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# High dose steroids

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## Patient Information

Patient name: .....

Hospital number: .....

Clinical unit: .....

Start date of steroid therapy: .....

Starting steroid dose: .....





This booklet is for patients prescribed high doses of steroids. Steroids include prednisolone, dexamethasone and methylprednisolone.

## What are steroids?

The body naturally produces substances called steroids. Steroids can also be manufactured as drugs and given as tablets or as an injection.

## Why are steroids used?

Steroids can be used to reduce inflammation. Inflammation can be caused by the cancer itself, or by anti-cancer treatment. For example, immunotherapy drugs stimulate the body's immune system to treat cancer, but can also cause inflammation of other parts of the body. This can lead to side effects such as diarrhoea, abnormal liver function and arthritis. Steroids can be given to treat these side effects.

## How should steroids be taken?

Take steroid tablets with or after food. Swallow the tablets with plenty of water or milk. If you have 'enteric coated' tablets, these should be swallowed whole, not crushed or chewed. If you have difficulty swallowing, your doctor can prescribe dissolvable tablets or a syrup. Steroids can cause difficulty sleeping, so take them in the morning or early afternoon if possible.

Steroid **injections** may be given into a vein via a tube (cannula) or a line such as PICC line or central line.

## Dose and duration of treatment

The dose of steroids is likely to depend on your weight. The dose will be gradually reduced as your symptoms improve. If your symptoms worsen, the dose may need to be increased. It is difficult to predict how long you will be on steroids as this will depend on how quickly your symptoms improve. Some patients are on steroids for a few weeks, but other patients may need to take them for months or even stay on a low dose of steroids continuously.

## **What other medications should I avoid?**

Some drugs interact with steroids so you should tell anyone else treating you that you are taking steroids. Do not take over the counter preparations (such as ibuprofen) or herbal remedies until you have discussed this with your doctor, nurse or pharmacist.

Avoid live vaccinations (such as yellow fever). The pneumonia and flu vaccinations do not interact with steroids so these will not affect you.

Both alcohol and steroids can upset the stomach, so it may be beneficial to cut back on the amount of alcohol that you drink.

## **What should I do if I am feeling unwell?**

We will have given you a steroid card, which you should carry with you at all times. If you need medical or dental treatment, you should show this card to the doctor or dentist so that they know that you are on steroids. A steroid card is not necessary if you are only having a short course (less than two weeks) of steroids.

There are a number of reasons why you could feel unwell. If you are having steroids to treat a side effect of immunotherapy drugs (such as diarrhoea), then the immunotherapy side effects can get worse as the steroid dose is reduced. This may mean that your steroid dose needs to be increased again. Or you may be feeling unwell due to side effects of the steroids.

If you are feeling unwell, call The Royal Marsden Macmillan hotline or contact your clinical nurse specialist (or research nurse if you are participating in a clinical trial). Please see the contact details on page 7.

## **What are the potential side effects of steroids?**

Steroids are often very helpful in managing cancer symptoms and the side effects of cancer treatments. Therefore many patients feel much better after starting steroids. In some cases, the side effects of steroids (such as increased appetite) can also be helpful.

Some patients will experience side effects from taking steroids. These are more likely if you take steroids for a long period of time or are on a high dose. Most patients do not experience all of the potential side effects. Most of the side effects are reversible and will go away when the steroids are stopped or reduced to lower levels. Please talk to your doctor if you have any concerns about side effects.

The most common side effects (experienced by more than 1 in 10 of patients) are:

- **Increased appetite, weight gain, fluid retention and leg swelling**
- **Difficulty sleeping**
  - If possible, take steroids in the morning and avoid taking steroids later than early afternoon.
  - You may need a short-term prescription for some sleeping tablets.
- **Mood changes**
  - Steroids can cause mood swings. You may feel very high or very low, agitated or anxious. Very rarely patients can have hallucinations, delusions or confusion. This may be more common in people with a previous history of mood disturbance.
- **Tummy pain, indigestion, heartburn**
  - Steroids can irritate the lining of the stomach. Your doctor should prescribe an anti-acid medication such as omeprazole, lansoprazole or ranitidine. This helps to protect your stomach whilst you are taking steroids.
  - Cutting down on alcohol can also be helpful.
  - Do not take anti-inflammatory painkillers such as ibuprofen as these can increase the risk of stomach ulcers.
  - If you notice that your stools are black and tarry, please let your doctor know, as this can be a sign of a bleeding stomach ulcer.

