

Debate Pack
8 November 2022
Number CDP 2022/0191

By Bukky Balogun, Nikki
Sutherland, Tom Powell

Huntington's disease

1	Background	2
1.1	Treatment	3
1.2	Clinical research	3
1.3	NHS services	4
2	PQs	6
3	News, blogs and press releases	12

Summary

A debate on Huntington's disease will take place on 9 November 2022 in Westminster Hall. The debate will be opened by Hilary Benn MP.

1

Background

Huntington's disease is a condition that stops parts of the brain working properly over time.¹

The underlying reason for Huntington's disease is damage to and the death of some brain cells (neurons), caused by faulty genes. An affected person will inherit these genes from one, or both, of their parents.

In some cases, a person without a family history can develop the disease, but it has been suggested that in such cases, a parent did in fact have Huntington's disease but did not receive a diagnosis.²

Huntington's disease is a degenerative condition, meaning that it gets progressively worse over time, and is usually fatal after a period of up to 20 years.

The symptoms of Huntington's disease can include:

- difficulty concentrating and memory lapses
- depression
- stumbling and clumsiness
- involuntary jerking or fidgety movements of the limbs and body
- mood swings and personality changes
- problems swallowing, speaking and breathing
- difficulty moving.³

Huntington's disease is a rare condition; the Huntington's Disease Association estimates that 8,000 people in the UK have the condition.⁴

An [NHS webpage](#) provides further information about Huntington's disease.

¹ NHS, [Huntington's disease](#), accessed 7 November 2022

² NHS, [Huntington's disease](#), accessed 7 November 2022

³ NHS, [Huntington's disease](#), accessed 7 November 2022

⁴ Huntington's Disease Association, [Impact report](#), 2019

1.1 Treatment

Currently, there is no cure for Huntington's disease and no way to stop it from progressing. Treatment is aimed at relieving the symptoms.

This can include medicines to treat depression, ease mood swings and irritability and reduce involuntary movements.

People with Huntington's disease may require support at home to help with daily tasks such as getting dressed and eating. It may also be necessary to make adjustments in the home to make mobility easier and safer, such as installing ramps for wheelchair access, stairlifts, grab rails and voice activated home controls.

Speech and language therapists may support an affected person if they are having difficulty communicating, while dietitians can advise on ways to make food easier to chew and swallow.

A physiotherapist can offer help with movement problems, and advise on exercise plans, movement and stretching of the joints and massages to alleviate the difficulties caused by Huntington's disease.

People with Huntington's disease will be able to access more general care from their GPs. Depending on the individual's symptoms, GPs will be able to refer them to more specialised NHS services, such as those mentioned above.

1.2 Clinical research

A [Government PQ response](#) in October 2022 set out total expenditure on research in 2020/21, and details of direct funding for studies into Huntington's disease:

The Department funds research on health and social care through the National Institute for Health and Care Research (NIHR). In 2020/21, the Government's expenditure on dementia and neurodegeneration research, including Huntington's disease, was £77 million.

In the last five years, the NIHR directly funded two studies into Huntington's disease with a total award value of £316,267. Additionally, the NIHR has supported the delivery of over 35 studies relating to Huntington's disease via the Clinical Research Network infrastructure, including 12 specifically focusing on symptom management.⁵

⁵ [PQ 70981](#), 7 November 2022

The [UK Clinical Research Network](#) is funded by the English, Welsh, Scottish and Northern Ireland health departments. The structure of the network varies between each country, but it aims to provide the infrastructure to support high quality clinical research studies for the benefit of patients.

People with Huntington's disease may apply to join clinical trials examining new treatments, subject to criteria. The following trial registries provide details:

- The National Institute for Health and Care Research (NIHR) maintains the [Be Part of Research website](#). It provides information about clinical trials taking place in the UK.
- [The Huntington's Disease Association website](#) provides details of ongoing clinical trials in the UK.
- [The Clinicaltrials.gov](#) website is a database of privately and publicly funded clinical studies conducted around the world.
- [The EU Clinical Trials Register](#) provides details of trials being conducted in the EU and European Economic Area (EEA), and outside the EU/EEA in the case of paediatric-medicine development.

