, too much oedema will lead to increased pressure in the brain. This in turn can cause symptoms such as headaches, nausea/vomiting; drowsiness; weakness down one side; speech and language problems or even fits (seizures). These symptoms can be severe and a serious threat to your health if left untreated.

**Dexamethasone** is the name of the steroid most often prescribed to reduce this swelling.

### Will steroids shrink my tumour?

No - steroids do not treat or shrink your tumour itself but they may help to reduce the symptoms caused by the brain tumour and subsequent oedema. Some make significant improvements whilst taking these tablets, where many of their symptoms resolve completely.

Steroids will not stop your tumour from growing. Eventually the effects of the steroids will stop working if the tumour grows too big, so they will not replace any surgical interventions which may be required.

## When are steroids prescribed?

Steroids may be prescribed if there is evidence of swelling in the brain caused by a brain tumour. This swelling evidence can be seen on the CT or MRI scans which you will have had undertaken. The severity of your swelling dictates how much Dexamethasone you will be prescribed.

Further medical treatments such as surgery, radiotherapy and chemotherapy (if applicable) can make swelling worse and steroids may be prescribed in anticipation to try to prevent this. You doctor / key worker will discuss these options with you should they be required.

## Are there any side effects?

The doses of Dexamethasone used to control your symptoms are much larger than what would normally occur naturally in your body. Everyone's body is unique and a person's response to any drug cannot be predicted. Our aim is always to use the lowest dose that keeps your symptoms under control. The most common side effects are listed here:

- Stomach irritation.
  - You will be prescribed an additional tablet to protect your stomach from acid reflux for the duration of the time you take steroids. If you have not been prescribed this, please check with your GP or Key worker.
- Difficulty sleeping
  - If you are prescribed Dexamethasone in the mornings and again in the evenings, you can take your evening dose at lunchtime / early afternoon. This may help you sleep better at night.
- Increased appetite
- Increased thirst / passing a lot of urine
  - Temporary increase in your blood sugar leading to sugar in your urine (diabetes). **This is a serious side effect of steroid use.** You must inform your GP immediately if you think you may be developing diabetes. If you are already diabetic, you must increase your blood monitoring frequency and inform your GP if you have persistently elevated blood sugars.
- Mood and behaviour changes
- Oral thrush
  - If your tongue has a white coating, or if you have altered taste/ discomfort when eating, you may have developed oral thrush. This is very easily treated via your GP.
- Increased risk of infections and delayed healing
- Acne
- Increased risk of bruising. Skin may feel thinner than usual
- Flushing and night sweats
- Muscle wasting and weakness if used over a long period of time

Side effects generally disappear once the dose is reduced or stopped. However, you must never reduce your steroid dose on your own accord in order to minimise any potential side effects. You must always take your Dexamethasone as prescribed. Please contact your doctor or key worker if you are worried about any of your side-effects.

## Stopping steroids

Dexamethasone reduces your body's production of its own natural corticosteroids. As a result it can be dangerous to stop taking steroids suddenly. The frequency and dose will need to be cut down gradually, so that it encourages your own body's production of steroids to re-start again.

Usually we try and reduce your Dexamethasone dose by one tablet (2mg) every three to five days. We aim to reduce your afternoon dose first. However, everyone is different and the rate at which your steroids are reduced depends on the type of surgery you have had (if any); the size/location of your tumour and any onward treatment planned.

## Discharge summaries – medication list

Prior to your discharge, you should be given a copy of your discharge summary. This will include a weaning regime (reducing plan) of your Dexamethasone. Please contact your neurosurgical ward or key worker if you have not been issued a copy of your discharge summary. You should follow the weaning regime which has been specifically designed to meet your individual needs.

Below is an explanation of the medical terminology found on your discharge summary. It may help you to better understand the abbreviations used and how/when to reduce your steroid dose:

- **Dose** – this is the total amount to be taken at any one time.
- **Frequency** – how many times a day you take your stated dose.
- **Mg** – this stands for Milligrams. This is the strength of your dose. Each Dexamethasone tablet usually contains 2mg (please check your tablet box).
- **OD** – Stands for once daily. You will take your Dexamethasone dose once daily in the morning only.
- **BD** – this stands for twice (Bi) daily. You will take your Dexamethasone dose once in the morning and again at lunchtime / early afternoon.

### Example: Dexamethasone 4mg BD.

- Your dose is 4mg
- This dose should be taken BD (= twice daily).
- Each Dexamethasone tablet contains 2mg
- You should therefore take 2x2mg tablets in the morning and again 2x2mg tablets at lunchtime / early afternoon.

If your discharge summary states to reduce the above dose by 2mg every three days, then after three days you take 4mg in the morning but only 2mg in the afternoon. After another three days you would only take 2mg of Dexamethasone in the morning and drop the afternoon (2mg) dose entirely.

## Minimum dose for biopsies and debulking

You should not stop your steroids completely until advised to do so by either your neurosurgeon or, in the event of further treatment – your oncologist.

If you have had a resection / debulking procedure, we usually like you to remain on a minimum dose of 2mg Dexamethasone once daily (OD). For biopsies, this would be slightly increased to 4mg OD.

The above is an average estimation only, so please follow the prescription on your discharge summary or contact your key worker / specialist nurse for advice if you have any questions about how and when to reduce your steroids. You will find all relevant numbers at the end of this booklet.

Please follow the help and advice of your doctor and contact your key worker if you have any questions or concerns. You will find all useful contact details at the end of this leaflet.

## Repeat prescriptions

Your GP will have been sent a copy of your discharge summary, including the list of medication you were discharged on. They will continue to prescribe all your medication, so please ensure you inform them if you need any repeat prescriptions.

Please ensure they are given plenty of notice to arrange any repeat prescriptions. If you run out of steroids you must inform your GP or key worker immediately as you should not stop taking your steroids suddenly.

## Contact details

Please do not hesitate to contact any of the numbers below if you have any questions or concerns regarding your steroids or if you wish to discuss any aspect of your neurosurgical care. We are here to help.

- **Neuro Oncology Specialist Nurse** (direct dial with answering machine): 01223 256246 or via Addenbrooke's contact centre 01223 245151 via bleep 154-506
- **Clinical Nurse Practitioner**: 01223 216127 or via Addenbrooke's contact centre 01223 245151 via bleep 152-090
- **Team Secretary** (direct dial with answering machine): 01223 216780

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## Additional information about taking steroids

- **Always take steroids with or after food.** This helps to reduce the possibility of side effects.
- Additional tablets named Adcal / D3 are sometimes started to help protect your bones from the thinning effects of steroids. If they were only started as a result of your Dexamethasone tablets, you can stop taking the Adcal / D3 as your steroids are not for long term use.
- Once you stop taking your steroids, you can usually stop taking your stomach protecting medication (unless you were already on this prior to starting your steroids). Please check with your GP.
- Get the advice of your doctor / key worker or pharmacist if you forget to take a dose or are sick immediately after taking your steroids.
- If you need dental treatment, let your dentist know that you are taking steroids.
- Remember, it is extremely important to take your steroids exactly as prescribed.

## Safety advice

- Always keep steroids in a safe place and out of the reach of children.
- Never let anyone else take your drugs.
- Once the course has finished, any remaining tablets should be returned to a chemist for safe disposal. Do not flush them down the sink or toilet.



We are currently working towards a smoke free site. Smoking is only permitted in the designated smoking areas.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169

### Help with this leaflet:



If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or

[patient.information@addenbrookes.nhs.uk](mailto:patient.information@addenbrookes.nhs.uk)



### Document history

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