



Huntington's
Disease
Association

Support at every step: Improving care coordination for people living with Huntington's disease



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About us

We are the Huntington's Disease Association. Our aim is to help people affected by Huntington's disease in England and Wales to live a better life. We provide advice and guidance for people affected by Huntington's disease, offer peer support for families, educate professionals and champion people's rights.

Methodology

We surveyed 258 people in England and Wales affected by Huntington's disease from February to March 2026. This included partners/carers who support someone who is living with, or at risk of, the disease. 72% of respondents stated they were a partner/carer of someone with Huntington's disease (or Juvenile Huntington's disease). The remaining respondents had symptoms of Huntington's disease (16%) or preferred not to state their

relationship to it (12%). We asked people responding to our survey to answer the questions on care needs (e.g. mobility, mental health, washing and dressing) in relation to the person living with Huntington's disease, rather than themselves.

This report also includes quotes from written responses to this survey and our 2024 survey of the care needs of people living with Huntington's disease.

Foreword

As a Member of Parliament, I see first-hand the devastating impact that Huntington's disease has on families in my constituency. This experience has driven me to work with the Huntington's Disease Association to improve care for everyone affected by this rare, neurodegenerative condition.

The recent news that a new gene therapy (AMT-130) may slow the progression of Huntington's disease has brought significant hope. Yet we must also recognise that it will take time before any potential treatment becomes widely available. This is why continued advocacy for better care and support remains essential.

Too often, people living with Huntington's disease do not have a single point of contact, such as a specialist nurse or social worker, to coordinate their care. As a result, family members frequently become de facto care coordinators, adding emotional and practical strain to an already challenging situation. Others may have no one to help them navigate the system at all. This is not inevitable, and there are solutions.

Care coordinators provide expert guidance, practical assistance, and emotional support, helping people manage complex conditions like Huntington's throughout their lives. Although this model of care has been recognised as a national health and social care priority, progress towards making it universally available has been far too slow.

I urge decision-makers at both local and national levels to implement the recommendations in this report. Everyone living with Huntington's disease should have access to a dedicated health or social care professional who can coordinate their care and act as a local expert on their needs.



Helen Grant OBE MP
Maidstone and Malling



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Huntington's
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Executive summary

This report explains why people living with Huntington's disease need support from professionals to coordinate their care and navigate the health and social care system, outlines the consequences of not having this support, and sets out best practice.

The reasons why people living with Huntington's disease need a care coordinator are:

- It is a disease which requires complex care from multiple healthcare professionals. Many people cannot coordinate this on top of managing their own condition.
- Due to the devastating impact of the disease across generations of families. Often, people will care for more than one relative with Huntington's disease, while coping with worries about developing the condition themselves. Young people who are at risk of Huntington's grow up facing daunting choices around starting a family and genetic testing.
- Huntington's disease is rare and professionals often lack an understanding of the condition. A care coordinator can educate community teams about Huntington's disease and how to provide the right care.
- Due to cognitive changes, a person may experience a lack of insight into their symptoms. This can mean they place themselves at risk because they do not understand the extent of their difficulties (or may think that they are not experiencing difficulties at all).
- Cognitive changes can also mean the person is at risk of exploitation (e.g. in relation to finances or emotional and psychological abuse).

"Many doctors still don't know the horrors of Huntington's disease, both for the person with the disease and their families/carers. Every family should have a local care coordinator..."

Family carer

"It has been down to the person I care for or myself as a carer to attempt to coordinate any kind of communication between services. Often things go full circle and are just pushed back to the Huntington's disease clinic, which isn't really of any use when we only have annual appointments there."

Family carer

“When a person is first diagnosed, it can be really overwhelming for families. They often have lots of initial appointments, such as with their general neurologist, Huntington’s disease clinic, a speech and language therapist, and dietician. But following this, they can feel left on their own. My job is to make sure people have someone to reach out to. I make clear from the start that I am there to support people as little or as much as they want, being aware it can take time to build trust.”

Sometimes it is simple things that make the difference. One person was having difficulties with cutting their tablets in half and putting themselves at risk by using a penknife to try and do this. So I arranged for the team to send them a pill cutter. They got back in touch to say how much easier this had made things.”

