

High dose inhaled corticosteroids & steroid tablets for people with lung disease

Information for patients



Leeds Centre for
Respiratory Medicine

This leaflet contains information about high dose inhaled corticosteroids & steroid tablets for people with lung disease.

This information is being given together with a new NHS Steroid Emergency Card. We ask everyone given a card to carry it with them at all times.

This leaflet tells you:

- Why we are giving you the Steroid Emergency Card
- What you can do to help keep yourself safe if you are ill.

Why have I been given this leaflet

The leaflet will help you to remember what your doctor has told you about this medicine. It will also help you to decide whether you want to go ahead with the treatment.

What are inhaled corticosteroids and steroid tablets and how do they work?

Steroids (also known as corticosteroids) are important treatments for managing a number of lung conditions such as asthma and chronic obstructive pulmonary disease (COPD), and other interstitial lung diseases such as sarcoid, chronic hypersensitivity pneumonitis and connective tissue diseases of the lung.

Steroids act by reducing inflammation, which can prevent symptoms from developing, and in asthma and COPD, they can protect you from attacks (exacerbations).

Corticosteroids can be given in a number of ways:

- Inhaled corticosteroids allow the drug to go directly to the lung and work well for asthma and COPD.
- Corticosteroid nasal sprays are also used for conditions such as sinusitis, allergic rhinitis and hayfever.
- Steroid tablets are used when bigger doses are needed, such as for treating interstitial lung diseases. These are also used to treat asthma and COPD attacks.

Corticosteroids are very important medicines, and you should never stop them without discussing this with your doctor. Generally, corticosteroids are very safe and free from serious side effects when used in standard doses in an inhaler or a nasal spray.

Asthma and COPD

Most people with asthma or COPD only need treatment with low to medium dose inhaled corticosteroids. Some people with more difficult to treat severe asthma may require high dose inhaled corticosteroids. Steroid tablets are rarely used as regular daily treatment, but may be prescribed to treat asthma and COPD attacks.

Interstitial lung diseases such as sarcoid, chronic hypersensitivity pneumonitis and connective tissue diseases of the lung

Steroid tablets are usually prescribed initially in big doses, and are gradually reduced over weeks or months as the condition improves.

Are there any side effects?

Most medicines cause side effects. The manufacturer's leaflet contains a list of the known side effects for this medicine. Everyone reacts differently to medicines. You may have some side effects or none at all.

We know that steroids can have some side effects. Because of this, doctors always try to keep the steroid doses to the smallest dose needed. If you have any concerns about your steroid doses, discuss these with your doctors.

Inhaled Corticosteroids

Inhaled corticosteroids can cause local side effects such as sore throat, hoarse voice or oral thrush (sore white patches in the mouth). The risk of these side effects may be reduced by rinsing your mouth out with water (and spitting out) after using any corticosteroid inhaler. If you use a Metered Dose Inhaler (sometimes known as a "spray" or "puffer"), using a spacer device can also help reduce the risk of these side effects.

Prolonged use of inhaled corticosteroids may lead to easy bruising or thinning of the skin, especially in older people. Very rarely, high doses of inhaled corticosteroids may temporarily reduce your body's ability to produce its own corticosteroids when under stress, such as in severe illness or undergoing surgery, or to fight off some infections (e.g. chickenpox).

Steroid Tablets

Side effects with steroid tablets are more likely to occur if they are taken for long periods (more than 2-3 months). These will be discussed with you and you will be monitored for them while receiving treatment.

Possible side effects include the following:

- Fluid retention e.g. swollen ankles.
- Increased appetite and weight gain.
- High blood pressure (hypertension).
- Raised blood sugar or worsening of pre-existing diabetes.
- Indigestion or worsening of a peptic ulcer.
- Changes in mood, sleep disturbance and insomnia.
- Increased risk of infection. If you have not had chickenpox in the past then you should seek medical advice if you come into close contact with someone who has an active chickenpox infection whilst you are taking corticosteroids.
- Thinning or softening of the bones (osteoporosis).
- Skin - impaired healing of cuts, risk of stretch marks, skin thinning, bruising, increased growth of facial hair, acne.
- Muscle and tendon weakness.
- Cataracts, glaucoma and other eye conditions.

Steroid Tablets

The risks of these side effects must be balanced against the benefits of treatment for your skin condition. Bear these points in mind:

- These side effects are very unlikely to occur if you are taking the treatment for a short period only, at the lowest effective dose.
- In some instances it is best to use preventative treatment to reduce the chance of side-effects such as osteoporosis.
- In some conditions that are treated with corticosteroids, a 'steroid sparing effect' can be achieved by the addition of other tablets that affect the immune system such as azathioprine, methotrexate, or mycophenolate mofetil.
- Oral corticosteroids and vaccinations: 'Live' vaccines are not recommended whilst taking oral corticosteroids, such as polio (oral drops only, the injections are safe), BCG, yellow fever.

Why have I been given a new steroid card?

Our bodies naturally make some steroid hormones, called 'Cortisol' every day from glands called our adrenal glands. Cortisol helps our body cope with stress, and our bodies make more cortisol during illness or times of severe physical stress such as infection, surgery and car accidents.

Sometimes if people are taking high dose inhaled corticosteroids, or steroid tablets, the body might stop making enough of its own cortisol, because it sees that steroids are already in the body. This can also sometimes occur in people

who are taking two types of corticosteroid such as an inhaler and a nasal spray.

