CARENTS.CO.UK

What 665 Carents Told the Carer's Allowance Call for Evidence: A Community Submission

A submission from 665 carents | August 2026

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Executive Summary

Who we are

Carents.co.uk is a national support hub for adults caring for ageing parents: a platform built specifically for people managing the care of their elderly parents, often from a distance, often while working, often alongside their own health conditions, and frequently without knowing where to start or what they are entitled to. We use the word "carent" deliberately, because the people in our community are not, by and large, people who think of themselves as carers. They are sons and daughters in their 40s, 50s, and 60s, managing the care of elderly relatives in their 80s and 90s, doing what they understand to be what family members do. Most of them did not know Carer's Allowance existed until they were already deep into caring. Many still do not know what they are entitled to. Some have been financially penalised for trying to find out.

Our community has grown to over 85,000 members, and we support over half a million carents each year through our platform. When the government launched the Carer's Allowance Call for Evidence, we ran an open survey through our community. 665 people responded. This is what they told us.

What they told us, in summary

Six themes emerged consistently across all 665 responses. Three dominate: a level of complexity that deters legitimate claims and traps people in financial difficulty, the damage done by the £204 earnings threshold, and the unjust exclusion of those who have reached pension age. Running through all of them is a fourth: an allowance whose weekly rate is so low as to constitute an insult to the people who rely on it.

More than a third of respondents (34%) currently receive Carer's Allowance. A further 32% do not qualify under the current rules, most because they earn too much, have reached pension age, or cannot meet the 35-hour caring requirement in a way the system recognises.

Theme	Scale of evidence
Complexity and confusion: rules most people cannot navigate	42.1% find the system confusing or very confusing
The earnings cliff edge: trapped between caring and working	22.9% turned down work; majority who work alongside carenting affected
Pension-age exclusion: caring continues, the allowance stops	99+ specific mentions in open text
An allowance that does not add up: the weekly rate	146+ responses calling for an increase
The shadow of debt: the overpayment scandal's chilling effect	Raised across multiple questions; 44 received letters directly
Universal Credit interaction: a system within a system	Named by 138 respondents in open text

What they are asking for

1. Replace the cliff edge with a taper.
2. Raise and index the earnings threshold.
3. End the pension-age exclusion.

4. Build a free online calculator.
5. Fund a proper helpline.
6. Raise the weekly rate.
7. Fix the Universal Credit interface.
8. Address the overpayment scandal and proceed carefully on payment reform.
9. Reform the 35-hour threshold.
10. Find people before they find the system.

The full detail behind each ask, with delivery mechanisms, follows in section 6.

1. Foreword

The word "carent" is not in any official dictionary. We coined it, and our community adopted it, because no existing word captured what these people were actually doing.

This matters for the Carer's Allowance Call for Evidence because the benefit was not designed with them in mind. It was designed for a simpler reality: someone living alongside the person they care for, available to provide hands-on care for 35 measurable hours per week, earning below a threshold that has not kept pace with wages or the cost of living. That reality describes some of the people in our community. It does not describe most of them.

The people in this submission are, predominantly, adult children in their 50s and 60s, supporting parents in their 80s and 90s, often with multiple conditions at once. Many are still working, not by choice, but because they cannot afford to stop. Many are approaching their own state pension age, at which point the allowance they may have been receiving will stop, regardless of whether their caring responsibilities continue. Many have tried to understand the rules and given up, discouraged by complexity they are not equipped to navigate alone. Several have been caught by rules they did not know existed, receiving overpayment letters years after the fact.

Carer's Allowance, as currently designed, does not serve this population well. It penalises them for working. It excludes them at retirement. It confuses them with rules that produce different answers depending on who in the system they speak to. And it pays them, when it pays them at all, £86.45 a week in 2026/27: equivalent to £2.47 per hour for the minimum qualifying 35-hour caring commitment.

This is the reality of carenthood: a predictable life stage that the benefit system has not yet designed for.

This submission is what 665 of them told us.

2. Who Responded

Who they are

665 people responded to the Carents Carer's Allowance survey, conducted in August 2026 through the Carents community: our newsletter, the Carents Lounge (our online community space), and our wider network.

Of the 665 respondents:

Relationship to Carer's Allowance	Responses	%
Currently receiving Carer's Allowance	226	34%
Do not qualify under current rules	215	32%
Received it in the past, no longer do	71	11%
Have not looked into whether they can claim	70	11%
Think they could claim but do not	40	6%
The person receiving care	2	0.3%

The spread is significant. This is not a survey only of people who receive Carer's Allowance. A third of respondents are outside the system entirely, excluded by rules they may not fully understand. Their voices matter as much as those of current recipients, because they represent the scale of unmet need the current rules fail to address.

Who they care for

The people being cared for are, in most cases, very old. Responses reference parents in their 80s, 90s, and beyond. Ages mentioned include a 97-year-old mother, a 94-year-old relative, and a 93-year-old husband. Many are living with multiple long-term conditions: dementia, Parkinson's, heart disease, visual and hearing impairment. Several respondents describe caring for more than one person simultaneously.

