

## Neuro-Oncology Service

# Advice for taking Dexamethasone when you have a Brain Tumour

### Introduction

Your doctor has advised you to take a steroid medication called Dexamethasone. The symptoms of a brain tumour can be made worse by swelling (oedema) around the tumour. Steroids can reduce this swelling and improve some of the symptoms you may be experiencing.

The dose of Dexamethasone may need to change from time to time, at different stages of your illness and treatments, or when other medicines are prescribed. You may be started on a high dose, which is then reduced to a level where your symptoms remain controlled.

Many patients are able to stop taking their Dexamethasone at the end of their treatments, or sometimes while they are still having treatment. It is important not to stop your tablets suddenly when you have been taking them for some time. Usually the dose is reduced in stages, over several weeks, before you stop taking them.

### Taking your Dexamethasone

You will be advised to take your tablets once or twice each day. The second dose (if you are taking two doses a day) should be taken before 2pm, as taking a dose of steroids later than this may cause sleeplessness.

Dexamethasone is usually taken in tablet form. Tablets are available in two



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strengths: 2mg and 0.5mg (sometimes written as 500 micrograms). Your dose may be made up of a combination of these two strengths and part, or all, of the dose might be given in liquid form.

If you have any problems swallowing your tablets they can be crushed, or dissolved in a tiny amount of water. Please tell your doctor or nurse if you have any problems with swallowing your tablets.

You will be asked to carry a card with you, giving details of the amount of Dexamethasone that you are taking. This is because other people, such as your GP, other consultants, your dentist and district nurse will need this information.

**Please contact a member of your healthcare team at the hospital if you have any persistent headaches, feelings of sickness, vomiting, or a return of previous problems, as this may mean we need to see you and possibly adjust your Dexamethasone dose. Contact numbers can be found at the back of this leaflet.**

## What are the possible side effects of taking Dexamethasone?

Please remember that you may not have any side effects from taking Dexamethasone. However, below is a list of some of the side effects you may experience. Any side effects that you do have will usually go away as the dose of Dexamethasone is reduced and then stopped.

- **Indigestion:** you should take your tablets with food or a milky drink as this will reduce the chance of stomach upsets. Your doctor will prescribe a tablet or capsule to reduce the amount of acid in your stomach, in order to prevent indigestion and other problems.
- **Increase in appetite:** most people who take Dexamethasone will have an increase in their appetite. Some may even have cravings for various foods. When you have been unwell this can be a good thing. However, it is important that you do not put on too much weight. Eat a balanced diet, reducing your intake of sugar and sugary foods.
- **Dry, sore mouth:** illness may change the way you would normally eat, drink and care for your mouth, teeth or dentures. This may mean that your mouth becomes sore.

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- Dexamethasone also lowers your usual ability to resist infections such as thrush (candida). This often shows as creamy white or yellowish patches in the mouth. Sometimes, if they are not noticed early, these patches become very thick, and your mouth and tongue may feel furry, sore, dry or just uncomfortable.
- Food and drink may taste different, and dry foods and tablets may be difficult to swallow
- Keeping your mouth moist and clean is important in preventing and treating thrush. If possible, brush your teeth or dentures twice a day and soak dentures overnight in a denture cleaner. Chewing sugar-free gum or small pieces of fruit can help the saliva to flow and help the mouth stay clean, moist and feel fresh. If you need advice about mouth care, please ask your specialist nurse.
- The hospital has information leaflets on good mouth care; please ask for copies of this information.
- Please tell your doctor if you have mouth ulcers or if you think you may have thrush. Your doctor will be able to prescribe treatments, which may be a liquid, gel, lozenge or capsule. Used correctly, treatments clear most infections within a few days.
- **A puffy face and swollen limbs:** many patients find that they become puffy around the face, neck, ankles and feet, or have a general swelling of the lower limbs when they are on steroids. This usually settles down when you reduce or stop taking the tablets. Sometimes doctors prescribe water tablets to reduce this swelling.
- **Thirst and passing water frequently:** Dexamethasone may increase the levels of sugar in your blood, leading to a type of diabetes. High sugar levels can cause you to feel very thirsty and pass water more often. If you have these symptoms, it is important that you tell your doctor or nurse. A blood or urine test can show the extent of the problem. If you have high sugar levels, you may be asked to modify your diet.
- **Restlessness and changes in mood:** most people will find that the improvement in their symptoms helps their mood and feeling of well-being to improve.
- **Dexamethasone can sometimes make you feel anxious,** agitated or restless, and sometimes low in mood. It can also lead to difficulties sleeping. Please tell your doctor, who will review your medication.
- Some people find that listening to music or relaxation tapes, or using breathing exercises can help to reduce the restlessness.

