

# Carers UK response to Timms Review on Personal Independence Payments

## Key points

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- Carers UK urges the Timms Review to adopt a whole-family approach to PIP reform. PIP does not operate in isolation: it supports disabled people directly while also underpinning the financial stability of millions of unpaid carers through linked entitlements such as Carer's Allowance and the Universal Credit carer element.
- PIP must continue to meet the additional costs associated with disability and long-term health conditions and support independent living and participation in society. Reform should not reduce overall support to disabled people and carers.
- Because entitlement to the Daily Living component acts as the gateway to carers' benefits, changes to PIP eligibility can have significant consequences for unpaid carers, household finances and poverty levels. Previous proposals to tighten eligibility would have resulted in around 150,000 carers losing Carer's Allowance entitlement.
- Restricting access to PIP does not remove support needs. Instead, it transfers costs onto unpaid carers, the NHS and social care services, often at greater long-term cost.
- The current system relies too heavily on unpaid carers to navigate complex assessments, mandatory reconsiderations and appeals in order to secure correct decisions. Reform should prioritise accurate first-time decision making, better use of existing evidence and transparent communication.
- Disabled households continue to face substantial additional living costs<sup>1</sup>, while carers are twice as likely as the general population to experience poverty.<sup>2</sup> PIP payment levels and eligibility criteria should reflect the real costs associated with disability, long-term conditions and caring responsibilities.

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<sup>1</sup> <https://www.scope.org.uk/campaigns/disability-price-tag>

<sup>2</sup> <https://www.carersuk.org/press-releases/12-million-unpaid-carers-across-the-uk-are-living-in-poverty-with-1-in-10-of-all-carers-in-deep-poverty/>

- Reforms should improve accessibility, fairness and administrative efficiency, including greater recognition of evidence from carers, more flexible assessment formats and better access to independent advice and support.
- Reforms should improve decision quality – for example, through greater use of medical evidence and recognition of carers’ input – rather than pushing claimants and their carers into lengthy appeals. Currently about two-thirds of PIP appeals succeed<sup>3</sup>, imposing extra stress and delay on families.

## **Theme 1 – Role and Purpose of PIP**

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PIP should provide reliable financial support that reflects the additional costs associated with disability and long-term health conditions and enables disabled people to live independently and participate fully in society. However, PIP also has a wider function within households and communities. It supports unpaid carers directly through linked benefits and indirectly through helping families manage the practical and financial realities of disability and long-term ill health.

### **PIP as a gateway benefit**

PIP’s Daily Living component acts as the gateway to Carer’s Allowance and the Universal Credit Carer Element. As a result, changes to PIP eligibility affect not only disabled people but also unpaid carers and their household finances. It is therefore vital that the Timms Review recognises the connection between PIP and carers’ benefits.

Over half of Carer’s Allowance awards are linked to PIP,<sup>4</sup> as the qualifying benefit and previous proposals to reduce access to PIP would have resulted in 150,000 unpaid carers losing access to their Carer’s Allowance award – a cut of around £500m of financial support to carers by 2029/30.<sup>5</sup> Over half of Carer’s Allowance awards are tied to PIP.<sup>6</sup> This demonstrates that PIP reform cannot be considered solely through the lens of the individual claimant. It has significant implications for family finances, caring arrangements and the sustainability of unpaid care more broadly.

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<sup>3</sup> <https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-july-2025/personal-independence-payment-statistics-to-july-2025#:~:text=tribunal%29%20%2A%2066,a%20PIP%20assessment%20have%20been>

<sup>4</sup> <https://www.carersuk.org/press-releases/carers-uk-responds-to-the-government-s-publication-of-the-welfare-reform-green-paper-proposing-changes-to-disability-and-health-benefits/>

<sup>5</sup> <https://assets.publishing.service.gov.uk/media/67e667fe4a226ab6c41b1fe2/spring-statement-2025-health-and-disability-benefit-reforms-impacts.pdf>

<sup>6</sup> <https://www.carersuk.org/press-releases/carers-uk-responds-to-the-government-s-publication-of-the-welfare-reform-green-paper-proposing-changes-to-disability-and-health-benefits/>

In 2025, Carers UK gathered evidence from more than 740 unpaid carers about the importance of PIP to their household income and wellbeing. We reference these findings throughout this submission.

