Consultation response: Modernising support for independent living: the health and disability green paper

About us

We are the Huntington's Disease Association. Our aim is to help people living with Huntington's disease (HD) in England and Wales to live a better life. We provide support services for people with Huntington's, educate families and professionals, and champion people's rights.

There are an estimated 8000 people living with Huntington's disease in the UK.

Summary

We welcome the opportunity to respond to the government's health and disability Green Paper. We agree that the benefits system must work better for those with the most severe disabilities and health conditions, including through improved models of assessment, treatment and support. We have gathered the views of our Specialist Huntington's Disease Advisers to inform our response to this consultation. Our advisers provide expert advice and support to people living with Huntington's disease, many of whom are Personal Independence Payment (PIP) claimants.

Huntington's disease is a genetic condition which affects the body's nervous system, impacting movement, cognition (perception, awareness, thinking, judgement), behaviour and mental health. Many people living with HD rely on the benefits system for essential support. Living with HD can impact on 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 HD, a person will need full-time nursing care

Our key concerns and recommendations are:

- The PIP assessment process does not meet the needs of people living with HD: We would value the opportunity to work with the DWP to improve the assessment process so it can better reflect the experiences of people living with HD. The current PIP descriptors make it challenging to effectively assess the ability of people living with HD to carry out specific daily living and mobility activities. PIP assessors also often lack the condition-specific knowledge required to ensure someone with HD can receive a fair and accurate assessment. For example, there is often a lack of awareness that cognitive impairment as a result of HD can mean people do not have insight into their level of disability.
- People with a diagnosis of HD should receive PIP on an ongoing basis: We

recommend that all people with HD should be entitled to an ongoing award of PIP. The nature of HD means that, over many years, the disease progresses until the end of life. There is no cure and a person's condition deteriorates over time. This is why it does not make sense to continue to assess someone living with HD for PIP throughout their lives. However, we recognise that a person may need to be reassessed if there is evidence they would be entitled to a higher award because of their worsening health.

- There are benefits to placing more emphasis on condition during the assessment process: Most people with HD have evidence of their diagnosis and would benefit from there being a greater emphasis on condition during the assessment process. However, we disagree with the proposal to make 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. One reason for this is that cognitive impairment can result in a person being unable to recognise their own needs. Some people may also be fearful of receiving an HD diagnosis and avoid seeking help from the NHS for this reason.
- Replacing a cash transfer with an alternative system will make the lives of people living with HD more difficult: We do not support the proposals to introduce alternatives to a cash transfer system, as a means of supporting someone through PIP. All of the proposed options risk making the life of people living with HD and their families more challenging. One reason for this is that the impact of cognitive impairment means that small changes for someone living with HD can be hard to adapt to. This means it would be challenging for many people to adapt to a system, such as a catalogue/shop scheme, where there were restrictions on where they could spend their money.
- More can be done by local areas to support people living with HD: There are a number of needs/costs related to HD which local areas could help with further.. People living with HD often struggle to get a wheelchair which meets their needs and routinely struggle to receive much-needed funding for hospital transport.
- There are challenges to aligning existing services and offers of support: We recognise the benefits of this approach and agree there is a need to simplify the application process for disabled people. However, many people living with HD who receive PIP do not have regular assessments by other agencies like Social Services or the NHS. Even if someone is being assessed by a health professional, this is often at a basic level by a practitioner who lacks specialist knowledge.
- All HD patients, family members and carers should be provided with coordinated multidisciplinary (MDT) care: This should include a Care Coordinator to coordinate care, provide practical and emotional support, and help people manage their condition.

Chapter 1: PIP – Overview and assessment reform

Q1. What are your views on an assessment that places more emphasis on condition rather than the functional impact of a condition on the person?

It is important that all PIP assessors who are assessing someone living with HD have an understanding of the condition and its impact on cognition, movement and mental health. We would like to continue to work alongside the DWP and its partners to help achieve this.

We are concerned that the functional assessment does not meet the needs of people living with HD. Due to the cognitive impact of HD, people may lack insight into the condition's impact on their life. The functional assessment does not take account of this. 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.

When functional assessments are effective, it is when an assessor listens to those who know the applicant best, and asks the right questions. One of our advisers gave an example of an applicant 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 the applicant used a wall to stabilise them when getting in and out of the bath. They also used a radiator to help them get off the toilet.

Most people living with HD have evidence of their diagnosis and would benefit from there being a greater emphasis on condition during the assessment process. However, we disagree with the proposal to make 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 HD due to the cognitive impact of the condition. Cognitive impairment can cause someone to be apathetic, have difficulties with organising and planning, and lack awareness that they are struggling. Some people may also be fearful of being diagnosed with HD and avoid seeking help from the NHS for this reason.

