



Huntington's
Disease
Association

*Legacy and Supporter Relationships
Manager*

About the Huntington's Disease Association

What is Huntington's disease?

Huntington's disease is a life-limiting, genetic disorder that causes the breakdown of nerve cells in the brain.

It is caused by a faulty gene and is passed down through families. If a person inherits the gene they will develop the disease. Every child conceived naturally to a parent who carries the Huntington's gene has a 50% chance of inheriting it.

Huntington's leads to symptoms affecting three main areas, movement, behaviour and cognition.

Although there is, as yet, no cure, some symptoms can be managed to improve the person's quality of life.

What do we do?

The Huntington's Disease Association provides specialist support to people affected by Huntington's disease across England and Wales.

The charity was founded in 1971 after a family who had been given a diagnosis of Huntington's put a letter in the local paper asking if anyone knew of any other families in a similar situation. It began as a self-help group with 76 members and was known initially as the Association to Combat Huntington's Chorea, later becoming the Huntington's Disease Association.

We raise awareness of Huntington's disease and offer practical advice and support, training to health and social care professionals and fund research into the disease. We want a better life for anyone affected by Huntington's disease.

Approximately 8000 people in the UK are currently living with Huntington's disease



We support over 8000 people in England and Wales



A further 32,000 are at risk of developing the disease



HDYES support over 700 individuals



We have a membership of over 5000 people, both Huntington's disease family members and professionals.



28k people visit our website each month



Our VISION

Together we will build a better life for anyone affected by Huntington's disease.

Our MISSION

To enable everyone affected by Huntington's disease to live life to their full potential by:

- *Improving care and support*
- *Educating families and the professionals who work with them*
- *Championing the needs of the Huntington's community by working together*
- *Influencing decision-makers to tackle discrimination and secure equity of access to services*

Our VALUES

We are:

Tenacious, Experienced, Compassionate, Inclusive, Inspirational



We will ensure everyone affected by Huntington's disease gets the care and support they need



We will help make each day with Huntington's disease the best possible day



We will make sure the voices of people affected by Huntington's disease are heard and are at the heart of everything we do



We will not rest until everyone with Huntington's disease has access to treatments



We will be a resilient charity

Job description

Job title:

Legacy and Supporter Relationships Manager

Job type:

Permanent, full-time, 35 hours per week

Responsible to:

Head of Fundraising

Office location:

Hybrid role (minimum two days in Central office, Liverpool)

Salary:

£35,200 per annum

Job purpose:

To steward and grow relationships with our individual supporters across every stage of their journey with the Huntington's Disease Association - ensuring that however someone first connects with us, they feel known, valued and inspired to stay with us for life.

This role leads on legacy and in memory fundraising, two areas of significant strategic importance to us, whilst sustaining and developing our wider base of individual donors through appeals, regular giving and digital communications.

Working closely with colleagues across fundraising and communications, you will help ensure that every supporter feels genuinely connected to our cause and to the community of people whose lives are shaped by Huntington's disease.

The Legacy and Supporter Relationships Manager is part of a small, collaborative fundraising team comprising a Trusts and Foundations Manager, a Community Fundraising Coordinator, a National Activity Events Coordinator and a Fundraising Administrator. The Head of Fundraising leads on corporate partnerships, major donors and fundraising strategy. Each team member works with a degree of autonomy whilst contributing to shared income goals and a collective approach to supporter care.

Main duties

Legacy fundraising

To develop and deliver a programme of legacy fundraising that builds long-term income for HDA. This includes:

- Monitoring Smee & Ford for new legacy notifications and managing all correspondence with solicitors and executors across our active estates in a professional and timely manner
- Recording and maintaining accurate legacy records on Donorfy and the First Class portal, and filing all relevant documentation
- Notifying the CEO and relevant trustees of new notifications, estate accounts and other significant updates
- Adding legacy gifts to Donorfy and ensuring solicitors and executors receive appropriate acknowledgement for their role in administering estates
- Developing and delivering a legacy marketing programme that builds awareness of gifts in wills, cultivates prospective pledgers and stewards existing pledgers with meaningful, personalised communication
- Monitoring the Free Wills Network for new referrals and pledges, maintaining accurate records on Donorfy and ensuring pledgers receive appropriate acknowledgement and ongoing stewardship
- Identifying opportunities to convert engaged long-term supporters into legacy pledgers, using supporter data and insight to inform approach In Memory Giving

In Memory giving

To steward and develop our in memory giving programme, recognising the particular sensitivity required when working with bereaved families and the long-term potential of these relationships. This includes:

- Building sustained and sensitive relationships with next of kin beyond the initial acknowledgement, deepening their connection with our charity over time
- Developing in memory giving as a growing income stream, identifying opportunities to improve the supporter experience and increase income
- Working with the Communications team to ensure in memory giving content across digital channels and the website is appropriate, up to date and compassionately presented

