Addison's Disease Self-Help Group (ADSHG)
Registered charity 1179825

ADDISON'S Self Help Group

ADDISON'S Clinical Advisory Panel

When an employee has Addison's disease or adrenal insufficiency.

What you need to know about their rare condition, and how you can best support them at work.

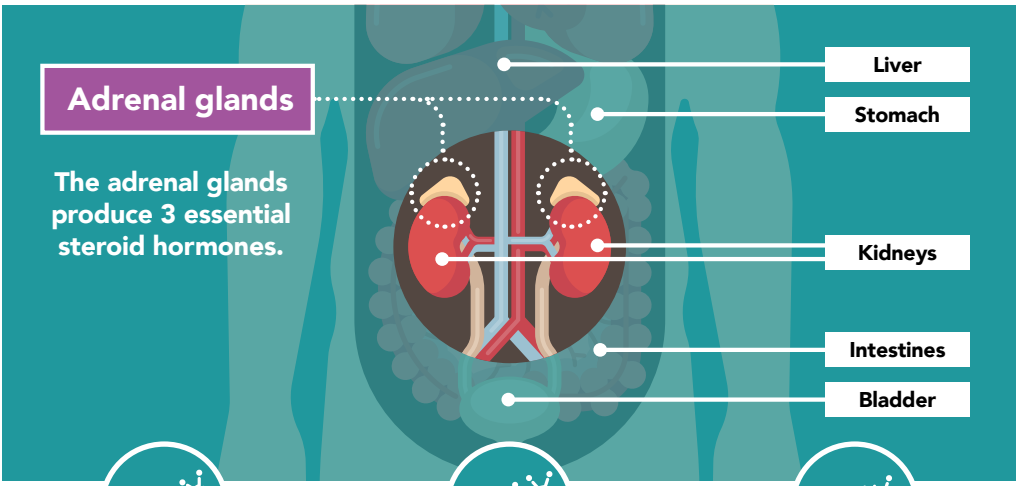
Addison's disease, also known as primary adrenal insufficiency, is a rare endocrine condition, where the adrenal glands stop functioning, no longer producing steroid hormones essential for life. This condition affects roughly 1 in 10,000 people in the UK, of all ages and genders.

Addison's disease is most often an autoimmune condition where the body causes inflammation and damage to the adrenal glands which stops them working.

There are 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 production of steroid hormones by the adrenal glands.

Tertiary adrenal insufficiency can occur when stopping long-term steroid medication taken for other conditions as they can alter the balance between hormones produced by the hypothalamus in the brain, the pituitary gland and the adrenal glands.

ADRENAL GLANDS & AFFECTED HORMONES



Cortisol

Cortisol is life-essential. It helps control your metabolism, blood sugar, energy, appetite and stress.

Aldosterone

Aldosterone helps the body manage its blood pressure and salt/fluid balance.

DHEA

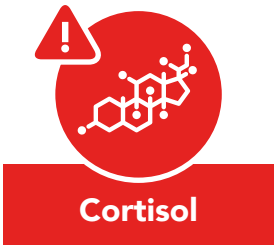
DHEA is important to help give the body stamina and libido.

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

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

ADRENAL CRISIS: A LIFE-THREATENING SITUATION

People with Addison's and adrenal insufficiency are steroid dependent. Without sufficient steroid hormone replacement, all patients with adrenal insufficiency are at risk of a life-threatening emergency called an adrenal crisis. They have to follow a strict medication regime; taking glucocorticoid treatment at carefully timed intervals every day to replace what their body can't produce.



An adrenal crisis occurs when cortisol levels are too low to sustain essential life processes. This can occur:

- If adrenal insufficiency has not been diagnosed and is not being treated.
- In the case of severe physical or emotional stress (e.g. illness, trauma, psychological stress) where replacement medication is insufficient to meet the body's need for cortisol.
- Where replacement medication has not been taken at the right time, or not been absorbed by the body due to vomiting, diarrhoea or other gastro-intestinal issues.

Adrenal crisis danger signs include:

- Extreme weakness, feeling terrible, vomiting, headache.
- Light-headedness or dizziness on sitting up or standing up.
- Feeling very cold, uncontrollable shaking; back, limb or abdominal pain.
- Confusion, drowsiness, loss of consciousness.

These may be similar symptoms to a pre-diagnosis illness.

