

# Call for Evidence response: Timms Review of Personal Independence Payment (PIP)

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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 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 condition and there is no cure. Around 8,000 people in the UK have the disease. 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, available 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.

## Our evidence

During April-May 2025, we surveyed people affected by Huntington's disease, including family members, about their experiences of PIP. The survey received 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 5 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 held a focus group in May 2026 with four participants who are, or were, family carers for a person living with Huntington's disease.

The insights from our Specialist Huntington's Disease Advisers have informed our response to this consultation. They provide expert advice and support to people living with Huntington's disease, many of whom are PIP claimants.

## Summary and recommendations

We welcome the opportunity to respond to the Timms Review of PIP.

Many people living with Huntington's disease rely on the benefits system for essential support. Their finances can be critically affected, particularly as the disease progresses, due to significant extra living and mobility costs. This can include spending on medicines, accessible transport, home adaptations, and specialist equipment to support with mobility and daily living activities. It is also difficult for the person, and family members who may look after them, to work or study.

Meeting a person's care needs can become expensive. If a person is experiencing uncontrollable, jerky movements (chorea), they will be using up more energy than they would be without the movements. This means that people with Huntington's disease usually need to eat a diet which is higher in calories than normal in order to minimise weight loss.

As Huntington's disease progresses, people find communication and daily activities increasingly difficult. Full-time nursing care is required in the later stages of the disease.

Our recommendations to the Timms Review and Secretary of State for Work and Pensions are to:

- **Amend the PIP activities and descriptors:** Almost four in five people (79%) who responded to our survey did not believe that the PIP assessment process met the needs of people living with Huntington's disease. We are calling for the following descriptors to be updated:
  - communicating verbally
  - engaging with other people face to face
  - moving around
  - taking nutrition
  - preparing food

We are also calling for the descriptors to be updated to ensure the impact of cognitive changes and dental care challenges are considered. Please see pages 4-5 for further details on these recommendations.

- **End unnecessary PIP assessments for people living with Huntington's disease, as well as individuals with other progressive, life-limiting conditions:** There is no reason why a person living with Huntington's disease who is already receiving the highest rates of PIP for both categories, should be reassessed. This is because the disease is progressive and people's needs will only increase over time. Yet DWP data (see pages 5-7) shows that more than one in five (23%) claimants living with Huntington's disease who were awarded the highest rate of PIP in both categories from January 2025-January 2026 received fixed-term awards. For people living with

Huntington's disease who are on the lower rates of PIP for mobility and/or daily living, compulsory reassessments should be replaced with a 'light-touch' check-in every five years. This would be followed by a voluntary reassessment if the person's needs had increased, with the option of a paper-based assessment.

- **End the possibility of someone living with Huntington's disease having their award reduced:** It should not be possible for a person living with Huntington's disease to have their award reduced, as their needs will only increase. Removing this possibility would ensure that people with the condition who have increasing health and social care needs are not deterred from requesting a reassessment, due to anxiety of losing essential support.
- **There are benefits to placing more emphasis on a claimant's specific medical condition during the PIP assessment process:** Most people living with Huntington's disease have evidence of their diagnosis and would benefit from there being a greater emphasis on condition during the assessment process. However, we would not support making provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP.
- **Ensure only professionals who have knowledge of neurological conditions assess people living with Huntington's disease:** Three in four people (75%) we surveyed told us their assessor did not understand the mental health or cognitive impact of Huntington's disease. That is why it is important that individuals who have some professional experience of neurological conditions, and who have received training developed by relevant charities, assess people living with the condition.

### Question 1: How effectively is PIP delivering on its intended role and purpose?

For people living with Huntington's disease who are able to access PIP, it can help with the significant extra mobility and living costs that they and their families face. However, changes are required to ensure the system meets the needs of people who have been diagnosed with this rare, neurodegenerative condition. Our recommendations are outlined in our responses to questions 2-3.

