

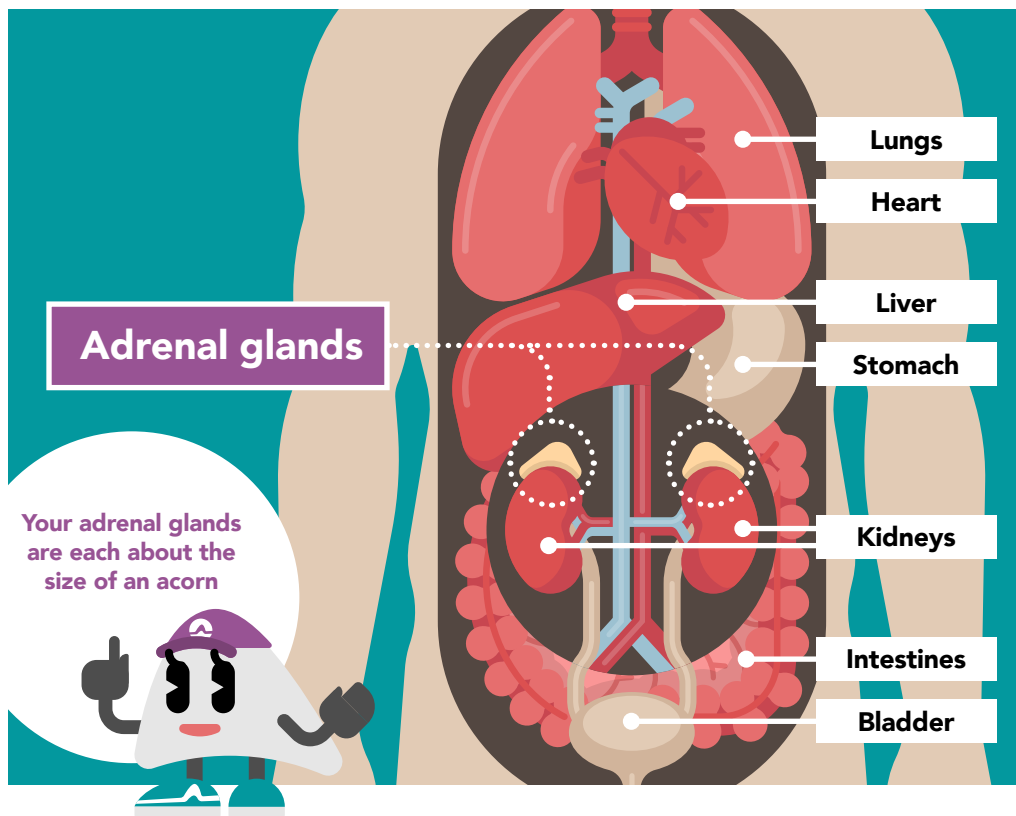


What are Addison's disease and adrenal insufficiency?

Helping you to understand
about Addison's and adrenal
insufficiency; rare and potentially
life-threatening conditions



Addison's disease, also known as primary adrenal insufficiency, is a rare endocrine condition, where the adrenal glands, that sit above your kidneys, do not produce enough of some life-essential steroid hormones. This condition affects roughly 1:10,000 people in the UK of different ages, and both women and men.



