Adrenal insufficiency – how to stay safe on steroids

Information for patients

Your healthcare professional thinks you are at risk of a condition called adrenal insufficiency. This is usually because you are taking corticosteroids (steroids) for a medical condition.

This leaflet explains how to stay safe while you are taking oral, injected or topical steroid medication and after you stop using it. If you have any questions or concerns, please do not hesitate to speak to any member of the team caring for you.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your name and date of birth and check your ID band. If you don’t have an ID band we will also ask you to confirm your address.

If we don’t ask these questions, then please ask us to check. Ensuring your safety is our primary concern.

www.kch.nhs.uk
What to do in an urgent or emergency situation
Show the information on this page to the doctors and nurses looking after you. You can take a photo of it on your phone.

Management of adrenal crisis: summary information for medical professionals*
Patients currently on steroids or who discontinued them in the last year, by any route, are at potential risk of adrenal crisis. **They should be advised to carry a Steroid Emergency Card.**

Steroids (hydrocortisone or prednisolone) should be increased if patients are unwell. The information below provides a simplified approach that will cover most situations*.

**Sick Day Rule 1** In the event of moderate intercurrent illness (eg. fever, infection requiring antibiotics), preparation for colonoscopy, surgical procedure under local anaesthetic:
- Double usual daily glucocorticoid use or give hydrocortisone 20mg 2 to 3 times daily or prednisolone 10mg daily for duration of illness.

**Sick Day Rule 2** In the event of severe intercurrent illness – usually in hospital – (eg. persistent vomiting from GI viral illnesses), acute physical trauma, surgery under anaesthetic or labour:
- Hydrocortisone 100mg intravenously at onset, followed by 50mg every six hours im or iv. Step down to **double their usual dose** of oral glucocorticoid or hydrocortisone 20mg 2 to 3 times a day until better.

With minor medical ‘stress’, such as a typical cold or a dental filling, increases in usual steroid doses are not required.

Sacrn here for further information or search https://www.endocrinology.org/adrenal-crisis

*Note: This is a guide only, healthcare professionals should follow local guidelines and make decisions based on individual patients.
Why have I been given this leaflet?
Your healthcare professional thinks you are at risk of a condition called adrenal insufficiency, which can cause certain symptoms and make you feel unwell. This is usually because you are taking corticosteroids (steroids) for a medical condition.

You may be at risk of adrenal crisis if you become medically unwell, have a procedure such as an investigation or surgery, or go into labour and are not given additional steroids to cover this period. Adrenal crisis can be life-threatening if not treated.

This leaflet explains the things you can do to stay safe. We recommend that you show your Steroid Emergency Card and this leaflet to healthcare professionals when you come in to contact with them.

What are steroid medications and what are they used for?
Corticosteroids (steroids) are an anti-inflammatory medicine prescribed for a wide range of conditions.

They are synthetic (manufactured) versions of a hormone called cortisol that your adrenal glands make naturally. You can take them in different forms:
• tablets by mouth (orally)
• by injections into your joints (intra-articular) and/or muscles (intramuscular)
• by inhalers, nasal sprays or drops
• by eye drops, or lotions, gels or creams that you put on your skin or use on your genitals or rectum (topically).
What makes me more likely to have adrenal insufficiency?
Taking steroid medication can interfere with your adrenal glands from making cortisol and cause adrenal insufficiency.

Your risk of this happening increases if you:
• are on oral steroids for four weeks or longer
• take repeated short-term courses of oral steroids
• take high-dose inhaled steroids
• have repeated steroid injections into your joints or muscles
• use steroids in any form and take certain drugs, such as some antivirals, some antifungals and an antibiotic called clarithromycin, if used long term
• are on multiple preparations of steroids.

This risk lasts for up to 12 months after you stop regular steroid medication.

If you have been on a long course of steroids, as described above, you must not stop taking this medication unless you have been advised to do so by your healthcare professional.

What is adrenal insufficiency?
Cortisol is your body’s natural steroid hormone. It plays many vital roles in maintaining and regulating normal healthy body functions, particularly when you are ill or under stress.

Adrenal insufficiency is where your adrenal glands do not make enough cortisol.

If you have adrenal insufficiency and do not get enough steroid medication, particularly when you are ill or having a procedure or surgery, you could become dangerously ill with adrenal crisis.
What are the symptoms of adrenal insufficiency?
Symptoms of long-term (chronic) adrenal insufficiency include:
• feeling more tired
• feeling dizzy
• feeling sick
• loss of appetite
• weight loss.

Symptoms of adrenal crisis (acute adrenal insufficiency), which means you need to see medical attention urgently includes:
• nausea and vomiting
• collapse
• low blood pressure
• confusion
• pale skin and sweating.