### **PIP is used to cover the costs of essentials**

PIP is used to pay for essentials and to meet the extra costs of disability. Recent research found disabled people still need ~£1,095 extra per month even after PIP.<sup>7</sup>

Many carers will find it harder to pay for essentials and may need to cut back on food and heating if they or the person they care for is unable to receive PIP. Carers told us that PIP is hugely important in helping them to pay for essentials, as well as other caring costs and disability costs such as mobility aids, cleaning products, specialist clothing or footwear, sensory products, paid care workers, home delivery of shopping, medication, physiotherapy or counselling, technology in the home (eg remote monitoring), the replacement of household items that have been destroyed or damaged, activities that improve wellbeing such as gym membership, and incontinence products. If the person they care for are unable to receive this benefit in the future, this could result in them cutting back on food or heating, falling into arrears with utility bills, or becoming increasingly housebound rather than spending money on transport.

Many described PIP and Carer's Allowance as forming a core part of household income, particularly where caring responsibilities limit employment opportunities. Many carers said that without PIP, as well as Carer's Allowance, they would need to reduce spending on essentials such as food and heating or would fall into debt. Nearly half (49%) of carers responding to our State of Caring survey 2025 said they have cut back on essentials such as food, heating, clothing and transport costs, while a third of carers (32%) have taken out a loan from the bank, used credit cards, or used a bank account overdraft.<sup>8</sup>

*"I am extremely worried, Carer's Allowance contributes to our total monthly income and goes towards all bills."*

*"If I lose Carer's Allowance I wouldn't be able to get shopping, pay bills etc. It would put us back into debt which we have literally just got out of via a debt relief order." "Carer's Allowance along with PIP is our income, if I lost Carer's Allowance, I would have to lose the car and somehow massively reduce the food, gas and electricity bills to be able to afford our rent."*

*"We wouldn't be able to survive as a household. It's as simple as that. We barely are making it now, losing PIP and subsequent carers element means*

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<sup>7</sup> <https://www.scope.org.uk/campaigns/disability-price-tag>

<sup>8</sup> <https://www.carersuk.org/media/mtvkquhy/cuk-state-of-caring-2025-cost-of-caring-report-web.pdf>

*we could not afford to live. And we already live under the poverty line and have cut back to the barest of bare essentials.”*

### **Financial insecurity and household poverty**

Carers have told us that reductions in financial support would lead directly to food insecurity, utility arrears and housing instability. Carers also highlighted the impact on wider household finances and dependent children. The costs of caring and costs of disability are often shared within households.<sup>9</sup>

Carers are 50% more likely to be living in poverty than the general population and 1.2 million carers across the UK are living in poverty.<sup>10</sup> For carers in receipt of Universal Credit Carer Element, two thirds are living in poverty, while for those who only receive Carer’s Allowance, a third are in poverty.<sup>11</sup> Carers responding to our latest State of Caring Survey last year said they are already struggling to make ends meet and would find it very difficult to manage any further reduction in income. 36% of carers in receipt of Carer’s Allowance are struggling to make ends meet.<sup>12</sup> PIP eligibility, being a gateway benefit, is tied to rates of poverty in carers, which would only get worse if eligibility to PIP were to be tightened.

Carers UK research found that many carers often end up covering the costs of the disabled person.<sup>13</sup>

*“As a carer for 3 disabled people it will decimate our finances and condemn us and our children in the future to poverty.”*

*“It would be dire. We’d have to cut back on heating (my wife needs the house warm because of her restricted mobility and poor circulation). We’d also have more problems with buying food to maintain a healthy diet.”*

*“We would lose our car as we would no longer be able to afford it, so I would no longer be able to take my partner anywhere or go out myself, this would include getting to doctors and medical appointments, hospital in an emergency, and ironically to the jobcentre or DWP appointments.”*

*“If my daughter is no longer eligible for PIP it would not only hurt her financially but also me as her carer. I use my Carer’s Allowance to buy food for her and use it for the higher costs associated with utilities.”*