- **Increased risk of infections**

- Steroids can make you more likely to develop infections. Tell your doctor if you are feeling unwell or have a fever.
- Steroids increase the risk of developing pneumonia. If you are taking more than 25mg of prednisolone (or an equivalent dose of another steroid) for more than four weeks, then your doctor should prescribe medication to help prevent pneumonia. This may be an antibiotic tablet called co-trimoxazole or a monthly nebuliser of a drug called pentamidine. Co-trimoxazole should be taken on Mondays, Wednesdays and Fridays. The antibiotics/ nebuliser should be continued for 6 weeks after finishing the steroids.
- Steroids can increase the risk of oral thrush, which can cause a white coating in the mouth, sore mouth and taste changes. This is treated with tablets or drops.
- If you are taking steroids and another drug that suppresses the immune system, then there is an increased risk of a viral infection called CMV (cytomegalovirus). Many people have previously had this infection and it does not usually cause symptoms in healthy people. However, the virus stays in the body and can reactivate and become more serious if your immune system is weakened. Your doctor should do a weekly blood test to check for the virus. You may need treatment with an anti-viral drug.
- Steroids also increase the risk of a severe form of chickenpox, so avoid contact with people with chickenpox or shingles.

- **High blood sugars**

- Your doctor should check your blood sugar levels from time to time. Symptoms of high blood sugars include feeling thirsty, feeling more tired and needing to pass urine more often. You may need medication to bring your blood sugar levels down.
- If you have diabetes, you should monitor your blood sugar levels more closely. Your diabetic medication may need

to be adjusted. You should let your regular diabetes team know that you are starting steroids.

Less common side effects (experienced by less than 1 in 100 patients) include:

- **Thinning of the bones** (osteoporosis).
  - This can increase the risk of fractures.
  - Your doctor should check your vitamin D and calcium levels - you may be prescribed calcium and vitamin D supplements.
  - If you are on 5mg or more of steroids for more than three months, your doctor will assess your risk of having a fracture. They may arrange a scan to see if you have any bone thinning and/or start medication to strengthen your bones.
- **High blood pressure**
  - Your blood pressure should be checked regularly. You may need medication to control your blood pressure, or your blood pressure medication may need to be adjusted.
- **Eye problems**
  - Let your doctor know if you have a history of eye problems/trauma - they may refer you to an ophthalmologist.
  - Steroids can cause or worsen glaucoma, so if you have glaucoma you may need your eye pressures checked.
  - Long-term steroids can cause cataracts. If you are on steroids for more than six months then your doctor may refer you to an ophthalmologist.
  - Tell your doctor if you notice any eye changes, such as blurred vision.
- **Muscle weakness**
  - This is most likely to affect the thigh and upper arm muscles. You may find it more difficult to do activities such as getting up out of a chair.
  - Try to remain as active as possible. Weight-bearing exercise is particularly helpful.

- **Skin problems**

- Steroids can cause thinning of the skin, stretch marks, easy bruising and delayed skin healing.

- **Changes in your menstrual cycle**

- Your periods may become irregular or stop. They usually return to normal once the steroids are stopped.

## Stopping steroids/steroid weaning

- You should not stop steroids suddenly.
- The adrenal glands in your body normally produce a type of natural steroid called cortisol. Cortisol is needed for many functions, such as maintaining your blood pressure.
- If you are taking steroids, your adrenal glands reduce the amount of cortisol that they produce.
- If you stop steroids suddenly or reduce the dose too quickly, then the adrenal glands do not have time to resume their normal function and produce enough cortisol. This can cause steroid withdrawal symptoms, which can be serious and even life-threatening. These include severe fatigue, nausea, vomiting, weakness, low blood pressure, low blood sugars and muscle aches.
- If your body has to cope with a stressful event such as an acute illness, accident or surgery, then you can become very unwell if your adrenal glands do not produce enough cortisol. **If you are unwell and are on steroids or have been on steroids within the last year, you should let doctors know, particularly if you need surgery.**
- If you have been on steroids for a long time, your doctor may arrange a test called a synacthen test. This measures if your adrenal glands are producing enough cortisol before stopping the steroids.

## Contact details

Please ask your specialist nurse or doctor if you have any questions or would like any further information about steroids.

Clinical Nurse Specialist

Research Nurse (clinical trial patients)

Alternatively, please call:

**The Royal Marsden Macmillan Hotline:** 020 8915 6899  
(available 24 hours a day, 7 days a week)

## Instructions for reducing doses of steroid treatment

This section is to be completed by pharmacy at point of dispensing. You may use the comments section if the steroid dose has changed for example, the steroid therapy has been increased via a telephone consultation in agreement with you doctor, nurse or pharmacist.

Patient name: .....

Hospital number: .....

Tablets supplied: .....

Date tablets supplied: .....

Additional instructions: .....

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.....  
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Start date of steroid therapy: .....

Starting steroid dose: .....

# Steroid weaning chart

Tablets supplied: .....

Day	Dose to be taken		
	After breakfast	After lunch	Comments
1			
2			
3			
4			
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14			

Pharmacist check: .....

# Steroid weaning chart

Tablets supplied: .....

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Pharmacist check: .....





## References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Freephone: 0800 783 7176

Email: [patientcentre@rmh.nhs.uk](mailto:patientcentre@rmh.nhs.uk)

No conflicts of interest were declared in the production of this booklet.

Should you require information in an alternative format, please contact The Royal Marsden Help Centre.



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[royalmarsden.org](http://royalmarsden.org)

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