



Carers in crisis



A survey of carers' finances in 2008



Summary

The nation's carers are living under extreme financial pressure and many are cutting back on essentials to make ends meet. Like other families they are feeling the pinch as living costs rise and the economic crisis spreads across the economy.

However unlike other people, carers have always found things difficult. Due to their caring responsibilities they have less opportunity to earn and many are forced to live on benefits. Yet carers also face higher costs associated with caring, such as higher heating, water and transport costs. At the same time many do not get any support from social services. Most families do not receive publicly funded care, so are forced to arrange their own care which can be expensive and poor quality.

This new survey reveals that in 2008 carers are in crisis. Despite providing essential unpaid support for their elderly, sick or disabled relatives, making a contribution worth £87 billion a year, they are not properly recognised or rewarded.

Main recommendations:

- The UK Government should publish a plan and timetable for ensuring that its 2018 vision that no carer falls into financial hardship because of their caring role, as promised in the National Carers Strategy, becomes a reality.
- The UK Government must urgently review and overhaul Carer's Allowance and other benefits for carers.

Key findings

Our survey of over 1,700 carers shows:

- 86% say their financial position is worse than 12 months ago
- 74% are struggling to pay essential utility bills
- 65% are living in fuel poverty (spending more than 10% of their income on fuel)
- 52% are cutting back on food to make ends meet
- 66% are spending their own income or savings to pay for care
- 32% of those carers paying rent or a mortgage say they cannot afford to pay it
- 24% are cutting back on essential car journeys e.g. to go food shopping, visit the doctor
- 54% are in debt – nearly a third of these owe more than £10,000 and many are resorting to bank overdrafts and credit cards.



Introduction

For many carers 2008 has been one of the hardest years they have known. The economic downturn is affecting every community in the UK, with job losses spreading and many people struggling to pay bills. Carers, many of whom are already living on the edge of poverty, have found things particularly tough.

Many carers rely on benefits and rising prices for essentials like food and fuel means that they get less for their money. Benefits do go up each year to account for inflation, but this is only an average measure across the whole of the economy. Carers are likely to spend a higher proportion on food and other essential expenditure, which have seen very high price increases, and therefore benefit increases are not likely to cover their additional costs. Additional costs that families containing a disabled person might face include high heating bills, high water bills from running a washing machine more regularly, food costs for special items, and high transport costs.

Those carers who are able to combine caring with paid work may find that they don't get a pay rise this year, and because of their caring role will find it hard to take on overtime or another job to bring more money into the household. Many carers are struggling to pay their rent or mortgage, adding the risk of losing their home to the stress and worry that they face daily.

This report paints a bleak picture of a group of people struggling to survive. Yet at the same time they are providing essential care to those who need it, often at a cost to their own

health and financial circumstances. The care that carers provide for free is worth £87 billion per year, nearly as much as the NHS and far more than the total spend on social services. They are the bedrock of communities, supporting many people and enabling them to remain in their own homes and take part in society.

This report shows how the rhetoric about how carers are valued and celebrated is far from the reality for many. We are calling on the Government to make urgent changes to carers' benefits and end the injustice of carers being penalised for the essential work that they do.

About the survey

The survey was carried out between September and October 2008, and completed by 1,707 respondents.

The questionnaire included both open and closed questions and was available to complete online.

For purposes of comparison, unless otherwise stated, where statistics have been compared to the 2007 survey the same questions were used, however additional questions were added to the 2008 survey.

(The *Real Change not Short Change* survey was completed between December 2006 and January 2007 by 2,950 respondents).

Carers UK would like to thank all those carers who completed our survey.



Policy background

Carers UK has been campaigning for many years for improved benefits for carers. Carer's Allowance is just £50.55 per week for at least 35 hours caring. This is equivalent to just £1.44 per hour. Carers also face a cliff-edge when they are working – if they earn a penny more than £95 they lose the entire benefit.

Our *Real Change not Short Change* campaign is calling on the Government to radically reform the tax and benefit system so that it is:

- Based on the contribution carers make, rather than on the work/income they have to give up.
- Transparent and fair to all carers.
- Easy to access and less bureaucratic.