Q2. What are your views on people receiving PIP without an assessment if they have specific health conditions or a disability as evidenced by a healthcare professional?

We recommend that a person living with HD should be entitled to an ongoing award of PIP. It can be devastating for a person and their family when they are diagnosed with HD. The nature of HD means that over a period of many years, the disease progresses until the end of life. Having to regularly undergo assessments for PIP can be a significant cause of distress for people affected by HD and their loved ones, at a time when they are already struggling. It can be a huge weight off a family's shoulders when the person receives an ongoing award of PIP. Every person living with HD should have this opportunity. However, we recognise a person may need to be reassessed if there is evidence they would be entitled to a higher award because of their worsening health.

Q3. What are your views on PIP claimants not being subject to an award review if they have a specific health condition or disability as evidenced by a healthcare professional?

We recommend that all people living with HD should be entitled to an ongoing award of PIP (see response to question 2).

Q4. Do you agree or disagree on making provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP?

We disagree with the proposal to make provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP, due to the impact this will have on people with high levels of need who do not have a diagnosis (see response to question 1).

Q5. In relation to Question 4, please explain your answer and provide evidence or your opinion to support further development of our approach.

Please see response to question 1.

Q6. How could we prevent the provision of evidence or a formal diagnosis by a medical expert from impacting the NHS? Please explain your answer and provide evidence or your opinion to support further development of our approach.

We are not providing a response to question 6.

Q7. Do you agree or disagree that eligibility for PIP should be based more on condition?

Most people with HD have evidence of their diagnosis and would benefit from there being a greater emphasis on condition during the assessment process.

However, we disagree with the proposal to make provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP, This is because of the impact this would have on people with high levels of need who do not have a diagnosis (see response to question 1).

Q8. How could we determine eligibility for the following conditions?

We are not providing a response to question 8.

Chapter 2: PIP – Eligibility reform

Q9. Do you think the need for an aid or appliance is a good/bad indicator of extra ongoing costs and why?

We acknowledge that for some people the need for an aid or appliance will be an indication of extra ongoing costs. However, there are people living with HD who have additional care needs but do not need an aid or appliance. An example of this could be a person experiencing cognitive impairment during the early stages of their condition.

In some circumstances, the use of an aid or appliance could increase the risk of harm for someone living with HD. People with the condition can experience chorea (a symptom that causes involuntary, random muscle movements), which impacts gait and eventually prevents someone from being able to walk. For someone experiencing these symptoms, a walking stick could increase risk due to the person's involuntary movements. The impact of HD on movement and cognition can also mean that using an electric wheelchair or scooter is unsafe.

Q10. Do you think the need for prompting is a good/bad indicator of extra ongoing costs and why?

A need for prompting and/or supervision can be a good indicator of extra ongoing costs. A person living with HD can experience cognitive impairment, leading them to struggle to plan their day and undertake daily living activities, such as washing and eating. Therefore, paid carers are often needed to provide prompting and supervision.

Q11. Do you think people who accumulate low points across activities have the same level of extra costs as those who score highly in one or more activities?

Our view is that people who accumulate low points across activities can have the same level of extra costs as those who score highly in one or more activities.

People living with HD can experience challenges in multiple areas of their life (see response to questions 12 and 13). Cognitive impairment can leave a person struggling to budget or communicate with people on the phone. A common physical symptom is an increased risk of choking on food due to swallowing problems.

Q12. Do you think any of the PIP activities measure similar functions and could be merged?

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 HD, 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.

Q13. Do you think any of the PIP activities should be removed or re-written and why?

Many of the current descriptors make it difficult to effectively assess the ability of people living with HD to carry out specific daily living and mobility activities. We would value the opportunity to work with the DWP to improve the assessment process so it can better reflect the experiences of people living with HD.

We recommend that the descriptors for ‘moving around’ are updated. 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 HD 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 swerving into the road. Cognitive impairment, which can lead to forgetfulness, also means that a person living with HD can struggle to walk somewhere without placing themselves at risk.

The descriptors under ‘communicating verbally’ do not reflect the challenges that people living with HD experience (see response to question 12).

The cognitive aspects of HD are not well represented in the PIP activities and descriptors. Someone in the early stages of HD 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.

Dental care is a particular challenge for people affected by HD, but the current descriptors for ‘washing and bathing’ do not cover brushing teeth. To avoid weight loss, people living with HD may have high sugar diets. Movement difficulties, swallowing problems and apathy make it difficult to brush teeth and keep them clean.

We are concerned that the ‘taking nutrition’ descriptors do not consider whether the applicant has swallowing problems. The descriptors under ‘preparing food’ do not cover bending down to get an item or reaching up to the fridge or cooker.