What can I do to stay safe?
1. Always carry your Steroid Emergency Card with you. This tells other people that you are currently or were recently on steroid medication. Ask for one from your community pharmacy, GP (home doctor) or hospital team, or download it from: https://pituitary.org.uk/media/615391/Steroid-card-v2-.pdf
2. If you are on long-term steroids (year or longer) you can buy a medical alert bracelet at www.universalmedicalid.co.uk or from your local pharmacy.

3. Take your steroid medication regularly as prescribed and do not stop unless advised to do so by your healthcare professional.

4. If you are advised to stop taking them by your healthcare professional, they will let you know if you need to slowly reduce your steroid dose to wean yourself off.

5. If you are advised to stop, your healthcare professional will ask you to let them know if you feel more tired, dizzy or sick when you are not taking the steroid medication. These symptoms may mean you have adrenal insufficiency, so they will ask you to start taking your steroid medication again while they plan extra checks for you.

6. If you are taking or have been on steroid medication and you become unwell or need to have a procedure or surgery, you must follow the **Steroid Sick Day Rules** below.

**Please note:** The risk of adrenal insufficiency from steroid medication last for up to 12 months after your last dose or course.
Why do I need to follow the Sick Day Rules?
When you become ill your adrenal glands naturally start producing more cortisol to help you maintain your normal body functions. But if you have adrenal insufficiency you cannot produce the extra cortisol that your body needs.

If you are taking oral steroid medication you need to mimic your body’s natural response by increasing the dose of your steroid medication.

The Sick Day Rules explain how to alter your dose of oral steroid medication tablets if you become unwell. For example, if you have an infection that is bad enough to make you want to stay indoors or in bed, or even consider coming to hospital.

Steroid Sick Day Rules
Please follow these rules if any of the following apply to you:

• you take steroids by mouth (orally)
• you have been taking 5mg or more of prednisolone (or equivalent) for more than four weeks
• you have a respiratory disease and are taking high-dose inhaled steroids with repeated short courses and you have been given a steroid emergency card.

Taking a higher dose of steroids for a short period of time while you are unwell is necessary and is not harmful. You do not need to change the doses of any other hormone or other tablets you take regularly.
They also apply if you are:
• on high doses of inhaled corticosteroid and often require additional courses of oral steroids
• have repeated steroid injections, or
• on some types of antiviral, antifungal or antibiotic medication as well as steroids.

If you are unwell, you should contact your healthcare professional who may prescribe you oral steroids.

**Sick Day Rule 1**
• If you are ill with a fever, need bed rest or need antibiotics, you need to increase your steroid dose.
• The table on page 7 explains what to do with your steroid dose when you are ill or if you are having procedure or surgery.

**Sick Day Rule 2**
If you have any of the following you must seek **urgent** medical help because you may need a hydrocortisone injection:
• severe illness
• persistent vomiting or diarrhoea.

If you are taking oral steroids, the table on pages 7 - 9 explains when and how to increase your dose of tablet steroid medication.

• If you are taking prednisolone at a dose less than 10mg, increase it to 10mg where the table says ‘double dose’.
• If you have stopped using steroids in the past 12 months, use hydrocortisone 20mg twice a day or prednisolone 10mg once a day instead of the ‘double dose’ instruction. If you do not have a supply of steroids then contact your GP or healthcare provider.
You will be given an emergency injection of hydrocortisone if your illness is not relieved with a double dose of steroids. Contact your healthcare provider if you remain unwell after 5 days.