Kirstie Allen, Neuro Navigator

Some of our key findings are:

- **Almost two in three people (65%)** do not have a named professional who coordinates care across different health and social care services.
- **Only 30%** of respondents agreed or strongly agreed that the different services involved in providing Huntington’s disease care (to them or the person they cared for) worked well together.
- **Over six in 10 people (62%)** needed to explain Huntington’s disease to a healthcare professional in the previous 12 months.

Improving care coordination for people living with Huntington’s disease aligns with national reforms and evidence-based recommendations to improve neurology services and develop a new model of community care. We are calling for:

1. Local NHS and social care leaders in England to ensure the shift towards neighbourhood health delivers for people living with Huntington’s disease.
2. NHS leaders in England and Wales to implement NICE’s recommendation on improving care coordination for people living with long-term neurological conditions¹.
3. NHS neurology services in England to deliver the minimum service requirements set out in NHS England’s Specialised Neurology Services Service Specification for adult care².
4. The Welsh Government to develop an implementation plan for the Quality Statement for Neurological Conditions³.

What is Huntington's disease?

Huntington's disease is a rare, genetic, neurodegenerative condition. Around 8,000 people in the UK are affected by Huntington's disease. It is caused by a complex genetic mutation that leads to widespread brain damage, which has made it difficult to develop effective treatments.



Movement

Movements may happen that you don't expect, while doing what you want to do becomes more difficult



Cognitive

Difficulties in thinking and processing information



Mental Health

Changes in behaviour and personality

Symptoms can start at any age, but onset is commonly between 30 and 50. Huntington's disease is usually fatal after a period of up to 20 years. In the later stages of the disease, people will find communication and daily activities increasingly difficult and need full-time nursing care.

Every child conceived naturally to a parent who has the faulty Huntington gene has a 50% chance of inheriting it. If a person is 18 or over they can take a genetic test to find out if they have the faulty gene.

Results from a major clinical trial (September 2025) showed that AMT-130, a gene therapy treatment, slowed the progression of Huntington's disease by around 75% in some participants⁴. This is the most promising clinical trial outcome seen so far and represents a significant step forward in the search for effective treatments.

Fatima (name has been changed)

CASE STUDY

Fatima is in her late 40s and has been experiencing Huntington's disease symptoms for over 10 years. Huntington's disease causes changes to cognition, which can make it harder to adapt thinking and behaviour. This can mean the person is unable to anticipate the consequences of their actions, placing themselves at unnecessary risk. For example, Fatima has received support from community therapy services but struggles to understand and follow their advice, particularly around eating and drinking, putting her at risk of choking. She lives at home with one of her adult children, who works full time, and their child. She has regular carers from 8am – 8pm, funded by the NHS. She is under the care of the local Consultant but, due to a lack of insight into her needs, does not always attend her clinic appointments. She is at risk of falls, choking on food, and setting fire to herself, as she is a regular smoker.

Recently, Fatima became aggressive towards her carers and refused to let them in. Following this, the care agency contacted her GP and Consultant. The GP advised they were unable to help. The following services were contacted but were unable to offer support:

- **Community Mental Health Team (CMHT):** The CMHT advised they were not able to help.
- **Crisis Resolution Team:** The Crisis team advised they were not an urgent care service and suggested admission via A&E.
- **Dementia Rapid Response Team:** This team said Fatima did not fit their referral criteria.

As a result of this, the care agency feel unsupported and are struggling to manage Fatima's complex mental health needs.

What is care coordination?

Care coordinators are health or social care professionals who act as a single point of contact and help manage the person's care. They can liaise with the range of providers a person may need support from, in areas including mental health, occupational therapy and social care. Crucially, they act as a bridge between a person's Huntington's disease clinic and community services. Their role involves educating health and social care professionals to ensure they have the knowledge to provide high-quality and joined-up care to people living with Huntington's disease.

Health and social care professionals who provide care coordination can have a range of professional backgrounds, such as nursing or social work, and different job titles. They are often in speciality-specific roles, such as Clinical Nurse Specialist in Huntington's Disease or Neuro Navigator.

“Having a Neuro Navigator means the person living with Huntington’s disease has someone closer to home who can see them and make sure they get the care they need. They are there to help monitor symptoms and take action if someone needs help. Neuro Navigators understand Huntington’s disease, meaning they can take on the role from families of educating healthcare professionals. Without this support, it can be such a drain to have to constantly explain what the condition is and how it affects someone.

