Huntington's
Disease
Association

Unseen and unheard: The need to improve mental healthcare for people living with Huntington's disease.

Contents

Who we are

We are the Huntington's Disease Association. We are here to help people living with Huntington's disease to have a better life. We improve care and support services for people with Huntington's disease, educate families and professionals, and champion people's rights.

Methodology

We surveyed 109 people in England and Wales affected by Huntington's disease from 26 February 2023 to 18 May 2023. This included people who support someone who is living with, or at risk, of the disease. During a similar timeframe (26 February 2023 to 30 May 2023) we also surveyed 83 health professionals who treat patients with Huntington's disease.

More recently (July 2024 -September 2024), three of the Huntington's Disease Association's Specialist Huntington's Disease Advisors (SHDAs) were interviewed about their experiences of supporting people living with Huntington's disease to access mental health support. This was the source of the anonymised case studies, which feature in this report.

We would like to thank everybody who shared their experiences as part of this project.

What is Huntington's disease?

Huntington's disease is a rare genetic neurodegenerative disorder.[1]
Around 8,000 people in the UK have the condition.[2]

There is no cure for Huntington's disease because it is caused by a complex genetic mutation that leads to widespread and irreversible brain damage, making it difficult to develop effective treatments. Despite ongoing research in areas like gene therapy, current treatments can only help to manage symptoms rather than stop or reverse the diseases progression.

Every child conceived naturally to a parent who has the faulty Huntington gene has a 50% chance of inheriting it.[3] If a person is 18 or over they can take a genetic test to find out if they have the faulty gene.

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 they commonly appear between 30 and 50. Huntington's disease is usually fatal after a period of up to 20 years.[4]

In the later stages of the disease, people will find communication and daily activities increasingly difficult and need full-time nursing care.

Foreword

The impact of Huntington's disease on mental health has long been recognised. In 1872, George Huntington's described a progressive, inherited neurological condition with "a tendency to insanity and suicide". Despite this, 150 years on, patients with Huntington's disease struggle to gain access to mental health support. Depression, anxiety, personality change, aggression, loss of motivation and suicidal feelings are some of the commonest features of Huntington's disease.

Yet time and again, patients with Huntington's disease are turned away from mental health services. While the underlying condition is not yet curable, many of the mental health symptoms can be treated effectively, offering relief to patients, carers and families. Mental health services have an important role to play in improving quality of life for people with Huntington's disease, but often lack awareness of the condition.

**Dr Akshay Nair, Consultant Neuropsychiatrist,
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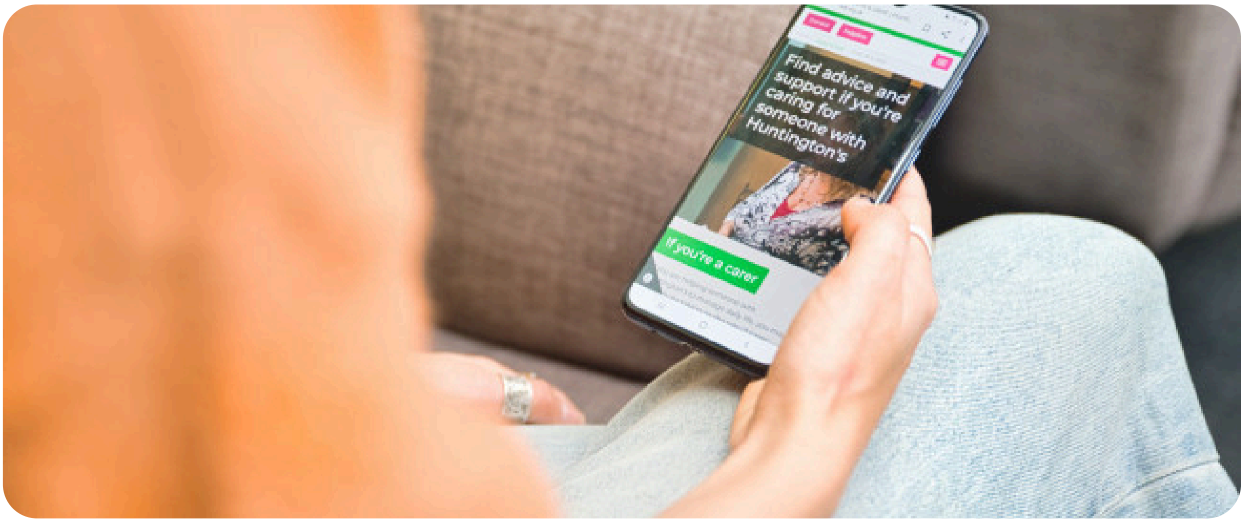
Department of Neurology, St. George's Hospital**

