



Briefing for Tessa Munt MP – DWP and ME/CFS

For Westminster Hall Debate: ‘Government support for people with ME’

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1. Overview

People with ME/CFS face intersectional and compounding barriers when interacting with the Department for Work and Pensions (DWP). These include structural flaws in benefit design, widespread misunderstanding of their conditions, systemic disbelief, inaccessible systems, poor-quality assessment practices, and the cumulative harm of being required to repeatedly prove their illness. The current benefit system and emerging reform agenda both fail to reflect the fluctuating, energy-limiting, multisystemic nature of these conditions.

The Universal Credit Act 2025, together with the proposed abolition of the Work Capability Assessment (WCA), and ongoing threats to PIP eligibility, signals a fundamental shift in how disabled people meet entitlement to financial support. For people with ME/CFS, the risks are significant.

2. Current Benefit System: Barriers for People with ME/CFS or Long Covid

Personal Independence Payment (PIP)

- PIP assessments often fail to capture core disabling symptoms: post-exertional malaise (PEM), cognitive dysfunction, orthostatic intolerance, sensory hypersensitivity, pain, and autonomic dysfunction.
- Functional descriptors do not account for fluctuation, relapse, or cumulative energy expenditure.
- The correct usage of the STAR criteria to ensure that functionality is “reliable” is still often not applied by health assessors or by DWP case managers. This is particularly pertinent to people with ME/CFS, where occasional ability to achieve an activity does not accurately reflect their general level of functionality due to their symptoms.
- Many claimants are assessed based on a "snapshot" understanding that overlooks how activity impacts function over time.
- Assessors frequently lack condition-specific knowledge; this results in assumptions, misrepresentation, poor-quality reports, and inappropriate decisions.
- Appeals are common and traumatic; the stress of challenging unfair and inaccurate decisions has led to documented health deterioration. Many people with ME/CFS simply do not have the available energy to continue to fight for their entitlement. Welfare advice “deserts” compound this issue, and the few available advice services are frequently overstretched and unable to offer adjustments to their working processes which can accommodate the needs of clients with ME/CFS. The very nature of this condition cuts people off from accessing essential specialised help and support.

Universal Credit and New Style ESA

- People with ME/CFS may qualify for support via the Limited Capability for Work and Work-Related Activity (LCWRA) element of UC or through New Style ESA.
- These routes currently depend on the WCA, which, despite its flaws, includes vital safeguarding clauses (Regulations 29 and 35) for those at risk of harm from work-related activity.
- These safeguards disproportionately protect people with ME/CFS or Long Covid who may not qualify for PIP but are unable to work or engage in work-related activity safely.
- From April 2026, the LCWRA element will be closed to most new UC claimants unless they meet a narrow Severe Conditions Criteria. This definition excludes most people with ME/CFS due to the required criteria of being considered a lifelong condition and of having no realistic prospect of recovery. For many

people with ME/CFS, there is a pattern of remittance/relapse or of partial recovery but without a return to full health.

(<https://meassociation.org.uk/2025/07/updated-booklet-prognosis-permanency-quality-of-life-in-me-cfs/#:~:text=for%20example%2C%20some%20people%20make,the%20development%20of%20me/cfs>)

3. Proposed and Emerging Reforms: Key Risks

Universal Credit Act 2025

- Scraps access to LCWRA for new UC claimants from April 2026 unless they qualify under the Severe Conditions route.
- Clause 5 (proposing linking UC health support to PIP scores) was withdrawn following parliamentary backlash.
- The government was defeated on Clause 5, but any future restrictions on PIP are now contingent on the outcome of the Timms Review. Secondary legislation is still a concern.
- The “Right to Try” scheme (designed to encourage voluntary work attempts) offers no safety guarantee for people with relapsing, energy-limiting conditions where harm can follow exertion.

Pathways to Work Green Paper (March 2025)

- Proposes abolishing the WCA entirely and using PIP as the sole gateway to all health-related UC support.
- Assumes PIP accurately reflects functional incapacity: this is demonstrably false for people with ME/CFS or Long Covid.
- Would eliminate Regulations 29/35 entirely, removing the last safeguard for claimants unable to meet conditionality without harm.
- Despite references to "voluntary" support, the policy direction is coercive: financial safety is being made contingent on passing an increasingly narrow test.

Replacement of ESA with Time-Limited Unemployment Insurance

The Government’s *Pathways to Work* Green Paper proposes replacing New Style Employment and Support Allowance (ESA) with a new contributory Unemployment Insurance scheme. This change would have serious implications for people with ME/CFS.

Currently, New Style ESA provides enduring income for those in the LCWRA group who have paid sufficient National Insurance contributions. It:

- Upholds the contributory principle and recognises those who have paid into the system;
- Enables disabled people to retain financial independence and personal dignity;
- Provides crucial support for those in households not eligible for means-tested benefits (e.g. where a partner works or savings exceed the UC threshold).

Replacing this with a time-limited form of Unemployment Insurance would create multiple risks:

- **It removes long-term security** for disabled people whose conditions do not improve and who are unable to return to work.
- **It penalises those in low-income but non-means-tested households**, who may find themselves with no access to benefits at all after the time limit expires.
- **It increases the risk of financial dependence**, particularly for women with ME/CFS, who are more likely to be in relationships where a partner's income disqualifies them from means-tested support.
- **It raises serious safeguarding concerns**. Loss of independent income is a recognised risk factor for coercive control and domestic abuse. This is especially relevant given the higher prevalence of ME/CFS in women and the gendered nature of financial abuse. The intersections of disability, gender and financial dependence all heighten the risk of abuse occurring.
- **It may undermine financial resilience long-term**, through impaired credit history (caused by lack of bills or bank accounts in one's own name) and erosion of money management skills.