The caring described is not always or only hands-on personal care. It includes managing appointments, administering medication, travelling to provide support, coordinating care agencies, and being available at all hours for someone who cannot be left alone. That the current system counts only certain hours in certain configurations is one of the themes this submission returns to repeatedly.

71.9% of respondents do not also receive Universal Credit. 10.5% do. A further 17.6% were unsure of their position. Among those receiving both, many describe the interaction between the two systems as a source of confusion, financial error, and unexpected debt.

A note on the sample

This is a self-selecting survey distributed through the Carents community. Respondents are people who have found us: by definition, people who are further along in their carenting experience, who have had time to seek out support and identify with a community. Those at the very start of caring, who may not yet have encountered the system's most acute failures, are less likely to be represented.

The picture here may understate the scale of what families face in the early stages, before they know where to look. What it does provide is a deep, detailed account of what happens to people who have been navigating the system for long enough to understand what it costs them.

The scale of the challenge

The responses in this submission sit within a population-level picture that makes their urgency clear. The 2021 Census recorded approximately 5 million unpaid carers in England and Wales alone, an increase in the number providing substantial care (20 or more hours per week) compared with 2011, even as the overall headline figure fell. [2] The full UK figure is higher. Within that population, a significant and growing subset are carents: adult children in their 40s, 50s, and 60s who are managing the care of parents in their 80s and 90s. This group, estimated at around 4 million people across the UK, is what this submission represents.

That population is set to grow significantly. There were approximately 1.75 million people aged 85 and over in the UK in mid-2024, but the population requiring regular care and support is considerably larger: it includes the full cohort of people in their late 70s and 80s managing multiple long-term conditions. ONS national population projections indicate that the 85-and-over cohort alone is expected to reach approximately 3.1 million by 2045, and 3.6 million by mid-2049. [3] The number of carents required to support that population is proportionally larger still.

The carents in this submission make an economic contribution that the formal care system depends on but does not adequately measure. The Centre for Care has valued unpaid care across the UK at £184 billion per year, exceeding the combined NHS budget. [4] A substantial portion of that value is generated by adult children managing the care of elderly parents: arranging assessments, administering medication, coordinating agencies, travelling to provide support, and being available at all hours for someone who cannot be left alone. Carer's Allowance, paid to those who meet the current qualifying criteria, represents a small fraction of that contribution. The gap between what carents provide and what the system returns to them is the context for everything that follows.

3. The Picture Through Their Eyes

Reading 665 accounts of Carer's Allowance is not an abstract policy exercise. These are people describing what it costs to care.

"I am self-employed and receive payment in chunks, which prevents claiming. I have taken the difficult decision to try and survive without much work but am racking up debt and frightened I will lose my home. I cannot manage much longer but dare not claim in case work is offered and I am then forced to pay it back. I have cancelled so much from my expenses and eat once a day now. Dreading winter."

CA-001

That is one account. Across the full dataset, the experience it describes, debt, fear, self-deprivation, and a benefit system that cannot accommodate the realities of self-employment, is not exceptional. It is representative of a pattern.

What emerges from these 665 responses is a benefit that is, in its current form, poorly matched to the people it is meant to support. The earnings threshold acts as a disincentive to work and a source of acute financial anxiety. The rules are so complex that many people who are eligible do not claim, and some who do claim find themselves in debt. The weekly rate is so low as to be inadequate as either a contribution to living costs or a recognition of what carenting costs. And the exclusion of people receiving a state pension means that some of the most intensive carenting in the country, carried out by people in their 60s and 70s caring for parents in their 90s, receives no recognition at all.

There are people in this survey who are grateful for what they receive. There are people who have found the application process manageable. But they are in the minority. What dominates is a picture of a system that creates additional difficulty for people who are already at or beyond capacity. Carenting is not a background responsibility. For the people in this submission, it runs alongside jobs, health conditions, family commitments, and their own approaching retirement. The financial pressures are real and immediate and the mental load is continuous. Against that backdrop, a benefit system that requires sustained administrative effort to engage with, and that penalises mistakes carents did not know they were making, is not a neutral administrative challenge. It is an additional burden on vulnerable people who are already stretched to capacity.

4. Six Key Themes

A thematic analysis of the open-text responses across all 665 submissions identified six dominant themes. These map onto the areas identified in the Carer's Allowance Call for Evidence and are presented in alignment with those consultation questions. Themes 4.1, 4.2, and 4.6 address questions the Call for Evidence poses directly. Themes 4.3, 4.4, and 4.5 are submitted under the Call for Evidence's invitation for wider views on Carer's Allowance (Question 12). They are not mutually exclusive: most respondents raised more than one.

4.1 Lost in Complexity: A System Few Can Navigate

Hero Quote

"To be honest, I still do not understand. I did not claim because it was too confusing. Yet I retrained to try and be able to support them with a new online career."

CA-012

The finding

42% of respondents find the Carer's Allowance rules confusing or very confusing (24.4% "quite confusing", 18% "very confusing"). A further 10% did not know that their earnings affected their Carer's Allowance at all. Only 13% find the rules very easy to understand.