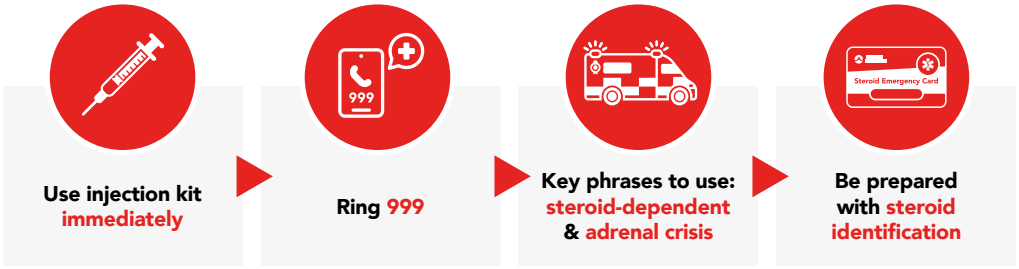
Adrenal crisis requires **immediate and time-critical treatment** with the administration of hydrocortisone via an emergency injection followed by medical monitoring and IV fluids.

It will typically develop over a period of hours with symptoms worsening, sometimes very quickly, if treatment is not administered. An individual will frequently know they are going into adrenal crisis before measures such as blood pressure will reinforce the diagnosis.

Preventing adrenal crisis and responding to an employee who feels unwell with low cortisol symptoms

1. Listen to your employee and be guided by them as they will know their low cortisol symptoms.
2. They should immediately increase their steroid medication (tablets or injection).
3. They should not be left alone whilst they feel low cortisol symptoms. If they show signs of improvement, they should return home for rest and to access more medication in case it is needed.
4. If their symptoms become worse, they immediately require their emergency injection of hydrocortisone. Ring 999 for an ambulance. Short-term high doses of hydrocortisone can do no harm, but could prevent them from becoming more seriously unwell, and save their life.
5. When they have recovered, and if they have used their emergency injection kit that was held at work, remind them to restock it.

If you suspect that an employee is in adrenal crisis, or if additional medication has not improved their symptoms, then it is an emergency situation.



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 and their individual health needs. Hydrocortisone is most frequently prescribed and must be taken 3 x each day, and at specific times to best mimic 'normal' cortisol production in the body.

When the body is under physical (e.g. illness or trauma) or severe emotional stress, it requires an increased level of cortisol. People with adrenal insufficiency need to increase their medication during these periods of time and must carry an emergency injection kit with them at all times to prevent or treat an adrenal crisis.

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 treated someone with adrenal insufficiency. It is important that people with this condition become experts in their own health.

As with most health conditions, the challenges vary a lot between different people. Up to 50% of people with Addison's disease, for example, will have an additional autoimmune condition, which can mean a larger effect on health and wellbeing.

Newly diagnosed

As Addison's and adrenal insufficiency are rare, and the symptoms shared with other conditions, the route to diagnosis can be long. During this time, health needs can be complex and severe. Even once a diagnosis is confirmed, an employee with adrenal insufficiency is more likely to require time off work whilst their medication regime is adjusted. Regular hospital appointments for blood tests will be required to monitor their condition and response to treatment.

It is likely that the number of appointments will reduce once the condition is stabilised, but this will depend on the individual and will be influenced by whether they have other health conditions that may pre-dispose them to more frequent episodes of adrenal emergency, such as Crohns, asthma or diabetes.

ADRENAL INSUFFICIENCY AND DISABILITY LAW (UK)

The law (Equality Act 2010) says someone is disabled if both of these apply:

- they have a 'physical or mental impairment'.
- the impairment 'has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities'.

Whilst not everyone with Addison's or adrenal insufficiency might identify as having a disability, they are covered by the definition of disability under the Equality Act 2010, or, if you live in Northern Ireland, the Disability Discrimination Act 1995.

Adrenal Insufficiency at a glance

A person with adrenal insufficiency;

- ✓ **Can hold a UK driving licence**
- ✓ **Needs daily medication**
- ✓ **Needs regular medical appointments**
- ✓ **Carries the risk of a medical emergency**
- ✗ **Doesn't need a specific diet unless they have other conditions also**

BEST PRACTICE IN EMPLOYMENT

- Clear and regular communication.
- Consideration of individual requirements.
- A willingness of all parties to discuss and negotiate to reach a practicable and reasonable outcome.
- Regular review with assigned responsibilities and timescales for action points.
- Having a policy on disability leave; making clear when this applies in place of sick leave.
- Respecting confidentiality as regards who, if anyone, is made aware of an employee's disability, and how. NB: it is recommended that the named first-aider is made aware of the diagnosis of adrenal insufficiency so as to be able to respond effectively in an emergency (adrenal crisis).

