

Sir Stephen Timms MP
Minister for Social Security and Disability
Department for Work and Pensions
Caxton House
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London
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Marie Curie
One Embassy Gardens
8 Viaduct Gardens
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28th May 2026

Dear Minister,

We are writing to you as a coalition of organisations representing people living with terminal illness and progressive, life-limiting conditions, regarding the Timms Review of Personal Independence Payment (PIP).

Our organisations work with and on behalf of people living with terminal illness and progressive life-limiting conditions. This is a cohort of people who are reliant on PIP for the extra costs these conditions bring. We write to you to urge you to ensure that PIP is reformed with their interests in mind.

We note that the Department for Work and Pensions has stated that the review will not make recommendations that lead to spending on PIP exceeding current projections. However, there is a clear and compassionate reform that meets this constraint: ending reassessments for people whose conditions will only worsen over time. This would involve:

- When it has been decided that someone's condition is terminal, they should have fast-tracked access to a lifetime award of the higher rate of PIP Daily Living and Mobility, enabling support with the additional costs that can come with that prognosis until the end of their life. This approach has already been adopted by Social Security Scotland, whereby an individual who receives ADP under the Special Rules route, is provided with a lifetime award that will not be reviewed unless their circumstances change.
- Anyone who does not access PIP via the Special Rules, but who has a progressive life-limiting illness and is on the highest award rates for both Daily Living and Mobility, should also be exempt from fixed-length awards.
- For people with progressive life-limiting conditions who are on the lower rates of PIP Daily Living and/or Mobility, compulsory reassessments should be replaced with 'light-touch' reviews to check whether they have become eligible for a higher award.

While few people who have been awarded PIP under Special Rules will live for 3 years – at which point a Special Rules claim can be reviewed – we know from the

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government's response to this parliamentary question¹ that it can and does happen. We consider this an unacceptable and unnecessary strain on people with a terminal illness, who should have assured and constant financial support until they die, so they can focus on the things that really matter – being as well as they can be and spending time with those who matter most to them.

“Hearing that you have 'lived too long' with a terminal illness and needing to renew PIP to keep a vital financially assisted car through the scheme - shocking that this is considered necessary on any level.” Marie Curie campaign supporter

There are also people with progressive life-limiting illnesses who may not qualify for the special rules, or may not be recognised as such because their PIP claim pre-dates the point at which they received a prognosis that they were likely to live for less than 12 months, but who are forced to endure damaging and unnecessary reassessments for their PIP. According to Marie Curie's analysis of Stat-Xplore, between February 2025 and January 2026, 38% of people whose main condition is Parkinsons, 16% of people whose main condition is Dementia and 9% of people whose main condition is Motor Neurone Disease – all conditions that are progressive and life-limiting - were put on fixed-term PIP awards. What's more, for this same time-period, only 2% of PIP awards where the recipients' main condition is Dementia, Parkinson's, or Motor Neurone Disease were decreased at an award review. This demonstrates the lack of value in the department reassessing people whose conditions are sadly only going to worsen. Especially when, as the latest figures show, each PIP assessment costs £282.² The department should stop giving those with progressive life-limiting conditions fixed-length PIP awards.

“I am disabled with severe Emphysema, it's not something I can recover from but PIP stopped my allowance for 10 months saying I wasn't as bad as I was saying...I had all the stress of trying to prove how my illness affects my life, eventually going to the tribunal. It was re-instated but now I face the same thing again in January. I am getting more and more anxious as the time gets nearer... Why aren't chronic illnesses exempt from these extremely stressful and nerve-wracking interviews? I am going to die through Emphysema, it doesn't magically get better...only worse.” – Marie Curie campaign supporter

We urge you to use the opportunity of the review to protect those living with terminal and progressive life-limiting conditions. To ensure that they are supported to live as well as they can, for as long as they can, by ending costly and often stressful and overwhelming reassessments.

Yours Sincerely,

Matthew Reed

Chief Executive, Marie Curie

¹ <https://questions-statements.parliament.uk/written-questions/detail/2026-04-10/126117>

² <https://www.nao.org.uk/wp-content/uploads/2023/06/transforming-health-assessments-for-disability-benefits.pdf>

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