These are not figures about people who have failed to engage with the system. Most respondents have looked into Carer's Allowance seriously enough to answer detailed questions about it. Their confusion is a product of the system's design, not their effort.

"There are very confusing rules around paid work and what counts. I just did not claim as it was too hard to work out if I qualified or if I was doing anything wrong."

CA-013

Several respondents describe not claiming, or claiming less than their entitlement, because the risk of getting it wrong felt more serious than the benefit of getting it right. The overpayment scandal described in section 4.5 has added weight to those concerns.

The interaction between earnings, hours, and qualification is described by many respondents as fundamentally unclear. Self-employed people, those with variable hours, those with income from multiple sources, and those approaching the threshold describe a system that offers no reliable way of knowing in advance whether a given week's income will cost them the allowance.

"On several occasions when I have phoned Carer's Allowance to ask for help regarding salary, back pay, and redundancy pay, I have not received a clear answer to my questions. 'Stab in the dark' is the closest I have got, which has made it impossible to organise my working life accordingly."

CA-014

"The form felt too long and daunting to complete. I suffer from fibromyalgia and have physical and mental exhaustion. I simply could not face nor focus on completing the form. Last year I found out I had been eligible all along."

CA-015

The 35-hour threshold is also raised as a source of confusion and exclusion. Several respondents describe providing substantial, intensive care that does not fit the system's definition of 35 qualifying hours, whether because it is provided remotely, because it is episodic rather than continuous, or because the person they care for spends time in hospital or respite.

"Why is there a minimum number of hours? Do we not count if we do not give 'enough' hours? I have to give my time because I am the only relative available."

CA-016

When asked directly what would help them understand how a tapered system would affect them, 577 respondents answered. Of those, 49% cited an online calculator as the tool they needed. 21% cited a telephone helpline. 6% asked for worked examples covering common scenarios. The Department has stated it is exploring a taper; the evidence here suggests that carents will engage with a taper, provided they can access a reliable way to know in advance what they will receive. Without that tool, the simplification the government is seeking to deliver will not reach the people who need it most.

Ask 4.1a: Build a free, publicly accessible online calculator that allows carents to enter their income, caring situation, and other benefits in order to understand, in advance, what they would receive under any revised Carer's Allowance structure. The calculator should be designed for people who are not benefits experts and tested with carents before it goes live.

Ask 4.1b: Invest in a properly resourced Carer's Allowance helpline, staffed by advisers trained to give accurate, specific guidance on individual circumstances, including self-employment, variable income, and the interaction with Universal Credit.

Ask 4.1c: Simplify the application process and the ongoing reporting requirements. The 35-hour caring rule should be applied with a realistic understanding of how care is actually provided, including remote care, overnight supervision, and coordination work that does not fit a conventional hours model.

4.2 The Earnings Cliff Edge: Trapped Between Caring and Working

Hero Quote

"I left my own home to care 24/7 for my parent with dementia. I am living off my own savings and have had to leave my career in my mid-fifties. The stress of trying to find work that fits around 24/7 dementia care and that also keeps me under the £204 threshold is a huge deterrent. I have paid higher rate tax most of my life, but there is scant financial support for me now."

CA-002

The finding

22.9% of respondents (152 people) have turned down work, reduced their hours, or limited their income specifically because of the £204 weekly earnings threshold. A further 29.2% do not work at all alongside carenting. Among those who have engaged with the earnings limit, the accounts describe a design that creates perverse incentives at every turn.

The earnings cliff, named as such by respondents throughout, means that crossing the £204 threshold by any amount results in the loss of the entire allowance. For someone on a low wage, this creates a rational decision not to work additional hours even when caring responsibilities might permit it. The financial logic is brutal: a single additional shift can cost more in lost allowance than it generates in wages.

"It effectively bars me from earning unless I can get a very well-paid job. Instead of falling off a cliff, there should be a sliding scale."

CA-003

"I worked shifts in a cafe and due to staff shortages was offered more shifts. It was a temporary situation so I declined because I did not want to risk going over the threshold."

CA-004

"I would work more but losing the Carer's Allowance all in one go is off-putting. If I earn £5 over the threshold I will lose the whole allowance. That does not make sense. If it were tapered so that if I earn £1 over the threshold, I lose £1 of the allowance, it would give me a great deal more flexibility."

CA-005

The constraint is not only financial. For many respondents, work is described as a form of respite, a way of maintaining identity, connection, and mental health beyond the caring role. The current threshold penalises that alongside everything else.

"I cannot afford to reduce my earnings and working hours to that level even though I am approaching burnout with the level of caring and working hours combined."

CA-006

Self-employed carents face a compounded problem. Irregular income, paid in chunks or fluctuating month to month, makes compliance with a weekly threshold genuinely unworkable. Several respondents describe not claiming because the complexity of managing self-employed income against a weekly limit feels too risky, or because a particularly good month could result in an overpayment demand months later.

The 36.2% of respondents who selected "the rules being simpler and easier to understand" as their top improvement priority, making it the single most commonly chosen option from a list of six, reinforces what the open-text responses describe in detail. Simplicity, not only generosity, is what carents are asking for.

