
High dose steroids

Pharmacy

Patient Information

Patient name:

Hospital number:

Clinical unit:

Start date of steroid therapy:

Starting steroid dose:



This booklet is designed to answer common questions for patients who are prescribed a high dose steroids. It is not intended to replace specific advice given by your doctor or any other health professional.

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What are steroids?

The body naturally produces substances called glucocorticoids also known as corticosteroids or steroids for short. They help to regulate several processes in our body such as inflammation. Steroids can also be made as drugs and given as tablets or as an injection. The most commonly prescribed steroids are prednisolone, dexamethasone, hydrocortisone and methylprednisolone.

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 steroids 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 will depend on the type of steroid prescribed, your condition and 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.

You should generally avoid live vaccinations (such as yellow fever). The pneumococcal (pneumonia), COVID-19 and flu vaccinations do not interact with steroids.

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

Special precautions

Carry a **Steroid Card**. Once you are started on steroids, we will give you a steroid card with details of your steroid treatment.

You must always carry this with you. There are two different steroid cards you may need to carry:

1. A Steroid **treatment** card (a blue card)

This steroid card is given to you if you have been prescribed steroids for more than two weeks. It contains a set of instructions for you and informs healthcare professionals of the current steroid treatment.

2. A Steroid **emergency** card (a red card)

This red card will be given to you if you are on prolonged course of steroids (you have been on steroids for four weeks or longer). It contains a set of instructions for you and informs the healthcare professionals of the current steroid treatment.

When the body is under stress, for example during a serious illness or after an injury, it makes extra cortisol (natural steroids) to help the body cope. But, if you have been taking a prolonged course of steroids, your body is less able to make this extra cortisol naturally. This is known as adrenal insufficiency and stopping of your current steroid treatment can lead to a medical emergency. This means that if you were unwell, in an accident, or need a surgery, you might need to be given a higher dose of steroids for a while. This is why it is so important to always carry this card with you so the healthcare professionals looking after you are aware of your current steroid treatment.

Avoid close contact with people who have infections. Steroids affect the way your immune system works so you may be more likely to get infections from viruses and bacteria.

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.

However, some patients will have side effects from taking steroids. These are more likely if you take steroids for a long period of time (four weeks or more) or if you are on a high dose (more than 25 mg of prednisolone daily or equivalent). 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. Please talk to your doctor at The Royal Marsden 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 or lansoprazole. 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 call The Royal Marsden Macmillan Hotline immediately as this can be a sign of a bleeding stomach ulcer.
- **Increased risk of infections**
 - Steroids can make you more likely to develop infections. Call The Royal Marsden Macmillan Hotline if you are feeling unwell or have a fever.
 - **Steroids increase the risk of developing a rare type of pneumonia called PJP. If you are taking more than 25 mg of prednisolone (or an equivalent dose of another steroid) for more than four weeks, then your doctor should prescribe medication to help prevent PJP 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 six weeks after finishing the steroids.

- Steroids can increase the risk of oral thrush (candidiasis), which can cause a white coating in the mouth, sore mouth and taste changes. This is treated with tablets (fluconazole) or drops (nystatin).
 - If you are taking steroids and another drug that suppresses the immune system (eg mycophenolate mofetil [MMF]), 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 (valganciclovir).
 - Steroids also increase the risk of a severe form of chickenpox, so avoid contact with people with chickenpox or shingles.
- **High blood sugars**
 - Before starting steroids you will be assessed for the risk of developing high blood glucose. If you have diabetes, or are at a higher risk of diabetes, we will give you a meter to check your own glucose levels **or** we will advise you to see your GP to obtain one. You will be taught how to use the meter.
 - If you are asked to check your glucose levels, you should check once a day whilst on steroids, preferably before your evening meal (but two hours after lunch or two hours after the evening meal are alternatives).

- **If your glucose is above 12mmol/L on two separate days**, you should see your GP as you may need to start medication for glucose whilst on steroids.
- **If your glucose is >20mmol/L**, please either see your GP on the same day **or** contact The Royal Marsden Macmillan Hotline for advice.
- Symptoms of high blood sugars include feeling thirsty, feeling more tired and needing to pass urine more often. If you develop these please call The Royal Marsden Macmillan Hotline for advice.
- 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.
- If you are not felt to be at high risk, then your glucose levels will be checked with a blood test when you attend clinic or the day unit.

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 prednisolone (or equivalent steroid) 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 (bisphosphonates) 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 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 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

What should I do if I am feeling unwell?

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 that another treatment is needed. 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 9.

Stopping steroids

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 body reduces the amount of cortisol that it naturally produces.

If you stop taking steroids suddenly or reduce the dose too drastically, then your body does not have time to resume its normal function and produce enough cortisol naturally. This can cause adrenal insufficiency and the steroid withdrawal symptoms can be serious and even life-threatening. These symptoms include severe fatigue, nausea, vomiting, weakness, low blood pressure, low blood sugars and muscle aches.

You should not stop steroids suddenly. If you are unable to take your steroid dose (eg due to vomiting) please call The Royal Marsden Macmillan Hotline immediately.

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 your specialist doctor know, particularly if you need surgery. This is because your doctor may need to increase your steroid dose while you are unwell.

If you have been on steroids for a long time, your doctor may arrange a test called a synacthen test. This tests if your body is producing enough cortisol before stopping the steroids.

Further information

Please ask your doctor, pharmacist or nurse if you have any questions or would like any further information about 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

You can ring the hotline 24 hours a day, 7 days a week.

Call us straight away if you are feeling unwell or are worried about the side effects of cancer treatments.

This service provides specialist advice and support to all Royal Marsden patients, as well as to their carers, and both hospital and community-based doctors and nurses caring for Royal Marsden patients.

Instructions for reducing doses of steroid treatment

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

Patient name

Hospital number

Indication

Date steroid therapy first started

Estimated duration of treatment

Starting steroid dose

Additional instructions

.....

.....

Example of completed steroid reducing chart regime

Tablets supplied *Prednisolone*

Strength of tablets supplied *5mg tablets* Date *4/11/21*

Day	Dose to be taken	Number of tablets to be taken		
		After breakfast	After lunch	Comments
1 to 7	40mg daily	FOUR tablets of 5mg	FOUR tablets of 5mg	Starting dose
8 to 14	35mg daily	FOUR tablets of 5mg	THREE tablets of 5mg	First reducing dose week

Steroid dose reducing chart

Tablets supplied

Strength of tablets supplied Date

Day	Dose to be taken	Number of tablets to be taken		
		After breakfast	After lunch	Comments

Steroid dose reducing chart

Tablets supplied

Strength of tablets supplied Date

Day	Dose to be taken	Number of tablets to be taken		
		After breakfast	After lunch	Comments

Steroid dose reducing chart

Tablets supplied

Strength of tablets supplied Date

Day	Dose to be taken	Number of tablets to be taken		
		After breakfast	After lunch	Comments

Steroids can cause side effects such as tummy pain/indigestion, increased risk of infections, high blood sugars and thinning of the bones. Therefore, you may require some supportive care medication to manage or prevent these side effects.

Your supportive care medication(s) to be taken whilst on steroid treatment

Medication name	Dose	Reason for prescription	Start date	Stop date

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

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: patientcentre@rmh.nhs.uk

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

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