Questions 14-17

We are not providing a response to questions 14-17.

Chapter 3 – PIP – What do we provide support for?

Q18. PIP provides an contribution towards extra costs. Which extra costs incurred by disabled people are the most important for a new scheme to address? Please rank the following options in your order of importance:

- Equipment and aids
- Medications and medical products
- Personal assistance (costs arising from hired physical and/or emotional support within and outside the home, eg. help with household tasks or assistance with transportation)
- Health and personal care (including physical therapies, talking therapies, massages, etc. Also includes greater spending on personal hygiene or appearance)
- Extra transport costs (from reliance on taxis or accessible taxis, hospital parking fees, vehicle adaptations, etc.)
- Additional energy and utility costs arising from disability or health condition (including digital access)
- Additional food costs arising from disability or health condition
- Additional spending on clothing, footwear, and bedding items arising from disability or health condition
- Higher costs of insurance
- Additional housing costs arising from disability or health condition, including home adaptation costs

It is difficult to rank these options in order of importance. However, our views on some of these areas are:

- Personal assistance: The extra costs created by the need for paid carers can be significant and it would be crucial for any new scheme to address this.
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- Loss of income: Living with HD can impact on finances, particularly as the disease progresses. It can create a significant loss of income if a person, and family members who look after them, have to stop working.
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- Equipment and aids: The need for an aid or appliance is not necessarily an indicator of extra ongoing costs for someone living with HD (see response to question 9).

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- Additional food costs: Cognitive challenges often mean that people struggle to plan for shopping and cannot cope with the choice or busyness of supermarkets. As a result, some will shop at smaller, more expensive shops. If people do choose to shop at a supermarket, they can struggle with having to use supermarket loyalty cards, which are required in most stores to avoid excessive costs.

- Medication: Some people living with HD also require as much as 5000 calories a day to maintain weight, due to increased movement[1]. Many people with HD do not have to pay for their prescriptions.

Q19. In relation to Question 18, please explain your answer below and tell us about any other important kinds of cost not listed above.

Please see our response to question 18.

Questions 20-23. What are the benefits and disadvantages of moving to a new system for PIP claimants?

We do not support the proposals to introduce alternatives to a cash transfer system, as a means of supporting someone through PIP. All of the proposed options risk making the life of people living with HD and their families more difficult.

The impact of cognitive impairment means that small changes for someone living with HD can be hard to adapt to. This means it would be challenging for many people to adapt to a system, such as a catalogue/shop scheme, where there were restrictions on where they could spend their money.

A particular risk of the catalogue/shop scheme is a person living with HD could need an item which was not on the list of approved providers. This is particularly likely to affect people living with HD as they often require specialist equipment. A voucher scheme, where disabled people receive vouchers to contribute towards specific costs, which would also create added complexity.

We do not agree with requiring claimants to buy aids, appliances, or services themselves, and to then provide proof of their purchase to claim back a contribution towards the cost. Many people tell us of the immense time and effort it takes to get the right support from the NHS, Social Services, and benefits system. A receipt-based system would place an added burden on families affected by HD, particularly those on low incomes.

People living with HD can experience apathy and mental health problems, leading them to disengage with services. For some, it can be too emotionally painful to receive a diagnosis of HD. Therefore, some people who do not have a formal diagnosis may struggle to provide medical evidence of their condition. However, they could still require support requiring significant funds, such as home adaptions. As a result, we do not support the introduction of one-off grants, which require medical evidence of a person's condition to be provided to demonstrate the need for an adaption.

Q24. If PIP could no longer be used to determine eligibility to passport to other benefits and services, what alternative ways could service providers use to determine disability status?

It is important that people can use a range of measures to determine disability status. We would support someone being able to use a letter confirming their HD diagnosis as a means to confirm eligibility to passport to other benefits and services.

Q25. If PIP could no longer be used as the eligibility criteria to additional financial support in Universal Credit, what alternative ways of determining eligibility should we use?

We are not providing a response to question 24.

Q26. Are there specific groups of people whose needs are not being met by the current PIP provision and have a need for a greater level of support? What form should this support take (eg. help with specific extra costs, access to improved healthcare such as mental health provision or enhanced local authority support such as care packages and respite)?

We would welcome increased support for people living with HD whose needs are not being met by current PIP provision. Mental health support is one area where people can struggle to get the help they need. We are aware of people being denied access to mental health services on the basis that HD is an organic brain disorder.

Q27. Instead of cash payment, are there some people who would benefit more from improved access to support or treatment (for example, respite care, mental health provision or physiotherapy)?

There are many people living with HD who would benefit from improved access to support or treatment (see response to question 26). However, this should be provided as additional support and not replace cash payments provided by PIP (see responses to questions 20-23). People who have the condition would also require significant help to access this support from a system which is fragmented and under-resourced. It is unclear as to who would provide this assistance.

