



About the Addison's Disease Self-Help Group

Supporting people with
Addison's disease and
adrenal insufficiency.

Be aware. Be prepared. Be understood.



The Addison's Disease Self-Help Group, also known as the ADSHG was founded in 1984. Today we are the leading UK charity supporting people with all types of adrenal insufficiency, including Addison's disease, their carers and families and those working with them. In collaboration with leading adrenal specialists and our own Clinical Advisory panel, we are striving for a world where Addison's disease and adrenal insufficiency are recognised early and managed effectively so that anyone affected can live confidently and thrive.

For over 40 years, we have worked to:



Support

Providing resources and building a community that helps people self-manage their Addison's disease and adrenal insufficiency and improve their quality of life.



Connect

Making it possible for the voice of people with Addison's disease and adrenal insufficiency to influence, inform and improve the way the healthcare service delivers their care.



Advance

Funding, contributing to and promoting the development of new innovations and research to improve quality of life.

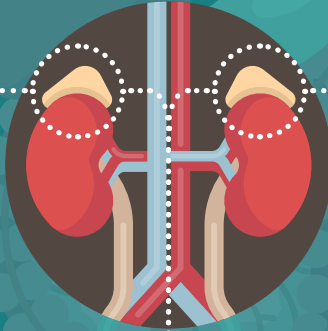
WHAT ARE ADDISON'S AND ADRENAL INSUFFICIENCY?

Addison's disease (AD) is a type of adrenal insufficiency (Primary adrenal insufficiency) where the adrenal glands, above your kidneys, fail to produce life-essential steroid hormones, particularly cortisol. Addison's is a rare endocrine condition which occurs, in the UK, at a rate of approximately 1:10,000 people, affecting both men and women, of all ages.

Addison's disease was first described by Dr Thomas Addison in the 1850s. It is most commonly an autoimmune condition, where the body mistakenly attacks and inflames the adrenal glands, preventing them from functioning properly. The exact cause of this autoimmune attack is still unknown.

Addison's is one of three types of adrenal insufficiency, each sharing some common symptoms. Each has different causes and varying degrees of alteration to the levels of steroid hormones that are produced by the adrenal glands.

The adrenal glands produce 3 essential steroid hormones.



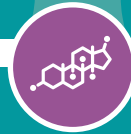
Cortisol

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.

| Secondary adrenal insufficiency

This is caused by a problem within the part of the brain that 'controls' the adrenal glands (the pituitary gland). There are several different reasons why the pituitary gland might not work as it should.

| Tertiary adrenal insufficiency

This can occur as a result of taking long-term steroid medication for other conditions, for example, 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 result in adrenal insufficiency.

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. They are **steroid-dependent**.

An adrenal crisis occurs when a person with AI is under severe stress (physical, such as illness or trauma, or psychological) and their usual steroid medication regime is insufficient to support the ongoing functioning of the body, due to an increased need for cortisol. **It requires the time-critical and life-saving administration of hydrocortisone.**

| Why is our work important?

1 in 200 adrenal crises are fatal and every death is a preventable death.

We help people with Addison's disease and adrenal insufficiency manage their condition safely and confidently. We work to raise awareness in the medical community, improving treatment and quality of care, our role as a well established and respected Patient Support Group also allows us to reach out to fight for improvements in patient safety, particularly around adrenal crisis management, ultimately working to save lives.



MANAGING ADDISON'S AND ADRENAL INSUFFICIENCY

Having adrenal insufficiency, a rare condition, can be challenging, especially as it is an 'invisible disability'. Many healthcare professionals are unfamiliar with adrenal insufficiency or have never treated a patient with the condition. This lack of awareness can be life-threatening during an adrenal crisis. That's why it's crucial for people with adrenal insufficiency to become experts in managing their own health.

As with many health conditions, symptoms and challenges vary a lot between different people. For example, frequently people with AD will have more than one autoimmune condition, which can lead to increased complications, and a larger effect on health and wellbeing. Sometimes people with adrenal insufficiency 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. However, they must always stay vigilant to prevent an adrenal crisis. Their condition is rare, making them especially vulnerable since many healthcare professionals remain unaware of it.

OUR HUMBLE BEGINNINGS

Founded by Deana Kenward following her own difficult journey to diagnosis, the charity began with hand-written newsletters and small gatherings of motivated individuals with passion, and a vision to make a difference to the lives of those with Addison's. Through hard work and determination, little by little, we developed to become a formally registered UK charity with an elected trustee body to support and define our strategic direction.

In 2012 Deana was awarded an MBE for her 27 years of dedicated service to the ADSHG, and she remains in close contact with the charity still.

