

CARERS UK
the voice of carers

**real change,
not short change**

Time to deliver for carers



Carers give so much to society yet as a consequence of caring, they experience ill health, poverty and discrimination.

Carers UK is an organisation of carers fighting to end this injustice. We will not stop until people recognise the true value of carers' contribution to society and carers get the practical, financial and emotional support they need.

Carers UK is here to improve carers' lives. We achieve this by

- Campaigning for the changes that make a real difference for carers
- Providing information and advice to carers about their rights and how to get support
- Training professionals who work with carers
- Mobilising carers and supporters to influence decision-makers
- Gathering hard evidence about what needs to change
- Transforming the understanding of caring so that carers are valued and not discriminated against

Acknowledgement

Carers UK would like to thank all those carers who took the time to complete the questionnaire.

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Contents

	Page number
Executive summary	2
1 : Introduction	8
2 : Carers are worse off as a result of caring	10
3 : Why are carers worse off?	11
4 : Struggling to make ends meet	19
5 : Results from around the UK	27
6 : Facing the future	28
7 : Conclusion	32
8 : Recommendations	36
Appendices	
a) Comparison with 2000 survey	
b) Carers' Benefits - a short guide	
c) About the respondents	
d) Methodology	

Executive Summary

The announcement by Chancellor of the Exchequer Gordon Brown MP in February 2007 that the National Carers Strategy would be reviewed has opened up the debate about carers' incomes and the role of the state in supporting them. Carers UK's surveys have consistently shown that carers place income issues very highly in their list of priorities for change.

There are six million carers throughout the UK who provide unpaid care by looking after an ill, frail or disabled family member friend or partner. 1.25 million of them provide over 50 hours of care per week.¹ Every year, 2.3 million people throughout the UK become carers.² Those providing substantial care are twice as likely to suffer ill-health and one in five carers has given up work to care.³ The support that carers provide has been estimated at a staggering £57 billion per year.⁴ Yet, as this research shows, the barriers that carers face in relation to their finances are enormous, despite the fact that they are providing much-needed care for a relative or friend.

Recent legislation has secured rights that would have been unthinkable thirty years ago - the right to an assessment of their needs, the right to request flexible working and rights to pension contributions based on caring.

Yet despite these improvements, too many carers are struggling financially and battling to survive. Carers tell us that the costs of looking after someone mean that they and their families cannot take opportunities that arise to improve their quality of life. The benefits they receive are completely inadequate and do not show that they are valued for what they do. Individually, they often cite barriers that get in the way of working and a lack of support to help them remain in work. It is a well established principle that for most people the best route out of poverty is to be in work, yet whilst Government has applied this policy to other groups, it has not provided targeted support for carers.

Carers also struggle to maintain social relationships and other important aspects of their lives which leaves them excluded from their friends, families and communities.

This report argues that the tax, benefit and support system is failing carers and should be reformed to:

- Help carers stay in work
- Help carers who are unable to work
- Help older carers enjoy a decent retirement

Key findings

Carers are worse off as a result of caring

- Three out of four (72%) carers are worse off as a result of caring, rising to four out of five (83%) among those aged 45-54.
- Nearly two out of three (58%) are worse off because of the extra costs of disability.
- More than half (54%) have given up work to care.
- Half (49%) end up subsidising the costs of the disability of the person they care for because of inadequate disability benefits.
- One in five (21%) have to reduce the hours they worked.
- One in four (28%) find the charges for services too high.
- Those caring long term are more likely to have extra costs related to the disability or illness - two thirds (65%) of those caring for more than 15 years.
- On average carers retire 8 years early, missing out on years of income and pensions contributions.

Struggling to make ends meet (how caring affects carers finances)

- One in three (33%) are, or have been, in debt as a result of caring.
- One in three (30%) struggle to pay utility bills such as electricity, gas or telephone.
- One in three (30%) cannot afford essential repairs to their house.
- One in three (35%) are spending their income or savings to pay for care.
- One in five (22%) have to ask their friends for assistance.
- One in ten (10%) cannot afford their rent or mortgage.

