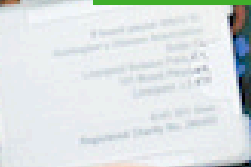




Huntington's  
Disease  
Association

*Specialist Huntington's Disease Adviser*



# 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:**

**Specialist Huntington's Disease Adviser**

**Job type:**

Permanent, 21 hours per week (Part Time)

**Responsible to:**

Team Leader – Advisory Service

**Areas covered by role:**

Merseyside and Isle of Man

**Office location:**

Home-based mobile working

**Salary:**

£21,716.55 per annum (£36,194.25 FTE)

**Job purpose:**

- Provide a professional, confidential and informative support service to people affected by Huntington's disease, including families, carers, and professionals.
- Offer support in sometimes complex cases, and to work with other professional agencies such as health, social care, multi-disciplinary teams and specialist Huntington's clinics to offer support.
- Provide information, support and training to professional agencies.
- Identify and support services suitable for people with Huntington's disease and their carers and families.
- Support local volunteer-led support groups and branches.

# Main duties

- Provide a professional, confidential and informative support service to people affected by Huntington's disease, including families, carers, and professionals. This will be achieved by telephone, and other virtual methods, some direct (home) visits and through attendance at specialist Huntington's clinics.
- Undertake a confidential needs-led assessment of the individual and/or carer, in consultation where necessary with other agencies.
- Work in a way that promotes safety and wellbeing. Identify and act appropriately where issues of risk, including safeguarding, arise and refer to the relevant leads and agencies where appropriate.
- Negotiate care and support to ensure the best possible service is provided by the appropriate agencies, monitoring the quality and effectiveness of service provision, and advocating where necessary on behalf of the recipient of services.
- Deliver training and information for professionals, ensuring that they have a comprehensive understanding of the needs of people affected by Huntington's disease.
- Organise and facilitate educational and peer opportunities for families and professionals.
- Promote and raise awareness of Huntington's disease and the Huntington's Disease Association.
- Establish new peer support opportunities where a need is identified and to promote the online support services facilitated by the Huntington's Disease Association.
- Contribute to the development and future planning of the Huntington's Disease Association such as through project work.
- Liaise with other neurological organisations.
- Maintain a high standard of accurate and up to date records and undertake necessary administrative procedures.
- Plan and participate in staff supervision and reflective practice, and personal annual appraisals as required.

# 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 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

	Essential or Desirable	How identified
<b>Qualifications</b>		
Recognised Social Work or Health Care qualification.	D	Application
<b>Experience</b>		
Working with adults and/or children with disabilities.	E	Application and interview
Assessment of care needs of adults/children with physical disabilities/mental health.	E	Application and interview
Multi-Disciplinary work across agencies.	E	Application and interview
<b>Knowledge and skills</b>		
Knowledge of the effects of a long-term disability on individuals and families/carers.	E	Interview
Understanding of ethical issues affecting people with a long-term disability.	D	Interview
Effective written and verbal communication skills including the ability to translate complex issues into clear, focused and understandable advice.	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 and interview
Ability to work remotely 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 and interview
Ability to present training sessions to families and professionals.	E	Application and interview



	Essential or Desirable	How identified
<b>Other</b>		
Ability to manage projects.	D	Application
A professional approach to vulnerable adults and children.	E	Interview
Ability to work alone and as part of a team.	E	Application and interview
A satisfactory level of attendance.	E	Application and references
Experience of working in a modern digital workplace.	D	Application
A private and confidential workspace within your home.	E	Application and interview
Understand the benefits of diversity and inclusion and have a personal interest in finding solutions to increase diversity	E	Application and interview
<p>Car owner with access for work purposes and hold a legal UK driving licence. Willingness to use public transport where more appropriate.</p> <p><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></p>	E	Application

# 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 Tuesday 11 March 2025, 9am.**

**Interviews will be held in Liverpool on Monday 24 March 2025.**

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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**



@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*