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<sup>9</sup> [https://www.carersuk.org/media/dnxerxqv/poverty\\_financial\\_hardship\\_uk\\_web.pdf](https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf)

<sup>10</sup> [https://www.carersuk.org/media/dnxerxqv/poverty\\_financial\\_hardship\\_uk\\_web.pdf](https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf)

<sup>11</sup> <https://www.carersuk.org/reports/poverty-and-financial-hardship-of-unpaid-carers-in-the-uk/>

<sup>12</sup> <https://www.carersuk.org/media/mtvkquhy/cuk-state-of-caring-2025-cost-of-caring-report-web.pdf>

<sup>13</sup> [https://www.carersuk.org/media/dnxerxqv/poverty\\_financial\\_hardship\\_uk\\_web.pdf](https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf)

## **Unpaid carers as recipients of PIP**

There are currently 150,000 people who receive both PIP and Carer's Allowance. Under the original proposals in 2024, around two thirds of carers would have lost entitlement to PIP.<sup>14</sup> PIP helps carers to pay for the extra costs of their own disability or health need in order for them to continue to provide unpaid care to someone else.

*“The extra costs we face as carers will not disappear if the health element is cut. And for those of us like myself who are carers AND disabled, this will be a double whammy.”*

Losing financial benefits could make it more difficult for carers with a health condition to start or remain in paid employment. Some carers said that being unable to claim benefits such as PIP and Carer's Allowance could make it even more difficult to stay in paid employment, as these benefits are often used to pay for transport costs, mobility aids, medication and treatment that minimises pain and discomfort, and other support that can help people stay in employment.

*“I have many health issues, but PIP helps me to get to work (part time) and covers taxi fares, extra costs I incur due to my health...Without PIP I not only will struggle to pay for my needs and transport to work but it will also have an impact on my mental health as I will be housebound, without any outside contact...I'm well aware that going to work, being with people and “moving” (within my limits) is good for my health, physical and mental. Without PIP I won't be able to do that and I can see myself declining.”*

*“For starters if I don't have enough income to buy the supplements and physio/osteopathic treatments then I don't see how I could work in the long run. I could maybe push through for a month or two but then I would risk going in burnout and my chronic pain and fatigue just getting worse.”*

*“The loss of PIP means that getting to work may be impossible---PIP often pays for aids and assistance to get to work. The loss of PIP won't get people back to work it will just make many people housebound.”*

*“I'd lose my job which is the opposite of what the DWP are trying to achieve. I receive pip and work, pip enables me to work.”*

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<sup>14</sup> 95,000 out of a total of 150,000 carers who receive both PIP and Carer's Allowance would have lost access to PIP for their own condition. <https://questions-statements.parliament.uk/written-questions/detail/2025-05-09/51241/>

### **PIP links to other financial support**

PIP is also linked to other financial help, such as council tax reduction or blue badges. Carers told us of the worry they have of not being able to afford to stay in their home if they were to lose their reduction in council tax and how moving home would be very costly, not least because homes are often adapted for the needs of the disabled person.

*“Would lose reduction in council tax. We would have to consider downsizing which is hard as my husband is in a wheelchair and it is difficult to find properties suitable for him. Our current home has been adapted.”*

*“Council tax reduction - we’d go under financially, not really breaking even now.”*

*“No PIP = no Blue Badge or bus pass, which would mean further social isolation and the inability to consider employment.”*

### **Sustainability of unpaid care and impact on public services**

Restricting access to PIP does not remove support needs. Instead, it transfers costs onto unpaid carers, the NHS and social care services. Many carers stated that without adequate financial support they would be forced to leave vulnerable relatives alone, seek emergency social care support or reduce the quality of care they are able to provide. Many carers were worried for the safety and wellbeing of the person they care for.

*“It would put us under huge strain financially, to the point we could be forced to have her put into care, this is NOT something any of us want or think would be suitable for her but without her benefits we could actually lose our home.”*

*“My partner would require a lot of additional support to prevent a deterioration in his mental health condition [and] to try and avoid a relapse into psychosis or crisis.”*

*“My caring role would go up ten fold as she would be suicidal and I would have to watch her 24 hours a day.”*

Carers also described the impact on the quality and sustainability of care if they were to lose access to their Carer’s Allowance: if they lost their financial benefits they may need to increase their working hours, and that leaving the person they care for alone could result in the person they care for being at risk of harm.

