Consultation response: Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper

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 support for people with Huntington's disease and their families, educate health professionals, and champion people's rights.

About Huntington's disease

Huntington's disease is a rare, genetic, neurodegenerative disorder and there is no cure. Around 8,000 people in the UK have the condition. It is caused by a 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 disease's progression. 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.

Symptoms of Huntington's disease can include:

- Movement (movements may happen that you do not 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.

Summary

We welcome the opportunity to respond to the government's 'Pathways to Work' Green Paper. We agree that the current benefits system is letting people down, but believe that many of the government's proposals will make it harder for people with Huntington's disease to access benefits.

Many people living with Huntington's disease rely on the benefits system for essential support. Living with Huntington's disease can critically affect finances, particularly as the disease progresses. It is difficult for a person, and family members who may look after them, to work or study. Meeting a person's care needs can also be very expensive. In the later stages of Huntington's disease, people will find communication and daily activities increasingly difficult and need full-time nursing care.

To inform our response to this consultation, we surveyed people affected by Huntington's disease about their experience of Personal Independence Payment (PIP), receiving 105 responses.

To take part in this survey, the person was required to have met at least one of the following criteria, within the last five years:

- Made their own application for PIP.
- Supported someone with their PIP claim (such as by helping them complete the form).
- Had their own PIP claim reviewed by the Department for Work and Pensions (DWP).
- Supported someone to respond to a review of their PIP claim.

We also interviewed two people who are family carers for someone living with Huntington's disease, as well as one person living with the condition.

Our key concerns and recommendations are:

- Conditionality requirements: People with Huntington's disease should have guaranteed exemption from any conditionality requirements and be protected from the risk of benefit sanctions. We are opposed to pressure being placed on a person with Huntington's disease to return to work. This is because it is a degenerative disease, meaning the person's condition will only worsen and never improve. Our view is that the 'support conversation' should not be mandatory.
- Support for people with terminal conditions: Currently, the Special Rules for Terminal Illness provide a way to identify people who are likely to have less than 12 months to live. However, only protecting people with claims under the Special Rules is not enough. There are people living with Huntington's disease who cannot claim under this route, despite dealing with the additional financial, medical, and emotional impacts of a debilitating, neurodegenerative condition. We are calling for people with a longer or highly uncertain prognosis to have additional protections and support within the benefits system.
- Tightening PIP eligibility: We do not support introducing the additional requirement to score at least 4 points on one daily living activity. This does not recognise that people who accumulate low points across activities can experience a similar, if not higher, impact on daily functioning as those who score highly in one or more activities. The cognitive impairment that people with Huntington's disease experience is extremely debilitating but often unseen.
- Reviewing the PIP assessment process: We support the government's commitment to review the PIP assessment process. Almost 4 in 5 people (79%) who responded to our survey did not believe that the PIP assessment process met the needs of people with Huntington's disease.
- Abolishing the Work Capability Assessment (WCA): We are concerned about the plan to abolish the WCA from 2028/29. This is because it will mean the additional element of Universal Credit (UC) (which would be frozen for existing claims and reduced then frozen for new claims) will depend on receiving the PIP daily living component. This means that people with Huntington's disease who are denied this support because of the 4-point requirement will face additional financial hardship. It is also unclear how conditionality would be determined if not through a WCA.

- Unemployment insurance: We would be concerned if people, who would otherwise be in the Employment Support Allowance (ESA) Support Group where support is provided without a time limit, are instead offered time-limited support through unemployment insurance.
- Personal Health Budgets (PHBs): If somebody with Huntington's disease loses their entitlement to PIP, then it is not sufficient to replace this with a PHB, as it is unlikely to cover the extra costs incurred by their disability.
- Access to UC: Young people living with Huntington's disease who are too unwell to work and qualify for the UC health element should not have to wait until they are 22 to make a claim.

Chapter 2: Reforming the structure of the health and disability benefits system

Question 1: What further steps could the Department for Work and Pensions take to make sure the benefit system supports people to try work without the worry that it may affect their benefit entitlement?

If somebody with Huntington's disease has left the workforce, in most circumstances this will be because the impact of their condition has made working impossible. However, if the person would like to return to work then they should be offered tailored employment support (see our response to question 4).

Question 2: What support do you think we could provide for those who will lose their Personal Independence Payment entitlement as a result of a new additional requirement to score at least four points on one daily living activity?