People get to a point where it is impossible for them to make the journey to their Huntington’s disease clinic. This could be because they do not have anybody to go with them, cannot get transport to meet their needs, or struggle to plan how to get there. In these circumstances, having someone to coordinate care is essential.”

Rachel Boothman, Huntington’s Disease Association Adviser

James (name has been changed)

CASE STUDY

James is in his 50s and is living with Huntington’s disease. He has significant struggles with his sleep-wake cycle, meaning he struggles to go to sleep and wakes up regularly at night. James also experiences perseverative thoughts, relating to medication he is prescribed to help him sleep.

“Perseveration” refers to when a person gets stuck on certain ideas and finds it difficult to move on. For example, James repeatedly demands medication to help him sleep, even after this has already been provided. This is exhausting for his wife, who is becoming increasingly stressed and sleep deprived, as she works full-time and has her own health problems.

James has received support from a social worker who tried to secure funding for a specialist placement for him, but this request was turned down.

There have been attempts to find activities to provide James more physical and mental stimulation during the day, which could help him sleep. However, neither social services nor NHS services have been able to help.

Why do people living with Huntington's disease need a care coordinator?

It is understandable that many people living with Huntington's disease are unable to manage the burden of coordinating their care. People living with the disease and their families face significant challenges throughout their lives. The physical and mental health difficulties identified in our survey highlight the daily challenges experienced by people living with Huntington's disease and the need for coordinated care:

- **Half of people (50%)** said they had difficulty walking and **over one in five (21%)** said they use a wheelchair.
- **Over three quarters (76%)** have difficulties washing and dressing themselves or need help with washing and dressing.
- **More than eight in 10 people (82%)** said they experienced some anxiety or low mood or significant anxiety or low mood.
- **Almost six in 10 people (59%)** reported experiencing some or a lot of pain or discomfort.

"As a result of living at risk of Huntington's disease, I have had significant mental health difficulty and have needed to privately pay for therapy and a psychiatrist. It has taken years to find a psychologist who understands Huntington's disease and what living at risk is like."

Person living at risk of Huntington's disease

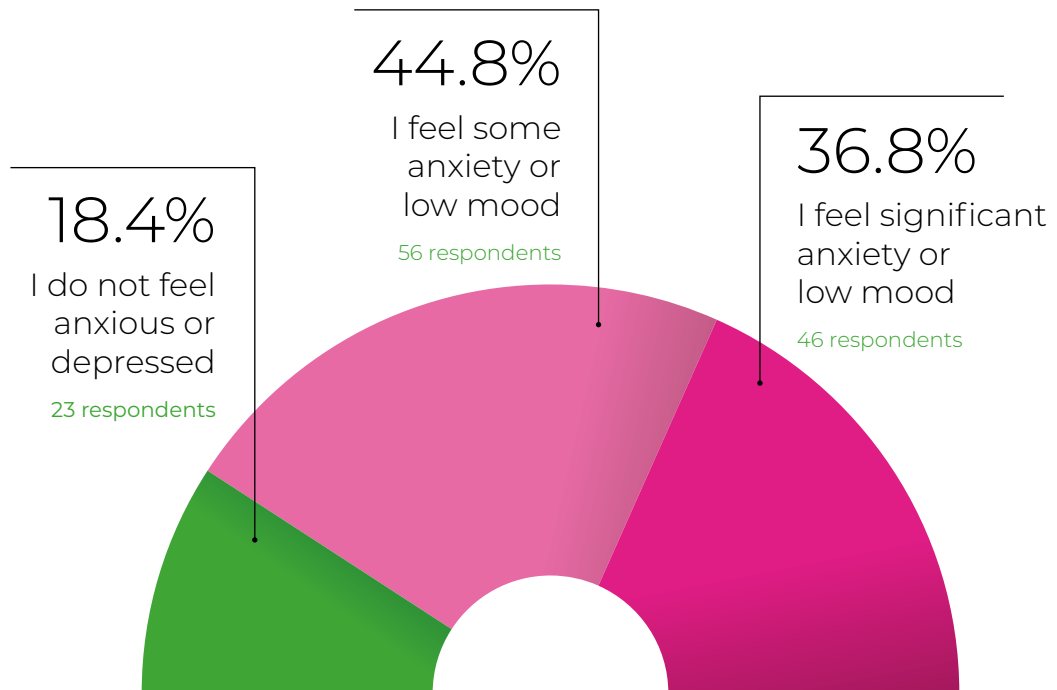
"I have had to explain to nursing staff and a social worker who kept calling my daughter's condition Parkinson's. The social worker didn't even know it was hereditary."