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[1] Evans et al (2013). Prevalence of adult Huntington's disease in the UK based on diagnoses recorded in general practice records. *Journal of Neurology, Neurosurgery & Psychiatr*y. Available here: https://jnnp.bmj.com/content/84/10/1156

Chapter 4 – PIP – Aligning support

Q28. Do people already receive support from local authorities or the NHS with the need/costs that come with having a disability or health condition?

The level of support that people receive from the NHS and local authorities varies according to individual need and location. We would like there to be improved health and social care support for people living with HD and consistency in support across local areas.

Q29. In relation to Question 28, please explain your answer and provide evidence or your opinion to support further development of our approach.

We are not providing a response to question 28.

Q30. Which of the following do local authorities or the NHS help with?

- Equipment and aids
- Medical products
- Personal assistance (eg. help with household tasks)
- Health services
- Social care
- Respite
- Transport
- Utility costs
- Other

The type and level of support that people receive from the NHS and local authorities varies according to individual need and location. We would like there to be improved health and social care support for people living with HD and consistency in support across local areas (see response to question 32).

Q31. In relation to Question 30, please explain your answer and provide evidence or your opinion to support further development of our approach.

We are not providing a response to question 31.

Q32. Which needs/costs that come with having a disability or health condition could local areas help with further?

There are a number of needs/costs related to HD which local areas could help with further. People living with HD often struggle to get a wheelchair that meets their needs. This is because if a person can mobilise in their own house then it can affect their entitlement for a wheelchair for outdoor mobility. Even if a person does qualify for a wheelchair on the NHS it is often not fit for purpose, being uncomfortable and too heavy for a carer to manage.

People routinely struggle to get much-needed funding for hospital transport. We are aware of people having to travel over an hour to their specialist neurology centre, which requires a car journey. PIP does not cover this and alternative funds are often not available.

We would like to see people diagnosed with HD receiving a timely assessment of need by Social Services, and early intervention and support.

People living with HD need multiple hospital appointments and complex condition management. The management of the condition can require the expertise of multiple different specialists, spread across different hospitals. Effective coordination of care is essential to ensure care is effectively managed, the burden on patients and their carers is minimised, and healthcare professionals are working together to provide the best possible joined up and high-quality care[2]. This is why we are calling for HD patients, family members and carers to be provided with coordinated multidisciplinary (MDT) holistic care as they progress along the stages of this disease. A Care Coordinator can provide expert advice on care, along with practical and emotional support, helping those with HD to manage their condition.

Q33. In relation to Question 32, please explain your answer and provide evidence or your opinion to support further development of our approach.

We are not providing a response to question 33.

Q34. If we align the support offered by PIP into existing local authority and NHS services how could this improve things for disabled people and people with health conditions?

We recognise the benefits of aligning existing services and offers of support available to disabled people and people with health conditions. We agree there is a need to simplify the application process for disabled people and individuals with health conditions, who currently must apply nationally and locally for different types of support. However, there are significant challenges to implementing this successfully. Many people living with HD who receive PIP do not have regular assessments by other agencies like Social Services or the NHS, and may only see their consultant once or twice a year. Even if someone is assessed by a health professional, this is often at a basic level by a practitioner who lacks specialist knowledge. Such assessments are usually focused on a narrow aspect of a person’s condition, such as whether their mobility difficulties require them to have a grab rail.

Q35. Do you think aligning PIP with local authority and NHS services could reduce the number of assessments a person with a disability or health condition would have to undergo? Would this help to reduce duplication?

Please see our response to question 34.

[2] The UK Rare Diseases Framework. 2021. Department of Health and Social Care. Available here: https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework

Q36. What disability support services in your community are the most important services or support to deliver?

The importance of different disability support services will vary according to the different needs of people living with HD and how their condition is progressing. However, one of the most important services to provide would be a Care Coordinator to coordinate care, provide practical and emotional support, and help people living with HD to manage their condition.

Q37. How much flexibility should local areas have to decide their priorities in supporting people with disabilities and health conditions?

Our view is that national standards would be required to ensure that the proposals do not exacerbate the postcode lottery of support among local areas. Priorities should be decided through working in partnership with people living with a disability and those that support them.

Q38. What capacity and capability would be required to better align PIP with local authority and NHS services?

Please see our response to question 34.

Q39. Are you an individual or an organisation supporting claimants applying for PIP?

We support claimants to apply for PIP through providing supporting letters, but will only help with completing a PIP form in exceptional circumstances. We have built positive relationships with assessors to increase their knowledge of Huntington's disease so effective assessments can take place.