The ME Association strongly opposes this proposal. The existing ESA model, while far from perfect, offers vital stability to people whose health condition makes sustained employment impossible. Stripping away that foundation will harm those who are already most vulnerable.

Work and Pensions Select Committee Findings (July 2025)

- Confirm that abolishing the WCA risks excluding people with serious limitations who do not qualify for PIP.
- Criticise the DWP for failing to publish adequate impact assessments.
- Warn that the reforms may breach safeguarding duties and disproportionately harm people with fluctuating or invisible impairments.

4. The Timms Review: Opportunity or Risk?

The Personal Independence Payment (PIP) Review led by Sir Stephen Timms MP will shape the future of disability benefits. It is intended to:

- Assess whether PIP remains fair, functional and future-fit.
- Examine descriptors, scoring systems, and evidence rules.
- Respond to rising claimant numbers, cost pressures, and consider the impact of abolishing the Work Capability Assessment.

Core Concerns:

- Co-production promises are already being diluted. The Tidball Amendment endorsed by Sir Stephen Timms would have enshrined independent oversight, a disabled-majority taskforce, and formal Parliamentary accountability.
- Steering group selection lacks transparency. There is no requirement for a majority of disabled members. Such a small panel cannot represent the full spectrum of disability and many people with ME/CFS are again excluded from meaningful contribution due to their symptoms. The voices of those that need to be heard most loudly are missing.
- Confidentiality clauses may prevent public scrutiny of deliberations.
- The scope of the review includes existing as well as new PIP claimants, raising fears of retrospective tightening of eligibility.

What We Need:

- Full alignment with CRPD Article 4(3): co-production with disabled people must be full, real and meaningful, not rhetorical or stage-managed.
- Statutory guarantees that no changes will be implemented without parliamentary oversight.
- Lived experience of fluctuating, invisible, and energy-limiting conditions must be central.

5. Assessment Guidance and the Risk of Mis-Decision

A recent FOI request for ME/CFS training guidance was almost entirely redacted, including key guidance for assessors, rendering scrutiny impossible. The justification (fraud prevention) is unconvincing and undermines public confidence. People with

ME/CFS are being judged against a set of assumptions which may or may not have any bearing on their lived realities.

What little guidance is visible relies heavily on the assumption that benefit claimants will have:

- Specialist ME/CFS clinical input (rarely available to patients with ME/CFS).
- Care plans and formal documentation (most people with ME/CFS have none).

This enshrines a "service-access model" that punishes people for gaps in NHS provision. Lack of documented care or consultant involvement is wrongly interpreted by the DWP as lack of impairment. This risks systemic under-recognition of genuine need and calls into question the fairness of any assessment relying on such flawed assumptions.

We call for:

- Full publication of DWP ME/CFS training content.
- Mandatory co-production of training materials with ME/CFS organisations and people with lived experience.
- Clear instruction that absence of services or input does not indicate absence of need.

6. Work-Focused Reforms and the "Keep Britain Working" Agenda

The DWP's new employment strategy, shaped by the Mayfield Review, risks embedding an assumption that work is universally attainable. For people with ME/CFS this is often not true.

Key concerns:

- The strategy promotes in-work retention, phased returns, and employer adjustments but says little about those too unwell to work at all.
- Proposals are silent on the need for income support for those excluded from the labour market.
- Failing to acknowledge fluctuating or unpredictable illness trajectories reinforces exclusion and shifts blame to individuals struggling with the consequences of a life-changing condition, stigmatising them as "lazy" or "greedy".

Our position:

- Work support must be truly voluntary.

- Recognition is needed that for some people, rest and medical care are the only viable interventions.
 - Employment strategies must not replace benefit rights or be used to justify further conditionality.
 - We are very concerned about any suggestion of disabled people being mandated into further work activity by DWP staff. This can be incredibly harmful for those with ME/CFS, leading to a permanent decline in functionality and risking any chance of meaningful recovery.
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7. Intersectional Barriers and Real-World Impacts

People with ME/CFS are not just battling their symptoms; they are navigating intersecting barriers:

- Women are disproportionately affected, particularly in the 30–60 age group.
- Many live in poverty, are single parents, or are unsupported carers.
- Ethnic minorities and migrants with ME/CFS may face diagnostic dismissal or language barriers.
- Access to specialist care varies wildly by region, postcode, and income.

Policy reform that ignores these layers of disadvantage will deepen existing inequality. DWP systems must recognise the complex reality of what it means to live with these conditions.

8. Summary and Calls to Action

The benefits system already fails too many people with ME/CFS. The reforms now underway threaten to make it worse. A fairer system is possible but only if the voices of those affected are placed at the heart of every stage.

We urge the Government to:

- Guarantee that access to health-related UC support will not be restricted through PIP alone.
- Retain or replace the Work Capability Assessment Regulations 29/35 protections to ensure safety and safeguarding is embedded into decisions.
- Ensure the Timms Review is transparently run, and co-produced with representative disabled people.

- Reform PIP descriptors to include fluctuating, energy-limiting and multisystemic conditions.
- Publish full DWP training materials and co-produce future guidance on ME/CFS.
- Commit to safeguarding people with ME/CFS and Long Covid from benefit loss or coercive work conditionality.
- Embed UNCRPD principles into all benefit decision-making.

Tessa, thank you for using your platform to champion this community. With your voice in Parliament, we hope that the lived reality of ME/CFS can no longer be ignored.

About the ME Association: The ME Association is a leading UK charity providing expert information, advocacy and support for people with ME/CFS. We campaign for improved research, healthcare and social protection for people affected by this often misunderstood and highly disabling condition.

