

The Cost of Caring

How money worries are pushing carers to breaking point





Introduction

What is the true cost of caring for families looking after ill, frail or disabled relatives?

There are an estimated 6.4 million people in the UK providing unpaid care and support to ill, frail and disabled friends and family members¹.

Families provide the majority of care in the UK, outstripping social care services and private care providers combined. This contribution is worth an estimated £119 billion a year to the UK economy – more than the total cost of the NHS².

However, caring can come at great cost to carers. Many are forced to give up work to care, at the same time as they are faced with the considerable additional costs of disability.

This means that, alongside the personal costs of ill-health, for many families, disability and caring pushes them into debt and hardship.

Based on a survey of over 4,000 carers, this report sets out the consequences of these financial pressures on carers' health – as worries about their financial future take their own toll.

Key UK findings

- **Choosing to eat or heat:** over 45% were cutting back on essentials like heating or food.
- **Falling into debt:** 4 in 10 were in debt as a result of caring
- **Sick with worry:** the stress of money worries had affected the health of 1 in 2 (47%) of carers.

Methodology

To assess the impact of caring on carers' lives, Carers UK surveyed 4,282 carers between September 2010 and July 2011. The majority of respondents completed the survey online, with 105 respondents completing paper versions.

2,758 of the respondents were from England, 401 from Scotland, 383 from Wales and 102 from Northern Ireland.

- 75% were aged between 40-64, 14% were over 65, 11% between 25 – 40, and less than 1% were under 25.
- 76% of respondents were women and 24% men.
- Respondents were weighted towards heavy-end carers, with 75% caring for 50 hours a week or more. 23% were caring for more than one person.
- 30% were caring for a parent or parent in law, 39% for spouse or partner, 38% for their son or daughter, 3% for a sibling and 9% for a friend or other relative.
- 88% of respondents were White British and 6% from Black, Asian and other ethnic minority (BAME) communities.

¹ *Valuing Carers* (2011) Carers UK and Leeds University

² *Ibid.*



The financial costs of caring

Families affected by illness and disability often face pressure on their finances from two directions. Many are coping with lost income, as disability and caring responsibilities limit their ability to earn. An estimated one million carers have given up work or reduced working hours to care, over two thirds (68%) of those who had given up work to care were more than £10,000 a year worse off as a result.

“We have spent so much money on things that we wouldn't have done otherwise - therapies, equipment, activities, wheelchair adapted car, respite holiday with care....”

The extra costs of caring

As they cope with reduced household incomes, illness and disability bring considerable additional costs:

- Higher heating and electricity bills: as families are at home all day and disabled, ill and older people need to be kept warm.
- Higher basic household costs: incontinence can mean washing bedsheets several times a week or even every day.
- Specialist equipment, foods and medicines: these range from everyday costs of food and incontinence pads, to big costs for aids and adaptations.
- If families do not qualify for social care support, they may face bills of hundreds of pounds for replacement care if they want to take a few days off from caring.
- Big travel and parking charges from frequent trips to hospital and GPs.

Carers are often shocked at the lack of financial support available to them. Carer's Allowance is the lowest benefit of its kind, just £55.55 a week. But many carers struggle even to access this limited support, and miss out because of a lack of information, advice and recognition of what they do.

Carers UK published estimates last year which showed that as £840 million in Carer's Allowance goes unclaimed every year³, reflected by the fact that nearly half (47%) of respondents to our survey felt they had missed out on financial support as a result of not having recognised themselves as carers.

Responses to our State of Caring survey also show the stark consequences of the financial pressures on families.

“I went from working and having a healthy credit rating to being constantly overdrawn, in debt, struggling, and food prices are getting out of reach to the point the heating has been turned off and we have used blankets and stayed in bed to keep warm.”

Cutting back

- A third (34%) were unable to afford their utility bills (electricity, gas, water and telephone bills).
- Almost half (45%) were cutting back essentials like on food and heating in order to make ends meet.
- 54% were in fuel poverty – spending more than 10% of their incomes on heating bills.
- Most carers had cut back on holidays (78%), leisure activities (74%) buying clothes (70%) and going out with friends and family (74%).

³ Carers Missing Millions (2010) Carers UK



“We do not go out anywhere except the hospital as we can't afford the expense of fuel.”

Carers from BAME communities were particularly hard hit, with 45% unable to afford their utility bills and 60% in fuel poverty.

Debt

Cutting back isn't the only way carers were coping. Many had been forced to use credit cards and loans too; 31% of the carers struggling to make ends meet are using their overdraft, 30% are using credit cards, and 14% have taken out a loan to cope with the financial challenges of caring.

The costs of caring can push many carers into debt. Over 4 in 10 surveyed (43%) said they had been in debt as a result of caring. Younger carers are more likely to have been in debt through caring; over half of carers between the ages of 18-54 have been in debt. However, of the older carers who had been in debt, they were more likely to have been in greater debt; 15% of carers over the age of 65 had had debts of at least £20,000.

Sick with worry

“It is just constant stress -worrying all time where the next bill payment coming from.”

Financial hardship, debt, and worries about money take their toll on carers' health. Almost half, 47%, of carers reported that their financial circumstances were affecting their health. By far the most common complaints were of stress, anxiety and depression.