1.3

NHS services

The Government has confirmed that there are currently no national guidelines for the diagnosis and management of Huntington's disease from the National Institute for Health and Care Excellence (NICE).⁶

A Government [response to a parliamentary question](#) in September 2022 noted that NHS England is developing a neuropsychiatry service specification, for patients with complex neurological conditions including Huntington's disease who require specialised assessment and mental health support.⁷ This response also noted that NHS England's neuroscience transformation programme (NSTP) is developing services for neurological conditions including Huntington's disease:

NHS England's neuroscience transformation programme (NSTP) is developing a number of optimal pathways for neurology services which includes Huntington's disease. Following extensive stakeholder engagement, the NSTP is developing a new definition for 'specialised' neurology and a model for neurology services. This will make it easier for integrated care systems (ICSs) to reduce the inequalities of access

⁶ [PQ 46174](#), 7 September 2022

⁷ [PQ45350, 7 September 2022. Service specifications](#) define the standards of care expected from organisations funded by NHS England to provide specialised care.

and bring specialist knowledge and skills into the patient pathway much earlier. It will help speed up the process for initial diagnosis for patients and whenever specialist interventions are indicated along a patient journey, enable that to be made available closer to the patient rather than predominantly at the specialist centres.⁸

General information on the diagnosis and management of Huntington's disease is available on the NHS website:

[Huntington's disease - NHS \(www.nhs.uk\)](https://www.nhs.uk)

Further advice and support can be found from the [Huntington's Disease Association](#), the [Scottish Huntington's Association](#) and the [Huntington's Disease Association of Northern Ireland](#).

An [Early Day Motion](#), tabled on 17 May 2022, calling for the expansion of specialist services and access to mental health and other support for people living with Huntington's disease has been signed by 93 Members.

⁸ [PQ45350, 7 September 2022](#)

[Huntington's Disease: Government Assistance](#)**Asked by: Benn, Hilary**

To ask the Chancellor of the Exchequer, if he will increase financial support to people living with Huntington's disease during winter 2022.

Answering member: John Glen | Department: Treasury

The Government understands that people across the UK and especially the most vulnerable members of society, such as those suffering from long-term health conditions and disabilities, are worried about the rising cost of living. That is why the Government is taking decisive action to get households through this winter and the next, while ensuring we act in a fiscally responsible way.

If individuals have extra-costs arising from their Huntington's disease, then they may qualify for disability benefits such as Personal Independence Payments (PIP). People in receipt of extra-costs disability benefits such as PIP, Attendance Allowance or Disability Living Allowance (DLA) will receive a one-off Disability Cost of Living Payment of £150 from 20th September, to help disabled people with the rising cost of living. The DWP has already processed around 6 million such payments.

A one-off £650 Cost of Living Payment is also being delivered to those on means-tested benefits. Individuals who have limited ability to work because of their health condition, and are in receipt of means-tested benefits such as income-related Employment and Support Allowance or the Universal Credit Health top up, are eligible for this support.

Those living with a long-term health condition, such as Huntington's disease, can also benefit from other forms of non-means-tested support which the Government is providing to assist with UK households' energy bills. We have taken decisive action to support millions of households and businesses with rising energy costs this winter through the Energy Price Guarantee. In addition to the Energy Price Guarantee, millions of the most vulnerable households will receive further support this year through the £400 Energy Bills Support Scheme. The £150 Council Tax rebate will also mean that all households in Council Tax bands A-D will receive a rebate, which will be delivered by Local Authorities. Lastly, to support households who need further help or who are not eligible for elements of the wider package of support, the Government is also providing an extra £500 million of local support to help with the cost of essentials, via the Household Support Fund.

We are continuing to keep the situation under review and are focusing support on the most vulnerable whilst ensuring we act in a fiscally responsible way.

HC Deb 02 November 2022 | PQ 70982

[Brain: Diseases](#)

Asked by: Benn, Hilary

To ask the Secretary of State for Health and Social Care, if she will ask mental health trusts to ensure that their eligibility criteria include patients with organic brain disorders, such as Huntington's disease, to help those people access mental health support services where mental health is the presenting symptom.

Answering member: Maria Caulfield | Department: Department of Health and Social Care

Access to mental health services is based on clinical need, including for people with organic brain disorders such as Huntington's disease. The NHS Long Term Plan commits an additional £2.3 billion a year to expand mental health services in England by 2023/24. This includes increasing access to National Health Service talking therapies through Improving Access to Psychological Therapies (IAPT) to ensure that 1.9 million adults, including those with Huntington's disease, can receive support for conditions such as anxiety and depression.

The NHS is developing the IAPT services include a focus on people with long term conditions. The IAPT - long term conditions services have been established to support integrated pathways between IAPT services and physical health for people with long term conditions, including neurological conditions. All integrated care systems are expected to commission IAPT services integrated into physical healthcare pathways as part of IAPT expansion plans locally.

HC Deb 02 November 2022 | PQ 70980

[Armed Forces: Huntington's Disease](#)

Asked by: Benn, Hilary

To ask the Secretary of State for Defence, whether people at risk of Huntington's disease are able to serve in the armed forces without the need to provide a negative predictive test upon recruitment.