*“It would mean I couldn’t claim Carer’s [Allowance] - would need to go out to work full time and he would be left alone all day everyday to fend for himself, which he cannot do, it wouldn’t be safe... he would become depressed not having anyone to stay with him during the day or take him out to do activities he may even become suicidal.”*

*“I would have to return to work in order for us to survive. This would mean leaving my extremely disabled husband alone all day risking serious harm to him.”*

*“I’d have to go to work, he has epilepsy and it’s totally unsafe to leave him home alone... I would be stressed the whole time, worrying that he has had a seizure or a fall and can’t call for help.”*

*“If I had to go out to work it would probably end with him sectioned under the mental health act (which has happened before). This would cost the government a lot more than he currently gets for PIP.”*

*“I may be forced to work full time, which would leave my husband without a carer and would put his life at risk (choking and falling).”*

Many carers said that if they had to increase their working hours, they would need to find alternative care provision, potentially increasing pressure on social care services.

*“I would have to return to work full time and my son would require full time adult social care, at the moment we don’t access adult social care. This would be very expensive for the council...”*

*“I would have to find paid work. My son cannot be left home alone or go out alone. Alternative care would have to be sought. There would be no finances to pay for this. We would have to turn to the local authority.”*

PIP should therefore operate according to the following principles:

- Recognition of the additional costs associated with disability and long-term health conditions, including the wider impact on households and carers
- Support for independence, participation and employment for both disabled people and unpaid carers
- Recognition of the role unpaid carers play in enabling daily living and preventing escalation of need
- Stability and reliability of support for people with ongoing conditions
- Administrative processes that are accessible and manageable for both claimants and carers
- Meaningful recognition of carers’ evidence and involvement throughout the claims process

## **Theme 2 - Eligibility, fairness and equity in the award of PIP**

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PIP must be fair, inclusive and capable of reflecting the real impact of disability and long-term health conditions in modern society. Current scoring does not always adequately capture cumulative limitations, fluctuating conditions or the role of supervision, prompting and oversight provided by unpaid carers.

Many carers provide substantial support even where the person they care for does not score highly within individual descriptors. Carers described situations where constant prompting, supervision or reassurance was necessary for activities such as eating, medication management or personal safety, but where this support was insufficiently recognised within the assessment process.

*“He currently does not score a 4 for preparing food or eating food. As a person with an eating disorder food has always been a challenge, and I have to coax him into eating, I have to remind him when I’m not there because he just won’t. Even then I worry because it’s not safe for him - he has burns on his hands from times he’s forgotten the stove was on, he forgets the oven...When it comes to managing money he can’t handle it because he forgets, he has PTSD and a core component of that is him forgetting things very fast and being easily distracted.”*

*“My daughter does not score 4 for many of them because she doesn’t need [things] doing for her but [needs] reminders, assistance if needed, encouragement, checks to see she is safe doing those activities. She wouldn’t be able to carry out those activities at all without that kind of care, so requires a carer, but that kind of care usually scores a 2.”*

We urge that any eligibility or criteria review focus on genuine need, not on restricting access:

- Broaden descriptors: Ensure PIP recognises cumulative limitations. For example, allow points where tasks can only be done with repeated prompting or at great expense (not just “unaided”).
- Fluctuation, episodic conditions, mental health and neurodivergence: Explicitly allow claims where needs vary day-to-day. Do not apply a “best-day” test that ignores bad days.
- Reasonable accommodations: Processes should remain accessible through reasonable adjustments, including interpretation, alternative formats and flexibility around communication needs

- Evidence from carers: Formally accept supporting statements from unpaid carers as evidence of everyday needs. A high level of informal care implies severe disability.

## **Theme 3 – Experience of Claiming PIP**

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*The current PIP process frequently depends on unpaid carers to compensate for administrative complexity, poor communication and inaccurate decision making. Carers routinely complete forms, gather evidence, attend assessments and manage reconsiderations and appeals alongside substantial caring responsibilities. This administrative burden can itself increase stress, ill health and caring pressures within households.*

### **Administrative burden on carers**

Unpaid carers frequently play a key role in managing the administration of PIP on behalf of the person applying, including:

- Completing lengthy application forms
- Gathering supporting evidence
- Preparing claimants for assessments
- Attending assessments
- Managing mandatory reconsiderations and appeals
- Responding to reassessment requests.

