

Information for Individuals on Glucocorticoid (Steroid) Therapy



This patient leaflet is based on the European Society of Endocrinology (ESE) and Endocrine Society (ES) Joint Clinical Guideline on the diagnosis and management of glucocorticoid-induced adrenal insufficiency. It has been written by an international panel of experts who were involved in the development of the Guideline. The Joint Guideline is designed to help clinicians manage patients who have, or are at risk of developing, glucocorticoid-induced adrenal insufficiency. You can read the guideline in the [*European Journal of Endocrinology*](#) (2024) and the [*Journal of Clinical Endocrinology and Metabolism*](#) (2024).

Background

This leaflet is designed to inform you about the cause, evaluation and management of glucocorticoid-induced adrenal insufficiency. The information in this leaflet is not intended to replace your clinician's advice.

What are glucocorticoids?

Glucocorticoids are medications such as prednisone or prednisolone, which can be used to manage many conditions including asthma, rheumatoid arthritis and eczema. They can be administered as tablets, injections, infusions, topical creams, drops or inhalation sprays. At least 1% of the population use glucocorticoids long term. While glucocorticoids are highly effective in the treatment of various diseases, they can cause adverse effects. One of these effects is glucocorticoid-induced adrenal insufficiency.

What is glucocorticoid-induced adrenal insufficiency?

Glucocorticoids mimic the effects of cortisol; a hormone produced by the adrenal glands (see Figure 1). Cortisol is involved in several important processes in your body, such as regulating your metabolism, immune system, blood pressure and response to stress. When you take glucocorticoids long term, this can lead to suppression of cortisol production by your own adrenal glands; a condition known

as glucocorticoid-induced adrenal insufficiency. People with untreated glucocorticoid-induced adrenal insufficiency may experience fatigue, muscle weakness, dizziness, nausea and joint pains, or more severe symptoms such as weight loss and low blood pressure.

The risk of developing glucocorticoid-induced adrenal insufficiency depends in part on the type, dose and duration of glucocorticoid treatment that you are receiving.



Figure 1: adrenal glands (shown in orange)

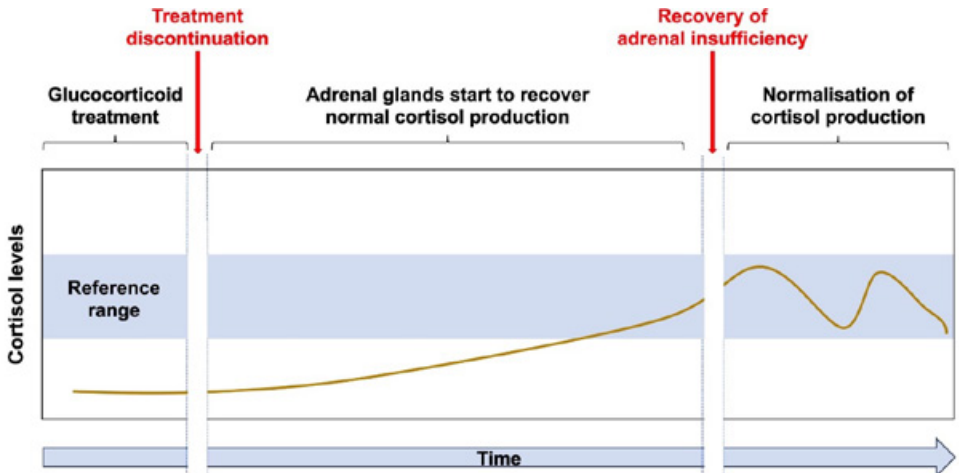


Figure 2: Blood cortisol levels during and after glucocorticoid treatment.

What happens when I stop taking glucocorticoids?

When stopping glucocorticoid therapy, it is important that your dosage is reduced in a way that allows your adrenal glands to recover normal levels of cortisol production on their own.

If you have been taking glucocorticoids for less than a month, the medication can be stopped immediately. If you have been taking glucocorticoids for longer, your clinician will gradually taper your dose and provide you with advice and support to do this safely.

If the glucocorticoid dose you take is equal to or higher than the cortisol levels your adrenal glands would produce on their own, generally you do not have to worry about developing symptoms of glucocorticoid-induced

adrenal insufficiency. Once your daily glucocorticoid dose has been reduced to normal cortisol levels or below, your adrenal glands will start to resume their own cortisol production. At this point, your clinician will decide whether it is best to continue lowering the glucocorticoid dose in small steps, while monitoring for signs of glucocorticoid-induced adrenal insufficiency, or they may check your morning blood levels of cortisol.