Family carer

"Both my daughters and myself have had to explain Huntington's disease to virtually all the services with whom she has had contact - the Job Centre, GP, hospital staff involved in her care when she was admitted with liver problems, the alcohol service and the alcohol rehabilitation service."

Family carer

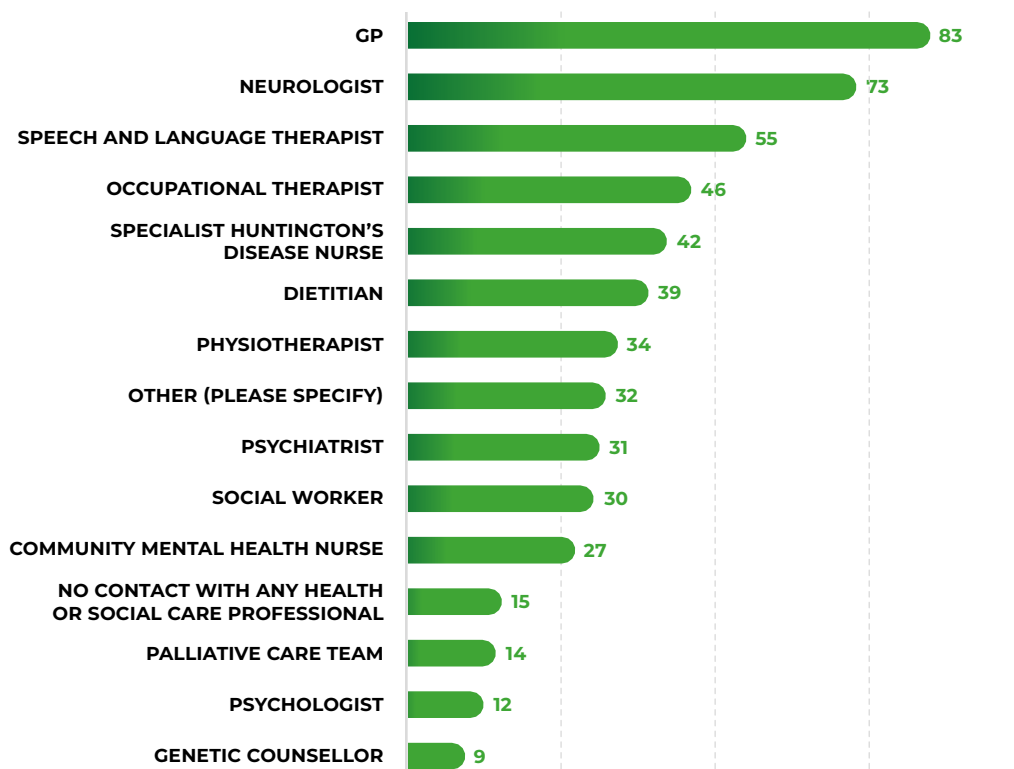
Anxiety and depression



The complex nature of Huntington's disease means there are frequently multiple professionals involved in a person's care, often with little knowledge of the disease. Over six in 10 people (62%) said they needed to explain Huntington's disease to a healthcare professional in the previous 12 months. Furthermore, only 30% of respondents agreed or strongly agreed that the different services involved in providing Huntington's disease care worked well together. These findings are supported by a study (2024) which found that over half of people affected by Huntington's disease (56%) said they needed to repeat information to different professionals 'most of the time' or 'always'⁵.

The graph below highlights our 2026 survey findings on the range of healthcare professionals that people living with Huntington’s disease can need support from.

In the past 12 months, which of the following health and social care professionals have you (or the person you care for) been in contact with in relation to Huntington’s disease?



People living with Huntington’s disease value the role of a care coordinator.

Research has found that 90% (112) of people affected by Huntington’s disease, including family members, believed it was very important or extremely important to have a care coordinator. Among those with a care coordinator, four out of five (81%) reported being somewhat or extremely satisfied with their services⁶.

“I would be a strong advocate for care co-ordinators as ours was invaluable and we would not have got through without her.”