For many carers, this work is undertaken alongside caring responsibilities, often with little formal support. Additionally, many disabled people and their unpaid carers find PIP assessments stressful, with poor communication and long delays. The assessment process can cause anxiety and extra health issues for the claimant, which can then increase the amount of care needed. Assessment methods should therefore be redesigned to be carer-aware and to try to minimise stress for both the applicant and carer.

Carers told us that they need to be present to advocate for the person they care for during a PIP assessment due to worry about variability of the outcome. This was often because they had concerns that the PIP assessment would not be done fairly. Some carers felt that the assessment outcome is dependent on the individual assessor and their level of understanding. Others said that the condition of the person they care for is variable, and that if the assessment took place on ‘a good day’ the outcome could be very different.

*“Depends on how much the assessor knows or understands of any particular disability, assumptions can be made erroneously and wrongly interpreted.”*

*“My husband has Parkinsons disease and everyday is different so someone could assess him on a reasonably good day but 95% of the time he is bad and would never be able to hold down a job!”*

*“I would have to attend with my son as he cannot travel on his own and he finds it difficult to know how to answer the questions they ask. He would not give the very detailed answers that would evidence his needs. I have to complete all the assessment forms. This is stressful!”*

### **Use of face-to-face assessments**

Some carers said that more face-to-face PIP assessments could increase their caring responsibilities and mean they would need to get more time off work to support the person they care for. Many carers felt they needed to be present at PIP assessments to manage any stress or anxiety experienced by the person they care for.

*“Having to go somewhere to see someone face to face rather than a phone call at home is so much more difficult. I would have to try & get time off work to take her & that is very difficult as I am a teacher.”*

*“My son has a severe learning disability and very complex Autism, he cannot cope with strangers especially strangers questioning him”*

*“The face to face assessment is nothing short of harrowing and the stress it brings worsens my husbands illness before and after. He once had a drink of water during a long assessment, and from that the assessor deemed him fit to prepare and cook meals! It is cruel, biased and inhumane dragging disabled people in front of these assessors.”*

### **Appeals and mandatory reconsideration**

The current reconsideration and appeals process places a significant burden on unpaid carers and too often relies on persistence to correct poor-quality initial decisions.

65% of tribunal appeals overturn initial decisions and 20% of decisions were changed in the applicant’s favour before an appeal was heard at tribunal,<sup>15</sup> indicating systemic errors in the initial assessment and decision making process.

Some carers felt that if the Government were to carry out more PIP assessments face-to-face, this could be beneficial in enabling the assessor to see first-hand how

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<sup>15</sup> <https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-january-2026/personal-independence-payment-official-statistics-to-january-2026>

the person they cared for was able to manage. However, carers who care for someone with a mental health condition or learning disability are concerned that the person they cared for would struggle to communicate their needs, or that the assessment would favour those who have a physical disability which is more visible.

Assessors must have a better understanding of the realities of daily care needs and the role carers play in enabling daily activities. Professionals with appropriate health background and a strong understanding of disability, long-term health conditions and caring relationships should carry out assessments.

The Scottish provides a better blueprint for assessments, allowing for better consistency, training, internal knowledge and expertise sharing, including:

- No face-to-face unless requested by individual or no other means of getting the information
- Social Security Scotland are responsible for gathering information from social work, health services etc. Carers and third sector information can also be gathered.
- Case workers can link with expert advisors on conditions in house
- Disabled people entitled to independent advocacy which is nationally commissioned

Evidence from carers and our advice service indicates that the current mandatory reconsideration (MR) and appeals process is inefficient, inaccessible and places a significant burden on unpaid carers. A key concern is that there is currently no statutory time limit for the DWP to complete a Mandatory Reconsideration. In practice, delays of many weeks or months are common. This leaves claimants and their carers in prolonged uncertainty and financial hardship while they wait for a decision.

