



About the Addison's Disease Self-Help Group

The Addison's Disease Self-Help Group was founded by Deana Kenward in 1984, just a few years after her diagnosis. What began as a newsletter hand-written at her kitchen table and posted out to a handful of fellow patients grew, over the years, to become the national UK patient support group. Over time, Deana was joined by others who also wanted to make a difference to the lives of their fellows. Out of this came the move to a formally elected trustee body and full accreditation as a registered charity in November 2004.

In Addison's disease, the adrenals cease to produce certain hormones essential for life, so that medication has to be taken at least twice daily at carefully timed intervals. With the right balance of daily medication and good medical support, individuals with Addison's can expect to live a normal life span and to lead full and rewarding lives. But they are also likely to need emergency medical intervention to prevent a near-death adrenal crisis at some stage.

Everything the ADSHG has done has been achieved by the voluntary efforts of people living with this rare, potentially fatal endocrine condition. The group is too small to pay anyone for their time and skills, and has no office space. Instead, the group has benefited from the generous contributions of people with Addison's, their families, and doctors around the UK, who have contributed to the group from their own homes, in their own time. The group is self-help in name and self-help in deed.

The group offers its members:

- A newsletter, published four times a year, available in print and PDF format
- An internationally-recognised website
- An electronic discussion group
- An annual medical lecture, regional seminars and social meetings
- A range of patient education materials, written by leading adrenal specialists

For information about the work of the Addison's Disease Self-Help Group, to join the group or to make a donation, please visit our website at www.addisons.org.uk

About our patient education and support materials

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

We work in co-operation with some of the UK's leading adrenal specialists to promote broader medical understanding and effective management of this rare condition. For example, we have worked together to develop simple guidelines for the treatment of adrenal emergencies (see picture).



We make all of our patient education materials freely available on our website at www.addisons.org.uk. This information can help people and their families to obtain the treatment they needed in an emergency, preventing adrenal crisis. Newly-diagnosed individuals and their families often find our website a valuable source of information and reassurance.

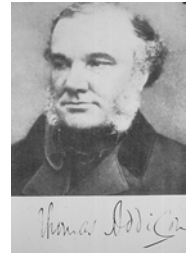


A brief history of Addison's disease:

1850's: the deadly loss of adrenal hormones is discovered

When Dr Thomas Addison first identified adrenal failure among his poor, tuberculosis-ridden patients in inner London in 1849, there were no medicines to keep such patients alive. Death inevitably followed within a short time. This is because two of the hormones produced by the adrenal glands – cortisol and aldosterone – are essential for life.

The condition of adrenal failure is named after the good Dr Addison. Whereas in Victorian London it was largely caused by a reaction to tuberculosis infection, in modern-day Britain it is mostly 'autoimmune' – of unknown origin.



It is fashionable to describe cortisol as the “stress hormone” and there are many popular journalistic articles to inform you that too much cortisol is bad for you. But only rarely will you find it explained that too little cortisol is just as damaging, leading to extreme muscle weakness, difficulty standing up, nausea, vomiting and, eventually, to a loss of consciousness and an early death. Typically, this severe but non-specific illness is accompanied by a deepening skin colour, so that a very sick individual can look deceptively healthy – fashionably thin and tanned.

The 20th century development of life-giving medication

It was not until the 1930s that scientists in the United States synthesized a chemical form of the vital adrenal hormone - cortisol - that could keep patients with Addison's disease alive. President John F Kennedy was one of the first to receive the new miracle drug, cortisone. It was not until the early 1950s that cortisone became available in commercial quantities in the UK.



Some of the first 'generation' of post-war Addison's patients are still with us today, now in their 60s or 70s. Pat Beeching, a member of the Addison's Disease Self-Help Group, recalls that her early Addison's medication was so expensive it required the personal authorisation of the Minister of Health for her to receive it. Today, a year's supply of Pat Beeching's essential, life-giving adrenal medication costs the NHS less than £52.00.

It is possible to lead a 'normal' life with Addison's

With the right balance of daily medication, people with Addison's disease can lead full and active lives. In 2006, Steve Dale completed both the **Bristol and Bath half-marathons**. Nick Willson went trekking in the **Himalayas**.

The deadly risks of adrenal crisis

Yet living with Addison's disease is not all plain sailing. The daily medication needs to be taken two or three times each day, at the right time of day. A delay of two hours in taking the next dose will see many people with Addison's disease become weak or dizzy, possibly nauseous and forgetful. In the event of serious illness or injury, extra medication is needed rapidly, and an emergency injection of 100mg hydrocortisone may be required. Without this extra medication, the patient may experience adrenal crisis. This is a life-threatening condition with a rapid drop in blood pressure, potentially leading to cardiac arrest or stroke.



Addison's disease: how rare is it?

The most recent research puts the rate of diagnosed, treated Addison's disease among European populations at 140 per million, or around 8,400 cases in the UK. This makes it roughly two hundred times more rare than diabetes, another endocrine condition which sometimes develops along with Addison's.

For further information about the work of the Addison's Disease Self-Help Group, to join the group or make a donation, please visit our website at www.addisons.org.uk