IMPLICATIONS FOR EMPLOYMENT

These will vary for each individual, but there are some considerations for all people diagnosed with Addison's or adrenal insufficiency, as they are considered as having a disability under UK law.

MAKING REASONABLE ADJUSTMENTS

Reasonable adjustments are changes an employer makes to remove or reduce a disadvantage related to someone's **disability.** By law, an employer must make **reasonable adjustments** if they know, or could be reasonably expected to know, that someone has a disability.

For example:

- finding a different way to do something
- making changes to the workplace
- changing someone's working arrangements
- providing equipment, services or support

They are specific to an individual person. They can be for physical or mental health conditions.

They can cover any area of work.

The employer must consider carefully if the adjustment:

- will remove or reduce the disadvantage – the employer should talk with the person and not make assumptions
- is practical to make
- is affordable
- could harm the health and safety of others

The employer does not have to change the basic nature of the job or make adjustments that are unreasonable. However, they should still find other ways to support the disabled person with adjustments that are reasonable.

There is a wealth of information available online. A great place to start is the ACAS website: **www.acas.org.uk/reasonable-adjustments**

POTENTIAL ADJUSTMENTS

- Reduced hours, such as a phased return to work, working part-time, and potentially building up to full-time over an extended period.
- Flexible or altered working hours; e.g. later start time to allow for morning medication to take effect, or a later end time etc.
- Part-time working or job sharing.
- Working from home.
- Allowing for calls during work hours to arrange medical appointments.
- Implementing a disability leave policy (that references time taken for medical appointments relating to their diagnosis) and relaxing trigger points of absence in sickness absence policies.
- Providing aids to assist an employee with physical aspects of their role.

WHERE TO START

1. Ensure you have a policy on disability leave.
2. Discuss the implications of their condition with your employee. Jointly assess the potential for the employee to continue with their current role. Identify the aspects they are comfortable they can complete without problem and those areas they believe they may struggle with.
3. Focus on areas of difficulty and identify how making reasonable adjustments might help these be done differently.
4. Consider whether temporary or permanent adaptations are required. In exceptional cases both parties may feel that an alternative role may be more suitable.
5. Exclude disability related absence from any calculations of absence for promotion and redundancy purposes. Ensure this is also taken into account in any disciplinary or capability procedures.
6. For more information see **www.addisonsdisease.org.uk/information-for-employers**

WHO ARE THE ADSHG?

We are a small charity, reliant on membership fees, fundraising and donations to allow us to work towards our vision of:

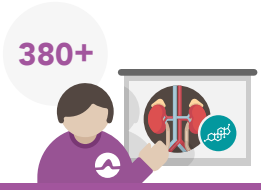
"A world where Addison's disease and adrenal insufficiency are recognised early and managed effectively so that every person with this rare condition can live confidently and thrive."

Did you know?

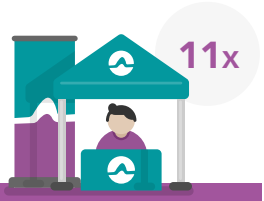
President John F. Kennedy had Addison's disease. He kept his diagnosis a secret in case people judged him to be unsuitable to be President of the United States. In the UK we now recognise 'Addison's Disease Day' as the 29th May, JFK's birthday!

Our impact in 2024:

2300+ ADSHG members supported



380+ paramedics trained in Adrenal Crisis Management during 2024



11 awareness stands held across the UK

We aim to support our members, connect with healthcare professionals and promote research in adrenal medicine.

With a social media reach of over 30,000, we are able to spread awareness, and information about the management of adrenal insufficiencyand adrenal crisis.

HOW YOU CAN SUPPORT US

If you are able to support us through fundraising or a one-off or regular corporate donation, we would be so grateful.

Fundraise for us

We have lots of ideas, or you may have your own?

www.addisonsdisease.org.uk/fundraising-ideas

Volunteer for us

Get in touch so we can match your skills and availability to our needs.

www.addisonsdisease.org.uk/volunteering

Scan to donate to 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.

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

Prof John Wass
Chair of ADSHG Clinical Advisory Panel
Churchill Hospital, Oxford

Last Reviewed: **July 2025**