Unpaid carers frequently take on responsibility for managing the MR and appeals process, including gathering evidence, completing paperwork and maintaining communication with the DWP. This reflects our wider evidence showing that many carers already spend significant amounts of time dealing with administration related to the NHS. 34% of carers were spending 10 or more hours per month on NHS admin in relation to the person they care for and 13% said they were spending 40 or more hours per month on this.<sup>16</sup> This taken together can influence a carer's ability to stay in paid work alongside their caring role.

There are also significant barriers to accessing appropriate advice at the MR stage. Many claimants request reconsideration over the phone without providing detailed supporting evidence, or submit written requests without sufficient understanding of the PIP criteria.

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<sup>16</sup> A fresh approach to supporting unpaid carers: our vision for delivering the NHS 10 Year Health Plan in England, Carers UK, Sep 2025.

This creates a system where claimants and carers must endure a lengthy and complex appeals process to secure the correct entitlement, contributing to avoidable stress and administrative work.

Importantly, these issues cannot be addressed in isolation. High volumes of reconsiderations and appeals are driven by poor-quality initial decision-making. Reform should therefore take a whole-system approach, including improving the quality and accuracy of initial assessments and making better use of existing evidence at the earliest stage.

The current system too often relies on the persistence of claimants and the unpaid labour of carers to correct incorrect decisions. A fair system should deliver the right decision first time, without requiring carers to navigate complex and prolonged appeals processes.

Improvements to the assessment process should include:

- Greater use of existing medical evidence and previous assessments to reduce the need for repeated assessments and duplication of information
- Flexible assessment formats, including telephone, video and paper-based approaches where sufficient evidence already exists
- Ensuring assessments capture the cumulative impact of multiple impairments, where several moderate limitations together can result in significant support needs.
- Greater recognition of evidence from unpaid carers, including mandatory training on the role of unpaid carers for assessors.
- Reducing unnecessary assessments would significantly reduce stress and administrative load for claimants and carers and the DWP.
- Better training on mental health, neurological and fluctuating conditions for assessors
- Greater use of evidence from professionals already involved in the claimant's care
- A statutory time limit for Mandatory Reconsideration (MR) decisions
- Genuine independent review at MR stage
- Full explanations of activity scores and decision rationales
- Improved access to independent advice and advocacy early in the process
- Easier online submission of evidence and reconsideration requests
- Faster resolution of appeals and reconsiderations

A fair system should deliver the correct decision first time, rather than relying on unpaid carers to navigate lengthy and complex appeals processes.

## **Theme 4 – Changing Context and Impact on PIP**

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Wider support offered is critical to the rate at which PIP is claimed as well as the opportunities for employment for the disabled person and their unpaid carer. With the right support in place, better outcomes can be reached for the economy and for people's own ambitions, aspirations and income now and in later years.

The complexity of support needed is increasing. A survey of local authorities found that adult social care budgets in 2023/24 were overspent by £586mn, the highest levels for at least a decade<sup>17</sup>. The complexity of people's adult social care needs means that more people now require more intensive care and support. This has a significant impact on unpaid carers. 88% of Directors of Adult Social Care agreed that unpaid carers are coming forward with an increased level of need in their local area over the past 12 months, as a result of shortages in health and care support.

### **Carers' juggle of paid work and unpaid care**

Many carers struggle to juggle work and care: Carers UK research shows 600 people give up jobs each day to care.<sup>18</sup> Support for carers to remain in and return to work are critical to helping to improve incomes for carers and their families as well as benefitting the wider economy. Social care provision and adequate and affordable replacement care can mean the difference between carers staying in paid employment and leaving work altogether.

Carers need good quality social care and support to be able to return to work or increase working hours. However, the lack of provision of breaks for carers means that it is difficult for carers to look after their own health and wellbeing. Burnout and the onset of health conditions are some of the common reasons why carers decide to leave paid employment altogether. Research shows that in 2023-24, 360,815 carers received Carer's Assessments – only about 8% of all carers<sup>19</sup>. Of those, 70% of carers who approached the local authority for support were only given information, advice and signposting, rather than getting any direct support, such as breaks and respite. Local authority gross expenditure on support to carers was £183 million in 2023-24, a drop of 6.1% from £195 million in 2022-23. This reduction in spend on

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<sup>17</sup> <https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf>

<sup>18</sup> <https://www.carersuk.org/press-releases/12-million-unpaid-carers-across-the-uk-are-living-in-poverty-with-1-in-10-of-all-carers-in-deep-poverty/>

<sup>19</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2023-24/carers>

carers by local authorities will have an impact on their ability to continue to juggle work and provide unpaid care, especially over time.