Answering member: Dr Andrew Murrison | Department: Ministry of Defence

The genetics of Huntington's disease are complex and the likelihood of an Armed Forces candidate developing the disease and the likely age of presentation are dependent on the number of gene repeats. In some cases it is possible to predict these with a high level of certainty, based either on genetic testing of immediate relatives or of the candidate themselves.

Candidates known to be carriers of the gene associated with Huntington's disease are normally graded medically unfit for service. Candidates with a proven, immediate family history of this condition are also normally graded medically unfit unless known not to carry the gene.

If there is clear evidence that a candidate is unlikely to develop Huntington's disease during a Service career then they may, on a case by case basis, be considered medical fit for service. It is for the candidate to provide this evidence, which must be supported by an appropriately qualified and experienced specialist.

HC Deb 02 November 2022 | PQ 70978

[Huntington's Disease: Medical Treatments and Research](#)

Asked by: Mishra, Navendu

To ask the Secretary of State for Health and Social Care, if she will make an assessment of the adequacy of the level of public funding for (a) research and (b) treatment of Huntington's disease.

Answering member: Robert Jenrick | Department: Department of Health and Social Care

Expenditure on research into dementia and neurodegeneration, including Huntington's disease was approximately £420 million from 2015/16 to 2019/20 and £77 million in 2020/21. The National Institute for Health and Care Research (NIHR) has funded two studies into Huntington's disease with a value of £316,267. In the last five years, the NIHR has also supported the delivery of 39 studies relating to Huntington's disease via the Clinical Research Network infrastructure. The NIHR is also supporting research on diagnosis and treatment of this condition through its Biomedical Research Centres.

No specific assessment of funding for the treatment of Huntington's disease has been made. However, integrated care boards are responsible for working with local communities, commissioners and organisations to understand the needs of the local population and how to commission

services to meet those needs, including the treatment of Huntington's Disease.

HC Deb 25 October 2022 | PQ 68019

[Huntington's Disease: Research](#)

Asked by: Nichols, Charlotte

To ask the Secretary of State for Health and Social Care, if he will make it his policy to increase funding for research into Huntington's Disease.

Answering member: James Morris | Department: Department of Health and Social Care

There are no national guidelines for the diagnosis and management of Huntington's disease. The Department has made no assessment on the clinical guideline on care for people who have Huntington's disease. However, the neuropsychiatry service specification is in development, which when finalised, will outline the multi-disciplinary approach to caring for patients with complex neurological conditions including Huntington's Disease who require specialised assessment and mental health support.

NHS England's neuroscience transformation programme (NSTP) is developing a number of optimal pathways for neurology services which includes Huntington's disease. Following extensive stakeholder engagement, the NSTP is developing a new definition for 'specialised' neurology and a model for neurology services. This will make it easier for integrated care systems (ICSs) to reduce the inequalities of access and bring specialist knowledge and skills into the patient pathway much earlier. It will help speed up the process for initial diagnosis for patients and whenever specialist interventions are indicated along a patient journey, enable that to be made available closer to the patient rather than predominantly at the specialist centres.

The Government remains committed to achieving parity between mental and physical health services and to reducing mental health inequalities with investment in National Health Service mental health services continuing to increase from almost £11 billion in 2015/16 to £15 billion in 2021/22. While no assessment has been made for people with Huntington's disease, there is work underway to review the Clinical Genomic Service Specification which includes the need to strengthen access to mental health support services. The revised specification will be subject to public consultation before receiving final approval. The NSTP includes developing optimal pathways for neurology services, which also includes common principles regarding access to appropriate timely mental health support.

In the last five years, the National Institute for Health and Care Research (NIHR) has funded two studies into Huntington's disease with a total award value of £316,267 and supported the delivery of 39 studies relating to Huntington's disease via the Clinical Research Network infrastructure. The Government has also committed to invest at least £375 million in neurodegenerative disease research over the next five years to fund projects into a range of diseases, including Huntington's disease.

HC Deb 07 September 2022 | PQ 46174

[Huntington's Disease: Mental Health Services](#)

Asked by: Allin-Khan, Dr Rosena

To ask the Secretary of State for Health and Social Care, whether his Department is taking steps to increase access to community mental health support for people with Huntington's disease.

Answering member: Gillian Keegan | Department: Department of Health and Social Care

Access to mental health services is based on clinical need, including for patients with Huntington's disease. We are investing an additional £2.3 billion a year to expand mental health services in England by 2023/24. We have committed to increase access to National Health Service talking therapies, such as Improving Access to Psychological Therapies, to ensure that 1.9 million adults can receive support for conditions such as anxiety and depression.