I urge decision makers in the NHS and government to implement the recommendations in this report. For too long, patients with Huntington's disease have struggled to get equitable and fair access to mental health services. Now is the time for change.

Summary of recommendations



Our recommendations to support people living with Huntington's disease in England and Wales are for the UK Government, Welsh Government and NHS providers and commissioners to:

Improve support offered by community mental health services to people living with Huntington's disease:

Community mental health services are difficult to access and often lack an awareness of Huntington's disease and its impact on mental health. Some community mental health services are reluctant to consider referrals when a person has Huntington's, despite there being nothing about the disease that prevents the treatment of any mental illness. Mental health teams should be supported to take on patients with Huntington's disease, through expansion of training and better links with Huntington's disease services.

Ensure that every person living with Huntington's disease is supported by a health professional, who acts as a local expert on their care needs:

Care coordinators provide expert care, helping people to manage their condition through their lives. They liaise with specialist Huntington's disease clinics and coordinate the input of health professionals in the community. 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. This is why it's vital that everyone who has the disease is supported by a health professional who can help coordinate their care.

Give every person with Huntington's disease access to specialist mental health support:

Many people with Huntington's disease do not have access to a neuropsychiatrist, who would have an understanding of the relationship between Huntington's disease and mental health. There is also a need for greater investment in research into psychological interventions for people living with Huntington's disease and better provision of specialist talking therapies.

Executive summary

If you are a person living with Huntington's disease who is struggling with mental health problems then you want help from professionals who understand your needs and how to offer support. We've found that time and again this isn't happening.

The UK Government committed in its manifesto to giving mental health the same attention and focus as physical health[5]. A priority for NHS England in 2024/2025 is to improve access to mental health services so that more people of all ages receive the treatment they need[6]. We support these goals but fear that the mental health needs of people with rare diseases, such as Huntington's disease, are being overlooked.

People living with Huntington's disease and their families face significant challenges throughout their lives. Young people who at risk of Huntington's grow up in the shadow of the disease, facing daunting choices around starting a family and genetic testing. Many people also care for relatives with Huntington's disease while coping with worries about developing the disease themselves.

The damage to the brain caused by Huntington's disease can have a profound impact on a person's mental health. Almost all of the 83 health professionals we surveyed (99%) said the Huntington's disease patients they supported had experienced mental health issues.

When people living with Huntington's disease seek help, mental health services can be reluctant to offer it. People tell us they have to wait until they reach crisis point before support is offered. If someone's referral is accepted by a mental health team, they are often faced with a lack of understanding about their condition, which leads to poor care. A 2023 study asked 153 people affected by Huntington's disease to identify their top three care needs. Mental health needs were mentioned most frequently, in relation to the person living with Huntington's disease and to caregivers' own unmet mental health needs.[7]

We recognise that many mental health professionals do their best under challenging circumstances to support people living with Huntington's disease. Some responded to our survey, calling for improvements in care.

"People with Huntington's disease who are denied access to mental health services often can access it when in crisis. At this point, the Huntington's disease has declined further, the neuropsychiatric symptoms take longer to treat - people often stay in hospital for 6-9 months (usual stay is a few weeks). This enforces institutional behaviour and needlessly separates the person from their home environment for longer than necessary ..."

Health Professional

"...He (Dad)was given the wrong medication, taken off medication that was prescribed by his Huntington's disease consultant... which resulted in things getting a million times worse ... Mental health doctors and nurses need to know more about Huntington's disease and the mental health effects it cause ..."