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- **Weakness of your muscles:** a few patients may have to take their Dexamethasone over a longer period of time, and may develop some weakness in their upper arms and legs. Walking is a good exercise for maintaining and improving the strength in your legs. If you are able, it is a good idea to go for a walk twice a day. Climbing stairs will also improve the strength in the muscles of your legs. If you do not have stairs, find a step and step up and down on each leg a few times, two or three times a day. Arrangements can be made for you to see a physiotherapist, who will be able to suggest other exercises if walking and climbing stairs are inadvisable or difficult.
- **Changes in the skin and bones:** long term use of Dexamethasone may cause the skin to become weak or thin, or to bruise easily. A few people get spotty rashes. Occasionally people will experience some loss of strength in their bones, which makes them prone to injury in minor accidents. You may be prescribed medication to help prevent this loss of strength.

Please speak to your doctor or nurse if you experience any of the above side effects. Your dose of Dexamethasone will be adjusted by your doctor as necessary.

**This is not an exhaustive list of side effects. If you have any concerns please discuss them with the doctor or nurse.**

### Other important points

- Dexamethasone lowers your usual resistance to infections. You should avoid people with colds or other infections, especially measles, shingles and chicken pox.
- Tell the doctor or nurse if you notice any wounds that are slow to heal, are painful, red, or hot to the touch.
- Tell us if you have any persistent soreness in other areas of your body, such as the mouth or throat.
- Some patients with brain tumours also need to take drugs for epilepsy, and these can reduce the effectiveness of Dexamethasone (as may other drugs). The doctors are aware of this and will review your medications as necessary.

### Safety checklist

- Never stop taking steroids suddenly.
- Make sure that you never run out of tablets.
- Carry your steroid card with you at all times.
- Inform your doctor, dentist, pharmacist and nurses that you have been treated with steroids.
- If you are not able to take your tablets for any reason, including sickness, tell your doctor or specialist nurse.
- Steroids may increase the levels of sugar in your blood leading to an increased risk of diabetes. Signs and symptoms include:
  - Increased Thirst
  - Increased frequency of urine
  - Feeling of tiredness
  - Weight changes (loss/increase)
  - Dry mouth
- If you experience any of these symptoms please contact you GP as first point of call, and then the specialist nurse for further support where required.

### Contact Number

Macmillan Neuro-Oncology Clinical Nurse Specialists

Ian Edwards / Sharon Sullivan      Tel: 024 7696 5326

### Further Information

Further information about brain tumours can be obtained from:

**Arden Cancer Centre: 024 7696 7304**

**Macmillan Cancer Information Centre: 024 7696 6052**

## Patient Information

This centre can offer free support, practical advice and information to anyone affected by cancer. No appointments are required and an answering machine facility is available. Open Monday to Friday 9.00am to 4.00pm (not bank holidays), the Centre is located on the ground floor in the main entrance.

### **Coventry Citizens Advice Bureau: 024 7625 2050**

Offers advice on benefits and other issues to cancer patients and their carers at University Hospital. This is an appointment only service. To make an appointment please telephone the above number.

### **National information sources:**

If you cannot access the internet, please contact the Cancer Information Centre where they will help you to obtain the relevant information.

### **The Brain Tumour Charity 0808 800 0004**

[www.thebraintumourcharity.org](http://www.thebraintumourcharity.org)

**Cancerhelp U.K:** Freephone 0808 800 4040 / [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

**Epilepsy Action Helpline:** 0808 800 5050 / [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

**Brain Tumour Support** (formerly Hammer Out): Brain Tumour Support  
01454 414 355

[www.braintumoursupport.co.uk](http://www.braintumoursupport.co.uk)

[support@braintumoursupport.co.uk](mailto:support@braintumoursupport.co.uk)

**Macmillan Cancer Support:** Freephone 0808 808 00 00 /

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Lines open Monday to Friday 9.00am - 8.00pm



## Patient Information

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### Questions I would like to ask

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The Trust operates a smoke free policy.

To give feedback on this leaflet please email [feedback@uhcw.nhs.uk](mailto:feedback@uhcw.nhs.uk)

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