We do not support introducing the additional requirement to score at least 4 points on one daily living activity.

DWP statistics show that over a third of current working age PIP claimants (36%/35,000 of 97,000) who cited 'other neurological diseases' as their primary disabling condition were awarded less than 4 points in all daily living activities[1]. If the additional requirement to score at least 4 points on one daily living activity is introduced then these people would be denied PIP.

People who accumulate low points across activities can experience a similar, if not higher, impact on daily functioning as those who score highly in one or more activities. Cognitive impairment can leave a person unable to budget, communicate effectively, plan their day, maintain hygiene and prepare food. Cognitive changes can also cause someone to be apathetic and lack awareness that they are struggling. This means that paid carers are often needed to provide prompting and supervision.

CASE STUDY: Becky (name has been changed)

Becky has severe Huntington's disease symptoms, including difficulty speaking because her facial muscles are weak (dysarthria). She struggles to manage personal and domestic routines, has an unsteady gait and experiences frequent falls.

Due to her loss of balance and slurred speech, people have often mistakenly thought she was drunk. She has not worked in over six years despite applying for a number of jobs, which is most likely the result of her Huntington's disease symptoms.

[1]Benefits and Work. April 2025. Available here: https://benefitsandwork.co.uk/news/most-at-risk-pip-health-conditions-revealed

It took courage for Becky to accept the impact that Huntington's was having on her life and to apply for PIP. Becky was refused PIP after claiming for the first time, but was successful on appeal.

She scored 12 points across the following categories and was awarded the enhanced rate of the daily living component of PIP:

- Preparing food: Needs an aid or appliance to prepare or cook a simple meal (two points)
- Eating and drinking: Needs supervision from another person to eat and drink (two points)
- Washing and bathing: Needs an aid to wash and bathe (two points)
- Using the toilet: Needs an aid or appliance to manage toilet needs (two points)
- Dressing and undressing: Needs an aid or appliance to dress or undress (two points)
- Making budgeting decisions: Needs prompting and assistance from another person to make complex budgeting decisions (two points)

Despite Becky's severe difficulties, she would not have been eligible for the daily living component of PIP, if there was an additional requirement to score at least four points on one daily living activity.

Almost four in five people (79%) who responded to our survey did not believe that the PIP assessment process met the needs of people with Huntington's disease. We support the government's commitment to review the PIP assessment process. PIP assessors often lack the condition-specific knowledge required to ensure someone with Huntington's can receive a fair and accurate assessment. Two out of three (66%) people who experienced challenges in applying for and being awarded PIP, said the assessor did not understand the physical symptoms of Huntington's disease and three in four (75%) said the assessor did not understand its mental health or cognitive impact. An example of the cognitive impact of Huntington's disease is the person experiencing apathy and a lack of insight into their level of disability.

"He really thought he could use the microwave, this was early on when I could leave him for a while and literally I came back and he'd just put so many minutes in the microwave it had literally gone on fire."

Family carer (June 2025)

"...They (PIP assessor) don't understand that they (the person with Huntington's disease) might look ok but not be ok or they could say they are ok but are not ok. Stubbornness is in this disease. All family members that have had Huntington's have been stubborn and don't want to say they are not fine and need some help."

Family carer (May 2025)

'I think it's very important that they have somebody who's doing the assessment that knows about the condition.'

Family member (June 2025)

The PIP assessment process will become even more challenging for people with Huntington's disease, if there is a new additional requirement to score at least four points on one daily living activity. People with cognitive impairment who are filling in forms without expert support will be particularly affected.

Losing PIP and other linked support will make it harder for people with Huntington's disease to meet their physical and mental health needs, as they will struggle to pay for vital aids and carers. This could potentially increase the risk of them reaching crisis point and having an expensive inpatient hospital admission.

The plan to abolish the WCA from 2028/29 means the additional element of UC (which would be frozen for existing claims and reduced then frozen for new claims) will depend on receiving the PIP daily living component. This means that people with Huntington's disease who are denied this support because of the four-point requirement will face additional financial hardship. It is also unclear how conditionality would be determined if not through a WCA.

