



Huntington's  
Disease  
Association



*Volunteer 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:**

**Volunteer Manager**

**Job type:**

Permanent, 35 hours per week (Full-time)

**Responsible to:**

Head of Services

**Areas covered by role:**

England and Wales

**Office location:**

Home -based, with travel throughout England and Wales

**Salary:**

£30,000 per annum

**Job purpose:**

The Volunteer Manager works with and inspires those who volunteer for the charity. They lead volunteers in line with the vision, mission and values of the charity and work with them to fulfil the goals of our strategic plan. The Volunteer Manager plays a leading role in strengthening the charity's current volunteering strands, making sure that effective governance and great communication is upheld at all times. They are also responsible for helping to develop other volunteering opportunities within the charity.

The Volunteer Manager provides support to our volunteer-led Branches and Support groups who enable people affected by Huntington's disease to access peer support and become involved in different activities locally.

The Volunteer Manager also supports HD Voice, a panel of volunteers, who contribute to the internal development of the charity and ensure that patient voice is integral to the development of Huntington's disease research.

The charity has a number of volunteers who help on an ad-hoc basis, such as at camps, events and with fundraising activities and the Volunteer Manager role is integral in supporting them throughout their volunteer journey.

The role involves regular travel and some out of hours work during evenings and weekends, due to many volunteer activities taking place at these times around day to day work and caring commitments.

# Main duties

- Develop a volunteering strategy, including a plan to recruit a diverse range of volunteers.
- Coordinate all aspects of the volunteer journey from recruitment, selection, induction, training and ongoing individual support to volunteers to ensure that volunteers feel connected, engaged, valued and they understand the purpose of their volunteering role and how it fits with the vision, mission and values of the charity.
- Liaise with our Operations team to ensure DBS checks on current and potential volunteers are undertaken as part of the screening process.
- Develop effective policies, procedures and guidance for current and future volunteers and ensure that all volunteers understand their roles and responsibilities and work in line with policies, procedures and guidance.
- Maintain a high standard of accurate and up to date records and undertake necessary administrative procedures, including logging and monitoring of enquiries received centrally.
- Develop a Monitoring and Evaluation process, which enables effective monitoring of the different volunteering strands, measuring outputs and impact and supporting the growth and expansion of volunteering at the charity.
- Create peer support opportunities for volunteers so that they can share experiences and learn from each other.
- Create and run a robust volunteer induction and an ongoing training programme.
- Work in a way that promotes safety and wellbeing and identify and act appropriately, where issues of risk, including safeguarding arise, referring to relevant leads and agencies where appropriate.
- Answer all responses to external and internal queries to HD Voice from staff or researchers who want to use the group to embed patient voice and link volunteers to specific research projects where volunteer support is required, acting as key point of contact with research teams and the charity's communications team.
- Ensure that co-production and service user voice is at the heart of volunteering.
- Work with our communications team and input into regular communications for our volunteers.
- Co-ordinate the Branch and support group financial returns on an annual basis as part of year-end processes.
- Help to develop other volunteering opportunities within the charity.

# Other duties

- Plan and participate in staff supervision and reflective practice, and personal annual appraisals as required.
- 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 and Fundraising Codes of Practice about 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 are paid on receipt of appropriate claim forms and invoices/receipts in line with relevant policies.

The post holder is expected to work in the areas stated above, but may be required to work anywhere in England and Wales as the needs of the service dictates. There is an expectation that the post holder will work occasional evenings and weekends. Time is normally 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. The post holder is therefore not entitled to withhold information about convictions which for any other purposes are 'spent' under the provisions of the Act. Failure to disclose such convictions could result in dismissal or disciplinary action by the Huntington's Disease Association. Any information given is completely confidential and considered only in relation to the positions to which the Order applies.

The successful applicant is required to complete an online enhanced DBS (Disclosure and Barring Service) application prior to joining the charity. This is completed 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 is expected to undertake training and retraining throughout their employment and is expected to discuss and identify their training goals, with their line manager, to develop their knowledge base and ability in their role.

# Person specification

	<b>Essential or Desirable</b>	<b>How identified</b>
<b>Experience</b>		
Strong volunteer management skills	E	Application and interview
Strong relationship management skills	E	Application and interview
Experience of writing policies, procedures and guidance in line with data protection guidance	D	Application and interview
Confident with numbers and able to support volunteers with budgeting, forecasting and financial reporting	E	Application
Experience of operating in a modern digital workplace using a data entry system and digital tools to work collaboratively and productively	E	Application
Experience of working in a Patient and Public Involvement setting	D	Application
<b>Knowledge and skills</b>		
Knowledge of the effects of a long term disability on individuals and families/carers	D	Application
Skilled communicator at all levels with effective written and verbal communication	E	Application and interview
Facilitation and engagement skills with the ability to work in an inclusive and user focused way	E	Application and interview
Ability to work collaboratively across a dispersed team of staff and volunteers	E	Application and interview
Use strong IT skills to keep accurate and up to date admin/records in line with policy and current data standards	E	Application

	<b>Essential or Desirable</b>	<b>How identified</b>
The ability to work in a way that promotes the safety and wellbeing of adults at risk, children and young people	E	Application and interview
Ability to manage and organise own workload	E	Application
Ability to present training sessions to volunteers	E	Application and interview
<b>Other</b>		
Ability to work alone and as part of a team	E	Application and interview
A satisfactory level of attendance Friendly and approachable, able to build and maintain strong working relationships	E	Application
Understand the benefits of diversity and inclusion, and have a personal interest in finding solutions to increase diversity	E	Application and interview
Car owner with access for work purposes and hold a legal UK driving licence	E	Application and interview
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. It is also recommended that a vehicle recovery service is engaged</i>	E	Application and interview

# 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*



## Generous annual leave

*25 days plus bank holidays (pro rata) plus 3 hour shutdown on Christmas Eve and New Year's Eve*



## Tax-free 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](mailto: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 Friday 3 May 2024, 5 pm.**

**Interviews will be held Friday 17 May 2024.**

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## Get in touch

For further information about the role contact us

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

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

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## Further information

For further information about Huntington's disease and the charity

**www.hda.org.uk**

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 Huntington's Disease Association

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Liverpool Science Park IC1,  
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Liverpool, L3 5TF

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*Inspired by our community*