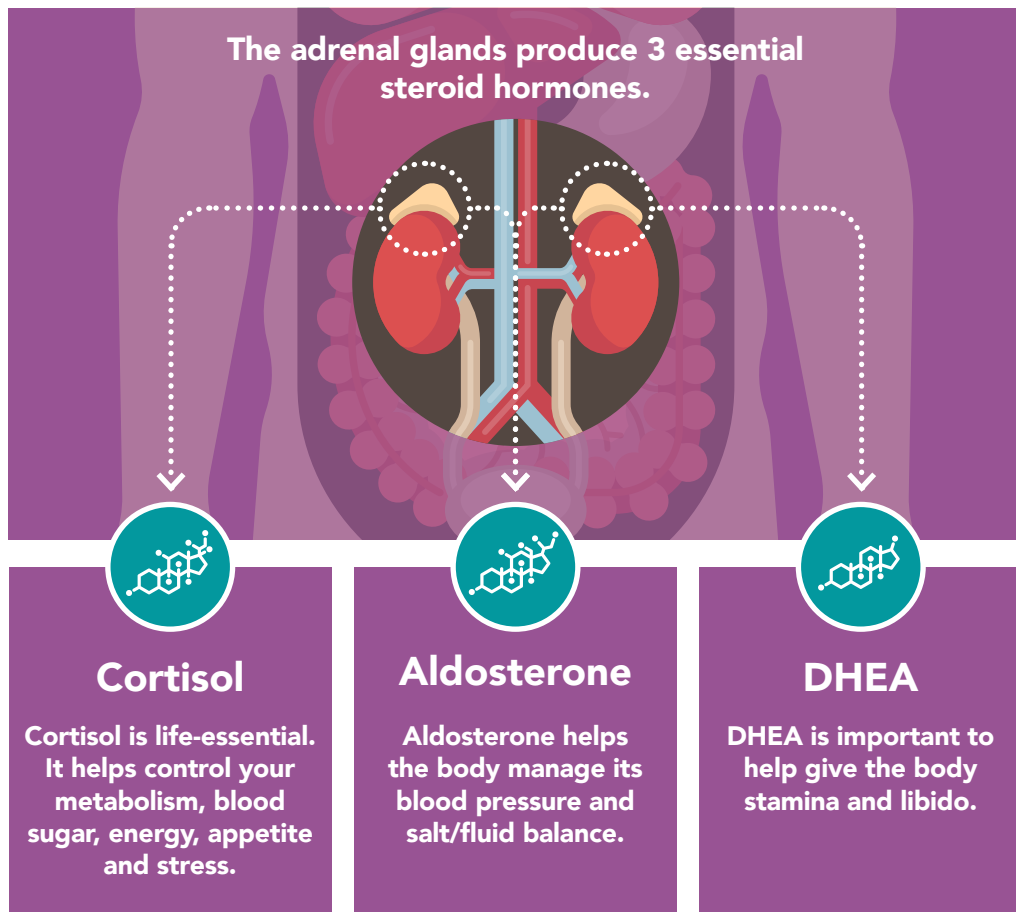
Addison's disease was first described by Dr Thomas Addison, who identified it in the 1850s. It is most often an autoimmune condition where the body causes inflammation in the gland which stops it working, for unknown reasons.

There are also two other types of adrenal insufficiency: Secondary adrenal insufficiency is caused by a problem within the pituitary gland, the part of the brain that 'controls' the adrenal glands. There are several different

reasons why the pituitary gland might not work as it should.

Tertiary adrenal insufficiency can occur as a result of taking long term steroid medication for other conditions, for example, chest (e.g. Asthma), skin or joint conditions. The balance between hormones produced by the hypothalamus in the brain, the pituitary gland and the adrenal glands is affected, and stopping the glucocorticoid medication may cause adrenal insufficiency.

THE AFFECTED HORMONES



Without enough of these steroid hormones, particularly cortisol, a person becomes unwell with symptoms such as:

- Changes in the skin colour (hyperpigmentation) – skin can become darker or look tanned
- Low appetite and weight loss
- Salt craving
- Light-headedness and brain fog
- Weakness and fatigue
- Nausea and abdominal pain

If Addison's disease and the other types of adrenal insufficiency are not diagnosed and treated, they lead to a life-threatening emergency called an **adrenal crisis**.

Without **time-critical emergency treatment** with hydrocortisone to replace the missing cortisol, **an adrenal crisis can be rapidly fatal**.

HOW IS ADRENAL INSUFFICIENCY TREATED?

Medication, in tablet form (or injection form in an emergency) can replace the steroid hormones that the body can't produce. The type and dose of medication taken depends on what type of adrenal insufficiency a person has..