30.4% selected "being able to earn more before Carer's Allowance starts to reduce", and 29.9% selected "being able to earn more overall before Carer's Allowance stops entirely." These three priorities, simplicity, a higher threshold, and a taper, describe the same underlying ask from three angles.

A further 32% selected 'something else', suggesting that the options provided did not fully capture the range of reforms carents are seeking, consistent with the themes raised throughout this submission around pension age, the weekly rate, and overpayments.

The overall picture is of a threshold that reduces carents' income, working hours, career prospects, and sense of self, while providing only partial compensation for what they give up.

Ask 4.2a: Replace the earnings cliff edge with a meaningful gradual taper so that Carer's Allowance reduces progressively as earnings increase rather than stopping abruptly. The taper rate and design should be developed with input from carents.

Ask 4.2b: Raise the earnings threshold substantially and commit to annual indexation in line with earnings growth so that it does not erode year by year in real terms.

Ask 4.2c: Develop a workable approach for self-employed carents, whose irregular income does not map onto a weekly threshold and who are currently excluded or deterred from claiming as a result.

4.3 The Pension Age Cliff: A Second Exclusion

Hero Quote

"Just because you reach pension age does not mean you are no longer a carent. If all these people suddenly decided to stop caring and asked social care to step in, the system would collapse overnight."

CA-007

The finding

In 99 or more open-text responses, carents raised the exclusion of Carer's Allowance for those receiving a state pension. It is one of the most consistently raised issues in the entire dataset, and one where the gap between the benefit's design and the reality of carenting is most stark.

The people being cared for in this survey are overwhelmingly in their 80s and 90s. Many of the people caring for them are in their 60s and 70s, approaching or beyond state pension age. The benefit stops when the carent's state pension begins, even when the caring responsibilities continue unchanged, often because the person being cared for is still alive and still needs the same level of support.

"I am 80 years old, looking after my 93-year-old husband. I have been doing this for the last seven years. The work does not stop."

CA-008

"We are both 68. We care for my mother 24/7. We are unable to take a holiday or be away from the house for more than a few hours. Why should caring stop mattering at pension age?"

CA-009

The position of people who are themselves retired but still providing full-time care to a very elderly parent is a particular gap in the current system. These are often women, who are more likely to have accumulated smaller pension entitlements, more likely to have spent periods outside paid employment, and more likely to be the person in the family who takes on caring responsibilities. The combination of a reduced pension income and ineligibility for Carer's Allowance can create significant financial difficulty.

"Carer's Allowance stopping when you receive a state pension is wrong. Given that most people have paid into the system to qualify for a pension, it should not be deemed a benefit. Just because you reach pension age does not mean you are no longer a carent."

CA-010

The overlapping benefit rule, which treats state pension and Carer's Allowance as overlapping in a way that prevents receipt of both, is experienced by those affected as a form of double penalty: having done everything right over a working life, they are told that the very contribution they made to the system is what disqualifies them from recognition for their caring.

"I was told that, because of the state pension, I was not entitled to anything else."

CA-011

Several respondents draw out the logical consequence directly. The most intensive carenting in the country, the kind carried out by people in their 60s and 70s supporting parents in the final years of a long life, currently receives the least financial recognition. An 80-year-old providing 24-hour care to a 93-year-old spouse does not qualify. A 68-year-old couple providing full-time care to a 97-year-old mother does not qualify. The age at which caring becomes hardest is the age at which the benefit stops.

Ask 4.3: End the pension-age exclusion from Carer's Allowance. Carenting does not stop at 66. People providing 35 or more hours of care per week should receive the same recognition regardless of whether they also receive a state pension. As an interim measure, where the overlapping benefit rule prevents full payment, the government should introduce a Carer's Supplement payable to pension-age carents as recognition of the caring they provide.

The following three themes fall outside the specific questions posed by the Call for Evidence. They are submitted under Question 12, the invitation for wider views, because they represent the most significant unmet needs identified by respondents, and because no reform of Carer's Allowance will serve this population adequately without addressing them.

4.4 The Weekly Rate: Too Low to Reflect What Carenting Costs

Hero Quote

"The amount paid is diabolical. It works out at approximately £2.57 per hour. We give up our lives and sacrifice our jobs and businesses. Our lives revolve around the person we care for. It is all-consuming, and a deeply inadequate recognition of what we do."

CA-017

The finding

Carer's Allowance stands at £86.45 per week in 2026/27, an increase of 3.8% from the previous year. [5] At the minimum qualifying threshold of 35 hours of care per week, this equates to £2.47 per hour. It was described repeatedly by respondents as inadequate, insulting, and unsustainable. 135 or more responses in the final open-text question called explicitly for an increase. The language used throughout, "derisory", "a pittance", "a joke", "not enough to survive on", reflects a level of frustration that goes beyond policy criticism.

This frustration has a straightforward basis. Carer's Allowance is not designed to be a living wage. But when the people providing care cannot afford to stop working, and cannot work enough to live on, and receive an allowance too small to fill the gap, the result is financial hardship for people already giving up economic security to support an elderly relative.

