

Advice about taking dexamethasone when you have a brain tumour

Cancer Services

Leaflet No: 777

Version: 6

Discharge information for patients

Produced Jul 2021

Review: Jul 2024

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. It may take several attempts before we find the best dose for you.

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 strengths: 2mg and 0.5mg (sometimes written as 500 micrograms). Your dose may be made up of a combination of these two strengths. If you have any problems swallowing your tablets they can be crushed, or dissolved in a tiny amount of water. Dexamethasone also comes in liquid form, so 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.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

Taking your dexamethasone (continued)

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 is the aim of treatment with dexamethasone?

The aim of the treatment is to improve your symptoms with the lowest possible dose of steroids.

What are the possible side effects of 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 protect your stomach and prevent indigestion.
- **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 become 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 your saliva to flow and help your 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 treatment, 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 (diuretics) to reduce this swelling.

What are the possible side effects of dexamethasone? (continued)

- **Thirst and passing water frequently:** dexamethasone may increase the level 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 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 if this happens, as your medication may need to be reviewed.

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 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.

We can arrange 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 and 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 problems please discuss them with your doctor or nurse. If in doubt, ask.

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 your 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.**

Contact numbers

Neuro-oncology Clinical Nurse Specialist (key worker)

Telephone: 0116 258 6433

Mobile: 07534 227 963

The nurse is available three days per week, usually Monday, Wednesday and Friday, 8.30am to 4.30pm.

For help and advice 'out of hours'

- Oncology emergency telephone **0808 1782212**
- Contact your GP
- Call 111

Further information

Further information about brain tumours can be obtained from:

Macmillan Information and Support Centre

Osborne Building, Leicester Royal Infirmary LE1 5WW

Telephone: 0116 258 6189

Website: www.leicestershospitals.nhs.uk/cancerinfo

Macmillan Cancer Support

Helpline: 0808 808 00 00

Website: www.macmillan.org.uk

The Brain Tumour Charity

Telephone: 0808 800 0004

Website: www.thebraintumourcharity.org

Brainstrust

UK-based brain tumour support charity

24/7 helpline: 01983 292 405

Website: www.brainstrust.org.uk