Family member

There are solutions. Firstly, community mental health services need to be more willing to support patients with Huntington’s disease and understand how the condition affects mental health. Mental health symptoms are a part of Huntington’s disease. To exclude patients based on their Huntington’s disease diagnosis creates an artificial boundary between physical and mental health.

Secondly, care needs to be more joined up, or “integrated”. Despite the NHS prioritising integration by creating Integrated Care Boards (ICBs), care is too often fragmented and inadequate. As highlighted in Lord Darzi’s investigation into the NHS in England (2024), the more the NHS has talked about integration, the less satisfied patients have become with the coordination of their care.[8]

The move towards integrated care reflects the fact that people living with long-term conditions need help from a range of different physical and mental health professionals and often rely on social care too. The frequency of their interactions with the NHS mean that their care is complex and therefore requires coordination.[9] People living with rare, neurological conditions, including Huntington’s’ disease, have complex health needs that require support across multiple health services. In 2021, the previous government set out a five-year goal to ensure rare disease patients experience better coordination of care throughout the patient journey. More needs to happen to make this a reality.[10]

Many people struggle with the burden of coordinating their care on top of managing their own condition. Care coordinators provide expert advice on care, along with practical and emotional support, helping people with diseases like Huntington’s disease to manage their condition throughout their lives.[11] They can liaise with the range of providers a person may need support from, in areas including mental health, benefits and social care.[12 13] They can also educate health professionals about Huntington’s disease and its impact on mental health, helping them provide high-quality and joined-up care. This is support that people living with Huntington’s disease want. A 2023 study of people affected by Huntington’s disease, including family members, highlighted how important it is to have this role. Although 90% (112) of people said it was very important or extremely important to have a care coordinator, less than one in five (19%) had one. Among those with a care coordinator, 81% reported being somewhat or extremely satisfied with their services.[14]

Given the budgetary challenges facing NHS commissioners and providers, we recognise that this role may cover a range of rare diseases and not just Huntington’s disease. The format of a care coordinator role can also vary depending on patient need and the way services are designed. In the example below, people living with Huntington’s disease are supported by a specialist practitioner based in a clinic.

First Community Health and Care (NHS Surrey Heartlands Integrated Care Board)

First Community Health and Care has a specialist practitioner caring for people living with Motor Neurone Disease (MND) and rare neurological conditions, including Huntington's disease, in east Surrey. They ensure patients have access to the services, support, equipment, and specialist care they need, and provide advice on appropriate referral pathways to patients, GPs and other community services. The service provides holistic support and advice to Huntington's disease patients, their carers and family members living in east Surrey to coordinate clinical care and improve overall quality of life.

Finally, we are calling for wider availability of specialist mental health support. This includes improved access to Huntington's disease services, where people can receive support from a neuropsychiatrist. These specialist teams can provide upskilling and support to surrounding mental health services. There is also a need for better access to specialist talking therapies for patients with Huntington's disease.

Nobody with a Huntington's disease diagnosis should struggle to get the mental health care they need and everyone who has the condition should be supported by a health professional who acts as a local expert on their care needs. We urge the UK Government, Welsh Government and NHS providers and commissioners to work with us to address the challenges outlined in this report.

Case study: Andrew

Andrew is a man in his 50s living with Huntington's disease. He has a diagnosis of mixed anxiety and depressive disorder, which led to him previously being under the care of NHS community mental health services. The wellbeing of Andrew and his family has been significantly impacted by his Huntington's disease diagnosis. His dad died of Huntington's disease and one of his siblings has the disease, as does one of his four children. Andrew has grandchildren and fears they will inherit the condition.

After experiencing a deterioration in his mental health, including severe paranoia, Andrew was referred by a neuropsychiatrist to a Community Mental Health Team (CMHT) for ongoing support.

His referral was rejected without an assessment taking place, on the basis that the CMHT was unable to provide care because Andrew's mental illness was related to his physical health needs.

Part 1: Getting help from mental health services

People are often unable to get the support they need from mental health services. Almost a third (32) of 109 people said they or their relative were denied access to mental health services because of having Huntington's disease. Of those whose referrals were rejected, over half (57%) said it was because of their Huntington's disease diagnosis. Often, there was a lack of understanding from mental health services that mental health symptoms are a part of Huntington's disease. This leaves patients with nowhere to turn for help with one of the most challenging aspects of their condition.

