What rheumatology patients taking long-term steroid tablets (prednisolone) need to know about adrenal insufficiency during the coronavirus outbreak

Dear patient,

If you have been taking corticosteroid (prednisolone) tablets for over a month, then it is possible that you have developed adrenal insufficiency.
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01. What is adrenal insufficiency?

Dear patient,

We have made this leaflet:

- To give you information about adrenal insufficiency, which can be caused by long-term steroid use.
- To explain what you should do if you get coronavirus (COVID-19) or other serious illness.

The first part of the leaflet tells you what adrenal insufficiency is, what are the early signs of it, and what to do if you think you’re having problems from it.

The second part is for healthcare professionals with links to the latest guidance.

Your adrenal glands sit next to your kidneys. Taking steroid tablets can make the adrenal glands “lazy” so they do not do their job properly.
The adrenal gland makes **steroids**, which are important for the body to work properly. If your body needs an extra "boost" in situations like **major injury** or **serious infection**, it usually makes some extra steroid for a few days to help you through.

Prednisolone is very similar to **cortisol**, one of these essential steroids.

If you take long-term prednisolone tablets, the adrenal gland can become "lazy" at making cortisol. This is **adrenal insufficiency**.

This is not normally a problem, as you will get your steroids from your tablets.

Adrenal insufficiency is usually only a problem if you have an **unexpected major illness** and your “lazy” adrenal gland doesn’t make that steroid “boost” the body needs. If you take long-term prednisolone and you get sick, you may need to take extra tablets ("**sick day rules**").

This is well-known to doctors, but during the coronavirus outbreak we want to keep you informed too.
If you have been taking **5mg or more of prednisolone**, for **4 weeks or longer**, then it is possible that you have developed **adrenal insufficiency**.

Adrenal insufficiency can last for some time. So if you are taking **less than 5mg now**, but you used to take **a bigger dose**, you could still **have adrenal insufficiency now**.

If you take long-term steroid tablets, adrenal insufficiency will only give you a problem if:

- You stop taking steroids abruptly.
- You are reducing your prednisolone dose below 5mg and you try to reduce it too fast.
- You have another illness, e.g. COVID-19 or major surgery: if you usually take less than 20mg prednisolone, you might need some extra steroid for a few days.
03. How do I know if adrenal insufficiency is causing me a problem?

If you have adrenal insufficiency, this can cause the symptoms shown in the box on the right. **These would normally only appear if you are now taking less than 5mg prednisolone.**

All these symptoms can have many different causes – including your rheumatology condition, side-effects of your medicines, or a new problem.

If you have any of these symptoms, **please talk to your doctor.**

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**Symptoms of possible adrenal insufficiency**
- Bad fatigue (worse than normal)
- Weakness
- Light-headedness
- Dizziness
- Muscle or joint aches
- Stomach-ache
- Feeling sick
- Feeling cold and sweaty

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If you have been told to gradually reduce (taper) your steroid dose, having **steroid withdrawal** symptoms for up to a week after reducing your steroid dose is to be expected: it can take a few days for your body to adjust to a lower dose.
04. How do I know what steroid dose to take and when?

NEVER keep reducing your steroid dose if doing so makes you feel worse the more you reduce it. NEVER skip a steroid dose and NEVER stop taking steroids abruptly.

Planning ahead in case you have a major illness

If you are not sure, ask your consultant or GP. Based on your own circumstances, they may give you further advice.

Keep enough spare steroid tablets that you could follow the “sick day rules” on the next pages if you are ill.

This leaflet is a general guide: if in doubt, ask your doctor or pharmacist.
 RULE 1. If you are ill enough to need to stay in bed, OR if you have an infection that makes you unwell and you have been given antibiotics, increase your usual steroid dose for the time that you are unwell.

- If you usually take less than 5mg prednisolone daily, take **10mg daily** while unwell.
- If you usually take 5-10mg daily, **double** your usual dose.
- If you usually take between 10mg and 19mg prednisolone, increase to **20mg**.
- If you usually take **20mg or more**, stay on your usual dose (**no need to increase**).

If you are well again within a week, you can go straight back to your usual steroid dose. If it’s more than a week until you’re better, seek medical advice about stepping down your dose.
RULE 2. A steroid injection might be needed instead of tablets if you have severe stomach upset or if you are very ill in hospital.

You might need a steroid injection in the following situations:

- If you have severe diarrhoea or vomiting that lasts more than a day.

- If you have a major injury or major surgery.

- During childbirth

If you have confirmed adrenal insufficiency, your GP may prescribe a hydrocortisone injection to keep at home.