In debt

- Working age carers are more likely to be in debt - over half (53%) of those aged 35-44.
- Nearly two-thirds (61%) of carers on Income Support and half of those on Incapacity Benefit (50%) are in debt.
- Those caring for disabled children under 18 are also more likely to be in debt (48%). These problems persist once the child is an adult.
- The results show that carers struggle financially in the first year of caring - for example 36% of those in the first year of caring have trouble paying the electricity, gas or telephone bills, compared with 30% of all carers.
- Nearly two-thirds (64%) of carers said they spent more than 10% of their income on fuel bills.

Cutting back on essentials

- One in five respondents (19%) is cutting back on food and one in four (25%) is cutting back on heating.
- Those caring for disabled children are slightly more likely to cut back on food (22%) which could have an impact on the whole family.

- Whilst these more severe indications of hardship are affecting three in ten carers, higher proportions are having to make difficult choices about things that most people take for granted :
 - Nearly three-quarters (72%) have cut back on holidays.
 - Seven out of ten (69%) have cut back on leisure activities.
 - Six in ten have cut back on going out with friends (57%) and buying clothes (58%).

Health affected by money worries

- Carers' health is affected by their worsening financial circumstances and cutting back on essential expenditure.
- More than six in ten carers (62%) worry about their financial circumstances a lot or all the time.
- Working age carers tended to worry far more (75% among those aged 35-44) as do those on Income Support (84%).
- More than half of respondents (53%) say that this worry is affecting their health.

Unable to work

- Nearly seven out of ten (69%) of those aged 55-59 have given up work to care. Those providing over 50 hours of care each week are far more likely to give up work to care – 59% compared with 28% for those caring for 20-35 hours per week.
- Two out of three (65%) working-age carers are not in paid work.
- One in four (24%) of those of working age who are not in paid work say they are unable to work because of their own sickness or disability.
- Nearly two-thirds (63%) of working age respondents have no-one in their household in paid work.
- Nearly nine in ten (87%) working age carers looking after their partner have no-one in the household in paid work.

Reduced earnings

- Seven in ten (72%) say that their caring responsibilities affect how much they could earn.
- One in seven (14%) say that the earning ability of others in the household is affected by their being a carer.

On benefits

- Six in ten (61%) receive Carer's Allowance.
- One in seven (15%) receive Incapacity Benefit.
- Three in ten (28%) receive Income Support.
- One in four (24%) receive Tax Credits.
- Four in ten (43%) receive a pension.
- One in four (23%) of those over 60 receive Pension Credit.

Low level of savings

- Nearly half (44%) of respondents have no savings at all and a further third (32%) have savings of under £1,500. This means that they have no buffer if they reach real financial hardship or rely on a very slim margin.

- Working age carers (particularly those aged 35-44) are less likely to have savings compared to older carers.

Facing the future

- More than half of all carers responding to the survey (54%) feel that their financial situation will be worse in the future.
- Nearly half (45%) of working age carers report that they would like to work – of these, two in five (41%) would like to work now and three in five (59%) after their caring role has ended.
- If a financial incentive were introduced for carers to return to or remain in work, three in five working age carers (58%) said this would make them more likely to seek employment.
- Nearly six in ten (58%) carers feel that the level and complexity of care they provide means that it is impossible for them to work.
- Two in five working age carers (38%) say that they cannot work unless they get the right care services and one in three (34%) say that the extra costs of care would outstrip their earnings.
- One in three (34%) say that they cannot work without a supportive employer.

Solutions

In order to make carers feel valued and prevent the excessive levels of hardship reported in this research, Government needs to address the following areas:

1. The low level of Carer's Allowance – the lowest benefit of its kind
2. Financial barriers to work – we currently have a system that does not promote work or help carers move in and out of work
3. Carer's Allowance – a benefit which does not help those caring long-term.
4. Carer's Allowance – a benefit which does not value the contribution carers make to the provision of care
5. Carer's Allowance – a benefit which does not recognise a person's inability to work in the same way as other benefits do
6. Carer's Allowance classed as an overlapping benefit – older carers feel they are not valued because many cannot receive it.
7. A complicated application process for older carers for Carer's Allowance which leaves them confused, angry and with little faith in how the system works, with advisers caught up in complicated advice.
8. The lack of funding of social care – from equipment to practical help – places a financial strain on carers by making caring harder and by giving carers no choice but to give up work when services are not available or accessible.
9. A system that does not help those in the first year of caring come to terms with the extreme challenges of their new financial and personal situation.