People who do not receive a PIP mobility award alongside a daily living award will lose their entire PIP award if they lose the daily living component. This would result in them also losing access to thousands of pounds worth of 'gateway' support that is linked to a successful PIP claim. This includes Carer's Allowance for the claimant's unpaid carer, travel concessions and protection from the benefit cap.[2]

Question three: How could we improve the experience of the health and care system for people who are claiming Personal Independence Payment who would lose entitlement?

[2] Department for Work and Pensions (2025). Spring Statement 2025 health and disability benefit reforms – Impacts. Available here: https://www.gov.uk/government/consultations/pathways-to-work-reforming-benefits-and-support-to-get-britain-working-green-paper/spring-statement-2025-health-and-disability-benefit-reforms-impacts

If somebody with Huntington's disease loses their entitlement to PIP, then replacing this with a PHB to meet their health and care needs is not sufficient, as it is unlikely to cover the extra costs incurred by their disability.

We recognise that some people living with Huntington's disease may benefit from having a PHB to allow them to manage their healthcare and support in a way that suits them. However, many people struggle with the burden of coordinating their care on top of managing their own condition. This can be particularly challenging as 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. Therefore, for many people and their loved ones the administrative burden of a PHB could make their lives harder. PHBs do not cover the same range of costs and many people with Huntington's disease would find them impossible to manage. People with Huntington's may also not have someone who is able to support them with the administrative side of a PHB.

Question 4: How could we introduce a new Unemployment Insurance, how long should it last for and what support should be provided during this time to support people to adjust to changes in their life and get back into work?

We would be concerned if people who would otherwise be in the ESA Support Group, who have support without a time limit, are instead offered time-limited support through unemployment insurance.

We are opposed to pressure being placed on a person with Huntington's disease to return to work because the person's condition is only going to worsen, never improve. People with Huntington's often face significant difficulties in maintaining employment. While many workplaces offer reasonable adjustments, there are limits to what can be accommodated without compromising basic responsibilities of the job, and managing risks in the workplace.

When a person with Huntington's disease leaves employment, it is not because they do not want to work, it is because they are unable to work safely. As cognitive abilities decline, risks — e.g. to safety, finance and operational effectiveness — can become too great. When individuals can no longer meet the demands of their role, this leads to involuntary job loss. This can be devastating for the person, who can experience a loss of income and purpose.

Our view is that the 'support conversation' should not be mandatory. If somebody with Huntington's disease has left the workforce, in most circumstances this will be because the impact of their condition has made working impossible. However, if the person would like to return to work then they should be offered tailored employment support, which could involve:

- Working with the Huntington's Disease Association: We can work with the person's employer to consider options to improve support for them at work, such as through the Access to Work scheme. This could include meeting the person's manager to explain about the disease and ways to offer support, which can help keep them in their role as long as possible. The person may also want support from us to tell their employer about their diagnosis.

- Tackling stigma: The lack of awareness of Huntington's disease can lead to unfair treatment in the workplace, for example, a person's motor symptoms can be mistaken for drunkenness.

Question 5: What practical steps could we take to improve our current approach to safeguarding people who use our services?

There can be additional factors to consider around adult safeguarding when working with people with Huntington's disease. Due to cognitive changes, a person may display more risky behaviours or be at higher risk of drug or alcohol misuse than the general population. Cognitive changes and mental health difficulties can also make people with Huntington's disease vulnerable to exploitation.

Assessors should be aware that Huntington's disease symptoms often make it harder to manage finances, leading to potential risks around budgeting, debt and financial exploitation.

Some practical steps to consider are:

- Being aware that many vulnerable people are likely to miss communications (not opening post/not answering the phone) and taking steps to manage non-engagement. This can help ensure people with Huntington's disease are not denied access to vital support.
- Being flexible with people who miss deadlines, providing extensions where necessary.
- Being flexible with those who are supporting the person. Family members are often burdened with coordinating care and support across multiple health and social care providers.
- The person may lack mental capacity to manage their benefit claim. If this is the case then they will require an appointee.
- Understanding that some people with Huntington's disease lack insight into the challenges they are experiencing because of their condition. This means that further prompting and questions might be needed. An example would be if the assessor is in someone's home and the person is saying they can manage all their nutritional needs, but this is contradicted by mouldy food on display.
- Allow space for someone who is supporting the person, such as a family member, to speak alone to the assessor. This is because they may have a different version of the person's life and challenges, but be uncomfortable giving their view if the person is present.