HC Deb 05 September 2022 | PQ 40877

[Huntington's Disease: Mental Health Services](#)

Asked by: Smith, Jeff

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to engage with people who have Huntington's disease as part of the consultation for the 10 Year Mental Health Plan.

Answering member: Gillian Keegan | Department: Department of Health and Social Care

We have launched a public call for evidence to support the development of a new, 10-year, cross-Government plan for mental health and wellbeing in England. We encourage those with lived experience to respond to the call for

evidence, including those with Huntington's disease. The call for evidence is open until 7 July 2022.

HC Deb 28 June 2022 | PQ 23327

[Huntington's Disease: Mental Health Services](#)

Asked by: Smith, Jeff

To ask the Secretary of State for Health and Social Care, what steps his Department is taking to help ensure that people who have Huntington's disease can access mental health services.

Answering member: Maria Caulfield | Department: Department of Health and Social Care

Patients with Huntington's Disease have access to a range of mental health support, through general practitioners, local mental health services, specialised neurology services and clinical geneticists and genetic counsellors through the clinical genomic service.

The clinical genomic service specification is currently being reviewed, which includes strengthening access to mental health support services. The revised specification will be subject to public consultation before final approval. NHS England's neuroscience transformation programme is developing optimal pathways for neurology services, which include common principles regarding access to appropriate timely mental health support.

In addition, the neuropsychiatry service specification is in development, which will outline the multi-disciplinary approach to caring for patients with complex neurological conditions who require specialised assessment and mental health support.

HC Deb 28 June 2022 | PQ 23326

3

News, blogs and press releases

UCL press release

16 June 2022

[**New system that defines Huntington's Disease will 'revolutionise' drug trials**](#)

Business Weekly

10 May 2022

[**Cambridge company's disease model sheds new light on Huntington's**](#)

Yorkshire Post

6 May 2022

[**Mental health needs of Huntington's Disease patients are key - Cath Stanley**](#)

UCL press release

28 April 2022

[**Hope for Huntington's disease after pioneering trials**](#)

Government Science and Engineering blog

26 April 2022

[**Pioneering research is key to England's Rare Diseases Action Plan**](#)

Department of Health and Social Care press release

28 February 2022

[**Millions of people with rare diseases to benefit from faster diagnosis and better access to treatment**](#)

Huntington's disease

Cambridge Independent

8 September 2021

Huntington's disease progression stopped in cell study by University of Cambridge and UCL researchers

Scotsman

15 July 2021

Call for expansion of services as Huntington's disease rates in northern Scotland five times higher than rest of world

Nature

5 May 2021

Failure of genetic therapies for Huntington's devastates community

Disclaimer

The Commons Library does not intend the information in our research publications and briefings to address the specific circumstances of any particular individual. We have published it to support the work of MPs. You should not rely upon it as legal or professional advice, or as a substitute for it. We do not accept any liability whatsoever for any errors, omissions or misstatements contained herein. You should consult a suitably qualified professional if you require specific advice or information. Read our briefing '[Legal help: where to go and how to pay](#)' for further information about sources of legal advice and help. This information is provided subject to the conditions of the Open Parliament Licence.

Sources and subscriptions for MPs and staff

We try to use sources in our research that everyone can access, but sometimes only information that exists behind a paywall or via a subscription is available. We provide access to many online subscriptions to MPs and parliamentary staff, please contact hocllibraryonline@parliament.uk or visit commonslibrary.parliament.uk/resources for more information.

Feedback

Every effort is made to ensure that the information contained in these publicly available briefings is correct at the time of publication. Readers should be aware however that briefings are not necessarily updated to reflect subsequent changes.

If you have any comments on our briefings please email papers@parliament.uk. Please note that authors are not always able to engage in discussions with members of the public who express opinions about the content of our research, although we will carefully consider and correct any factual errors.


You can read our feedback and complaints policy and our editorial policy at commonslibrary.parliament.uk. If you have general questions about the work of the House of Commons email hcenquiries@parliament.uk.

The House of Commons Library is a research and information service based in the UK Parliament. Our impartial analysis, statistical research and resources help MPs and their staff scrutinise legislation, develop policy, and support constituents.

Our published material is available to everyone on commonslibrary.parliament.uk.

Get our latest research delivered straight to your inbox. Subscribe at commonslibrary.parliament.uk/subscribe or scan the code below:



 commonslibrary.parliament.uk

 [@commonslibrary](https://twitter.com/commonslibrary)