Family carer

How many people living with Huntington's disease have support from a care coordinator?

It is difficult to map the provision of care coordinators for people living with Huntington's disease in England and Wales. One barrier is that "care coordinator" is not a single standard job title or service across the NHS and social care system. However, we know that many people living with Huntington's disease do not have support from a care coordinator and there are significant inequalities in provision.

Almost two in three people (65%) who responded to our survey said they do not have a named professional who coordinates care across different health and social care services. In reality, this statistic is likely to be higher as some respondents incorrectly identified the Huntington's Disease Association as providing care coordination. While we offer advice and emotional support to people affected by Huntington's disease, we do not provide care coordination as this should be undertaken by a healthcare professional sitting within statutory services.

"I am doing all the coordination and arrangements for my partner. This includes all the appointments including at the hospital, GP, Speech therapist, social services, bank, occupational therapist and all other things relating to their care. It is impossible to contact some of the services directly and often replies take a long time."

Family carer

"My daughter does not have a care coordinator. She is currently asymptomatic but has mental health issues and alcohol addiction from dealing with her own confirmation of having the Huntington's disease gene and from witnessing the deterioration and eventual death of her father who had Huntington's disease. It would have been helpful to have a care co-ordinator to explain Huntington's disease to her GP practice and to coordinate a response with mental health services and the alcohol service."

Family carer

Jean (name has been changed)

CASE STUDY

Jean is in her 50s. She has very complex needs, including severe chorea (uncontrollable, jerky movements), which is resistant to medication. As a result, performing all activities of daily living is incredibly challenging for her. Her chorea causes Jean to injure herself. She regularly propels herself from her chair and has headbutted the table whilst eating.

Jean experiences recurrent urinary tract infections (UTIs) which exacerbate her other symptoms, including low mood and her involuntary movements. Jean has had several hospital admissions as a result of the UTIs and injury from her chorea. Jean has had input from an NHS occupational therapist in the community and from neuro-therapy outpatient services, but this is not meeting her care needs. Jean does not have enough help to coordinate her care and her physical and mental health are deteriorating.

Do you, or the person you care for, have a named professional (not including someone from the Huntington’s Disease Association) who coordinates care across different health and social care services? E.g. a ‘Clinical Nurse Specialist in Huntington’s disease’ or ‘Neuro Navigator’.



There is existing academic evidence of gaps in care coordination for people living with Huntington’s disease. In a 2023 study of 153 people in England affected by Huntington’s disease, less than one in five people (19%) living with Huntington’s disease indicated that they had a care coordinator and the presence of a care coordinator was identified in only 19 English counties. The role of care coordinator was mainly taken on by nurse specialists (48%), consultants (19%, e.g. neurologists and neuropsychiatrists) and social care workers (14%)⁷. In the same study, people who had a specialist Huntington’s disease nurse to coordinate their care reported that it had a “life-changing effect”, including increased continuity of care and education on what to expect as their disease progressed.

What does good care coordination look like for people living with Huntington's disease?

Good care coordination has been identified as support which (among other factors):

- Coordinates complex medical care.
- Delivers well-organised logistical support.
- Bridges the gap between healthcare and other services, such as benefits.
- Integrates support from charities and support groups⁸.

"...It was good to have someone who understood what was needed without long explanations and who was able to liaise with organisations such as social services when necessary. Her support of the family was invaluable through difficult times."

Family carer

"We had a Consulting Specialist Neuro Nurse for five years who developed a very deep understanding of our son and his Huntington's disease and also ourselves as parents/carers."

Family carer

Kirstie's story:

The role of a Neuro Navigator



Kirstie is a Neuro Navigator, who has a background in nursing. She supports people in West Hertfordshire living with rare and progressive conditions, including Huntington's disease.

What is the approach to working with the person and their family?

The approach of Kirstie's caseload is to never discharge people, meaning they are always known to her. This cuts out the bureaucracy of the person having to go back to their GP for another referral. Kirstie works on a multidisciplinary team, alongside occupational therapists, physiotherapists, technical instructors and clinical psychologists.

Kirstie will arrange to visit the person yearly to review their needs. She encourages the person and their family to contact her if they have concerns, letting them know she is their point of contact in the community. In between these yearly reviews, Kirstie will often help people troubleshoot problems, chase referrals and signpost to services.