For people who were denied access to mental health services, 8 in 10 (81%) experienced worsening mental health, with some sectioned in a mental health hospital. Patients with Huntington's disease often fall between general and older adult psychiatric services. Although most patients with Huntington's are too young for older adult and dementia services, their cognitive and neurological symptoms often sit outside the comfort zone of general adult services. As such, if they are not rejected, referrals are often passed between teams, who are reluctant to take responsibility for seeing the person. This can lead to significant delays in accessing support.

Case study: Sam

Sam is a man in his 50s living with Huntington's disease. His daughter was concerned after he became increasingly agitated and paranoid, refusing to take his antidepressants. Sam started to believe his neighbour was listening to his conversations. He would send texts and call family members every day, threatening his neighbour and making paranoid claims about them. He also told family members that he was struggling to cope with life.

A referral was made to social services, who forwarded it to a Community Mental Health Team (CMHT). The CMHT's response was that this was an inappropriate referral and they sent it to another mental health team, who told the CMHT they would not be able to offer support. This situation continued for four weeks, during which time Sam's mental health deteriorated. He was eventually assessed by the CMHT, who were satisfied by Sam's assurances that he would take his medication and declined to offer further support. This is despite the fact that Sam's refusal to take medication had contributed to his referral to mental health services.

Two weeks after his assessment by the CMHT Sam attempted suicide and was left with head injuries and broken bones. He spent over a month in hospital and required multiple surgeries.

Sam's family have been left devastated by what happened to him. They are also frustrated that, despite their repeated warnings to different health and social care services, not enough action was taken to keep him safe.

Access to psychological services for people with Huntington's disease varies across England and Wales, with few psychologists having specific expertise in Huntington's disease. The NHS Talking Therapies programme has widened to address long-term conditions but does not offer tailored support to patients with rare neurological conditions, such as Huntington's disease.

> "...A lady with advanced Huntington's disease was trying to decorate and was going to cut through live electric wires with a pair of scissors because they were in the way. The GP made an urgent referral to the mental health team. Referral was refused by the mental health team as they informed the GP her mental illness was because of Huntington's disease."
>
> **Health professional**

Even if a person with Huntington's disease can access mental health support, the care they get is often inadequate.

Families and specialist health professionals working with Huntington's disease patients tell us that mental health services can be unsure about how to work with someone with the condition and treat their mental illness effectively. They can also be reluctant to liaise with a patient's specialist Huntington's disease service to gain a better understanding of their care needs. Research (2023) focused on people living with Huntington's disease in England found that half (48% n = 63) were somewhat or extremely dissatisfied with health and social care services and only 28% were somewhat or extremely satisfied.[16] This highlights the need for all people living with Huntington's disease to be supported by a health professional who acts as an expert on their care needs, liaising with specialist clinics and providing support to non-specialist health professionals in the community.

"As a partner of a Huntington's disease sufferer, I have been on the receiving end of aggression/mood swings. We (partners/carers) also need help which is difficult to come by. Was advised by a consultant/GP to contact the local mental health crisis team in an emergency. There was an emergency one weekend and the mental health crisis team was useless as they had no idea what Huntington's disease was."

Family member

"We battled for 7 years to get my husband the help he needed but was constantly told he had capacity. The crisis team eventually came in… it was soon referred back to adult social services as deemed to have no mental health issues. He was eventually sectioned after endless meetings. Whilst in a psychiatric hospital, he escaped, got body lice. No medication was given to him for months … Finally he is in specialist neurological unit after years of distress to him and his family."

Family member

Case study: Precious

Precious is in her 60s, has Huntington's disease and lives on her own in a one bedroom flat. A friend of Precious contacted her Specialist Huntington's Disease Association advisor (SHDA), concerned that she was self-neglecting, not washing herself and that her clothes weren't clean. Precious's advisor discovered that her toilet was blocked, but she has no interest in getting it fixed. The growing amount of rubbish in her flat is attracting flies, but she is unbothered by this.