HOW WE WORK TODAY

Our goals of **Support - Connect - Advance** are very similar to the charity's original aims, and give everyone involved a focus and drive to meet the needs of our members and the wider Addison's and adrenal insufficiency community.

We are a small team of employed staff managing Operations, Communications, Fundraising and Research, supported by a team of talented and enthusiastic trustees who volunteer their time, and a wider group of wonderful and skilled volunteers who assist with many other aspects of running the charity. They help us to manage our enquiries, attend events and medical conferences, raise awareness in local hospitals, and help us to moderate and offer peer support and experience on our member forum.

We are also exceptionally fortunate to enjoy the support of a group of experienced healthcare professionals, specializing in the field of endocrinology, who come together on our Clinical Advisory Panel to ensure that the information and resources we develop as an organization, are accurate and up-to-date.



Support

- An information rich and internationally recognized website (www.addisonsdisease.org.uk) accessible to all.
- Peer support and experience in an online community forum, private to members; a safe space to ask questions, seek support and share experiences.
- Regular articles and views from the Addison's and adrenal insufficiency community in our bi-annual magazine and 'Keeping You Posted' newsletters.
- Face-to-face events with an opportunity to hear from the endocrine-focused medical community as well as connect with other members.
- An online shop; emergency injection kits, medical alert products and informative publications and leaflets for patients and healthcare professionals.



Connect

- We represent our community in endocrine and medical societies, as well as a Patient Support Groups. in the Rare Disease Network.
- We are directly involved in raising awareness in healthcare professionals through online teaching webinars (live) and e-learning modules. We work with a variety of professional groups including Paramedics (JRCALC Guidelines and Paramedic Awareness Training) and GPs (RCGP and BMJ e-learning modules).
- We link closely to, and collaborate with, other rare disease and endocrine charities to work together, sharing knowledge and experience.
- We work in co-operation with some of the UK's leading adrenal specialists on our Clinical Advisory Panel, to promote broader medical understanding and effective management of Addison's and adrenal insufficiency.



Advance

We are there to help healthcare professionals who are focusing research on Addison's and adrenal insufficiency, offering letters of support, small funding grants, and 'lived experience' through the patient voice.

We are particularly interested in supporting the business case to improve the current options available for administering emergency hydrocortisone in the case of adrenal crisis. We recognise that the difficulties reported with drawing up the required medication and self-administering via an intramuscular injection, are serious obstacles to safe, timely and effective emergency management of the condition.

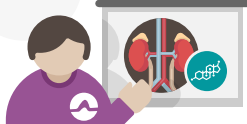
Our typical impact in a year:

2500+



2500+ ADSHG
members supported

900+



900+ paramedics trained in
Adrenal Crisis Management

12+



12+ awareness stands
held across the UK

35K+



35k+ people reached
on Social Media

10+



10+ research
projects supported



As many member events
organized & medical
conferences attended as
resources allow!

WHAT OUR MEMBERS THINK OF US:

// The single most useful thing after diagnosis of adrenal insufficiency was becoming a member of ADSHG. Thankyou so much.



// Our membership has been a lifeline.



// Without this group, there would still be so much ignorance surrounding Addison's and adrenal insufficiency, including within the medical sector. Thank you ADSHG for helping to support and save lives.



// Such a huge source of advice and support since my diagnosis. I can't thank ADSHG enough...



// Diagnosed during COVID I was told I had Addison's, then I picked up a prescription, that was it. I've learnt everything from your website.



// If I hadn't found your website I don't know what I would have done. I didn't know the emergency injection existed. I used it for the first time last week. If me and my family hadn't known about it I dread to think about the outcome.



// The ADSHG has given me the tools to take my life back.



Your support helps us
grow our impact further



HOW YOU CAN SUPPORT US?

We rely on membership fees, donations and fundraising to allow us to continue the essential work we carry out. If you would like to support us you can:

Scan to donate to the ADSHG



We are grateful for any amount, as a one-off or regular donation:

- £33** allows us to offer a sponsored membership to someone who otherwise couldn't afford to join.
- £50** allows us to print 150 leaflets.
- £100** allows us provide 7 branded t-shirts to fundraisers.
- £350** allows us to host a Paramedic Adrenal Crisis Management training webinar.
- £1k** allows us to attend a medical conference to represent your voice.

Scan to join the ADSHG from £33/yr



Fundraise for us

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

fundraising@addisons.org.uk

Volunteer for us

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

enquiries@addisons.org.uk

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:

Prof John Wass

Chair of ADSHG Clinical Advisory Panel
Churchill Hospital, Oxford

Last Reviewed: **March 2026**

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