

Taking Dexamethasone when you have a brain tumour

Your doctor has advised you to take a steroid drug called Dexamethasone. Steroids may reduce the swelling around a brain tumour and improve some of the symptoms caused by the tumour.

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 would normally start 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. 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.

Please contact the consultant's team at the hospital if you have any persistent headaches, feelings of sickness, vomiting, or a return of previous problems, as this may indicate the need to adjust your Dexamethasone dose. Contact numbers can be found at the bottom of this leaflet.

Using your Dexamethasone

You will be advised to take your tablets 1 to 3 times a day, avoiding a dose later in the evening. Tablets taken after 6.00pm can sometimes cause sleeplessness. 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 at your next visit about any problems with swallowing your tablets.

You will be asked to carry a card with you detailing the amount of Dexamethasone that you are using. Your GP, other consultants, dentist and district nurse will need this information.

Some of the possible side-effects of taking Dexamethasone

These side effects will usually resolve when you stop your tablets. Please note that this is not a fully comprehensive list.

Indigestion

You should take your tablets with food or a milky drink as this will reduce the chance of stomach upsets. If you have indigestion, please tell your doctor so that medication can be prescribed to settle it down. When starting on Dexamethasone some patients will be asked to take a tablet to reduce the amount of acid in their 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. It is sensible to eat a balanced diet while 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. Dexamethasone also lowers your usual ability to resist simple infections such as thrush (Candida). This often shows as creamy white or yellowish patches in the mouth. Sometimes if these are not noticed early, these patches become very thick, your mouth and tongue may feel furry, sore, dry or just uncomfortable.

When you have thrush, food and drinks may taste strange and dry foods or tablets may become uncomfortable to swallow. A few people may find that these problems make them feel sick.

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.

Please tell your doctor if you notice signs that you feel may be 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. Please tell your doctor if you have problems using your treatment.

A puffy face and swollen limbs

Many patients find that they become puffy around the face, ankles and feet or have a general swelling of the lower limbs when they are on steroids. This usually settles down when you stop taking the tablets. Sometimes doctors prescribe water tablets to reduce this swelling.

Some less common side-effects

Thirst and frequency passing water

Dexamethasone may increase the levels of sugar in your blood. 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 simple 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 or advised about medications you may have to take.

Restlessness and changes in mood

Most people will find that the improvement in their symptoms helps their mood and feelings of well-being to improve. Infrequently, Dexamethasone can make you feel anxious, agitated or restless, sometimes low in mood. Please tell your doctor who will be able to review your medications.

Some people find that using complementary therapies such as relaxation tapes, listening to music, or using breathing exercises can help settle 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 of the 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 the legs. If you do not have stairs, find a step and step up and down on each leg a few times, 2 or 3 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 the 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. 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. The occupational therapist and physiotherapist can help you to adapt to problems and advise about exercises. Your dose and any problems will be kept under review by your doctors and discussed with you.

Other important points

Dexamethasone lowers your usual resistance to infections. You should avoid people with colds or other infections such as shingles and chickenpox. It is important to tell the doctor or nurse if you notice any wounds that are slow to heal, are painful, red, hot to the touch or if you have any persistent soreness in any other areas of the 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 the Dexamethasone (as may other drugs). The doctors are aware of this and will review your medications when necessary.

This information and advice is intended to help you understand any problems that you may experience whilst using Dexamethasone. **You may not experience any problems at all.** The aim of treatment with Dexamethasone is to get you on the lowest possible dose to improve your symptoms. If you seem to develop any side-effects or other problems that concern you, please speak to your doctor or nurse.

Source of further information

Macmillan CNS

Julie Coventry

United Lincolnshire Hospitals NHS Trust

Macmillan Nurses Office, Portakabin,

Maternity Wing Site, Lincoln County Hospital

Greetwell Road, Lincoln. LN2 5QY Tel:01522 572313

Patient Advice and Liaison Service, Queen's Medical Centre

Tel: 0115 924 9924 ext 62301

The Brain and Spine Foundation

Tel: 0808 808 1000

Website: www.brainandspine.org.uk

Brain Tumour Action

Tel: 01506 436 164

Website: www.braintumouraction.org.uk

Useful contact numbers:

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|-------------------------------------|-------------------|
| Lincoln County Hospital | 01522 512 512 |
| Julie Coventry Macmillan CNS | 01522 572313 |
| Waddington Unit | 01522 572255/2257 |
| Ingham Ward (chemotherapy) | 01522 572260/2261 |

References

If you require a full list of references for this leaflet please email patient.information@ulh.nhs.uk

The Trust endeavours to ensure that the information given here is accurate and impartial.

If you require this information in another language, large print, audio (CD or tape) or braille, please email the Patient Information team at patient.information@ulh.nhs.uk