Carers UK's tests for a new system of financial support for carers:

- a system that is based, not on what carers have given up, but on their contribution to society
- financial support for carers which is equitable and fair
- financial support which promotes carers' opportunities for work, leisure and learning, building in flexibility to move in and out of work
- financial support which recognises and values care
- simpler procedures for accessing financial support
- less bureaucracy, particularly the need to provide information time and time again
- a system which considers the wider impact of carers' financial hardship on other family members
- solutions which look at short and long-term financial improvement for carers, including pension provision
- solutions for improving carers' incomes which are cross-Governmental and joined up
- a system which takes into account the long-term impact of caring
- a system which takes into account the impact of caring for more than one person

Recommendations

Strategic

1. Government should undertake a wholesale review of the income that carers have, whether it be through employment, tax credits, benefits or pensions in order to provide financial support that is fit for purpose. This should fit the tests that carers have identified (see box above). This needs to be addressed through the National Carers Strategy.
2. The Scottish Executive, Welsh Assembly Government and Northern Ireland Assembly all contribute to this agenda within their devolved powers and share a common vision to improve carers' financial situation.
3. A question on carers must be included in the 2011 Census to mark progress, aid local planning and help service providers target particular support for employment, housing and other services.
4. There should be targeted solutions which recognise carers' diversity, for example the different needs of carers from Black and Minority Ethnic (BME) groups and those caring long-term.

Employment services

5. Carers should have access to one-on-one support from employment services which recognises the complexity of their situation, without the threat of excessively punitive sanctions which can increase stress.

Health and social care services

6. The UK and devolved governments should develop new strategies to look at how services, including social care services, can help carers stay in or take up employment. This would also aid independent living for disabled people.
7. The UK and devolved governments should look at developing a long-term strategy for funding social care in the context of improving carers' financial situation.
8. All health and social care bodies throughout the UK should review their policies and procedures to make sure that carers are better able to combine work and care, for example recognising that the timing of hospital appointments and social care services impact on carers' ability to work.

Benefits and pension system

9. The UK Government should include carers' benefits as part of its work on simplifying benefits.
10. The UK Government should continue to build on and implement policies to help carers gain access to the Basic State Pension, State Second Pension and to build up Personal Accounts.

Information and advice

11. The Welsh Assembly Government should introduce a specific duty on health bodies to inform carers about support services and their rights and the Scottish Executive should ensure that NHS Carer Information Strategies are fully implemented.
12. The UK Government should implement its pledge to fund a national helpline to help guide carers through advice and entitlements, particularly in the first year of caring.

Social inclusion

13. Carers should have wider access to schemes to help them pay fuel bills.
14. The UK and devolved governments should improve carers' access to learning opportunities.
15. The UK Government should continue to fund the Carers Grant in England.

About the respondents

A total of 2950 responses were received. The vast majority of respondents have long-term caring commitments. Nine out of ten has been caring for three or more years. The results show that the longer caring lasts, the worse the risk of poverty and social exclusion.

Nearly four out of five respondents (77%) care for over 50 hours per week. Most respondents (84%) care for only one person, but 12% care for two.

The largest single group of carers is aged 45 to 54 (17%), the peak age for becoming a carer. However, four in ten (40%) are over the age of 65. Two-thirds of respondents (67%) are female and a third male. Three in ten (30%) care for someone aged over 80. Nearly half (46%) are caring for a partner or spouse and a quarter (24%) for a parent. Of the remaining respondents, 13% care for a disabled child and 15% for an adult disabled son or daughter.

Nine in ten (90%) respondents are white British, with the remaining respondents from a wide range of ethnic backgrounds including Asian, Black British, Caribbean, African, Chinese. Given the small numbers in some of the Black and Minority Ethnic (BME) groups, we have not conducted an analysis of responses based on ethnic origin and we know from other research that there is a huge diversity between different BME groups.

2097 respondents live in England, 232 in Scotland, 191 in Wales and 45 in Northern Ireland. Key findings from the four nations can be found in the full report.

¹ Census 2001

² Hirst, M (1999) *Informal Carers - A Moving Target?*, Cash and Care 23, Social Policy Research Unit, University of York

³ Carers UK (2004) *In Poor Health*, using statistics from 2001 Census

⁴ Carers UK (2002) *Without Us? Calculating the value of carers' support*.

1 : Introduction

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. There are more than 6 million carers in the UK, many of them caring around the clock.