We have included comments below from focus group participants on their experiences of claiming and using PIP.

*"I managed the days caring for my five children, as well as my husband. I don't know how but I did. The money from PIP was used for carers for a couple of times a week, so I got two nights of sleep out of seven. So PIP for me, allowed me to actually focus the next day when I'd had a sleep and cope. The other nights, you're half listening and half*

*sleeping, aren't you? It's like having another child, you know. I always said it was like having six children, not five".*

Family carer

*"My grandson's PIP covers his care and just that. You know, it's not as though we're going off on a jolly cruise or something with the money".*

Family carer

**Question 2: Does the PIP assessment, including the assessment criteria, effectively capture the impact of long-term health conditions and disability in the modern world, and provide fair access to the right support at the right level across the benefits system?**

We are concerned that the PIP assessment process does not meet the needs of people living with Huntington's disease. Our reasons for this are outlined below.

People who are not receiving support from the Huntington's Disease Association when making their PIP application are at a particular risk of having an assessment which is not accurate and then being denied PIP.

### Assessment criteria

Many of the current descriptors make it difficult to effectively assess the ability of people living with Huntington's disease to carry out specific daily living and mobility activities. Our recommendations to the Timms Review and Secretary of State for Work and Pensions are to:

- **Update the descriptors for 'communicating verbally' and 'engaging with other people face to face':** There is significant overlap between the descriptors under 'communicating verbally' and 'engaging with other people face to face'. These descriptors also do not accurately reflect the experiences of people living with Huntington's disease, who have specific communication difficulties. For example, someone may struggle to express themselves clearly or to understand the meaning of what others are saying. Impulsivity is another symptom.
- **Update the descriptors for 'moving around':** The current focus is on the distance a person can walk, but it does not cover the ability of someone to do this safely. A person living with Huntington's disease may be able to walk to their destination, but be unable

to do this safely because they experience movement difficulties, which leaves them at risk of injury through falls.

- **Ensure that cognitive changes are better represented:** The cognitive aspects of Huntington's disease are not well represented in the PIP activities and descriptors. Someone in the early stages may have difficulty with organising and planning, become more forgetful, find activities take longer or are harder to finish, and find it challenging to deal with new situations. This can make activities of daily living very difficult - such as budgeting, dealing with paperwork and cooking a meal safely. This means that paid carers are often needed to provide prompting and supervision. Due to the cognitive impact of Huntington's disease, people may also lack insight into the condition's impact on their life. The PIP assessment does not take account of this.
- **Ensure dental care challenges are considered:** Dental care is a particular challenge for people living with Huntington's disease, but the current descriptors for 'washing and bathing' do not cover brushing teeth. To avoid weight loss, people living with Huntington's disease may have high sugar diets. Movement difficulties, swallowing problems and apathy make it difficult to brush teeth and keep them clean.
- **Update the 'taking nutrition' descriptors:** We are concerned that the 'taking nutrition' descriptors do not consider whether the claimant has swallowing problems.
- **Update the 'preparing food' descriptors:** The descriptors under 'preparing food' do not cover bending down to get an item or reaching up to the fridge or cooker.

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

Family carer

*"My dad and brother had a complete lack of insight and believed they were managing fine. No symptoms, no problems".*

Family carer

## Ending unnecessary reassessments

We are calling for an end to unnecessary PIP assessments for people living with Huntington's disease, as well as those with other progressive, life-limiting conditions.

In 2018, the DWP issued updated guidance<sup>12</sup> so that people receiving the highest level of support under PIP, and whose needs are unlikely to change or may get worse, would receive an 'ongoing award' of PIP with a 'light touch' review after 10 years. Despite this, some people living with Huntington's disease, even when receiving the highest level of support under PIP, are being given fixed-length awards.

As of 31 January 2026, 2,683 people had a claim with entitlement to PIP and had their main disabling condition recorded as Huntington's disease.

