



Your Guide to Gifts in Wills

Leaving a lasting legacy for the Addison's and adrenal insufficiency community.



Most of us want to be remembered for something special; to know we have left our mark, and even left the world in a better place. The legacy you leave in your will is an opportunity to have your voice heard, and make a final impact.

// In loving memory. May everyone with Addison’s disease get the help and support they need, throughout the world.

Addison’s disease is a type of adrenal insufficiency. It is a rare, potentially fatal condition, where the adrenal glands cease to function. Life-long treatment with replacement steroid hormones is required.

The Addison’s Disease Self-Help Group (ADSHG) was founded in 1984 by Deana Kenward MBE, after her diagnosis with the condition, and realisation that, at that time, there was almost no information about it, and even less support. She founded the charity to help members support each other and share

information. In more recent years, our strategy is to help members manage their own condition and set them on a journey to become an ‘expert patient’, to raise awareness within the medical community and to help advance medical research that would benefit those with Addison’s and adrenal insufficiency.

Since its founding, the charity has contributed significantly to improvements in the treatment and quality of life of individuals with Addison’s and adrenal insufficiency, and, with your help, can continue to do so into the future.



Support

Providing resources and building a community that helps people self-manage their AD and AI and improve their quality of life.



Connect

Making it possible for the voice of people with AD and AI 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.

SUPPORT

With just 1 in 10,000 people diagnosed with Addison's disease, it is recognised as a rare condition.

Everyone with Addison's or adrenal insufficiency is on their own personal journey. Some people with Addison's and other adrenal conditions can enjoy levels of fitness and general health similar to the wider population with the right medical support and balance of daily medication. Others have additional or ongoing challenges to face, and a diagnosis of Addison's can, at times, feel like a lonely experience.

The Addison's Disease Self-Help Group is here to support its members and the wider Addison's and adrenal insufficiency community, to ensure that no one feels alone.

We do this through: annual member events, local member gatherings and regular member communication. Our online forum offers peer support and experience, on top of our freely accessible and informative website, with information advised on and checked by our Clinical Advisory Panel.

CONNECT

The ADSHG works with leading adrenal specialists to promote good clinical practice and to enable peer learning and support among individuals with Addison's and adrenal insufficiency.

Our presence at medical conferences and our proactive engagement in patient safety issues through dialogue with national bodies such as the Society for Endocrinology (SfE), NICE, Genetic Alliance and Joint Royal Colleges Ambulance Liaison Committee (JRCALC),

aims to ensure that those with adrenal insufficiency receive the correct essential clinical care during acute illness and surgery, or community healthcare, with the goal of preventing life-threatening adrenal crisis.

We also provide regular Adrenal Crisis Management Training sessions to Paramedics across all the UK ambulance trusts and services, giving them increased knowledge and confidence to support patients in an emergency situation.

ADVANCE

We work with researchers to advance the medical understanding of the role of cortisol in the body, and its patterns of production. We are available to offer them our endorsement towards grant funding in applications and ethics and safety approvals, as well as engaging our community to support individual projects. We offer insight into the patient 'lived experience', enabling clinicians to better understand the realities of life with a diagnosis of Addison's and adrenal insufficiency.

We also offer small medical research grants and awards to advance good clinical practice in the diagnosis and management of adrenal conditions. The charity's approach to medical research grants is to offer small grants towards hard costs such as laboratory processing charges, to allow clinicians to innovate

// Our grandson has Addison's which has changed all our family's lives. Please accept this gift and good health to you all.

in areas of practical application around therapeutic approaches to patient management.

Some of the past projects funded by ADSHG can be found on our research page of the website:

**Scan for
our research projects**



MAKING A DIFFERENCE

We rely on membership fees, individual donations, fundraising and legacy income to continue the impactful work we do and to support research to change the future for the Addison's and AI community.

As a charity supporting a rare disease community, we inevitably struggle to attract donations from the wider public. Most of those who support our work have Addison's or adrenal insufficiency, have a family member with the condition or have lost a loved one to an adrenal crisis.

Medical and community awareness have made great strides since the ADSHG became a charity in 2004; the implementation of the NHS Steroid Emergency card, the JRCALC guidelines for Paramedics, and more recently, the publication of the NICE guidelines into the identification and management of

adrenal insufficiency, but there is still so much to be done.