If there is no evidence of glucocorticoid-induced adrenal insufficiency, your clinician will either stop treatment abruptly or continue to lower and eventually stop your glucocorticoids.

For most people, gradually tapering off glucocorticoids will result in normalisation of your body's ability to produce cortisol (see Figure 2).

What happens if I develop glucocorticoid-induced adrenal insufficiency?

When there is evidence of glucocorticoid-induced adrenal insufficiency, the aim of treatment is to maintain adequate blood cortisol levels. To achieve this, you will need to continue to take a daily dose of glucocorticoids to replace the cortisol shortage until your adrenal glands resume normal production. Several glucocorticoid options are available, and your clinician will discuss the most appropriate treatment option with you.

Self-management is very important in the treatment of glucocorticoid-induced adrenal insufficiency. You should be informed and trained on how to manage your medication when you are under stress (for example if you are sick or injured).

This is called 'Sick Day Rules'. 'Sick Day Rules' training involves education for you and your support network on how you should be supported during periods of illness or when you need a medical procedure or surgery, including; how your medication dose should be adjusted to prevent an adrenal crisis (see Q4 below), when to seek medical help and when to administer an emergency steroid injection.

For an example of Sick Day Rules for adrenal insufficiency in general, which also apply to glucocorticoid-induced adrenal insufficiency, see <https://adrenals.eu/stress-instructions>. Please ask your clinician how to apply 'Sick Day Rules' tailored to your situation. In addition, you should be equipped with a steroid Emergency Card which has information about emergency treatment with hydrocortisone (see below).

After a period of time, your clinician may suggest a repeat blood test to assess if your cortisol levels have normalised. Your clinician will then advise you on further management.



Download a steroid emergency card:

www.eso-hormones.org/EC-AI
or adrenals.eu/emergency-card/

Q & A

Q1: My clinician is reducing my glucocorticoid dose and is monitoring me for symptoms of glucocorticoid-induced adrenal insufficiency. Will I need to have any blood tests?

A1: Most patients will be able to safely reduce the dose of their glucocorticoids and not develop any symptoms. In this situation, blood tests are not necessary during the period of glucocorticoid dose reduction. However, your clinician might decide to test your cortisol level depending on their concerns for glucocorticoid-induced adrenal insufficiency.

Q2: What is 'glucocorticoid withdrawal syndrome'?

A2: When you have been on glucocorticoid therapy for a long period of time, your body may become dependent on its effects. If your glucocorticoid dose is lowered or stopped, this may lead to withdrawal symptoms, called 'glucocorticoid withdrawal syndrome'.

The risk for developing glucocorticoid withdrawal syndrome is dependent on the type, dose and duration of glucocorticoid therapy you are taking. The difference with glucocorticoid-induced adrenal insufficiency is that your own cortisol levels are sufficient, and the symptoms are not due to glucocorticoid-induced adrenal insufficiency, but due to the withdrawal effects from glucocorticoids.

Pain in your joints or muscles, weakness, fatigue, sleep disturbances, and mood changes may be symptoms of glucocorticoid withdrawal syndrome. As these symptoms overlap with symptoms of glucocorticoid-induced adrenal insufficiency, it may be difficult to distinguish between the two. A slower reduction in glucocorticoid dose can help prevent glucocorticoid withdrawal symptoms.

If you continue to experience severe symptoms of glucocorticoid withdrawal, your clinician may advise you to increase your glucocorticoid dose for a short period of time.

Q3: I have been diagnosed with glucocorticoid-induced adrenal insufficiency. Is this permanent?

A3: No, usually it is not. In most instances, your body's cortisol production will recover to normal levels. Recovery time varies between people and may take some months or some years. In a small minority of individuals however, glucocorticoid-induced adrenal insufficiency can be permanent.

Q4: What is an adrenal crisis?

A4: When you are under stress, your body normally produces more cortisol. However, when you have glucocorticoid-induced adrenal insufficiency you may not be able to do so. This may lead to a potentially life-threatening condition called an adrenal crisis. Potential triggers include vomiting, infection or severe physical injury or abrupt stopping of glucocorticoids after a long treatment period. Warning signs of an adrenal crisis include extreme weakness, nausea, vomiting, dizziness, drowsiness, headache and fever. Fortunately, adrenal crises are rare in glucocorticoid-induced adrenal insufficiency, but if this happens, you should receive or self-administer an emergency steroid injection and seek immediate medical attention.

Q5: Where can I find more information and support?

A5: You can find more information at the European Society of Endocrinology website: www.ese-hormones.org/patient-zone

Read the full guidelines here:
www.ese-hormones.org/guidelines



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