<table>
<thead>
<tr>
<th>Illness/stress situation</th>
<th>Increase of usual dose</th>
<th>Duration of dose change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common cold but no fever</td>
<td>You: No change</td>
<td>You: Take usual dose</td>
</tr>
<tr>
<td>Fever/Flu/Infection</td>
<td>You: Double your current dose</td>
<td>You: For as long as you have the fever or infection</td>
</tr>
<tr>
<td>Vomiting or diarrhoea</td>
<td>You: Double your current dose when vomiting/diarrhoea starts</td>
<td>You: Start taking your usual dose once you are better</td>
</tr>
<tr>
<td>Severe illness</td>
<td>You: Seek urgent medical attention.</td>
<td>You: Follow the advice you have been given by your healthcare provider, usually this will be to remain on an increased dose of steroids until you have recovered.</td>
</tr>
<tr>
<td></td>
<td>If you have been provided with one, administer your emergency Hydrocortisone kit (100mg intramuscularly) and then seek urgent medical attention.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Healthcare professional*: Administer Hydrocortisone by IV or IM route as an emergency in line with your local protocol/ guidance</td>
<td></td>
</tr>
<tr>
<td>Barium enema</td>
<td>You: Double your usual dose before procedure after you have taken laxatives</td>
<td>You: Take your usual dose on the morning after the procedure</td>
</tr>
<tr>
<td>Illness/stress situation</td>
<td>Increase of usual dose</td>
<td>Duration of dose change</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>-----------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>You: Double your usual dose before you have taken laxatives</td>
<td>You: Take your usual dose on the morning after the procedure</td>
</tr>
<tr>
<td></td>
<td>Healthcare professional*: administer Hydrocortisone 100mg IV-30 minutes prior procedure</td>
<td></td>
</tr>
<tr>
<td>Cystoscopy</td>
<td>You: Double the usual steroid dose on the day before the procedure</td>
<td>You: Take your usual dose after the procedure</td>
</tr>
<tr>
<td></td>
<td>Healthcare professional*: Administer Hydrocortisone 100mg IV at start of procedure</td>
<td></td>
</tr>
<tr>
<td>Gastroscopy</td>
<td>You: Double your usual dose before the procedure</td>
<td>You: Take double your usual dose for 24 hours, then go back to your usual dose</td>
</tr>
<tr>
<td>Minor surgery such as having a tooth out</td>
<td>You: Double your usual dose before the procedure</td>
<td>You: Go back to your usual dose the next day</td>
</tr>
<tr>
<td>Minor surgery with general anaesthetic, such as hernia repair</td>
<td>Healthcare professional*: Administer Hydrocortisone 100mg injection at induction</td>
<td>You: Follow the advice you have been given by your healthcare provider. Usually if there are no complications you can resume your usual dose the day after the procedure</td>
</tr>
<tr>
<td>Illness/stress situation</td>
<td>Increase of usual dose</td>
<td>Duration of dose change</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------------------------</td>
<td>-------------------------</td>
</tr>
</tbody>
</table>
| Major operation, such as gastrointestinal, respiratory, thyroid, neurosurgery | Healthcare professional*: Administer Hydrocortisone 100mg IV at start of procedure  
Healthcare professional*: Administer Hydrocortisone 50 injection every 6 hours until eating and drinking | You: Usually you will receive IV/IM hydrocortisone followed by an increased (usually double) dose of oral steroids for approximately 48 hours. The normal dose can be resumed if there are no complications. Follow the advice you are given by the healthcare provider. |
| Labour and vaginal delivery | Healthcare professional*: Hydrocortisone 100 mg intravenously at onset of labour, followed by immediate initiation of a continuous infusion of hydrocortisone 200mg per 24 hours  
Alternatively, hydrocortisone 100 mg intramuscularly followed by 50 mg every 6 h intramuscularly | You: Follow the advice you have been given by your healthcare provider. Usually the dose is doubled for 48 hours and if there are no complications you can resume your usual dose after this. |
<p>| Caesarean section | Your healthcare provider will follow local guidelines and advise you. | You: Follow the advice you have been given by your healthcare provider. |
| Long Haul Flights (over 12 hours) | You: Double your usual dose or take extra dose on day of flight | N/a |
| General stress/taking exams Dental work such as fillings, cleaning | You: Not usually required | N/a |</p>
<table>
<thead>
<tr>
<th>Illness/stress situation</th>
<th>Increase of usual dose</th>
<th>Duration of dose change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shock/bereavement</td>
<td>You: Double your dose of oral steroid</td>
<td>You: Go back to your usual dose once you feel stable. See your GP/hospital doctor for more advice if you feel unwell.</td>
</tr>
<tr>
<td>Road traffic accident</td>
<td>If you cannot take a tablet your will be given a 100mg hydrocortisone into your vein or muscle</td>
<td></td>
</tr>
</tbody>
</table>

*Note: This is a guide only, healthcare professionals should follow local guidelines and make decisions based on individual patients.*

**What can I do when travelling away from home?**

Take an extra supply of oral steroid medication with you, in case you need to increase your dose because of illness. Take your Steroid Emergency Card with you to show to healthcare professionals if needed.

**Who can I contact with queries and concerns?**

If you have any questions, please contact your medical team or your GP, or phone 111. If it is an emergency, please call 999.

**Sharing your information**

We have teamed up with Guy’s and St Thomas’ Hospitals in a partnership known as King’s Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care so you might find we invite you for appointments at Guy’s or St Thomas’. To make sure everyone you meet always has the most up-to-date information about your health we may share information about you between the hospitals.
Care provided by students
King’s is a teaching hospital where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS
The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. They can also pass on praise or thanks to our teams. The PALS office is located on the ground floor of the Hambleden Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King’s College Hospital, Denmark Hill, London SE5 9RS
Tel: 020 3299 3601
Email: kch-tr.palsdh@nhs.net

If you would like the information in this leaflet in a different language or format, please contact our Communications and Interpreting telephone line on 020 3299 4826 or email kch-tr.accessibility@nhs.net