As someone who recognises the need for the ADSHG to continue its vital work, we hope you will consider leaving a gift in your will and help us to improve the future for the Addison's and adrenal insufficiency community.

// My beautiful, caring, loving daughter passed away aged 25 years with Addison's and in her courageous honour we would like to continue to support the ADSHG in their hard work.

THANK YOU

The ADSHG is so grateful to everyone who supports its work. The size of your gift is of less significance to us than knowing that you value and support what we do; to make the world a safer and more supportive place for those with Addison's and adrenal insufficiency.

For other ways to donate, please visit our website **addisonsdisease.org.uk/donate** or get in touch with us at **fundraising@addisons.org.uk**

Memory Giving and Much Loved: we are a registered charity at Memory Giving and Much Loved, websites used by many funeral directors.

The ADSHG adheres to the Code of Fundraising Practice and is registered with the Fundraising Regulator.

FREQUENTLY ASKED QUESTIONS (FAQs)

I want to make a gift in my will to the ADSHG. What do I do next?

Making a will, or updating an existing will, can be straightforward, but it is advisable to do it through a solicitor to ensure that everything is legally correct. If you would prefer to make your own will, then it would still be advisable to have it checked by a solicitor.

You can alter an existing will by adding a codicil or make a new will and choose the type of donation that you would want to make. You must clearly identify the charity as the beneficiary of your gift, so you need to provide your solicitor with the ADHSG's registered details and ensure they are clearly recorded:

Name: Addison's Disease Self-Help Group

Charity number: 1179825

Registered Address:

117 Kingsley Avenue, Rugby, CV21 4JZ

A residuary legacy, for example, might say:

I direct that the receipt of the Treasurer or duly authorised officer shall be a valid and appropriate form of discharge.

All donations, whether made in a codicil or through a new will, should be followed with this statement:

I give the (% in words) of the residue of my estate to the Addison's Disease Self-Help Group, registered charity 1179825, 117 Kingsley Avenue, Rugby, CV21 4JZ, to be used for its general and charitable purposes.

Is it worth leaving just a small amount or a % of my estate to charity?

Absolutely. As a small charity with big goals, we are deeply grateful for every donation.

Even a modest percentage of your estate could help change the lives of people living with Addison's or adrenal insufficiency, now and in the future.

What difference can your gift make?

● Under £100

Provides 'Sponsored Memberships' for people facing severe financial hardship, giving them vital support and connection.

● £400 - £500

Funds essential training for healthcare professionals, including paramedics, so they can recognise and respond to adrenal crises quickly and safely.

● £1,000 - £5,000

Supports member events that bring our community and medical professionals together, raising awareness and understanding of adrenal insufficiency, including Addison's disease.

● Over £5,000

Contributes to groundbreaking research aimed at improving the quality of life for people with this rare disease. For the latest research projects we are supporting, please visit: addisonsdisease.org.uk/supported-research-projects

Whatever you are able to give, your gift will leave a lasting legacy of hope, support, and progress for people with Addison's disease and adrenal insufficiency.

What are the different options to leave a gift in my will?

Residual legacy

This is a gift of the remainder of your estate after all the other gifts have been made and any debts cleared. This type of legacy can be expressed as a proportion of your residual estate, when there is more than one charity you wish to support.

Pecuniary legacy

This is the gift of a fixed sum of money in your will. If you decide to leave a fixed sum, it is worth considering whether to include a clause allowing for inflation adjustments over time.

How will my family feel about me leaving a gift in my will to the ADSHG?

Family and friends must come first when it comes to ensuring their needs are met and it's usually a good idea to let them know about your wishes.

Once they're all looked after, you may find family members would be proud of you leaving a legacy to charity, to remember the causes close to you.

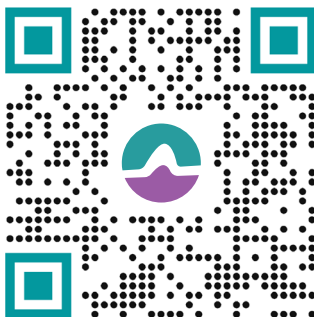
Where do I go for more information?

For clear and detailed steps on writing a will, and including a charity in your will, refer to Remember A Charity for information.

Scan for
RememberACharity.org.uk



Scan for
gov.uk/make-will



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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