

# Information on immune checkpoint inhibitor (ICI) therapy and hormone disorders



This patient leaflet is based on the European Society of Endocrinology Clinical Guideline on hormone disorders caused by immune checkpoint inhibitor (ICI) therapy, written by an expert pan-European endocrine team. The aim of this guideline is to help clinicians in managing persons who have hormone disorders due to ICI therapy, and is published in the *European Journal of Endocrinology* (2022) 187:G1–G21. The information in this leaflet is not intended to replace your doctor's advice.

## Background

Immune checkpoint inhibitor (ICI) therapy helps your own immune system attack and destroy cancer cells. However, this increased immune function can also affect normal tissue, resulting in autoimmune side effects in several organs. When hormone-producing (endocrine) glands are involved, this may cause hormone disorders. This patient leaflet is designed to inform you about the hormone disorders that ICI therapy can cause.

### Risk of hormone disorders

The risk for developing hormone disorders is, amongst other factors, dependent on the type and dose of ICI you are receiving (for frequency, see Table 1). Hormone disorders can occur soon after ICI therapy is started, but can also occur later during therapy, and even after the therapy is completed. One or several endocrine glands may be affected.

### Symptoms

Symptoms of hormone disorders vary and will depend on the type of endocrine gland involved as illustrated in Table 1. Symptoms caused by hormone disorders may be difficult to distinguish from symptoms caused by cancer, or the cancer treatment itself. For instance; weakness, fatigue, weight change, increased sweating and nausea can all be caused by both hormone disorders as well as by cancer or

**Table 1: Risk of endocrine gland disorders**

Endocrine gland	Disorder	Frequency
Pituitary	Hypophysitis (inflammation of the pituitary gland, resulting in low levels of multiple hormones)	Common
Thyroid	Hyperthyroidism (overactive thyroid gland, resulting in high thyroid hormone levels)	Common
	Hypothyroidism (underactive thyroid gland, resulting in low thyroid hormone levels)	Common
Pancreatic islets	Diabetes mellitus (destruction of insulin-producing cells)	Rare
Adrenals	Adrenal insufficiency (low cortisol and aldosterone levels)	Very rare
Parathyroid	Hypoparathyroidism (low parathyroid hormone and calcium levels)	Very rare

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cancer treatment. Therefore, it is important that you, together with your cancer doctor/nurse, monitor the (severity of) symptoms you experience during ICI therapy. Your hormone levels should be checked if any suspicion arises.


## Diagnosis

In addition to careful evaluation of signs and symptoms you experience, your doctor will perform screening blood tests to check your hormone levels on a regular basis. When a hormone disorder is suspected, additional blood tests may be performed, or, in the case of a suspected pituitary gland disorder, an MRI scan of the pituitary region may be required.

## Treatment

If you have developed a hormone disorder, your doctor/nurse will discuss with, or refer you to a hormone specialist (endocrinologist). Depending on the type and severity of the hormone disorder, treatment may be needed. If one or more hormones are missing, they can be replaced by tablets (e.g. levothyroxine, hydrocortisone, fludrocortisone) or an injection (insulin).

Self-management is very important in the treatment of hormone disorders, especially when you receive treatment for low cortisol levels. In this case, you should be informed and trained on how to manage your medication during periods of illness (this is called 'Sick Day Rules'). 'Sick Day Rules' training involves education for you and your family on how you should be supported during periods of illness including: how your medication dose should be adjusted or increased, when to seek medical help and when to administer an emergency steroid injection. All patients should be equipped with a steroid emergency card with information about emergency treatment with hydrocortisone (see Q4). The same goes for diabetes mellitus: self-management of insulin injections is key to maintaining well-controlled blood glucose levels. All information and instructions will be provided by your endocrine clinician if required.



## Q & A

### **Q1: I already have a hormone disorder due to an endocrine autoimmune disease: does this keep me from starting ICI therapy?**

A1: No, your existing hormone disorder will not affect the efficacy and safety of ICI therapy. Your response to ICI therapy should be no different from those people without hormone disorders.

### **Q2: Now that I have developed a hormone disorder, should I stop ICI therapy?**

A2: No, ICI therapy can be continued in almost all cases. Stopping ICI therapy will not result in a (quicker) recovery of your hormone disorder. Only in rare cases of pituitary enlargement or thyroid eye disease ICI therapy may be paused for a certain period.

### **Q3: Is my hormone disorder, caused by ICI therapy, reversible?**

A3: Most hormone disorders are permanent and will therefore require ongoing endocrine care. The exception to this are low levels of thyroid and sex hormones. Your doctor may suggest a repeat test at a certain time point to assess if the levels of these hormones have normalised.

### **Q4: Where can I get more information and support about hormone disorders caused by ICI therapy?**

A4: You can find more information through the following website:  
[www.ese-hormones.org/for-patients/patient-advocacy-groups](http://www.ese-hormones.org/for-patients/patient-advocacy-groups)

And to download a steroid emergency card:

[A Standardised European Emergency Card for Patients with Adrenal Insufficiency | ESE \(ese-hormones.org\)](#)



European Society  
of Endocrinology

T: +44 (0)1454 642247

E: [info@euro-endo.org](mailto:info@euro-endo.org)

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