TIMMS REVIEW OF PERSONAL INDEPENDENCE PAYMENT

The Brain Tumour Charity's submission of evidence May 2026

About The Brain Tumour Charity

The Brain Tumour Charity is the largest dedicated funder of research into brain tumours globally. We also provide support, benefits advice and advocacy delivered in partnership with Citizens Advice Bureau for people affected by brain tumours across the UK. This response draws on evidence from our latest policy report, ***The Cost of a Brain Tumour: The Economic Case for Urgent Action***, our 2025 *Understanding the Impact* survey, which received responses from 222 people affected by brain tumours, including patients and carers, and insights collated from the affected community via social media in April/May 2026.

1. Please provide your response here

Personal Independence Payment (PIP) is not an additional luxury; it is a lifeline for those in the brain tumour community. It plays a vital role for many people in our community helping to meet the costs of a life-changing diagnosis, supporting independence, enabling access to care and appointments, and helps people maintain family, work and community life where possible. It should not be understood simply as a passive out-of-work benefit.

The Cost of a Brain Tumour

Brain tumours are complex and often devastating neurological conditions. This includes both high-grade and low-grade brain tumours. While some low-grade tumours may not be classified as terminal or aggressive, they can still cause significant and lifelong neurological, cognitive, psychological and physical effects, including fatigue, seizures, memory difficulties, visual impairment and reduced ability to work or live independently. Several people emphasised that lower-grade tumours can still have a profound impact on independence, work and day-to-day life. One person said:

"Benign is not fine - having a lower grade tumour can cause just as many problems and disabilities as those of a higher grade."

It is important that future PIP reforms do not unintentionally exclude people whose diagnosis may be misunderstood as less severe, despite the substantial long-term impact on daily life, employment and financial security.

More than 88,000 people in the UK are living with a brain tumour, and more than 13,000 people are diagnosed with a primary brain tumour each year. The latest economic analysis from our policy report, ***'The Cost of a Brain Tumour: The Economic Case for Urgent Action'*** (2025), estimates that brain tumours diagnosed in 2025 alone created an **£18.7 billion financial burden to the UK**.

Most of this burden does not fall on the NHS. Our report states that the greatest financial costs of a brain tumour diagnosis extend far beyond healthcare, falling instead on individuals, families, carers and the wider economy contributing to lost income, reduced economic productivity and long-term financial insecurity.

This includes £5.17 billion in individual financial costs, stemming from reduced earnings, welfare needs, treatment and unpaid care, and loss of independence. The estimated monetary value of lost health and life is £13.5 billion. On average, each primary brain tumour diagnosed in 2025 is associated with a **financial burden of more than £1.4 million**.

This is central to the future purpose of PIP. Disability support must recognise the real-world costs of serious illness and disability, widening the criteria to include less visible or fluctuating functional impairment. For people affected by brain tumours, symptoms and side effects from aggressive treatments can include fatigue, seizures, speech difficulties, visual or motor impairments, memory loss, cognitive dysfunction, reduced concentration and changes in behaviour or personality. These symptoms can fluctuate significantly and may not be immediately visible to an assessor.

Our 2025 *Understanding the Impact* survey (2025) found that **63% of respondents said losing PIP would have a very severe impact on their lives**, and a further 30% said it would have a severe impact. The additional insights gathered from people affected by brain tumours through our Facebook community in 2026 further highlights the ongoing financial insecurity associated with reduced working capacity, loss of employment and delays to support. One respondent said:

“2 years off work, credit card is now maxed out.”

Another shared:

“I know I need to reduce my working hours for my health, but without financial support I cannot afford to.”

It is clear that PIP enables people to meet basic needs and retain some degree of autonomy, dignity and social participation.

A PIP system not fit for purpose

The current assessment system does not adequately reflect the reality of neurological, cognitive and fluctuating conditions. In our survey, 78% of respondents felt that current benefits assessments do not adequately reflect their experience, and over half said the process itself had a negative impact on their mental health.

Symptoms such as fatigue, seizures, memory problems and reduced concentration may vary significantly from day to day, but can still have a major impact on someone’s ability to work, travel independently, drive, manage household tasks or safely participate in everyday life. Current assessment approaches do not always capture the cumulative or unpredictable impact of these symptoms, particularly where people experience periods of relative stability alongside significant episodes of impairment.

Others described feeling that assessments relied too heavily on outward presentation or a snapshot of functioning during a short assessment. Respondents described feeling penalised for having a “good day” or for masking symptoms. One respondent told us: “The form asks if you can walk so many yards – this is inappropriate for my condition.” One respondent said they were:

“Turned down because I was smartly dressed, washed, made eye contact and could hold a conversation.”

Respondents consistently described a system they felt did not always recognise the reality of living with a brain tumour, particularly where symptoms are neurological, cognitive, fluctuating or not immediately visible.

Another reflected:

"On paper, I can walk, talk and work. But the reality is that every day is a struggle."

Taken together, these experiences underline the importance of a PIP system that properly recognises fluctuating neurological conditions, hidden disabilities and the cumulative impact of living with a brain tumour. Assessments must consider not only whether someone can complete a task once, but the impact that doing so has afterwards, including on fatigue, cognition, safety, independence and ability to remain in work.

A system difficult to navigate

People affected by brain tumours that cause severe, life-limiting or long-term functional impairment should have access to simplified and appropriately fast-tracked routes into PIP and Employment and Support Allowance, with assessment criteria that properly reflect fluctuating neurological and cognitive symptoms.

People interviewed as part of our '**The Cost of a Brain Tumour**' (2025) report described long delays, distressing assessments and the stigma attached to seeking support. Direct testimony includes:

"I applied in August and got the first payment in December"

"It took more than half a year for my disability payment to be processed"

"They asked the most invasive questions ever"

and "The PIP system is punitive."