How does the assessment of the person's needs take place?

When a person living with Huntington's disease is referred to Kirstie she carries out a holistic needs assessment, which includes an assessment of psychological needs, eating, breathing, mobility, and toileting.

After carrying out this initial assessment, Kirstie has a better understanding of what the person's current needs are and what they might need in the future. She will then make referrals to any services, such as physiotherapy, that the person needs help from. Kirstie sends a summary of her assessment to the person's GP and Huntington's disease clinic.

What is the approach to working with other services supporting the person living with Huntington's disease?

An important part of Kirstie's role is acting as a bridge between the person's Huntington's disease clinic and community health and care services. This can involve speaking to the person's GP about potential changes that may be needed to medication. Kirstie will also alert the person's Huntington's disease clinic if there has been a change in symptoms that they need to be aware of. For example, somebody could be experiencing a decline in their mental health and require input from the team's neuropsychiatrist. In these circumstances an earlier face-to-face appointment, or telephone appointment, could be offered.

If Kirstie is supporting a person with particularly complex needs, then she will discuss this at a complex case meeting, attended by social services and NHS representatives, including mental health services. In one instance, a person with Huntington's disease, who lived alone, was receiving hospital treatment due to malnutrition. Kirstie was able to discuss the person's needs at a complex case meeting. This led to social services arranging for their house to be deep cleaned and de-cluttered, and providing support with applying for benefits. They also secured funding for a meal delivery service. Following this meeting, an occupational therapy and rehabilitation plan was implemented to support the person to safely cook microwave meals at home.

How are people in the later stages of Huntington's disease supported?

To support people in the later stages of Huntington's disease, Kirstie chairs a monthly neuropalliative multidisciplinary team meeting. This is attended by speech and language therapists, a dietician, physiotherapy and local palliative care services. The focus is not just on end of life care, but on supporting the person to live well.

What are the opportunities to improve care coordination for people living with Huntington's disease?

The NHS's shift towards neighbourhood health

The NHS 10 Year Health Plan recognises that the NHS is detached from communities and organises its care into multiple, fragmented silos. The plan sets out a vision of continuous, accessible and integrated care.

The goal is to develop 250 new neighbourhood health centres by 2035, with 120 being operational by 2030. These centres will act as a 'one stop shop' for patient care and will be the place from which multidisciplinary teams operate. They will be open at least 12 hours a day and six days a week⁹.

This model has the potential to improve care for people living with Huntington's disease. For example, people would benefit if services such as physiotherapy, speech and language therapy, occupational therapy, and mental health support, were all provided in one place, closer to home.

NHS England's Neighbourhood Health Guidelines 2025/26 highlight the importance of hospital-based clinicians working collaboratively with community-based teams who are in neighbourhood health centres. An example of this approach would be a person's Huntington's disease clinic providing specialist input to neighbourhood multidisciplinary teams through joint clinics¹⁰.

Local areas have been given flexibility to design neighbourhood health centres that reflect the specific needs of their populations. However, local systems will have to ensure the needs of people with rare, neurodegenerative conditions, such as Huntington's disease, are considered as plans are developed. It will be crucial to ensure that people with Huntington's disease have a single point of contact to coordinate their care. This is essential to ensuring there is an effective relationship between Huntington's disease clinics and neighbourhood multidisciplinary teams.

Implementing NICE's recommendation on a single point of contact for people with long-term neurological conditions

In October 2025, NICE published its guideline on rehabilitation for chronic neurological disorders. A key recommendation is for there to be a single point of contact for people living with chronic neurological disorders, including complex case managers within each of the Integrated Care Boards (ICBs) in England. These specialists would co-ordinate care across health, social care, and third-sector organisations, ensuring people receive the rehabilitation services they need.

The guideline states that a single point of contact could come from a range of professional backgrounds including a nurse, GP, allied health professional, or speciality-specific coordinator, such as a Neuro Navigator. Depending on the complexity of needs, the single point of contact may signpost, provide information, help navigate rehabilitation services, and refer to other services as needed.

Implementing NHS England's standards of care for neurology services

In August 2025, NHS England published its Specialised Neurology Services Service Specification for adult care. This sets out minimum service requirements for both specialised neurology services and core (Integrated Care Board (ICB) commissioned) neurology services. Since April 2026, it has been necessary for services to meet these standards of care.