In May 2007 we published the report *Real Change not Short Change* which contained the results of a survey of 2,950 carers¹. It showed how bad the situation was for carers. Using real life quotes and case studies, we showed how carers were struggling to get by, let down by inadequate benefits and unable to work. We called on the Government to conduct an urgent review of carers' benefits, and continue to do so.

Since then the UK Government has published its *National Carers Strategy*² which looked at the entire range of support that carers need, both to help them in their caring role and to ensure they have a life of their own. As part of the consultation process in developing the Strategy, the Government set up an Income Task Force.

This brought together civil servants and experts from the voluntary sector, local government and trade unions. The Task Force agreed that Carer's Allowance needed reform and made a number of recommendations³ for short-term changes, which it saw as a stepping stone to a more radical overhaul. There was an agreement across Government, from Ministers downwards, that Carer's Allowance is not fit for purpose and needs to change.

Despite this the final Strategy contained no changes to carers' benefits, much to the disappointment of Carers UK. Although progress was made in other areas with commitments worth a total of £255 million for England, the lack of any changes to benefits was a source of real anger and disappointment for carers.

The Strategy did, however, contain a bold vision for the future of support for carers. It pledged that by 2018 carers should no longer face financial hardship because of their caring role. This aspiration is a clear statement that Government sees existing hardship as unacceptable and intends to act.

Through its lobbying and campaigning work, Carers UK has been calling on the Government to set a timetable for the action needed to make this vision a reality. Major changes to legislation can take several years and the systems are complex. They need to start now to avoid more carers falling into poverty.

¹<http://www.carersuk.org/Newsandcampaigns/Shortchanged/CampaignFAQ>

²Carers at the heart of 21st century families and communities. HM Government, June 2008

³http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086585



In August 2008 our campaign received a boost with the publication of a report by the Work and Pensions Select Committee⁴. In its report *Valuing and Supporting Carers* the Committee called for carers benefits to be radically overhauled at the earliest opportunity. It recommends a two-tier support system for carers consisting of a Carer Support Allowance similar to today's Carer's Allowance, and a Caring Costs Payment on top, which is available to all carers in intensive caring roles to compensate them for the additional costs of caring. The Committee recommended that this be set at somewhere between £25-50 per week, similar to Child Benefit.

With support from this influential group of MPs, the campaign is building momentum, but there have still been no firm commitments from Government. The publication of this report coincides with a lobby of Parliament and hundreds of carers are expected to come to Westminster and ask their MP to back our campaign for change. We need to tell the Prime Minister, Chancellor and other key Ministers that carers are in crisis: they need real change now.

⁴Valuing and Supporting Carers, House of Commons Work and Pensions Committee, August 2008



Survey results

Carers in Crisis

2008 has been a difficult year for carers. Many were already living on the edge of poverty, but rising food and utilities prices have reduced their standard of living yet further.

- 86% say their financial position is worse than 12 months ago. Just 2% think their situation has got better.
- 74% struggle to pay utility bills like gas, electricity, water and telephone bills. Failure to pay could result in them falling into debt or facing legal action.



"It's very bad and getting worse each day."

"I have cut back on everything I can and still cannot meet all of the bills and associated living costs."

Eat or heat?

After years of cutting back on luxuries, rising prices will force over half of carers to cut down on food and heating this winter.

- 52% of carers are cutting back on food, compared to 19% in 2007.
- 56% are reducing their heating, whilst only 25% were doing so last year.
- For carers living with an elderly, disabled or ill person, or who are themselves disabled, cutting back on food or heating could have a long-lasting negative impact on their health.



"Because of these huge increases in fuel costs I cannot afford to feed my family properly."

"Every day is a struggle to buy food."

Fuel Poverty

Carer households often need extra heating for elderly, ill or disabled occupants. As some carers see their fuel costs spiral, many are spending more than 10% of their income on fuel bills.

- Help the Aged estimate that 1 in 4 older people are in fuel poverty: our survey has found that 65% of carers are living in fuel poverty.
- 72% of those on Carer's Allowance and 82% of carers in receipt of Income Support are in fuel poverty.



"It is impossible to live, how will we manage the coming fuel bills?"

"Because the house is used 24/7 gas and electricity consumption is higher than those who go out to work, I estimate at least double that of working people."

In debt

As essential living costs have soared, more than half of carers have fallen into debt.

