



The MND Carer Triple Burden: Rising Costs, Falling Earnings and Benefits Shortfalls

Background

Unpaid carers provide essential support for people living with MND, enhancing their quality of life and alleviating pressure on local health and social care systems. However, the recent cost of living crisis has significantly worsened financial challenges for these carers, exposing major gaps in support and benefits.

Key findings

A survey conducted between May and July 2024 reflects the experiences of MND carers over this period:

Rising costs – The cost of being an MND carer has never been higher. 68% have had to make significant changes to their budget for essential items to cover disability-related expenses. This has led to families using large amounts of savings and even going into debt to cover these expenses.

“I have lost my salary, home, car, business, job, family, friends, savings and I can no longer see my grandchildren more than once a fortnight or once a month.”

Falling earnings – Carers face an impossible choice between work and care. Over one-fifth (21%) of carers have had to reduce their work hours with a further third (36%) leaving full employment altogether. This is having a major impact on household income – 58% of carers said that current carer related benefits do not cover earnings from loss of employment.

“The financial impact isn’t just that of a carer, but you lose two household incomes. Everything has changed.”

Benefits shortfalls – The current safety net is insufficient. Almost all (94%) respondents believe the current rate of Carers Allowance, £81.90 per week, is insufficient to meet their needs as carers, with 54% saying they require at least £200 per week. Moreover, many reported being ineligible for support entirely.

“The whole system is unfit for purpose and an insult to carers. (Our care is) cheap slave labour done out of love and necessity.”

Policy recommendations

Given rising costs, loss of earnings and benefit shortfalls faced by MND carers it is essential the welfare system is reformed, namely Carer’s Allowance which is not adequately meeting their needs.

To address this, the Government should:

- Address strict eligibility requirements for Carer’s Allowance such as removing the age threshold, tapering the earnings threshold and the minimum time-spent caring condition, and removing the limited eligibility rules if a person is cared for by more than one person.
- Reform Carer’s Allowance by uplifting the rate to a level that reflects the value unpaid carers offer.
- Modernise and digitise the delivery of Carer’s Allowance to make it less complicated for claimants and to protect carers from overpayments.

What you can do

- Write a letter to the Minister of State for Social Security and Disability outlining the findings from this report and asking for a review of Carer’s Allowance which factors in the recommendations detailed.