The specification outlines how specialised and local NHS services should work together in joined-up networks called Integrated Neurology Systems. The aim of this model of care is to make it easier for people to move between services and receive more of their care closer to home. This would reduce the need for people living with Huntington's disease to travel long distances to get the care they need. A key principle of delivering integrated care in an Integrated Neurology System is to provide a single point of access to specialised care for patients with complex needs, such as Huntington's disease.

Implementing the Welsh Government's Quality Statement for Neurological Conditions

The Welsh Government published the Quality Statement for Neurological Conditions in 2022. The purpose was to ensure people of all ages affected by a neurological condition have timely and equitable access to high-quality services. It calls for integration and coordination of care across services, professions and agencies, recognising the wider health and care needs of people living with a neurological condition. Implementing this model of care could lead to significant improvements in care for people living with Huntington's disease in Wales. However, progress has been slow, with the 2024/25 My Neuro Survey¹¹ of over 600 people affected by neurological conditions in Wales finding that:

- **Only two in five adults (40%)** affected by neurological conditions, including carers, felt that the healthcare services they accessed met their needs, highlighting a gap in care and service delivery.
- **Just 35% of adults** agreed that they felt supported by the health system in Wales, leaving **almost half (44%)** feeling unsupported.
- **Almost half of carers (45%)** care for more than 50 hours per week, highlighting the need for people affected by Huntington's disease to have support with the burden of coordinating care.

Access to care coordination in Wales is particularly difficult for people with rare, neurodegenerative conditions, such as Huntington's disease. A 2024 survey of neurological services found that there are 53 (full time equivalent) neurology specialist nurses in Wales, or one per 58,976 of the population. The majority specialise in epilepsy, multiple sclerosis and Parkinson's disease¹².

Our recommendations

Our key ask is every person living with Huntington's disease should have a named professional responsible for coordinating their care.

Our recommendations to improve care coordination for people living with Huntington's disease in England and Wales are for:

1. **Local NHS and social care leaders in England to ensure the shift towards neighbourhood health delivers for people living with Huntington's disease:** To ensure a neighbourhood health model improves care coordination for people living with Huntington's disease, we recommend that local health and social care system leaders:
 - Ensure there is a named professional, acting as a single point of contact to coordinate care for people living with rare, neurodegenerative conditions.
 - Work in partnership with people affected by rare, neurodegenerative conditions and the charities that support them to co-produce neighbourhood health plans.
 - Identify in neighbourhood health plans which team/service has responsibility for coordinating care for people living with Huntington's disease across all health and social care settings.
 - Ensure that neighbourhood health centres work in partnership with a person's specialist hospital-based Huntington's disease clinic. This could include joint clinics, delivered in primary or community settings.

2. **NHS leaders in England and Wales to implement NICE's recommendation on improving care coordination for people living with long-term neurological conditions:** We are calling for NHS leaders to implement the recommendations in NICE's guideline on rehabilitation for chronic neurological disorders. A key recommendation is for there to be a single point of contact for people living with progressive, neurological conditions.

3. NHS neurology services in England to work together to improve care for people living with Huntington's disease: We are calling for specialised and local NHS services to deliver the minimum service requirements set out in NHS England's Specialised Neurology Services Service Specification for adult care. This would make it easier for people to move between services, receive more of their care closer to home, and provide a single point of access to specialised care.

4. The Welsh Government to develop an implementation plan for the Quality Statement for Neurological Conditions: The Welsh Government published the Quality Statement for Neurological Conditions in 2022. However, progress has been slow and there is a need for a plan with measurable targets and milestones to ensure the statement leads to improved care for people living with rare, neurological conditions, such as Huntington's disease.

We recognise that securing improvements in care and support for people living with Huntington's disease will require actions from the government, the NHS and care services working together.

Proper coordination of care can ensure that all affected by Huntington's are able to focus on managing the condition instead of navigating the health system, thereby making it easier for people to receive more of their care closer to home.

The Huntington's Disease Association will continue to work towards ensuring that increased access to a care coordinator, a clear call from our community, moves from being provision available in a select few areas to becoming the standard across England and Wales.

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Get in touch

For advice and support or
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Get involved

For your fundraising pack,
please get in touch with
the fundraising team

email fundraising@hda.org.uk
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Join the conversation



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