Precious's GP made an urgent request for her to be assessed by her local Community Mental Health Team (CMHT) but no-one responded.

Precious has a social worker who struggles to contact her as she doesn't have a phone and behaves aggressively towards them if they attempt a visit. Her social worker lacks an understanding of Huntington's disease and how the condition is impacting Precious's mental health.

Part 2: Effective mental health support for people living with Huntington's disease

There are a number of specialist clinics for people with Huntington's disease in England and Wales and many have a neuropsychiatrist linked to them. Neuropsychiatrists provide evaluation and treatment for emotional, behavioural and cognitive difficulties a person is experiencing, due to having Huntington's disease. The two examples highlighted in this section of our report (The Barberry and Leicestershire Huntington's Disease Service) emphasise how invaluable specialist clinics can be in the treatment of Huntington's disease.

However, many people with Huntington's disease don't live in an area where they can receive support from a specialist team. The Neurological Alliance has identified gaps in specialist mental health support for neurological conditions, such as Huntington's disease. Its 2022 report found there were just 64 consultant neuropsychiatrists in the UK, with people waiting up to two years for inpatient support. It is also estimated that there were less than four (3.61) psychologists per every 100,000 people in the UK undertaking working sessions in neuropsychology.[17]

Even if a person can see a neuropsychiatrist, they may still need support from community mental health services. This is likely to be when they are experiencing a mental health crisis which cannot be managed in specialist services. We recognise that community mental health services are overstretched and have limited knowledge of Huntington's disease. However, neuropsychiatrists within specialist Huntington's disease services are often willing to provide in-reach and advice on cases to colleagues from community services.

The Barberry, Birmingham and Solihull Mental Health NHS Foundation Trust

The Barberry is a clinic of excellence for the treatment of Huntington's disease. The centre cares for 400 patients currently, with around 170/180 patients who are taking part in research studies. The clinic offers holistic care, working closely in partnership with the medical professionals needed to treat Huntington's disease.

The service includes nurses, dietetics, occupational therapy, speech and language therapy, physiotherapy and access to mental health services. The clinic is overseen by a consultant neuropsychiatrist.

The team are world-renowned for their expertise. They have written international guidelines for the treatment of Huntington's disease, are part of international research projects and were one of nine sites worldwide, participating in the first trial of huntingtin reducing therapy in humans with Huntington's disease (huntingtin is the gene that causes Huntington's).

Although the majority of patients are from the West Midlands, the centre is visited by people from other parts of the UK.

Leicestershire Huntington's Disease Service

The Leicestershire Huntington's Disease service is one of the Leicestershire Partnership NHS Trust's specialist services and is part of its mental health directorate.

The service works closely with local authorities, health commissioners, social services and the Huntington's Disease Association to provide clinical, social and practical support for patients in with Huntington's disease and their families. The service provides the following support:

- **Specialist inpatient unit**

There is a highly specialised 14 bedded inpatient unit with dedicated multi-disciplinary team (MDT) input from a range of health professionals, including a consultant neuropsychiatrist and clinical neuropsychologist. The team supports people living with Huntington's disease who need to be admitted for a period of assessment and treatment before being discharged to the community with a package of care recommended by the specialist MDT.

- **Community MDT team**

This team supports Huntington's disease patients and their families (including those with Juvenile Huntington's disease) within Leicestershire. The team benefits from psychology, speech and language therapy, physio, dietetic, and nursing and occupational therapy input, as well as a consultant neuropsychiatrist.

- **Advisory Service**

There is an advisory service to support patients in the neighbouring county (Northamptonshire), which provides neuropsychiatric and nursing advice for Huntington's disease patients. The service is offered both face to face and remotely (phone, email, virtual calls). The number of active cases open to the team is about 60 to 70 patients who are visited at their place of residence for a review on a 6-12 monthly basis.

- **Research clinic**

The clinic is involved in the world's largest observational study for Huntington's disease families (Enroll-HD). It also leads on funded research projects and recruits for other national or international studies. The participants also include those from neighbouring counties.