For all types of adrenal insufficiency, the medicine needs to be taken every day, at specific times, to try and 'copy' the hormone levels that working adrenal glands would usually give (natural circadian rhythm), and to avoid the risk of an adrenal crisis.

Adrenal glands produce more cortisol when the body is under physical or severe emotional stress (e.g. illness,

trauma, psychological stress). This means that more medication needs to be taken during these periods of time. More medication also needs to be taken if there is a chance that the normal dose hasn't been absorbed by the body e.g. due to vomiting or diarrhoea.

As an adrenal crisis can be fatal, people with Addison's and adrenal insufficiency need to be very careful to take their medication every day, at the right time of day. They also need to carry a 'Steroid Dependent' emergency medical card, wear medical alert jewellery and always have an emergency injection kit with them, so that if needed, they can give themselves, or be given, an emergency dose of hydrocortisone.

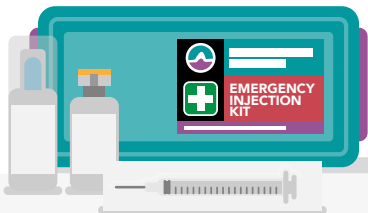
Essential items for individuals with Addison's or adrenal insufficiency:



**Steroid Dependent
emergency medical card**



**Medical alert
jewellery**



**Emergency
injection kit**



**ADSHG
leaflets and forms**

WHAT IS LIFE LIKE FOR PEOPLE WITH ADDISON'S AND ADRENAL INSUFFICIENCY?

Having a rare condition like Addison's and adrenal insufficiency can be challenging, especially as it is an 'invisible disability'. Not all healthcare professionals have heard of or have treated someone with adrenal insufficiency. It is important that people with this condition become 'experts' in their own health.

As with many health conditions, the challenges vary a lot between different people. Sometimes people will have more than one autoimmune condition, which can lead to increased complications, and a larger effect on health and wellbeing. Sometimes people will find that, as long as they carefully manage their medication, they are able to do the things they want to do in their life.

They will however, always need to be fully alert to avoiding an adrenal crisis, and are vulnerable in that theirs is a rare condition, that many healthcare professionals are not aware of.

People with Addison's disease can crave salty foods



Did you know?

President JF Kennedy (JFK) had Addison's disease. He kept his diagnosis a secret in case people judged him as unsuitable to be President of the United States of America. In the UK we now recognize 'Addison's Disease Awareness Day' as the 29th May, JFK's birthday!

At one time Addison's disease was known as 'Bronze Disease' as one common symptom of undiagnosed Addison's is deepening skin pigmentation. Often people look like they have a sun tan even when they haven't been out in the sun.

HELP SUPPORT THE ADDISON'S AND ADRENAL INSUFFICIENCY COMMUNITY

We work hard as a charity to support our members, ensure their voice is heard in the endocrinology community, and help healthcare professionals to provide the most comprehensive support to their

patients. We also support research into improved treatments for Addison's and adrenal insufficiency.

We rely on donations, fundraising and memberships to fund our impactful work. Together we can save lives through better awareness and improve the quality of life for those with Addison's disease and adrenal insufficiency!

Our 2024 archiverments:

2300+

ADSHG members supported

700+

Medical alert devices sold via our online shop

380+

Paramedics and Emergency Technicians given Adrenal Crisis Management training

Scan to
donate to the ADSHG



Scan to
join the ADSHG



For further advice please contact:

Email: enquiries@addisons.org.uk

Website: addisonsdisease.org.uk

The Addison's Disease Self-Help Group works to support people with Addison's and adrenal insufficiency and to promote better medical understanding of this rare condition.

The ADSHG is supported and advised by a Clinical Advisory Panel: a group of medical professionals with an interest in adrenal medicine. Registered charity 1179825, established 1984.

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This leaflet has been authored by the ADSHG and reviewed by:

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Last Reviewed: **February 2025**

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