From 1 January 2025- 31 January 2026 there were 250 PIP clearances relating to a claimant who attended a PIP assessment that identified their primary disabling condition as Huntington's disease. PIP clearances are the final decisions made by the DWP on PIP claims, marking the end of a claim's registration process. Clearances include awards, disallowed claims, and withdrawals. However, any claimant who withdraws or is disallowed from the process prior to completing their assessment will not have a primary disability recorded on their PIP record. They instead will appear in the 'Unknown or missing / Disability not recorded' disability category.

The key findings related to the 250 PIP clearances from January 2025-January 2026 are:

- **Number of cases where PIP was awarded:** In 61% (153) of these cases, the person was awarded PIP whilst in 39% (97) of cases the person failed the assessment (i.e. the claimant not scoring enough points at the assessment to be awarded the benefit).
- **Ongoing awards of PIP:** In 30% (75) of cases, the person received an ongoing award of PIP – these are claims that have no end date but will have a light-touch review after 10 years. They are designed to be awarded where the claimant's needs are unlikely to improve.
- **Fixed-term awards of PIP:** 21% (52) of these PIP claims resulted in the person facing an award review within two years and 6% (16) of people will be reviewed between two and five years.
- **Awards for both enhanced mobility and enhanced daily living rates:** In 95 (38%) of the 250 cases, the person was awarded both the enhanced daily living rate and enhanced mobility rate for PIP, with 73 (77%) people awarded the enhanced rates for both components receiving an ongoing award.
- **Awards for the enhanced rate of one PIP component (daily living or mobility):** 18 people received enhanced daily living but not enhanced mobility rates (one of whom received this on an ongoing basis), and a further seven received enhanced mobility but not enhanced daily living rates.

The data above highlights that, contrary to UK Government guidance, more than one in five (23%) claimants living with Huntington's disease who were awarded the highest rate of PIP for both mobility and daily living components from January 2025-January 2026 received fixed-term awards. This means they may face the prospect of a pointless, anxiety-provoking, compulsory reassessment.

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<sup>1</sup> DWP. 2018. Setting an award period. Available [here](#).

<sup>2</sup> House of Commons Library. May 2023. Personal Independence Payment. Available [here](#).

*"It took us a couple of years of claiming before I said 'for crying out loud, it's a degenerative neurological disease. She ain't going to get any better. Why have we got to keep going through annual bloody assessments?' And in the end, they wrote to me and said, fair play, you don't have to be assessed again".*

Family carer

We recommend that people who have progressive, life-limiting conditions, such as Huntington's disease, should never have to go through a compulsory PIP reassessment again. For people living with Huntington's disease who are on the lower rates of PIP for mobility and/or daily living, compulsory reassessments should be replaced with a 'light-touch' check-in every five years. This would involve contacting the person to ask if their condition has changed. If they report that it has worsened they should have the option of being reassessed. People should be able to choose the type of light-touch contact (phone, email, text or post) that would work best for them, when they first get their award. When the person makes their initial PIP claim, they should have the option of providing permission for a third party to be contacted - such as a family member - as part of the light-touch check-in. This is important because, as Huntington's disease can cause a person to lack insight into their symptoms, they may not provide an accurate account of their needs when this check-in takes place. These preferences should be recorded and respected in future communications.

If the needs of the person awarded the lower rate of PIP for mobility and/or daily living increase during the five period between the light touch check-ins, they would be able to report a change to their circumstances and be assessed to see if they are eligible for a higher award.

When undergoing a voluntary reassessment to see if they are eligible for a higher award, the person should have the option of a paper-based assessment, based on medical evidence. Importantly, it should not be possible for a person living with Huntington's disease to have their award reduced. Removing this possibility would ensure that people with the condition who have increasing health and social care needs are not deterred from requesting a reassessment, due to anxiety of losing essential support.

