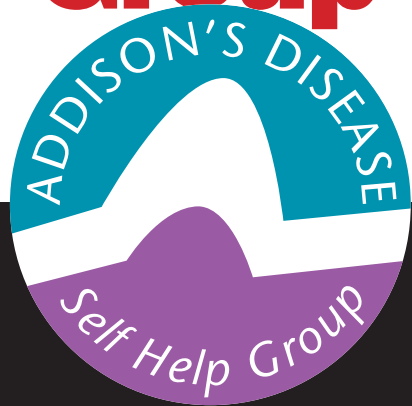


About the Addison's Disease Self-Help Group



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.

WHAT WE DO

The Addison's Disease Self-Help Group is the UK support group for people with Addison's and their families. First started in 1984, the group is now a registered charity governed by a body of elected trustees, which works to support its members with adrenal failure and to promote better medical understanding of this rare condition.

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

WHY OUR WORK IS IMPORTANT

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.

HOW WE STARTED

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 2004.

HOW WE WORK TODAY

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 maintain a paid staff 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.

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 & SUPPORT MATERIALS: WORKING IN CO-OPERATION WITH MEDICAL PRACTITIONERS

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 with our Clinical Advisory Panel to develop simple guidelines for the treatment of adrenal emergencies (see picture). Our Clinical Advisory Panel has developed a range of guidance leaflets for patients, their GPs and surgical teams explaining the best approach to medication and lifestyle management and associated issues.

We have also worked with ambulance trusts and the national ambulance clinical regulatory committee so that paramedical crews are now able to give hydrocortisone injections to prevent or treat adrenal emergencies.

We make all of our patient education materials freely available on our website. This information can help people and their families to obtain the treatment they need in an emergency, preventing adrenal crisis. Newly-diagnosed individuals and their families often find our website a valuable source of information and reassurance. To read our patient education materials, or to make a donation towards their development and production, please visit

www.addisons.org.uk



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

The Addison's Disease Self-Help Group works to support people with adrenal failure and to promote better medical understanding of this rare condition. Registered charity 1106791.



www.addisons.org.uk

WHERE CAN I GET FURTHER INFORMATION?

Information and support are available from the Addison's Disease Self-Help Group (ADSHG), a registered charity run by and for people with Addison's.

For a small annual subscription, the group offers: an information manual, emergency card, print newsletter, electronic discussion group, website, seminars and meetings.

Please contact: **ADSHG information,**
PO Box 1083, Guildford GU1 9HX.
Email: info@addisons.org.uk
Website: www.addisons.org.uk

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. Only in the early 1950s did cortisone become 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. One founder 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, modern manufacturing technology means that her essential, life-giving adrenal medication is inexpensive; a year's supply only costs the NHS around £55.



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 welcome suggestions and feedback on our activities. Please contact trustees@addisons.org.uk to let us know how we are doing or to discuss fundraising on our behalf.

Registered charity 1106791.

www.addisons.org.uk

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. Within the past few years, members of the ADSHG have completed half-marathons and long-distance sailing voyages, been trekking in the Himalayas, gone sky-diving and bungee-jumping.

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 more information about the nature of Addison's disease, how it is diagnosed and treated, please visit our website at www.addisons.org.uk