Insights gathered from 2025 and 2026 feedback surveys reinforce the challenges many face when navigating the PIP system:

"My husband had to fill out the PIP form… I had word finding problems and I would say one thing and mean another."

Others described how symptoms such as fatigue, cognitive overload and communication difficulties were difficult to explain within standardised assessments, particularly where these symptoms fluctuate or worsen after activity.

"Struggled to find the right words" and *"couldn't understand what they were asking."*

"The current PIP system focuses too heavily on whether someone can physically complete a task, rather than the impact it has afterwards."

Another explained:

"My weekends are spent recovering enough energy to start again on Monday."

A recurring theme was that some respondents felt the assessment process did not adequately reflect specialist understanding of brain tumours or neurological conditions. One person said:

"I don't believe that the assessor had any idea about the problems that a brain tumour causes."

Another reflected:

"I do not believe it is possible to fairly assess the impact of a condition without properly understanding the condition itself and the cumulative effect it has on daily life."

Several respondents also described long delays, repeated reassessments and the emotional strain associated with navigating the process at a time of serious illness and uncertainty. One person said:

"It took more than half a year for my disability payment to be processed."

Another reflected that:

"The default assumption was that I was trying to defraud the system."

Others described the process itself as:

"Humiliating and exhausting."

and:

"The constant need to justify my condition is exhausting."

In this context, any reform must start with faster and fairer access to support. Support should also be better integrated into care pathways. Embedding welfare and vocational advice within neuro-oncology services would help people receive financial, employment and practical guidance prior to entering financial hardship. Not only would this help ensure that people with the most serious and complex needs are not forced through repeated or inappropriate assessment processes where the impact of their condition is already clinically well evidenced, but this approach would also support a more preventative approach, helping people understand their entitlements, remain in work where possible, and plan around changes in health, caring responsibilities and income.

Support returning to work

Many people affected by brain tumours want to remain in, or return to, work. However, they face major barriers including fatigue, cognitive impairment, treatment side effects, seizures, loss of driving licence and employer inflexibility for appointments, sickness or recovery. Our Impact Survey (2025) found that 51% of patients had to stop working altogether, 13% of carers had reduced their hours or stopped working, and 61% said the Government does not provide adequate support to help them or their loved ones stay in employment.

Our Cost of a Brain Tumour report (2025) estimates £4.4 billion in lost economic productivity from people diagnosed in 2025, including an average loss of £120,000 in earnings per person, rising by a further £225,000 where someone dies earlier than expected. These figures demonstrate why PIP should be understood as enabling support. It can help stabilise people's lives, sustain independence and make work possible where it is realistic, safe and appropriate. Financial support does not deter work. For many people affected by brain tumours, it provides the foundation needed to remain connected to employment, education and society.

Employers also have an important role to play. Better promotion of Access to Work, clearer guidance on reasonable adjustments, and stronger leadership from public sector employers would support job retention and re-entry for people affected by brain tumours. This is particularly important where symptoms fluctuate, or where cognitive impairment, fatigue, seizures or loss of driving licence make a return to previous working patterns unrealistic.

The hidden carer cost

The Review should also recognise the impact on carers and households. Our report highlights that care becomes a full-time role for many families, including managing medication, monitoring seizures or cognitive changes, providing personal support and navigating a fragmented system. Interviewees told us: "You never switch off; you're on duty 24 hours a day" and "I had to give up work to look after them full-time — it's not paid, but it's constant." For those diagnosed in 2025, care-related costs are projected to create a £78 million burden on families.

Recommendations

A coordinated national approach would reduce welfare pressures, protect productivity and support people affected by brain tumours to rebuild independence. The costs of inaction are high, but the benefits of inclusion are far greater.

We therefore believe the future PIP system should:

- Protect access to PIP for people with serious, complex and fluctuating conditions, including people affected by both high-grade and low-grade brain tumours who experience long term functional impairment.
- Ensure assessment criteria properly recognise neurological, cognitive and invisible symptoms and treatment side effects, including fatigue, memory loss, seizures, communication difficulties and fluctuating capacity.
- Assessment processes should focus on the functional impact of a condition, rather than relying too heavily on diagnostic labels or assumptions around prognosis alone.
- Place greater weight on clinical evidence and lived experience, rather than relying too heavily on standardised functional descriptors.
- Reduce unnecessary reassessments for people with long-term, progressive or life-limiting conditions.
- Simplify and accelerate access to support for people affected by brain tumours that cause severe, life-limiting or long-term functional impairment, including consideration of fast-tracked or reduced-assessment routes where appropriate.
- Ensure assessment routes are accessible, with options for remote assessments, recorded assessments and support for people with cognitive, visual or fatigue-related barriers.
- Recognise PIP as a tool for independence, dignity and participation, including where it enables people to remain in work, education or family life.

The Timms Review is an important opportunity to build a fairer system that reflects the realities of modern disability. For people affected by brain tumours, this means a system designed around fluctuating, neurological and often invisible impairment, rather than one that only recognises the most visible forms of disability.

2. Is there anything else you would like to tell us?

A brain tumour diagnosis changes every aspect of life: health, work, education, income, relationships and independence. The evidence from our community is clear that PIP is a lifeline for many people affected by brain tumours.

Future policy development should not narrow access to support or increase the distress experienced by people navigating the benefits system. Instead, it should create a system that is fair, compassionate, evidence-led and grounded in the lived reality of people with complex neurological conditions.

We would encourage the Review to continue engaging directly with people living with fluctuating, neurological and invisible conditions, and to ensure any future changes to PIP are co-designed with people with disabilities, carers, clinicians and specialist organisations.

3. Optional respondent category

An organisation that supports and/or represents disabled people and people with health conditions.