"Unpaid carents save money for the government and councils. They are doing it on their knees, exhausted, often lonely, and struggling financially."

CA-018

"I have had to give up my profession to deal with my parents' needs. I am 61 and unfortunately dealing with everything was making me ill. The only extra money that comes in is their attendance allowance. I have no personal income now."

CA-019

"I gave up a decent paid job to be sole carent to my mother and avoid her having to go into a nursing home. Seven years later, at 63, I see my life and any hope of working again passing me by."

CA-020

The economic case for adequate recognition is made repeatedly by respondents themselves. Research by the Centre for Care valued the contribution of unpaid carers across the UK at £184 billion per year, exceeding the combined NHS budget for all four nations. [4] In the context of that contribution, the weekly Carer's Allowance rate represents a fraction of the economic value transferred from individuals to the state by those who provide care without pay.

Several respondents also raise the question of pension accrual. Years spent caring, particularly at the level required to qualify for Carer's Allowance, are years in which carents may not be building National Insurance contributions or occupational pension savings. The financial cost of caring extends well beyond the caring years.

"Carents also need to be supported to save into a pension fund. It is a great concern to me that years spent caring do not allow this."

CA-021

"The allowance given is an insult. If I did not provide this care it would be very costly to the government."

CA-022

Ask 4.4: Commission an independent review of the Carer's Allowance weekly rate, with a mandate to recommend a level that reflects both the economic contribution carents make and the genuine costs carenting imposes on those who provide it. The review should consider indexation to earnings, not only inflation, going forward, and should address the long-term financial impact on carents' pension positions.

4.5 Carer's Allowance Overpayments: Scale, Ongoing Impact, and Unresolved Cases

Hero Quote

"Knowing about the scandal over people having received Carer's Allowance overpayments they did not know about for years, and were then suddenly asked to repay in full or be charged with fraud, made the whole process of understanding what to declare incredibly stressful. The fact this was allowed to happen at all is appalling."

CA-023

The finding

In 2024 and 2025, widespread reporting revealed that thousands of Carer's Allowance recipients had received overpayments they were unaware of, some stretching back years, and had subsequently received demands for repayment, in some cases totalling thousands of pounds. Several had been investigated for fraud. In December 2024, the National Audit Office published its *Investigation into Overpayments of Carer's Allowance*, finding that outstanding overpayment debt had risen to £251.7 million in 2023-24, up from £150.2 million in 2018-19, with between 32,500 and 60,800 new overpayment cases identified each year. [1]

The consequences of that scandal continue to be felt in this survey, conducted in August 2026. 44 respondents described receiving unexpected DWP letters directly. Many more referenced the scandal in expressing anxiety, distrust, or a deliberate decision not to claim:

"Yes, I received letters and am still paying back every month."

CA-024

"I am not sure if I may get one in the future, and have no idea if I might get one many years from now. It makes it incredibly alarming to have to apply."

CA-025

"I dare not claim in case work is offered and I am then forced to pay it back."

CA-001

The chilling effect of the overpayment scandal is not confined to people who have personally received a letter. The prospect of receiving one, years after the fact, for an error the carent did not knowingly make, has persuaded a significant number of people not to claim at all, or to reduce their claims to a level they feel they can defend, even if this means forgoing a legitimate entitlement.

"Yes, I received a letter. And then they ended up paying 9 months back. The stress and uncertainty of that period was immense."

CA-026

The scandal also intersects directly with the complexity theme in section 4.1. When the rules are hard to understand, and when the penalty for getting them wrong can be a demand for repayment months or years later, the rational response for many people is not to engage with the system at all.

"When I temporarily increased my hours and stopped claiming, and then reduced my hours again, they did not process the new claim for 10 months. I received no money for that time."

CA-027

A note on the proposed move to four-week arrears

The Call for Evidence asks for views on a proposal to pay Carer's Allowance four weeks in arrears rather than weekly in advance, on the basis that this would allow more time for changes in circumstances to be processed and could reduce overpayments.

21% said it would cause real financial difficulty. A further 28% said it would be manageable but not ideal. Combined, nearly half of respondents, 49% of those who answered, have concerns about the proposal.

The open text makes the reason clear - for many respondents, Carer's Allowance is their primary or only personal income.

"I don't work. The Carer's Allowance is the only money I receive. I have to go shopping at Lidl every Monday with it. If they don't pay me weekly I have no income for groceries."

CA-033

"I can barely survive as it is financially. If the money is paid monthly after the caring period then I would be in rent arrears immediately and face eviction not to mention not being able to buy food for my loved one!"

CA-034

"Knowing what is in your pocket to spend and when is vital. If plans change, how will I bridge that gap?"

CA-035

"Why should we have to cover our living costs in advance? I save the government a huge amount of money by keeping my parents in their own home. Why should I be penalised?"

CA-036

The Department's rationale for the proposal of reducing overpayments is acknowledged by some respondents but the proposed mechanism transfers the cost of a systemic administration problem onto the people least equipped to absorb it. Those who are already barely managing week to week cannot buffer a four-week payment gap, however temporary.