- 54% of carers are, or have been, in debt as a result of caring.
- 30% of these owe £10,000 or more, with a further 57% owing between £1,000 and £10,000.
- More than a third of carers are turning to bank account overdrafts (33%) and credit cards (35%) to make ends meet.



15% have taken out a loan and 24% have asked for help from friends or family. For families already living on a low income, it will take years to pay back these debts, having a long lasting impact on their quality of life and ability to make ends meet.



“I went bankrupt earlier this year as debts had mounted up over the previous 13 years of caring for my severely disabled son.”

Paying to care

Rather than see loved-ones go without, carers are spending their own money to support the people they care for

- 66% of carers are spending their own income or savings to pay for care.
- 49% have cut back on caring support services or supplies (like extra breaks, equipment or supplies) because they cannot afford them. This risks damaging the health or the carer and the person they care for.



“I spend my own money on things for mum, taxis for her to get around as she is sick and also taxis for myself late at night when she needs me in emergencies (usually 3 times per week).”

Housing crisis

Essential costs, like mortgage payments, rent and home repairs are becoming unaffordable for many carers.

- Nearly a third (32%) of those paying rent or a mortgage, cannot afford their payments.
- 72% are unable to afford essential repairs to their home.

- The risk of losing your home can be extremely worrying, adding to the stress that many carers already face on a daily basis.



“Having to go without food just to keep roof above our heads”

“The biggest problem of all is trying to maintain my house with repairs and decorating. As I have no savings, any emergency such as washing machine breaking down or car repairs have to be paid for from normal household budget which means cutting down on food or heating.”

Social isolation

As money barely covers living costs, carers are being left socially isolated, many unable to afford any social life.

- A large majority of carers are cutting back on leisure activities and hobbies (81%), holidays (85%) seeing friends (80%) and buying clothes (83%).
- The cost of petrol has forced 72% to cut down on journeys to visit friends and family members and 24% have cut down on essential journeys. With many carers relying on a car to travel to the person they care for, or to take them to hospital, collect shopping and medication, the rise in fuel prices has had a huge impact.



“I have not been out in years, never had a holiday, now food and heating is being cut back.”

“The lack of money leaves nothing left to have anything to look forward to, no trips to the cinema let alone a holiday.”



Worries for the future

Going into debt to afford essential costs, and seeing food and fuel costs rise month on month, carers are fearful for their financial future.

- In 2007, 54% of carers felt their financial situation would get worse in the future.
- Today, 87% of carers think their financial situation will get worse in the next year.
- Carers are far more fearful for the future than the general public. A MORI poll in November showed 39% of people expected their own personal financial situation would worsen in the coming year⁵.



“I can't think how we are going to manage another year.”

“I have now been caring for 10 years and have gradually used up all our savings and are now in debt. I cannot see a way out of this situation.”

The hardest hit

Carers in receipt of means tested benefits, and those caring for disabled children are amongst those hardest hit by the financial crisis.

- Carers on Income Support do worse than any other group according to all major indicators - 77% are in debt

(compared with 54% for all groups), 82% are in fuel poverty (compared with 65% for all groups) and 67% are cutting back on food (compared with 52% for all groups).

- 92% of carers on Income Support struggle to pay their utility bills. This leaves them at real risk of falling further into debt.
- People caring for a disabled adult child aged over 18 are more likely to be in fuel poverty compared to other groups – 71% compared to 65% overall. They are also most likely to be cutting back on heating.
- People caring for a disabled child under 18 are also among the worst off – they are most likely to be cutting back on food (58% compared with 52% overall) and to be in debt (67% compared with 54% overall). This is particularly worrying since their caring responsibilities are likely to last for the rest of their lives, making it harder for them to repay the debt.



“We are suffering badly and it is getting harder each week to live on Carer's Allowance and Income Support.”

“Everything goes up, but not Carer's Allowance, but as you end up cutting back on the essentials caring gets more difficult.”

⁵ http://www.ipsos-mori.com/_assets/pdfs/november08_political_monitor_topline.pdf



Results from around the UK

Most of the findings are broadly similar across the UK, however there are some differences. For example, carers in Northern Ireland, Scotland and Wales are up to 10% more likely to be living in fuel poverty than carers in England. Carers in England were most likely to be unable to afford essential repairs to their homes. In Scotland they were most likely to be struggling to pay utility bills or be in debt. Carers in Northern Ireland were most likely to have cut back on essential journeys such as to the doctor. In Wales, they were most likely to have cut back on services to help them in their caring role.