*"Surely, there shouldn't be reassessment unless the person is going from the lower level to the high level, because there's not going to be any improvement is there?"*

Family carer

## The role of medical evidence

Most people living with Huntington's disease have evidence of their diagnosis and would benefit from there being a greater emphasis on condition during the assessment process. However, we would not support making provision of evidence, or a formal diagnosis by a medical expert, a mandatory requirement for eligibility for PIP. We are aware of people with high levels of need who do not have a diagnosis, due to not engaging with NHS services. This is a particular risk for people living with Huntington's disease, due to the cognitive impact of the condition. Cognitive changes can mean that some people with the condition have no insight into their difficulties, even when they have severe symptoms and high care needs. Some people may also be fearful of being diagnosed with Huntington's disease and avoid seeking help from the NHS for this reason.

### Question 3: What is the experience of people claiming PIP and does this vary for different groups of people?

Almost 4 in 5 people (79%) who responded to our survey did not believe that the PIP assessment process met the needs of people living with Huntington's disease.

*"Our experience of the PIP assessment process was very poor, until the appeals court. At that point I felt we were dealing with people who genuinely listened and tried to understand Huntington's disease".*

Family carer

Assessments are more likely to be accurate when an assessor listens to those who know the claimant best and asks the right questions. A Huntington's Disease Association Adviser gave an example of a person stating they did not use a grab rail to get out of the bath. It was then assumed by the assessor that this was something they were able to do without assistance. However, follow-up questioning would have identified that they used a wall to stabilise them when getting in and out of the bath. The person also used a radiator to help them get off the toilet.

It is important that all PIP assessors who are assessing someone living with Huntington's disease have an understanding of the condition and its impact on cognition, movement and mental health. Yet, 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, told us 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.

*"Someone doing the assessment needs to have at least some understanding about Huntington's disease".*

Family member

*"...They (PIP assessor) don't understand that they (the person with Huntington's disease) might look ok but not be ok..."*

Family carer

One reason why it is important for assessors to have knowledge of Huntington's disease is the additional factors to consider around safeguarding. Due to cognitive changes, a person may engage in risky behaviours such as drug or alcohol misuse, poor financial decisions, unsafe use of appliances or medication, impulsive spending, reduced awareness of danger, aggression or disinhibited behaviour, and neglect of personal hygiene or nutrition, and difficulty recognising the consequences of their actions.

Cognitive changes and mental health difficulties can make people living 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, scams, debt and financial exploitation.

Some important considerations for assessors are:

- Many vulnerable people are likely to miss communications (not opening post/not answering the phone), so taking steps to manage non-engagement is important. This can help ensure people living with Huntington's disease are not denied access to vital support.
- The person may lack mental capacity to manage their benefit claim. If this is the case then they will require an appointee.
- Some people living with Huntington's disease lack insight into how their condition is affecting them. This means further prompting and questions might be needed, as well as input from a third party, such as a family member, who is aware of the person's care needs. 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.
- The need to 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.



Our recommendation is for people living with Huntington's disease to be assessed by an individual who has some professional experience of neurological conditions and who has received training developed by relevant charities.

In addition to concerns about the lack of condition-specific knowledge of assessors, people affected by Huntington's disease have told us of their frustration with the time it takes to have a PIP assessment and the complexities and demands of the application process. These concerns are highlighted in the comments from focus group participants below.

*"The waiting time for an assessment needs to be reduced, so that people are financially supported sooner. Some people and carers are going to be anxious, overwhelmed and discouraged from completing the form.*

Family carer

*"What used to push me over the edge was the bureaucratic red tape. That's the bit that always, always tipped me over. The process needs to be much easier to navigate".*

Family carer

**Question 4: What has changed in wider society and the workplace since 2013 (and might be expected to change in the future), how has this impacted PIP and does PIP need to change accordingly?**

We are not providing a response to question 4.

If you have any questions about this consultation response, please contact [david.stephenson@hda.org.uk](mailto:david.stephenson@hda.org.uk)