Recent legislation has secured rights that would have been unthinkable thirty years ago - the right to an assessment of their needs, the right to request flexible working and rights to pension contributions based on caring.

Yet despite these improvements, too many carers are struggling financially and battling to survive. Carers tell us that the costs of looking after someone mean that they and their families cannot take opportunities that arise to improve their quality of life. The welfare benefits they receive are completely inadequate and do not show that they are valued for what they do. Individually, they often cite barriers that get in the way of working and a lack of support to help them remain in or take up work. They also struggle to maintain social relationships and other important aspects of their lives which leaves them excluded from their friends, families and communities.

Policy thinking on carers' needs to go to the next level. It needs to recognise that six million people's lives are affected by caring in many different ways, and that there are 2.3 million new carers every year.⁵ We need to find solutions that fit their lives.

Some steps have already been taken to support those juggling work and care, such as the introduction of the right to request flexible working in April 2007. The best way for carers to avoid poverty is to keep in work and better support and advice to help them do this will work for the majority of the six million carers. However, the Government has to acknowledge that for a small but significant minority, work will not be an option.

These carers are providing such high levels of complex and specialised care that the NHS and social services simply could not replace it. Policymakers need to recognise that these carers are not unemployed or economically inactive, but in fact are contributing in a positive way to society. They need to be recognised, financially supported and given the practical back up and support they need to continue caring.

Other carers want to work but find that there are inadequate support services or a lack of flexible working opportunities. A long period out of the labour market can lead to deep isolation and leave carers lacking in skills and confidence. This leads to a poverty of expectation which can remain long after someone's caring responsibility ends. Demographic trends mean that we will need an additional 3 million carers over the next 30 years⁷. This means that by 2037 nearly ten million people may experience the discrimination and social exclusion that comes from being a carer, as well as being forced to rely on the state rather than contributing to the economy and society. These effects may last a lifetime.

With a pledge from Government to review the National Carers Strategy and a strong mandate from carers to look at what issues they felt still needed tackling, Carers UK undertook a survey of carers' finances. It has given us a detailed picture about how carers are struggling financially because of their caring responsibilities and the detrimental impact this has had on their lives. We know that carers' top priority is recognition of their role from professionals⁶, which is tied up with how they feel treated by the system of support. But lack of recognition is also reflected in the benefits system which is based on replacement income rather than recognising the contribution carers make to society. Reforming the benefit system would go a long way towards giving carers the recognition they deserve.

The purpose of this report

The purpose of this report is to explore the financial situation of carers in the UK and in particular to identify:

- how carers' financial situations change as a result of caring
- the impact that these changes have on the lives of carers, their families and society
- the changes that carers want Government to make to improve their financial situation
- how things have changed since 2000 when we undertook a similar survey

2 : Carers are worse off as a result of caring

Caring has a widespread and significant impact on carers' finances. Nearly three-quarters (72%) of carers said that their financial circumstances had become worse since they became a carer (see Figure 1 below). Those under 65 were more likely to report that they were worse off than those who had retired. The age group most likely to report that they were worse off since becoming a carer were those aged 45-54 (83%), followed by those aged 55-59 (81%). Beyond the age of 65 the numbers reporting that they are worse off fell steadily until the group aged 80+ where it is 42% (see Figure 2 below).

Figure 1: Compared to before I became a carer, my financial circumstances are...