Carents does not oppose the goal of reducing overpayments. It supports it. But the evidence here suggests that four-week arrears, implemented without adequate transition support or alternative payment arrangements for those in financial difficulty, would cause harm to already vulnerable people in the system. The overpayment problem should be solved at source, through real-time data sharing with HMRC, not by shifting financial risk onto carents.

Ask 4.5a: Publish a full and transparent public account of the number of carents affected by the overpayment issue, the amounts involved, and the DWP's plan for handling existing cases, including those currently under dispute.

Ask 4.5b: Commit to a time-limited retrospective review of overpayment cases where carents were not clearly informed of the rules they were said to have breached, with repayment waiver as the default where there is evidence of systemic failure in DWP communication.

Ask 4.5c: Introduce real-time earnings reporting to DWP through HMRC's existing infrastructure, so that carents are not left in a position where earnings are reconciled retrospectively, often years later, with no warning and no opportunity to correct.

Ask 4.5d: If the government proceeds with four-week arrears payments, it must introduce a hardship exemption for carents who can demonstrate that the change would cause financial difficulty, with a simple self-declaration process and continued weekly payment as the default for those who request it. The transition period must be long enough for carents to adjust bill payment dates and financial arrangements.

4.6 Universal Credit: A System Within a System

Hero Quote

"It is not Carer's Allowance when you get Universal Credit. It is a carers element, and it is less money. I get nothing. People on Universal Credit get more for doing nothing than I get for looking after someone 84 hours a week."

CA-028

The finding

138 respondents raised the interaction between Carer's Allowance and Universal Credit in open-text responses. It is a relationship that is poorly understood by most people navigating it, and one that the two systems have, in practice, made worse by failing to communicate with each other.

The core problem is straightforward: Carer's Allowance and Universal Credit are administered by different parts of the DWP but affect each other in ways that respondents consistently describe as difficult to navigate. Many report receiving different information depending on who they speak to, and several describe being passed between teams without receiving a clear answer.

The result is that carents can receive an incorrect total, often without knowing it, and then face a demand for repayment when the two systems are eventually reconciled.

"They had not been communicating and I had been receiving too much. It will be taken back monthly, through no fault of my own, leaving me short every month."

CA-029

"We told Universal Credit who updated their systems, but it did not communicate to Carer's Allowance. I was penalised and am still paying back the overpayment."

CA-030

For many respondents, the entanglement of the two systems makes planning impossible. The carers element within Universal Credit is smaller than the Carer's Allowance rate, and the rules governing it differ in ways that are not consistently explained. Carents describe being told different things by different parts of the DWP, or receiving no clear guidance at all.

"The DWP and council do not know how it is worked out. I was passed from one to the other many times with no answers."

CA-031

"Yes, I received a letter saying that UC and Carer's Allowance basically had not been communicating and that I had been receiving too much and that it would be taken back monthly. This has left me short each month through no fault of my own."

CA-032

The connection between this section and the overpayment scandal in section 4.5 is direct: a significant proportion of the £251.7 million in outstanding overpayment debt is attributable not to carents knowingly breaking the rules, but to the failure of two DWP systems to share information with each other in real time. The debt is systemic in origin. The recovery falls on individuals.

A note on study and training

The Call for Evidence asks how carents can best be supported to combine study or training with caring.

The picture is consistent with the demographic profile of this community. Most respondents are in their 50s and 60s and a substantial number are retired. For many, retraining is not a current priority, not because they lack the inclination, but because the intensity of caring leaves no capacity for it. As one respondent put it: "I cannot afford to add more stress or something else to juggle in my life."

Where the rules are relevant, the evidence points to confusion rather than clear deterrence. Several respondents were unaware that study could affect their Carer's Allowance entitlement at all. A small number were denied Carer's Allowance while studying part-time, despite meeting the caring hours requirement. One was told their part-time university course disqualified them despite providing a letter from their institution.

The clearest finding on this question is that the rules are not well understood, consistent with the complexity theme set out in section 4.1. Carents who wish to study should be able to find out in advance, and without risk, how doing so would affect their entitlement. The online calculator ask covers this need.

Ask 4.6a: Require Carer's Allowance and Universal Credit systems to share earnings and payment data in real time, so that overpayments arising from system failure rather than carent error do not result in retrospective debt.

Ask 4.6b: Publish a clear, plain-English explanation of how Carer's Allowance and Universal Credit interact, including worked examples for common scenarios: a carent receiving both, a carent moving between employment and caring, and a carent on UC already when they begin receiving Carer's Allowance.

Ask 4.6c: Guarantee that carents experiencing overpayment arising from a failure of the two systems to communicate are not required to repay, and are protected from fraud investigation.

5. What the Government Should Understand

Before setting out the specific asks, it is important to acknowledge what the evidence makes clear about the people providing this care and the conditions under which they are doing so.

Carenting is not a lifestyle choice. It is not an occasional contribution. For the people in this survey, it is a full commitment, often running alongside a job, often alongside significant personal health challenges, and often with no clear end point except the death of the person being cared for. The language of "support" that the benefit system tends to use does not capture what they are actually doing.