<p>England Fuel Poverty: 64% Cutting back on food: 52% Cutting back on heating: 56% Using own savings to pay for care: 65% Cutting back on leisure activities/hobbies: 82% In debt: 55% Debt over £10,000: 30%</p> <p>Based on 1236 responses</p>	<p>Wales Fuel Poverty: 72% Cutting back on food: 51% Cutting back on heating: 58% Using own savings to pay for care: 62% Cutting back on leisure activities/hobbies: 82% In debt: 55% Debt over £10,000: 28%</p> <p>Based on 109 responses</p>
<p>Scotland Fuel Poverty: 73% Cutting back on food: 53% Cutting back on heating: 60% Using own savings to pay for care: 69% Cutting back on leisure activities/hobbies: 82% In debt: 57% Debt over £10,000: 34%</p> <p>Based on 122 responses</p>	<p>Northern Ireland Fuel Poverty: 75% Cutting back on food: 46% Cutting back on heating: 54% Using own savings to pay for care: 67% Cutting back on leisure activities/hobbies: 82% In dDebt: 46% Debt over £10,000: 20%</p> <p>Based on 24 responses</p>

A total of 1,491 respondents specified which country they live in.



Conclusion

This survey shows that carers are being hit hard by the economic downturn. Things were bad in 2007 – they are worse now. Rising food and fuel prices have a huge impact on carers, many of whom are surviving on low levels of benefit and face higher costs because of the additional needs of the person they care for. They need real change now and Government must act immediately.

Recommendations

1. The UK Government should publish a plan and timetable for ensuring that its 2018 vision that no carer falls into financial hardship because of their caring role, as promised in the National Carers Strategy, becomes a reality.
2. The UK Government must urgently review and overhaul Carer's Allowance and other benefits for carers. This review should involve carers and the organisations that represent them, and the system created must be fair and sustainable. Carers UK would like to see a two tier benefit for all carers providing 35 hours care per week, irrespective of age and raised to the level of the State Pension (currently £90.70). It would have:
 - A higher level of income for carers who cannot work.
 - Flexibility to recognise the different circumstances of carers and the impact that caring can have on people's lives. This includes the hours spent caring and the number of people being cared for.
 - Financial incentives that help carers combine work and care.
 - Removal of restrictions on the number of hours carers can study.
3. The UK Government must review the overall incomes that disabled people and their families are entitled to. Disability benefits are inadequate and carers are spending their own money on care services and equipment. Many are also cutting back on the support they purchase, risking damaging their own health and wellbeing, and that of the person they care for. In particular, winter fuel payments should be extended to people receiving disability benefits and their carers. Carers should be entitled to claim tax credits when they are working for 16 hours per week, in the same way that lone parents are, rather than being required to work for 30 hours per week.
4. The social care system must support carers better so that they are able to have more choice about their lives, and are able to combine caring with paid work if they wish. Carers should not have to sacrifice their own health, career and independence because of a lack of appropriate and affordable services. People needing support from care services and their families should be clear what they are entitled to so that they are able to plan for any private contribution they may be required to make. The Green Paper on care and support in England, which will be published shortly by the Department of Health, should consider the financial impact on carers of any proposed new system of funding for care. Devolved governments in Scotland, Wales and Northern Ireland should also consider the financial impact on carers of all proposed or future legislation or policy development.



5. It must be made easier for carers to combine paid work with caring. A reformed benefit system should include a taper so that Carer's Allowance is not removed entirely once the earnings limit is reached. Carers' rights in the workplace should be strengthened by extending the right to request flexible working to all carers. Carers should be entitled to a period of paid leave to deal with emergencies.
6. The forthcoming Equality Act should clarify that carers are protected from discrimination in the workplace, following the Sharon Coleman case which ruled that disability discrimination legislation applies to those 'associated with disability'. The Equality Act should extend protection for carers in the provision of goods and services, and public bodies across the UK should be required to promote equality for carers, as is already the case in Northern Ireland.
7. Local authorities should give carers discounts on social activities/local services to combat isolation and social exclusion. Carers should also be entitled to free bus travel when they are travelling with the person they care for, and decisions about local transport should take into account the impact on carers.

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the voice of carers

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