Individual Giving - Stewardship and development

To sustain and develop our individual giving programme, ensuring donors at every stage of their journey feel valued and engaged. This includes:

- Stewarding and retaining our existing base of regular and single donors, ensuring they receive warm, timely and relevant communication throughout the year
- Monitoring retention indicators across the individual giving portfolio, identifying and responding proactively to any signs of lapsing
- Using supporter data and insight (including findings from our ongoing supporter research) to improve segmentation, personalisation and the overall donor experience
- Identifying opportunities for supporter upgrade and conversion, recognising that many of our supporters move through multiple giving relationships with us over the course of their lives

Appeals and mailings

To lead on the planning and delivery of our fundraising appeals and impact communications. This includes:

- Project managing a small number of fundraising appeals across print and digital channels, and our impact report mailings, working with the Communications team on creative development, our data manager on segmentation and coordination of the mailing house
- Writing compelling fundraising copy that reflects the deeply personal nature of our cause and the long-term relationships our supporters have with our charity.

Digital donor journeys

To ensure our digital supporter communications are active, personalised and of the same quality as our print-led activity. This includes:

- Working closely with the Communications team on digital donor journeys, including onboarding and email stewardship, providing clear fundraising briefs and sign-off on fundraising content
- Ensuring individual giving is actively and consistently promoted digitally, identifying opportunities in collaboration with Communications across email and social media channels
- Using supporter segmentation to ensure digital communications are relevant and personalised to different donor groups and stages of the supporter journey

Cross team collaboration

- Working collaboratively with the Community Fundraising and National Activity Events Coordinators to ensure that supporters who both fundraise and give individually receive joined-up, consistent stewardship, with clear mutual respect for each colleague's supporter relationships
- Contributing positively to a team culture of shared ambition, open communication and collective problem-solving

Reporting and income accountability

- Monitoring and reporting regularly on individual giving income performance, contributing to the fundraising team's collective accountability for income goals
- Maintaining accurate and up to date records across all individual giving activity in Donorfy, ensuring data integrity and GDPR compliance

Other duties

- Attend and contribute to team and charity-wide meetings.
- Be familiar with and adhere to relevant legislation.
- Work collaboratively with colleagues from other teams across the organisation.
- Understand our obligations under the Data Protection Act, Fundraising Codes of Practice and Information Commissioner's Office in relation to data management, and ensure the Huntington's Disease Association acts in accordance with legislation.
- Respect the confidentiality of all information obtained whilst working for the Huntington's Disease Association.
- Work in a manner that facilitates inclusion, particularly of people affected by Huntington's disease.
- Carry out other tasks as directed by your line manager.



General

All applicants must be able to demonstrate the right to work in the UK and are subject to a three-month probationary period.

Details of how data provided as part of the recruitment process is securely handled can be found in our [privacy notice for job applicants](#) on our website.

This job description is a representative document. Other reasonably similar duties may be allocated from time to time commensurate with the general character of the post and its grading.

Out of pocket expenses including travel and mileage allowances will be paid on receipt of appropriate claim forms and invoices/receipts. The post holder will be expected to work across the areas stated in their role title and job description, but may be required to work anywhere in England and Wales as the needs of the service dictates. There will be occasional overnight stays. Time will normally be taken back in lieu of hours worked.

This post is exempt from the provisions of Section 4(2) of the Rehabilitation of Offenders Act 1974 (Exceptions) Order 1975. You are therefore not entitled to withhold information about convictions which for any other purposes are 'spent' under the provisions of the Act. Any failure to disclose such convictions could result in dismissal or disciplinary action by the Huntington's Disease Association. Any information given will be completely confidential and will be considered only in relation to the positions to which the Order applies.

The holder of this post is required to hold an enhanced DBS (Disclosure and Barring Service) certificate (at the expense of the charity).

All staff are responsible for the implementation of the Health and Safety Policy so far as it affects them, their colleagues and others who may be affected by their work. The post holder is also expected to monitor the effectiveness of the health and safety arrangements and systems to promote improvements where necessary.

The post holder will be expected to undertake training and retraining throughout employment in this post and will be expected to discuss and identify their training goals, with their line manager, to develop their knowledge base and ability in their role.