One respondent put it plainly: "Carents save the government millions. So the allowance should be more. What happens when you reach pensionable age and lose Carer's Allowance? You might be retiring, but the person you care for still needs to be cared for."

The people providing unpaid care to ageing parents are, in the main, people in the middle of their own lives. They are in their 50s and 60s. They have mortgages, careers, their own health conditions, and their own retirements to think about. The decision to care, or the arrival of caring as a situation they did not choose, reshapes all of that. The financial consequences last well beyond the caring years.

Carer's Allowance was designed to provide a degree of financial recognition for people whose caring role affects their ability to work. In its current form, it does not do that effectively for many of the people it is meant to reach. It excludes people who are working above a low threshold. It excludes people who are retired. It confuses people who do not have access to specialist advice. It has created debt for thousands of people through a systemic failure that the government has been slow to address. And it pays those who do receive it a weekly amount that, for those relying on it as their main income, does not cover the costs of caring.

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6. Carents' Asks: Consolidated

The following ten asks are drawn directly from the responses of 665 carents. They are what this community has told us they need.

Ask 1: Replace the cliff edge with a taper. Design and implement a gradual reduction in Carer's Allowance as earnings increase, so that carents are not penalised disproportionately for any increase in income. The taper rate and design should be co-developed with carents.

What delivery looks like: DWP to publish a proposed taper design for consultation by the end of 2026. The taper should be tested with carents through Carents.co.uk and other carent organisations before implementation. An online calculator must be available before any taper goes live.

Ask 2: Raise and index the earnings threshold. Increase the weekly earnings limit substantially, and commit to annual uprating in line with average earnings growth, so that the threshold does not continue to erode in real terms.

What delivery looks like: An interim increase to be announced in the next fiscal statement. Earnings indexation to be legislated rather than left to annual discretion. A specific workable framework for self-employed carents, whose irregular income does not fit a weekly threshold model, to be developed in consultation with carents and published alongside any change to the threshold.

Ask 3: End the pension-age exclusion. Carenting does not stop at 66. Remove the overlapping benefit rule that prevents pension-age carents from receiving Carer's Allowance, or introduce a pension-age Carer's Supplement as an interim measure.

Many of the carents this submission represents are in their 60s and 70s, providing care for parents in their 80s and 90s who would otherwise require residential care. Average care home costs in England in 2025 exceeded £1,100 per week. The carents who keep parents at home at that scale of need are providing a function the formal care system could not afford to replace. Withdrawing Carer's Allowance at the point of state pension precisely when many carents are least able to absorb the financial impact is poor policy economics, not just a moral failure.

What delivery looks like: A defined date by which the overlapping benefit rule will be reviewed. Evidence on the number of carents affected and the cost of extending eligibility to be published within six months.

Ask 4: Build a free online calculator. Provide a public-facing tool that allows carents to calculate their entitlement in advance, including interaction with Universal Credit, state pension, and variable income scenarios.

What delivery looks like: Calculator to be available on GOV.UK within six months, built in consultation with carents and tested for accessibility and plain-English clarity before launch. The application process and ongoing reporting requirements to be reviewed for simplification in parallel with calculator development, with particular attention to carents with variable or self-employed income.

Ask 5: Fund a proper helpline. Invest in a Carer's Allowance helpline with advisers trained to give clear, accurate guidance on individual circumstances, including self-employment, variable income, and interaction with Universal Credit.

What delivery looks like: Published waiting time targets for the helpline. Specialist advisers trained on self-employed income rules. A named escalation route for complex cases.

Ask 6: Raise the weekly rate. Commission an independent review of the Carer's Allowance weekly rate, with a mandate to recommend a level that reflects both the economic contribution of unpaid carents and the real costs of carenting.

What delivery looks like: Independent review to be commissioned and report within 12 months. Terms of reference to include an assessment of pension accrual gaps and the long-term financial impact of caring on those who provide it.

Ask 7: Fix the Universal Credit interface. Require Carer's Allowance and UC systems to share data in real time and ensure that overpayments arising from system failure do not result in debt recovery from carents.

What delivery looks like: A defined timeline for real-time data-sharing between Carer's Allowance and UC. A retrospective review of cases where overpayment was generated by system failure rather than carent error. Published outcomes within 12 months. Earnings data from HMRC to be shared with the Carer's Allowance system in real time, so that changes in income are reflected immediately rather than being reconciled retrospectively, often months or years later. Publish a plain-English guide to how Carer's Allowance and Universal Credit interact, with worked examples covering the most common scenarios: a carent receiving both, a carent moving between employment and caring, and a carent already on Universal Credit when they begin receiving Carer's Allowance. To be published on GOV.UK and updated whenever either system changes.

Ask 8: Address the overpayment scandal and proceed carefully on payment reform. Publish a full account of the number of carents affected by overpayments, the amounts involved, and the DWP's plan for existing cases. Commit to a time-limited review of cases where carents were not clearly informed of the rules they were said to have breached, with waiver as the default where systemic failure is evident. If the government proceeds with paying Carer's Allowance four weeks in arrears, introduce a hardship exemption before the change takes effect, with a simple self-declaration process and continued weekly payment as the default for those who request it.