If you need a steroid injection for unexpected illness and you can’t give this yourself, seek medical advice urgently – call 999 or 111 if you need to. Tell them you take long-term steroids.
Symptoms of COVID-19 include:

- Fever (>37.8°C)
- Loss of sense of smell/taste
- Muscle Aches and Pains
- Running Nose
- Dry Cough
- Sore Throat

Some of these symptoms are commonly reported by many rheumatology patients because of their condition. If your symptoms are part of your usual experience of your condition, try not to worry, but if you do develop new symptoms, or if for any reason you think you may have coronavirus infection, please seek medical advice.

Remember you are just as important as any other patient, and we in the NHS are all here to look after you. Please do not hesitate to call 111 or 999 if you feel you need to.

Coronavirus infection can have a big impact on the body even if you don’t need hospital admission.

If you take long-term steroids, there is a special version of the Sick Day Rule 1 to follow if you have coronavirus infection. See next page.
If you are told you have suspected or confirmed coronavirus infection, and you take long-term steroids:

Take the steroid dose shown below AND split it into a morning and evening dose, as shown. After 5-7 days, or once you start feeling better, talk to your doctor about stepping back down to your usual steroid dose.

If you usually take less than 20mg prednisolone daily, then increase to 10mg in the morning and 10mg in the evening.

If you usually take 20mg prednisolone or more, then take your usual number of tablets over 24 hours, but split the dose equally between morning and evening.
For patients taking long-term steroids: what to do if you have COVID-19?

Coronavirus infection?  

Rule for adjusting steroid dose in coronavirus infection:
- If on less than 20mg: take 10mg in the morning and 10mg in the evening.
- If on 20mg or more: take usual dose, but split into morning and evening.

Some people improve then get worse again after 7-10 days.

If in doubt always seek medical advice.

You can take two 500mg tablets of paracetamol, four times per day. Taking more than this is dangerous—check whether your other medicines contain paracetamol too.

Drink enough that you need to pass urine several times per day. You might need to wake in the night to drink extra water. Drink more if:
- You feel dizzy when you sit up or stand up.
- Your hands and feet feel cold.

Call 111, use https://111.nhs.uk/covid-19/ or call 999 if you have:
- Dizziness
- Intense thirst
- Uncontrollable shaking
- Drowsiness
- Confusion
- Worsening shortness of breath
- Shortness of breath on walking upstairs
- Shortness of breath on talking
- Vomiting
- Severe diarrhoea
FOR DOCTORS
Why might adrenal insufficiency be important in patients taking long-term steroids?

FOR DOCTORS: Long-term prednisolone and adrenal insufficiency

- Up to **50%** of patients taking 5mg prednisolone long-term have adrenal insufficiency (1,2,3).
- According to the BNF, adrenal insufficiency can persist after tapering the dose **below 5mg**, or even after stopping.
- In patients with adrenal insufficiency, acute intercurrent illness can cause **adrenal crisis**.
- If patients taking long-term steroids become **acutely unwell**, it is safest to assume they have adrenal insufficiency and treat accordingly.

Follow this link for more information about how to manage adrenal crisis in patients with adrenal insufficiency.

https://www.endocrinology.org/adrenal-crisis


FOR DOCTORS
What to do with patients who take long-term steroids during the COVID-19 pandemic

• Check your patients taking long-term steroids (<20mg) have a stand-by course of “rescue steroids” (10mg twice daily for 2 weeks) in case they have to self-isolate with COVID-19.

• Do not check cortisol levels at prednisolone doses above 5mg: it will likely be suppressed.

• You can check cortisol levels in patients taking 5mg or less, if they plan to taper or stop steroids. The blood test should be taken at 9am, before their usual daily dose of prednisolone. If the cortisol is very low (<50-100) discuss with endocrinology.

• Endocrinology or rheumatology can organise Synacthen tests, which give more information than a one-off cortisol, but these involve a hospital visit.

• For patients acutely unwell who take long-term steroids, consider adrenal crisis, especially if confusion/GI upset causes you concern over whether they are taking/absorbing their steroid tablets.

• If patients have suspected/confirmed COVID-19, follow steroid dosing advice in section 7 of this leaflet.

FOR DOCTORS: Quick guide to steroids for quick adrenal crisis

For hospital doctors:
Patients taking long-term steroids who are admitted with acute, severe illness may need IV or IM steroids.

https://www.endocrinology.org/adrenal-crisis

For ANY patient with adrenal insufficiency who is extremely unwell, on ITU or needing respiratory support for any disease, including COVID-19:

Hydrocortisone 50mg iv/im every 6 hours
A 24 hour infusion of 200mg hydrocortisone.
We thank the University of Leeds, Vasculitis UK and NRAS for their assistance in developing this leaflet.