



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 can 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. This will be managed by your neuro oncology team.

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 different strengths: 4mg, 2mg and 0.5mg (sometimes written as 500 micrograms). Your dose may be made up of a combination of these doses, 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 blue card with you at all times which shows dosing information on Dexamethasone. This is because other people, such as your GP, other consultants, your dentist and district nurse, will need this information. **This is in addition to the red emergency card you are given by the pharmacy at Queen Elizabeth Hospital Birmingham (QEHB).**

Please contact a member of your hospital healthcare team 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 on 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, please find a list below detailing 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.

Information for Patients

- **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, 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.
- 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.
- 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 and sometimes you may need medication to manage this.

Please liaise with GP/nurse at your GP surgery if you experience increased thirst, excessive urine output or changes in your normal blood glucose levels.

If you already have diabetes, then you should liaise with diabetic nurse regarding your sugar level monitoring.

Information for Patients

- **Restlessness and changes in mood:** most people will find that the improvement in their symptoms helps their mood and feeling of wellbeing 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.
- **Weakness of your muscles:** a few patients may have to take their Dexamethasone over a longer period 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 hospital 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.

Long-term (more than four weeks) use of Dexamethasone can cause adrenal insufficiency. This is when your adrenal glands are not able to produce an adequate amount of the hormone cortisol. Cortisol is a very important hormone which is essential for life. It is important that you do not stop your Dexamethasone abruptly as it might need to be switched to a different type of steroid when Dexamethasone is no longer required for your brain tumour. You will be informed by a member of the oncology team if you need to be switched to a different type of steroid.

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 your 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.

Safety checklist

- Never stop taking steroids suddenly. See questions below for further guidance.
- Make sure that you never run out of tablets.
- Carry your blue and red steroid cards with you at all times.

Information for Patients

- 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 your GP as first point of call, and then the specialist nurse for further support where required.

Dexamethasone dosage

You may find it helpful to record the dose of Dexamethasone you are taking:

Dexamethasone Chart		
Date	Dose	Effect of Increase

QUESTIONS I WOULD LIKE TO ASK:

FREQUENTLY ASKED QUESTIONS:

What do I do if I miss a Dose?

Please continue to your next dose and contact your clinical nurse specialist if you become unwell.

Will it interfere with my other medication?

No, this is very unlikely.

Can I increase the dose on a day I have headaches?

No, we would advise to seek support about headaches.

Information for Patients

What happens if I suddenly stop taking dexamethasone?

You may quickly become unwell and develop symptoms like headache, nausea or weakness due to swelling in the brain.

You may also develop more serious symptoms such as sickness, fatigue, weakness, abdominal pain, diarrhoea, low blood pressure and low blood sugar. You may become sleepy/drowsy and need urgent hospital admission.

YOU MUST NOT STOP TAKING DEXAMETHASONE SUDDENLY. Your health care worker will advise how to wean and stop your steroid IF appropriate.

What happens if I am vomiting and I cannot take my dexamethasone?

You must seek advice from your GP, specialist nurse or consultant as you may need to have this given as an injection. You will need hospital admission to control this.

Is there an alternative drug other dexamethasone?

There are other steroid drugs, but they are lower in concentrated dose. These can be used when you get to a very low dose of Dexamethasone and your consultant will advise on this.

Contact Numbers

**Clinical Nurse Specialists Neuro Oncology : -
0121 371 4740**

or

braintumourspecialistnurses@uhb.nhs.uk

Brain tumour support workers (BTsw)

btsw@uhb.nhs.uk 07880422965

Further Information

The Patrick Room)Patrick.room@uhb.nhs.uk) can be found in Cancer Centre.

Macmillan Cancer Information Centre: 024 7696 6052

The Brain Tumour Charity 0808 800 0004

www.thebraintumourcharity.org

Cancer help U.K: Freephone 0808 800 4040 / www.cancerhelp.org.uk

Brain Tumour Support

01454 414 355

www.braintumoursupport.co.uk

support@braintumoursupport.co.uk

Macmillan Cancer Support: Freephone 0808 808 00 00

www.macmillan.org.uk

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