What delivery looks like: A formal government response to the NAO findings within three months. A dedicated review team, independent of the DWP operational team responsible for the original overpayments, to assess individual cases and publish outcomes. If arrears payments proceed, the hardship exemption must be operational from day one of implementation, and carents must be given sufficient notice to adjust their bill payment arrangements before any change takes effect.

Ask 9: Reform the 35-hour threshold. Recognise the full reality of modern carenting, including remote care, overnight supervision, crisis response, and the coordination work that constitutes a substantial part of what carents do. The threshold should be applied in a way that reflects how care is actually provided, not only what happens in the same room.

What delivery looks like: DWP to publish revised guidance on what counts towards the 35-hour threshold, co-developed with carents and carent organisations, by the end of 2026. Pilot a self-assessment approach for complex caring arrangements.

Ask 10: Find people before they find the system. Invest in proactive public information so that eligible carents know what they are entitled to before they have first been caught out by what they did not know. GPs, hospitals, discharge teams, and social workers should all have a role in identifying carents and signposting them to financial support.

What delivery looks like: Outreach designed around how carents actually describe themselves before they enter the system: as sons and daughters managing a parent's care, not as carers. Information campaigns and proactive signposting should use that language, and should reach people before they know to search for Carer's Allowance. A national awareness campaign targeting people approaching the carenting years, funded and timed to coincide with any reform of the benefit. Mandatory training for NHS and local authority frontline staff on identifying and signposting carents to financial support.

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7. Conclusion

The 665 people whose responses form this submission did so in their own time, around jobs, around caring commitments, and around lives that are already stretched thin. They responded because they believed their words might make a difference. We hope the government will prove them right.

Carer's Allowance, as it currently operates, is not fit for the people it serves. It excludes those who earn above a low threshold. It excludes those who have reached retirement age. It penalises those whose income fluctuates. It confuses those who do not have access to specialist advice. It has created debt for thousands of people through a systemic failure that the government has been slow to address. And it pays those who do receive it a weekly amount that falls far short of reflecting what they contribute.

The people in this survey are not an abstract demographic. They are daughters who left careers in their 50s to care for parents in their 90s. They are retired couples caring for elderly parents with no family to share the responsibility. They are working carents trying to balance a job, their own children, and a parent with dementia, managing the arithmetic of a £204 threshold every week. They are people who went to apply for a benefit they needed and gave up because the rules were too hard to understand.

Carents represent a substantial and growing population providing essential unpaid care. The formal care system is, in practice, dependent on this contribution. Carer's Allowance, in its current form, does not reflect that dependency adequately.

The Call for Evidence is an opportunity to change that. We hope the government will take it.

Carents is ready to provide further evidence, facilitate access to our community, and support the government's work in any way that would be useful.

Submitted by Carents.co.uk, August 2026 | carents.co.uk | sarah@carents.co.uk

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References

[1] National Audit Office. *Investigation into Overpayments of Carer's Allowance*. HC 229, Session 2024-25. Published 11 December 2024.
https://www.nao.org.uk/reports/investigation-into-overpayments-of-carers-allowance/

[2] Office for National Statistics. *Unpaid Care by Age, Sex and Deprivation, England and Wales: Census 2021*. Published 2023.
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/unpaidcarebyagesexanddeprivationenglandandwales/census2021

[3] Office for National Statistics. *National Population Projections: 2020-based Interim*.
https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2020basedinterim

[4] Petrillo, M. and Bennett, M. *Valuing Carers 2021/22: The Value of Unpaid Care in the UK*. Centre for Care / Carers UK. Published November 2024.
https://www.carersuk.org/reports/valuing-carers/

[5] Department for Work and Pensions. *Carer's Allowance*. GOV.UK. Rate of £86.45 per week applicable from 6 April 2026. https://www.gov.uk/carers-allowance

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About Carents.co.uk

Carents.co.uk is the UK's national support hub for adults supporting ageing parents: a platform built specifically for people managing the care of an elderly mother, father or both. Our community has grown to over 85,000 members. We support more than 500,000 carents annually through our platform.

We exist because the formal care system was not built for the people who use it most. Our members are, in the main, adult children in their 40s, 50s, and 60s, managing the care of parents in their 80s and 90s. They are navigating assessments, agencies, benefits, and discharge planning, often from a different town, often while holding down a job, often with no professional who holds the whole picture. They are not, by and large, people who think of themselves as carers. They are daughters, sons, and partners. The word "carent" is ours: coined because no existing word described what they were actually doing.

We provide information, practical tools, peer community, and guidance across every aspect of the carenting journey. We are not a formal care service. We are the place people find when the formal system has not yet found them, and we exist because that gap should not be as large as it is.

The community whose responses form this submission represents a substantial, engaged, and knowledgeable group. Their evidence is grounded in direct experience of a system that has, in many cases, let them down. It deserves to be taken seriously by those with the power to change it.

Carents.co.uk is a social enterprise and not-for-profit organisation.

We are not affiliated with any political party. Our sole interest is in improving the experience of adults who find themselves responsible for the care of an ageing parent.