

Department of Neurosurgery

Dexamethasone for brain tumours

Information for patients



Dexamethasone

This leaflet tells you what dexamethasone is. It also contains information which may help you reduce any possible side effects you may experience whilst taking dexamethasone.

What is dexamethasone?

Dexamethasone is a steroid drug. Steroids occur naturally in the body and are needed to help you function normally. In people who have a brain tumour, steroids are often prescribed for their anti-inflammatory effect as they can reduce the swelling and inflammation sometimes caused by the tumour.

Any swelling within the brain may cause symptoms such as headache, sickness, drowsiness or fits. By taking dexamethasone, symptoms caused by swelling may be improved and you should feel better.

How to take dexamethasone

The strength of tablets is usually either 2mg or 0.5mg.

You would normally start on a high dose of dexamethasone, which is then reduced to a level where your symptoms remain controlled.

It is important not to stop your tablets suddenly. The dose is usually reduced in stages over several weeks before you stop taking them.

You will be advised to take your tablets in 1 or 2 doses, avoiding doses after 2pm as this sometimes can cause problems with sleeping.

When to seek advice

Please contact your keyworker, GP or the team presently treating you at the hospital if you have any of the following symptoms:

- a persistent headache
- feeling or being sick
- a return of previous symptoms.

These symptoms may mean there is an increase in swelling within the brain. You may need us to adjust the dexamethasone dose.

You will be asked to carry a steroid card or sheet with you detailing the amount of dexamethasone you are using. This is to help health professionals such as your GP, other hospital consultants, dentist and district nurses who will need this information.

Possible short term side effects

Increase in appetite

Most people taking dexamethasone will have an increase in their appetite. Some people may even crave certain foods. If you have been unwell an increase in appetite may be viewed as a good thing. However, it is important you don't put on too much weight. If you need to snack inbetween meals try to eat fruit or protein rich snacks (for example: nuts, cheese or lean meats) rather than 'sugar rich' food. If you are concerned about weight gain speak with your doctor or keyworker.

Indigestion

Dexamethasone can cause irritation on the lining of the stomach, causing indigestion. To help prevent this you will often be prescribed another tablet. Most people find it also helps to take their dexamethasone with or just after a meal (not on an empty stomach).

Increased thirst and frequency passing urine

Dexamethasone can increase levels of sugar in your blood and this may make you feel very thirsty. It may also make you want to pass urine more often. If you have these symptoms it is important that you tell your doctor or keyworker. A simple blood or urine sample can reveal the extent of the problem. If you have continuing high sugar levels you may be asked to change your diet or you may be prescribed medication to help balance your blood sugars.

Difficulty sleeping

Sometimes people taking dexamethasone find it difficult to sleep at night. This may be more of a problem if the tablets are taken in the evening. If this happens it may help to change the time of your last dose so you have it earlier in the day. Discuss this with your keyworker or doctor. As an example, dexamethasone could be taken after breakfast and following lunch.

Restlessness and changes in mood

Most people will find the improvement in their symptoms helps their mood and feelings of well-being. Very rarely, dexamethasone can make you feel anxious, agitated or restless, or sometimes low in mood. Some people find that using complementary therapies such as relaxation tapes, listening to music or using breathing exercises can help settle the restlessness.

Risk of infections

Dexamethasone lowers your usual resistance to infections. You should avoid people with infections such as shingles or chickenpox. It is important to tell the doctor or keyworker if you notice any wounds which are slow to heal, or you have signs of infection such as a high temperature or flu like symptoms.

You may be at risk of a fungal infection called thrush (candida). This may be found in your mouth or around your genital area.

Oral (mouth) thrush often looks like creamy white or yellowish patches in the mouth. Your mouth and tongue may feel furry, sore, dry or just uncomfortable. When you have oral thrush food and drinks may taste strange and dry foods or tablets may become uncomfortable 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.

Genital thrush may cause discomfort, itchiness, redness or a rash may be found in and around the groin. Sometimes genital thrush also causes a white or cream/yellowish coloured discharge.

If you think you have any form of thrush you will need to see your doctor who will prescribe simple medications to treat it.

A puffy face and swollen limbs

Many patients find that they become swollen around their face, ankles and feet or have a general swelling of their lower limbs when they are on dexamethasone. The swelling in the limbs is caused by water retention. Keeping active and moving around may help this. Also, when you are lying in bed try and raise your legs up so that they are higher than the level of your heart. This will help drain the fluid away from your legs and ankles. In extreme cases your doctor may prescribe a medication that will help reduce the water retention.

Possible long term side effects

Weakness of your muscles

A few people may experience a generalised weakness in their muscles, mainly those in their arms and thighs. Walking (especially upstairs if you are able) is a good exercise for maintaining and improving strength.

Changes in the skin and bones

Some people may experience their skin becoming papery and thin. A few people get spotty rashes. Occasionally, changes in bone density (thickness) occurs which can lead to possible injury or minor accidents. Your doctor may discuss certain medications with you which can help maintain and promote the strength in your bones.

Important points to remember

- Always carry your steroid card with you so that it can be shown to any doctors or nurses who treat you.
- You must not stop taking your tablets unless your doctor tells you to. Steroids should be reduced slowly and not stopped suddenly.
- If you forget to take your tablets or take too many please seek advice from your doctor, keyworker or treating hospital.

This information is intended to help you understand what side effects you may experience. It is important to remember that not everyone taking dexamethasone will experience all or any of the side effects.

For more information contact the neuro oncology advanced nurse practitioner or key worker who is currently supporting you. The neuro oncology nurses' telephone numbers are listed below. This may also be the number for your keyworker. Other keyworkers may include your community nurses or community palliative care nurses working with your GP.

Neuro oncology nurses:

Oxford: **01865 234 372**

Reading: **01183 228 542**

Northampton: **01604 523 880**

Stoke Mandeville Hospital: **01296 316 097**

If you need an interpreter or need a document in another language, large print, Braille or audio version, please call **01865 221473** or email **PALSJR@ouh.nhs.uk**

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