- The impact on carer health was greater amongst certain groups, with 56% of carers from BAME communities, and 52% of parents caring for disabled children reporting that their finances were taking a toll on their health.

“I have to struggle every week to make ends meet, I now have health issues and it has put huge strain on my marriage.”

- 76% said they had suffered mental ill-health as a result of caring. This figure was higher amongst the carers who had been in debt; 85% of carers who had been in debt also had suffered poor mental health. Carers who had missed out on financial support were also more likely to have suffered mental ill-health as a consequence of being a carer (81%).

“I gave up working to care for an elderly relative and receive no financial help or support. I feel like a nobody. I feel very lonely and depressed most of the time.”

- Almost (84%) of the carers who were in fuel poverty reported that their health had been affected; whilst fuel poverty is a reflection of the poor financial circumstances these carers are in, it may also suggest that fuel poverty itself, and living in an under-heated home, impacts on carers' health.

“Having a disabled partner meant we could never afford our own home and have been in dire debt several times that it has taken me years to earn my way out of.This had an impact on my physical and mental health. At times we could not afford heating and lived in a succession of appallingly damp flats. This led to constant chest problems for me.”

Conclusion

Poverty and ill-health can push carers to breaking point, leaving them unable to care. This brings great costs to family life, but will also cost the state more in the long-term as the NHS and social care services are forced to step in. Carers UK urges the Government to take urgent action to better support carers:



Recommendations

- 1. Radical reform of carers' benefits:** At just £55.55 a week Carer's Allowance is the lowest benefit of its kind and is failing to protect carers from poverty. The Government has acknowledged this and that Carer's Allowance is not 'effective in meeting the wider needs of carers'⁴. We call on the Government to examine ways of urgently reforming Carer's Allowance outside of Universal Credit, to better support carers to stay out of poverty and, where possible, to work and study alongside caring.
 - 2. Welfare Reform:** we are disappointed that the impact on carers of the Government's current package of welfare reform has not been adequately assessed. It is crucial that welfare reform is 'carer-proofed' to ensure it does not have a negative impact on families providing care.
 - 3. Regular information campaigns** to ensure that carers are aware of their entitlements. Local and national Government should support frontline staff across public services, along with employers; disability, community and BAME groups and encouraging members of the public to identify carers, and guide them to support.
 - 4. Cross-government work** to make information on carers' rights available across public services. For example, local authorities carrying out take-up work; or GPs surgeries, libraries and schools holding welfare days and having benefits
 - 5. Spread good practice on carer health** within the NHS; working to ensure that all
6. **Health and wellbeing strategies** should integrate improving carers' incomes with wider work on carer and public health.
 - 7. Support to help carers juggle work and care.** The Government must work more with employers, like members of Employers for Carers⁵ to promote good practice in creating carer-friendly workplaces which enable carers to combine work and care. Too often a lack of flexibility means that a short-term caring crisis leads to carers falling out of work, rather than being supported to juggle work and care.
 - 8. Fuel poverty:** Carers UK has submitted evidence to the independent Hills' Fuel Poverty Review arguing that carers should be recognised as a vulnerable group in its fuel poverty strategies. We urge energy firms to introduce or enhance social tariffs for families with caring responsibilities. Governments across the UK should also ensure that carers are including in existing schemes to improve energy efficiency and heating in homes to help reduce fuel costs and improve health and wellbeing.
 - 9. Funding of social care:** Carers UK and the 50 members of the Care & Support Alliance have called for urgent action to reform social care funding. It is crucial that Governments across the UK work to deliver well-funded, high quality and consistent care which enables families to juggle work and care where possible.

⁴ *Universal Credit: Welfare that works* (2010)
Department of Work and Pensions

⁵ An employment forum established by Carers UK whose 50 members include BT, British Gas, Unison, Sainsbury's, PricewaterhouseCoopers and the Metropolitan Police www.employersforcarers.org



Findings by nation

	England 2759 responses	N. Ireland 102 responses	Scotland 401 responses	Wales 383 responses
Cut back on luxuries	85%	83%	86%	82%
Cut back on holidays	78%	69%	77%	77%
Cut back on leisure activities	75%	66%	74%	72%
Cut back on clothing	70%	70%	68%	70%
Cut back on going out with friends/family	74%	79%	73%	72%
Cut back essentials (like food and heating)	45%	43%	47%	49%
In fuel poverty	53%	68%	58%	53%
Using overdraft to cope	31%	23%	32%	38%
Using credit cards to cope	30%	25%	29%	39%
Taking out a loan to cope	14%	14%	12%	16%
In debt as a result of caring	43%	37%	45%	46%
Money worries impacting carers' health	47%	51%	45%	50%
Suffered mental ill-health as a result of caring	76%	75%	79%	74%
Have been in debt and suffered mental ill-health	85%	89%	85%	86%
Missed out on financial support as a result of not recognizing themselves as carers	48%	53%	45%	49%
Have missed out on financial support and suffered mental ill-health	82%	78%	83%	74%
Carers health affected by fuel poverty	85%	83%	82%	82%

A total of 3645 respondents specified which country they live in.