Some carers said that they hadn't been able to find social care services that were affordable or suitable for the person they cared for. Those carers felt that in addition to focusing on welfare benefits reform it is important for the Government to invest in social care services so that affordable and good quality alternative care is available.

*"The government needs to remember LAs are also cutting services, we're currently fighting a drop in day services... We're actually saving the government and LA money by caring for our daughter in our home, yet we feel like we're being punished for having a disability."*

*"Who looks after my vulnerable son instead? Unpaid carers save the government billions and social care is hard to access so who does the government think is going to provide the care instead? Work just isn't possible unless someone else steps into the caring role."*

*"I already help with everything, help her to wash, dress, cook food, manage meds, manage finances etc. I would have to find work to try and bring money in but this would leave my wife unattended in the day unless social care provide carers which we tried in the past and it was awful."*

Carers incomes are not just affected whilst they are providing vital care but also when they reach retirement. Not supporting carers well during their working-age years risks further poverty and hardship in their later years. Leaving paid employment can have a negative impact on carers' finances and ability to save for the future, as well as their health and wellbeing.

*"I had to give up my career as a Chartered Accountant due to my caring responsibilities so has significantly affected my financial position."*

*"As my husband's progressive illness got worse I had to give up a career I loved to care for him full-time. This impacted on pension entitlement and reduced our retirement income."*

*"I've had to give up my job to care for my disabled adult daughter. My being away from home at my nursery job made her suicidal and I couldn't really concentrate while I was at work, either."*

*"I now work part time. I gave up a stressful well paid role to take on a lower paid less stressful role. It has limited how far I can travel to work as I need to be able to get home/ to the person I care for if need be. I have not applied for promotion etc due to caring. These choices will affect my work pensions."*

*“I have had to resign from my full-time job twice in the past five years due to burnout from juggling a full-time job on top of caring duties.”*

A comprehensive package of support, including from employers, is needed to help carers stay in and return to work, where they are able to combine caring with paid work. Inflexible policies of employers can push carers out of work.

*“I had to give up work. I was a carer for my son but then lost my dad to Covid so had to care for my mum who is blind. I tried to carry on with reduced hours but the NHS wouldn't allow me to work the amount of hours I needed to be within threshold at that time.”*

*“It became necessary for me to start providing full-time care for my husband at the end of 2017. I discussed with my employer beforehand and they told me that they were unable to offer a part-time position. I therefore had to leave employment in order to care full-time.”*

*“I already find that my workplace, line manager etc can be very inflexible or look down on me if I have to change working hours due to hospital appointments, even though I do my utmost not to have to do that. Flexible working laws are okay on paper but not necessarily in practice.”*

Several older carers are worried about finding employment later in life and are concerned about experiencing age discrimination. Additional and tailored support is needed to help carers find confidence and update their skills after a long time out of paid employment.

*“I have given up work to care for my three disabled daughters and for my elderly mother. She has since died but it feels impossible to get back in to work at 62 after being out of paid employment for 10 years.”*

*“I have cared for my older daughter for 37 years, full time. I am now 60 and have my own health problems, the thought of employment is alien and I wouldn't know where to start.”*

It is vital that the government considers wider impacts and support provision, rather than looking at the welfare support system in isolation. Cuts in other places or a failure to invest in services and support is likely to push up need and reduce opportunities for carers and disabled people to return to work where they may be able to, with the right support in place. Allowing carers to return or stay in work has benefits for the wider economy as well as the carer and their family.

## **About Carers UK**

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Carers UK is a charity set up to help the millions of people who care for family or friends. We are a membership organisation of carers, run by carers, for carers. We provide information and advice about caring alongside practical and emotional support for carers. We also campaign to make life better for carers and work to influence policy makers, employers, and service providers, to help them improve carers' lives.

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