

Steroid replacement therapy

Information for patients



The aim of this leaflet is to explain about cortisol deficiency and how it is treated with steroid replacement therapy. It also contains information about how to deal with illnesses and other stressful events.

Why have I been given this leaflet?

Your body is deficient in a steroid hormone called cortisol and your doctor has prescribed tablets to bring this level up to normal. The most common form of steroid replacement therapy is called hydrocortisone. The most common form of steroid replacement tablet used is called hydrocortisone, although other forms can be used.

Whichever form of steroid replacement you are taking it is important you know:

- Why you are taking it
- What to do if you are ill
- What to do if you can't take it for any reason

It is important that you read this leaflet in conjunction with the manufacturer's leaflet that comes with your tablets.

Why do I need to take steroids?

Your body would usually make its' own steroid called cortisol. This is produced by the adrenal glands and its production is stimulated by the hormone ACTH, made by the pituitary gland. If you have a problem with either the pituitary gland or the adrenal glands then you may not be making enough cortisol to keep you well.

Your doctor will assess this and if your level of cortisol is low you will be prescribed replacement therapy. It is important for you to remember that this is just to replace your own steroid levels to keep you healthy, rather than as treatment for an illness, for instance for some kinds of arthritis, when much higher doses are prescribed.

Why do I need cortisol?

Cortisol is vital for life. It is required to maintain the bodies own metabolism and maintain blood pressure.

What is cortisol deficiency?

Cortisol deficiency occurs when the adrenal glands do not produce enough cortisol.

How might I feel if I was cortisol deficient?

You may feel very unwell, with some or all of the following: weakness, dizziness, tiredness, feeling sick, poor appetite, weight loss and abdominal pain. These can be very subtle initially and may vary over time. Not everyone has the same symptoms.

When should I take hydrocortisone?

This will be individualised for your specific needs and you will be advised about this when you are prescribed the tablets. However the general principles are:

- Take the first dose as soon as you wake up. This is usually the biggest dose of the day because this is how our body normally produces steroids
- If you are required to take it twice a day, take the next dose between 4.00pm to 6.00pm
- If you are required to take it three times a day, take a lunchtime dose at 12.00pm to 1.00pm, then a further dose between 4.00pm to 6.00pm

The reason for this is if you take the hydrocortisone later than 6.00pm you may find it difficult to sleep at night. However, in some conditions steroids are deliberately given last thing at night, and if this is the case your doctor will have given you instructions on this.

If you are planning a late night you may find it helpful to take the evening dose slightly later.

Your hospital doctor will usually prescribe your tablets to start with but it is essential you continue this treatment unless a doctor advises you otherwise. For this reason your hospital doctor will inform your G.P. that you have been started on steroids and you must obtain follow on prescriptions from them so that there is no break in your treatment.

What do I do if I miss a dose?

If you miss a dose of hydrocortisone it is essential you take it as soon as you remember. Some people have found it helpful to set their mobile phone alarm to help them remember to take it.

What do I do if I am unwell while taking the hydrocortisone?

The level of cortisol produced by the body naturally increases during illness or times of severe physical stress such as infection, surgery and car accidents. For this reason patients on steroid replacement need to do the same.

In such circumstances therefore, it is essential you double the dose of hydrocortisone for three days in the event of illness (anything which raises your temperature) and inform your doctor. This is particularly important if you are very unwell, if your symptoms are deteriorating, or last longer than three days, in which case it is **absolutely essential to seek medical advice**, usually from your G.P..

If you are feeling unwell but are unsure whether to increase your dose it is always better to double the dose of hydrocortisone and speak to your doctor who will give you further advice. Extra doses of hydrocortisone taken for a couple of days will not cause you any harm.

What about stressful times?

If you are under a considerable amount of sudden severe stress, for instance bereavement, you may need to double your dose for two - three days. If in doubt, consult your doctor.

What if I am seriously unwell or have diarrhoea and / or vomiting and cannot take my tablets, when should I give myself a hydrocortisone injection?

You would need to contact your doctor urgently, as you will require a hydrocortisone injection and may need hospital admission.

In some circumstances patients may be able to give their own hydrocortisone injection in an emergency. Sometimes a partner or other member of the family can help. We can issue you with a hydrocortisone injection pack for use in these circumstances.

Your endocrine specialist nurse or another member of the clinical team will explain this to you. You will also be provided with a leaflet explaining this to you. You must receive training to do an injection before attempting an injection.

What do I do if I am admitted to hospital for any reason or go to the dentists?

You must tell any doctor, dentist, nurse, or pharmacist who deals with you that you are taking steroid tablets and the reason why. For procedures such as endoscopy, angioplasty or certain types of dental work, the doctor or dentist will give you an injection of hydrocortisone before the procedure.

I have heard that steroids can cause side effects such as osteoporosis, will this affect me?

Since we are replacing your body's natural steroid production, the sort of side effects that can happen when high dose steroids are given for treatment of other conditions such as asthma or arthritis such as:

- Osteoporosis
- Weight gain
- An increase in blood pressure
- High blood sugar
- Skin problems such as thinning skin, easy bruising or stretch marks
- Muscle weakness
- An increased risk of infections because excess steroids can suppress the immune system are much less likely to occur.

These side effects may be mentioned in the manufacturers' patient information sheet included with the tablets, as they will explain all aspects of steroid therapy.

If you are concerned about this please discuss it with your medical team but **do not stop your treatment**.

Why should I carry a steroid card?

You will be given a steroid card, which will give details of your current dose of steroid tablets and the names, addresses and telephone numbers of your hospital doctors. This is vital information for any doctor who has to look after you in an emergency.

Why should I wear a Medic Alert bracelet / necklace / watch?

We recommend that all patients carry a Medic Alert. In an emergency (for instance if you are unconscious), a medic alert bracelet or necklace is immediately visible to any doctor or paramedic and may be of vital importance. In addition, information on your condition is stored on a central database, which is always available by phone to any health professional. For further information on how to obtain a medic alert bracelet / necklace contact your endocrine nurse specialist/ doctor or medic alert directly (Tel: 0207 833 3034).

What should I do if I become pregnant?

You must continue taking the same dose of hydrocortisone and inform your doctor. Your dose of steroid replacement may need to be adjusted through pregnancy and you will need specialist advice on this.

Is it safe to breastfeed while taking hydrocortisone replacement?

Yes.

Key points

- If you are ill - infection, surgery, severe illness, severe sudden stress you must double your dose of hydrocortisone for 3 days and contact your doctor
- If you remain unwell it is vital you see your doctor
- Always tell any doctor, dentist, nurse or pharmacist whom you consult with that you are taking steroid tablets
- Always carry a steroid card in your pocket or bag
- Never stop your hydrocortisone tablets suddenly as your body will not be able to **'take over'** producing cortisol
- Do not run out of tablets and always get a new prescription well in advance
- Always keep a spare supply of tablets at home / work
- Always keep a hydrocortisone emergency kit at home
- If you are going on holiday, particularly abroad, take plenty of hydrocortisone tablets with you, enough to double your dose should you need to, in both your hand luggage as well as your main luggage. Take a hydrocortisone emergency kit with you, and carry a letter from a doctor certifying that you need to carry this with you
- Always tell your doctor if you need to double the dose of hydrocortisone for any reason or have been given an injection of hydrocortisone
- We recommend that you wear a Medic Alert

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