This means that someone taking bigger doses of corticosteroids may not make enough extra cortisol of their own if they have another serious illness. In the worst cases, people can become seriously ill with what is called an 'adrenal crisis'. The NHS wants to warn everyone who is on bigger doses of corticosteroids about this, and give them information about what to do when they are ill.

Adrenal crisis is rare in people who are only taking inhaled corticosteroids, but it can happen.

What are the signs of adrenal crisis and when might it happen?

Adrenal crisis can happen if you suddenly stop taking corticosteroid treatments, or if you have another illness whilst you are taking high dose inhaled corticosteroids or steroid tablets.

Signs of crisis can include severe dizziness with serious vomiting and/or diarrhoea. People having an adrenal crisis may have sudden confusion, tiredness, or headache.

How can I prevent adrenal crisis?

Do not stop taking your inhaled corticosteroid or steroid tablets suddenly. You may also need to take extra steroids if you are unwell. Your doctor may give you a personal plan, or 'sick day rules' to follow.

If you need an operation you should also tell your surgeon and their anaesthetist that you are on steroids.

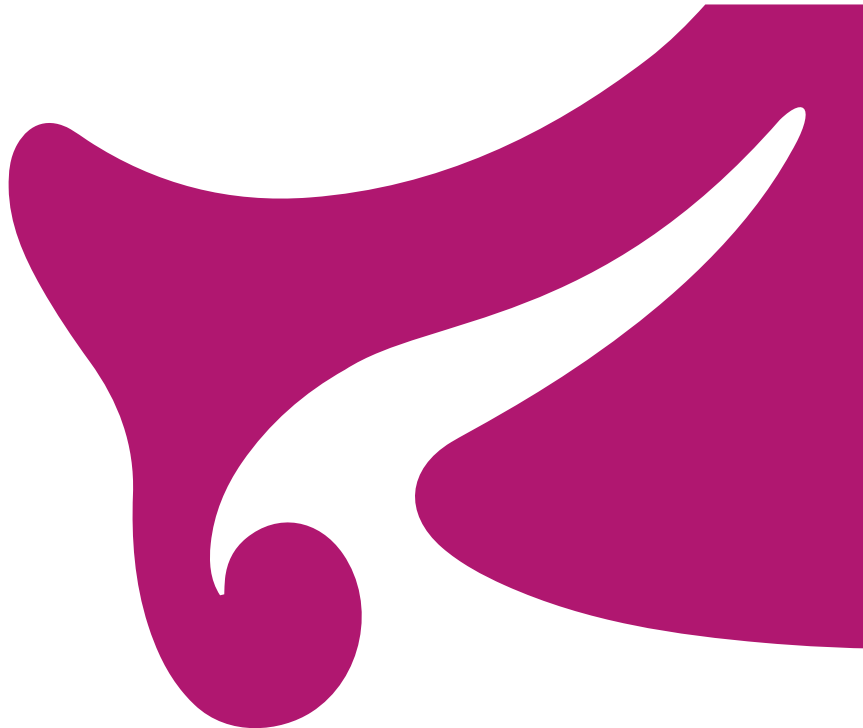
Sick day rules if you are on high dose inhaled corticosteroids or steroid tablets:

High Dose Inhaled Corticosteroids

- **If you have a mild to moderate illness** with fever like a cold, then you do not need to change your treatment, unless your underlying illness (e.g. asthma) is getting worse.
- **If you have a more nasty illness with a bad fever or with some mild diarrhoea and vomiting**, but you are able to drink and keep these fluids down, then you do not need to change your treatment. You should rest and be prepared to action if you get worse. If you're not improving after a day or so call your GP or 111. Ring 111 or 999 if you deteriorate.
- **If you have severe diarrhoea or vomiting and are unable to keep fluids down, or you have new dizziness, confusion or drowsiness, you may have adrenal crisis.** This is a medical emergency. You must urgently telephone 999, as described in your steroid warning card.
- If you have steroid tablets in hand and sometimes increase your steroid treatment for other reasons, such as bad asthma, then follow any personal action plans you have if your underlying illness is worse.

Steroid Tablets (if you are taking a steroid other than prednisolone, speak to your doctor or specialist nurse)

- **If you have a mild to moderate illness** with fever and are taking prednisolone at the following doses:
 - **Prednisolone 5mg once a day or less**, you should increase your steroids to 10mg once a day until you are well.
 - **Prednisolone between 5mg and 15mg once a day**, you should increase the dose to 15 mg per day.
 - **Prednisolone 15 mg per day or higher**, stay on the same dose.
- **If you have a nasty illness with a high temperature and/ or some mild diarrhoea and vomiting**, but you are able to drink and keep your tablets down, then you should increase your steroids to 15 mgs a day until you are well. If your dose is equal to or above 15 mg per day of prednisolone, stay on the same dose. Be prepared to take action if you don't quickly improve and warn anyone you live with to watch out for you.
- **If you have severe diarrhoea or vomiting and are unable to keep your steroids or fluids down**, this might mean that you may not absorb your steroids. This is a medical emergency and you must telephone the NHS on 999, as described in your steroid warning card. Some people who are especially at risk of adrenal crisis may also have an injection of steroid to give themselves at home and should follow those instructions as well as urgently telephoning for help on 999.
- If you sometimes increase your steroid treatment for other reasons, such as bad asthma, then follow any personal action plans you have if your underlying illness is flaring. Doses of steroids to treat worsening of lung illnesses will be guided by your GP or specialist.



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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