Huntington's
Disease
Association

[NAME]
Prime Minister
10 Downing Street
London SW1A 2AA

[DATE] September 2026

Dear Prime Minister

I am writing to congratulate you on your appointment, and to ask you to take action to support the thousands of people in England and Wales affected by Huntington's disease.

Huntington's disease is a rare, hereditary, neurodegenerative condition that affects movement, cognition, behaviour and mental health. Around 8,000 people in the UK are living with the disease with a further 32,000 at risk. There is currently no cure, due to the complex genetic mutation that causes progressive and irreversible damage to the brain. Every child conceived naturally to a parent with the faulty gene has a 50% chance of inheriting it.

We are urging the UK Government to take action on five key priorities to improve the lives of people affected by Huntington's disease:

1. **Care coordination**: Huntington's is a condition which requires complex care from multiple health and care professionals. That is why it is understandable that many people living with the disease are unable to manage the burden of coordinating their care. We are calling for all people living with Huntington's disease to have a single point of contact (such as a nurse or social worker) to coordinate their care. The physical and mental health difficulties identified in our May 2026 report[i] (based on a survey of 258 people) highlight why this support is urgently needed:

    - Half of people (50%) said they had difficulty walking and over one in five (21%) said they use a wheelchair.
    - Over three quarters (76%) have difficulties washing and dressing themselves or need help with washing and dressing.

   - More than eight in 10 people (82%) said they experienced some anxiety or low mood or significant anxiety or low mood.
   - Almost six in 10 people (59%) reported experiencing some or a lot of pain or discomfort.

2. **Mental health services**: Far too often, people living with Huntington's who are struggling with mental health conditions cannot access the care they need. When they seek help, mental health services can be reluctant to offer it. People tell us they have to wait until they reach crisis point before support is offered. If someone's referral is accepted by a mental health team, they are often faced with a lack of understanding about their condition, which leads to poor care[ii].

3. **Benefits system**: Some people living with Huntington's disease, even when receiving the highest level of support under Personal Independence Payment (PIP), are being given fixed-length awards. This means they face the prospect of a pointless, anxiety-provoking, compulsory reassessment, which costs taxpayers at least £282[iii] each time. We encourage you to use the Timms Review of PIP to help put an end to compulsory reassessments for people with progressive, life-limiting conditions such as Huntington's disease.

4. **Knowledge of Huntington's disease across health and care services**: Due to the complex nature of Huntington's disease, there are frequently multiple professionals involved in a person's care, often with little knowledge of the disease. In our 2026 survey, more than six in 10 people (62%) told us that they needed to explain Huntington's disease to a healthcare professional in the previous 12 months[iv]. We appreciate that health and care professionals undertake important work in challenging circumstances, and we would like to work with the UK Government and NHS to ensure professionals have the support they need to care confidently for people living with Huntington's disease.

5. **Access to treatments**: Progress is being made in the development of treatments for Huntington's disease. The results published last year of one successful trial for an experimental gene therapy found that the treatment slowed progression of Huntington's disease by around 75%[v]. It is crucial that people with Huntington's disease are able to access any new and effective treatment.

We work across England and Wales to provide support for people affected by Huntington's disease. We encourage you to work with colleagues in the NHS and wider care sector, as well as in the Welsh Government, to ensure that all people living with Huntington's disease receive better care and support. I look forward to hearing from you and we are ready to work with the UK Government to secure these improvements.

Yours sincerely

CAStanley

Cath Stanley BEM
Chief Executive
Huntington's Disease Association

Signed by over [NUMBER] people supporting the Huntington's disease community

---

[i] Huntington's Disease Association (2026). Support at every step: Improving care coordination for people living with Huntington's disease. Available at: https://www.hda.org.uk/seecmsdownload/546

[ii] Huntington's Disease Association (2024). Unseen and unheard: The need to improve mental healthcare for people living with Huntington's disease. Available at: www.hda.org.uk/seecmsfile/?id=405

[iii] National Audit Office (2023). Transforming health assessments for disability benefits. Available at: https://www.nao.org.uk/wp-content/uploads/2023/06/transforming-health-assessments-for-disability-benefits.pdf

[iv] Huntington's Disease Association (2026). Support at every step: Improving care coordination for people living with Huntington's disease. Available at: https://www.hda.org.uk/seecmsdownload/546

[v] Huntington's Disease Association (2025). A positive development from uniQure. Available at: https://www.hda.org.uk/news/a-positive-development-from-uniqure/