Chapter 3: Supporting people to thrive

Our new support offer

Question 6: How should the support conversation be designed and delivered so that it is welcomed by individuals and is effective?

We would welcome increased employment support for people with Huntington's disease who are capable of meaningful work. However, this must be tailored to their needs (see our response to question four). We also recognise that having a 'support conversation' which

leads to a range of personalised support, could be preferable to undergoing a WCA. It is essential that reforms to WCA do not result in claimants who currently have no work-related requirements being reassessed or losing benefits.

Our view is that the 'support conversation' should not be mandatory. The professional undertaking a 'support conversation' with someone who has Huntington's disease should have the required condition-specific knowledge. This means recognising that Huntington's disease is a debilitating, progressive, neurodegenerative condition, which has a significant impact on people's ability to work.

Question 7: How should we design and deliver conversations to people who currently receive no or little contact, so that they are most effective?

For these conversations to be effective there needs to be increased awareness of how Huntington's disease affects cognition and communication. The disease makes it harder to plan, organise, initiate activities and problem solve. People may not always respond to calls, letters or visits. This should not be taken as a refusal to engage – it may be a sign of disease progression.

Some people prefer text or email communication, because it gives them time to process information and respond at their own pace. However, from a safeguarding perspective, recognise that it could be someone else sending/responding to texts and emails.

People with Huntington's disease can find it difficult to deal with changes or unexpected events, such as a change of plan or postponing a meeting. Giving adequate notice of an appointment and not changing the agreed time or arriving late, can help to build trust.

A new baseline expectation of engagement

Question 8: How we should determine who is subject to a requirement only to participate in conversations, or work preparation activity rather than the stronger requirements placed on people in the Intensive Work Search regime?

People living with Huntington's disease who have symptoms that mean they are unable to work should be exempt from these requirements and any risk of benefit sanctions.

They also need particular protection within the benefits system. Currently, the Special Rules for Terminal Illness provide a way to identify people who are likely to have less than 12 months to live. However, only protecting people with claims under the Special Rules is not enough. There are people living with Huntington's disease who cannot claim under this route, despite dealing with the additional financial, medical, and emotional impacts of a debilitating, neurodegenerative condition. This is because of the high degree of uncertainty as to when someone with Huntington's will die.

We are calling for people with a longer or highly uncertain prognosis to have additional protections and support within the benefits system. People with Huntington's disease should not be required to prepare or look for work, when it is extremely unlikely they will be able to take up or retain employment as their condition worsens. There should be protections, not just for people with more advanced terminal conditions, but also those

with terminal conditions that will only worsen over time – even if their condition does not yet have a very significant impact on their function.

Question 9: Should we require most people to participate in a support conversation as a condition of receipt of their full benefit award or of the health element in Universal Credit?

We are opposed to requiring people with Huntington's disease to participate in a support conversation as a condition of receipt of their full benefit award or of the health element in UC (see our response to question 6).

Question 10: How should we determine which individuals or groups of individuals should be exempt from requirements?

People with progressive, neurodegenerative conditions, such as Huntington's disease, should be exempt from any conditionality requirements and the risk of benefit sanctions. This is particularly important in relation to people with Huntington's disease, as cognitive impairment often causes apathy and results in a loss of drive and initiative. This means people can find it hard to engage with services (see our response to question 7).

Delaying payment of the health element of Universal Credit

Question 11: Should we delay access to the health element of Universal Credit within the reformed system until someone is aged 22?

Young people with Huntington's disease who are too unwell to work, and qualify for the UC health element, should not have to wait until they are 22 to make a claim.

Some young people who have Juvenile Huntington's disease could be affected by this proposal. Juvenile Huntington's disease is diagnosed when someone experiences symptoms of Huntington's before the age of 20.

Raising the age at which young people start claiming adult disability benefits

Question 12: Do you think 18 is the right age for young people to start claiming the adult disability benefit, Personal Independence Payment? If not, what age do you think it should be?

We are not providing a response to question 12.

Chapter 4: Supporting employers and making work accessible

Questions 13-18

We are not providing a substantive response to the questions in chapter four. However, we would like to reiterate that to improve access to work people with Huntington's disease should be offered voluntary, tailored employment support. The Huntington's Disease Association is also able to work with a person's employer to improve support for them at work.

If you have any questions about this consultation response, please contact david.stephenson@hda.org.uk