Despite the positive examples of specialist mental healthcare, where these services exist they can struggle to meet demand, as highlighted below by a neurologist who responded to our 2023 survey.

> "I have had a few patients who unless they were in a crisis situation were not seen by mental health services. This meant the GP and myself as the neurologist are trying to manage their psychiatric difficulties. We are lucky that we have a neuro-psychiatric department, but that is currently being manned by 1 neuropsychiatrist, hence the waiting lists are very long."
>
> **Neurologist**

There is nothing about Huntington's disease that prevents the treatment of any mental health condition. Generally, people with depression, anxiety and psychosis can be treated in the same way as people with these conditions who do not have Huntington's disease. The physical impact of Huntington's disease can contribute significantly to a person experiencing anxiety and/or depression. For example, swallowing difficulties are a common problem for people with Huntington's disease, which can lead to choking and eating phobia.[18]

It is difficult to identify which psychological therapy would most help someone living with Huntington's disease, due to a lack of research. Practitioners are advised to refer to general guidance published by NICE for more common difficulties (e.g. depression in individuals with chronic conditions).[19] However, there is promising research taking place on the use of Acceptance and Commitment Therapy (ACT) for people with neurological conditions, such as Huntington's disease.[20]

People with Huntington's disease can experience personality changes. Reducing demands on the person with Huntington's disease and keeping to regular routines can help people feel less irritable. Pain, infection, hunger or cognitive overload (when a person receives too much information at once) can also contribute to irritability.[21]

Case Study: Sarah

Sarah is a woman in her 60s living with Huntington's disease, who also experiences psychosis. This has led her to lose touch with reality and behave aggressively towards her family members.

Sarah refused professional support and was assessed by health professionals who decided that she had capacity to make decisions about her care and treatment. Her family disagreed and were concerned that the seriousness of Sarah's escalating, unsafe behaviour wasn't being recognised.

People living with Huntington's disease can lack insight into their condition and give a false impression of having mental capacity when assessed. The assessor should consider information provided to them by others and ask questions that will highlight any lack of insight (e.g. can you describe how you get to the shop?/how do you prepare a meal?). This did not happen in Sarah's case.

Due to Sarah's unsafe behaviour, her family refused to allow her to return to the family home after she was admitted to A and E due to a physical health problem. During this admission, Sarah's neurology team sent repeated emails to the hospital team, requesting a Mental Health Act Assessment. After this took place, Sarah was detained under a section 2 (up to 28 days) in a mental health hospital for treatment of psychosis. Due to the seriousness of Sarah's mental illness, she was later placed under a section 3, allowing her to be detained in hospital for up to 6 months.

Recommendations

Our recommendations to support people living with Huntington's disease in England and Wales are for the UK Government, Welsh Government and NHS providers and commissoners to:

Improve support offered by community mental health services to people living with Huntington's disease:

People with Huntington's disease who have a mental health condition will sometimes need support from community mental health services. However, too often these services are reluctant to accept referrals for Huntington's disease patients and lack an understanding of the condition. This means that people are denied help and receive poor care. Mental health teams should be supported to take on patients with Huntington's disease, through training and better links with specialist Huntington's disease services.

Ensure that every person living with Huntington's disease is supported by a health professional, who acts as a local expert on their care needs:

Care coordinators provide expert care, along with practical and emotional support, helping people to manage their condition throughout their lives. They can help people access services in their area, such as by making referrals to mental health services and ensuring that they are aware of the relationship between Huntington's disease and mental health. They also help liaise with specialist clinics and provide support to non-specialist health professionals in the community, either directly or by signposting those professionals to appropriate specialist services.

Give every person with Huntington's disease access to specialist mental health support:

Neuropsychiatrists provide evaluation and treatment for emotional, behavioural and cognitive difficulties a person is experiencing, due to having Huntington's disease. Yet, many people with Huntington's disease don't have access to this essential service.

There is a need for greater investment in research into psychological interventions for people living with Huntington's disease. The NHS in England and Wales should also provide specialist talking therapies programmes that meet the needs of people with rare neurological conditions, such as Huntington's disease. This is crucial if NHS England is to achieve its 2024/25 priority of improving access to mental health services.[22]

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