Person specification

	Essential or Desirable
Experience, knowledge and skills	
Demonstrable experience in individual giving fundraising, with experience across at least two of the following areas: legacy marketing, in memory giving, fundraising appeals, regular giving	E
Strong project management skills, with experience of taking fundraising or communications projects from brief through to delivery	E
Excellent written communication skills with the ability to write warmly, compellingly and sensitively for a fundraising audience	E
Confident and accurate working with a CRM system, including maintaining data quality, running reports and using data to inform stewardship decisions	E
Digitally confident and able to work effectively with an email platform, contribute to digital donor journeys and understand the principles of digital stewardship	E
Highly organised and self-sufficient, with the ability to manage a varied and sometimes emotionally demanding portfolio of work in a small team environment	E
A clear understanding of and commitment to income accountability - comfortable contributing to and reporting against individual giving income performance	E
A genuine commitment to relationship-led fundraising and an understanding of the particular value of long-term donor stewardship in a cause with a close-knit, personally connected community	E
Experience of legacy fundraising specifically, including legacy marketing and/or the administration of estates going through probate	D

	Essential or Desirable
Experience of in memory fundraising and working sensitively with bereaved families	D
Experience of working in a small charity or with a cause community where supporters have a deep and personal connection to the work	D
Familiarity with Donorfy or a comparable CRM system	D
Familiarity with Mailchimp or a comparable email platform	D
Personal qualities	
Warm, empathetic and emotionally intelligent. Able to communicate with authenticity and sensitivity with supporters who have a deeply personal connection to Huntington's disease	E
Resilient and pragmatic - comfortable with the breadth of a small team role and able to work independently without significant infrastructure around them	E
Collaborative and collegial - a genuine team player who builds trust across the organisation and works openly across teams	E
Proactive and curious - interested in understanding supporters more deeply and motivated by finding ways to improve their experience of Huntington's Disease Association	E

	Essential or Desirable
Other	
A satisfactory level of attendance.	E
Experience of working in a modern digital workplace.	E
A private and confidential workspace within your home.	E
Understand the benefits of diversity and inclusion and have a personal interest in finding solutions to increase diversity	E
Car owner with access for work purposes and hold a legal UK driving licence. Willingness to use public transport where more appropriate. <i>NB Vehicles must be: (i) subject to statutory inspections; (ii) serviced regularly; (iii) maintained in a good condition; and (iv) subject to adequate user checks. Staff using cars for work must have business insurance. It is also recommended that a vehicle recovery service is engaged.</i>	D

Employment benefits



Medicash

Discounted Health Club Membership

Health and stress related support through a 24-hour helpline

Skin vision - skin health related tracker

Virtual GP and prescription service

Optical care

Routine dental treatments



Salary deduction travel to work scheme

Interest-free loan of up to £10,000 per year to cover the cost of a season ticket for your travel to and from work. Repayments can be spread over 12 months. Central office staff only



Salary deduction workplace parking scheme

Interest free loan to cover the cost of your parking permit. Repayments can be spread over 12 months. Central office staff only



Salary sacrifice cycle to work scheme

Receive a brand new bike and cycling accessories of your choice for use in commuting to and from work. Deductions are taken from gross salary providing tax savings. Central office staff only



Enhanced annual leave entitlement

25 days plus bank holidays (pro rata) plus 3 hour shutdown on Christmas Eve and New Year's Eve, plus 1 additional days' leave (pro rata) as a Wellbeing/Cultural day



Working from home allowance

For fully remote staff - annual payment



Learning and development opportunities

Both organisation-wide and individual training



Flexibility

Working arrangements flexible to meet the needs of our employees



Pension

3% employer contribution to workplace pension



How to apply

If you would like to be considered for this role, please apply below.

To ensure your application is considered, please upload both your CV and a cover letter. Your cover letter should include why you are applying for the role and how you meet the requirements of the person specification.

Applications submitted without a CV and cover letter will **not** be considered.

[Apply here](#)

As an organisation we value diversity and we are committed to equal opportunities in our recruitment process. Should you need any adjustments at any stage of the recruitment process, please contact us via recruitment@hda.org.uk or 0151 331 5444 (option 4). We collect monitoring data via a form sent to you following your application to ensure our recruitment processes are inclusive and reaching a diverse range of candidates. This will not form part of the selection process in any way, the data collected will be used for monitoring purposes only and the completion of the form is voluntary.

The Huntington's Disease Association is looking for someone with the ability to work in a way that promotes the safety and wellbeing of adults at risk, children and young people. We follow safer recruitment practices to ensure we are safeguarding the people we work with. We require the successful candidate to provide two employment references and undergo a Disclosure and Barring Service (DBS) check for enhance disclosure before joining the charity.

Full details of how we securely handle the data you provide to us as part of the recruitment process can be found in our [privacy notice for job applicants](#) on our website.

Closing date for applications is Monday 17 August 2026, 5pm.

**First round interviews will be held online on Thursday 3 September 2026.
Second round interviews will be held in-person in Liverpool on Friday 11 September 2026**

Get in touch

For further information about the role contact us

email **recruitment@hda.org.uk**

phone **0151 331 5444 (option 4)**

Further information

For further information about Huntington's disease and the charity

www.hda.org.uk



@hda_tweeting



@hdauk



@hdauk



@hda_uk



Huntington's Disease Association

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A company limited by guarantee.

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Registered office - Huntington's Disease Association,
Liverpool Science Park IC1,
131 Mount Pleasant,
Liverpool, L3 5TF

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Inspired by our community