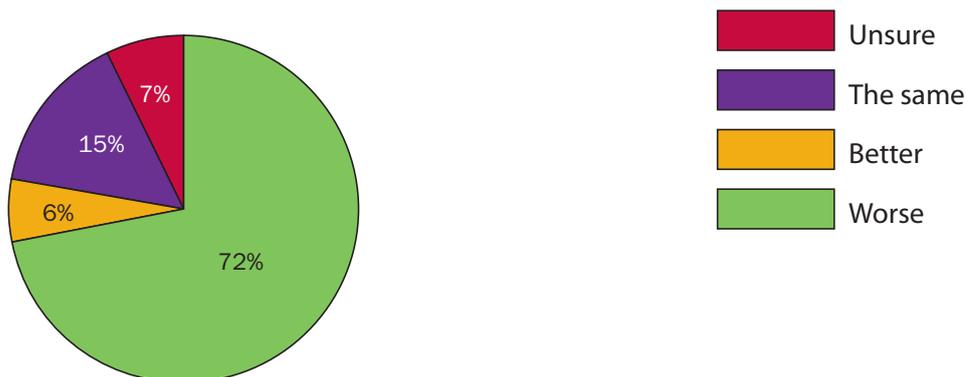
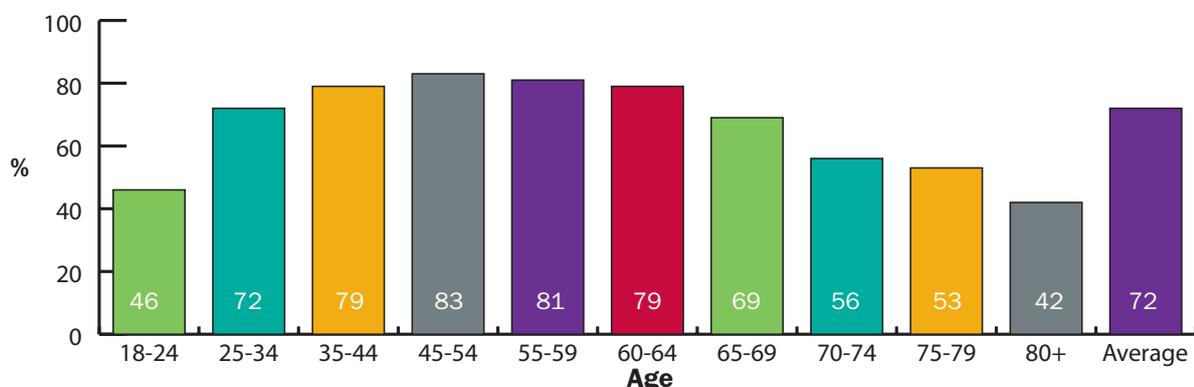


Figure 2: Percentage of carers whose finances are worse since they became a carer, by age



“ I find it hard to do the things we used to because of financial restrictions. I’m trying to live on less than half the salary I was earning 12 years ago. ”

“ In the space of two years we have gone from living to existing. We used to go out at the weekends. Now we feel we are trapped in our home. ”

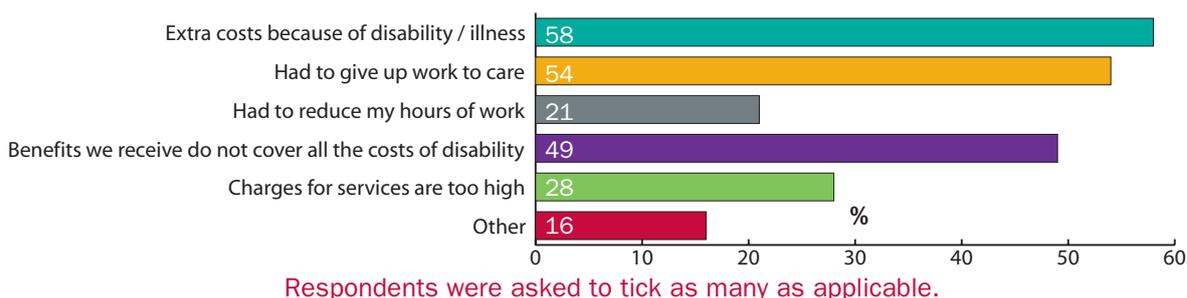
3. Why are carers worse off?

3.1 Many carers give up work, yet the extra costs they face are not covered by benefits

The most common reason given for the worsening of finances is the extra costs associated with disability or illness, which was stated by 58% of respondents (see Figure 3 below). Half of respondents (49%) reported that the benefits they received did not cover all the costs of disability. This highlights the extent to which finances are pooled within households. If disability benefits are inadequate to cover the cost of that disability – for example additional heating, water or transport costs – then carers will meet the extra out of their own, often meagre, resources. It also proves the need for a review of disability benefits to ensure that support is getting to those that need it. Calls to Carers UK’s helpline demonstrate the difficulties in applying for Disability Living Allowance and Attendance Allowance and the poor decision-making associated with them. This can have huge consequences for carers.

“My husband is young, disabled and needs a warm home. The cost of fuel is crippling. It would help if disabled people were allowed the fuel allowance.”

Figure 3: Reasons why carers finances have got worse since becoming a carer



“There are only two children’s hospitals in the whole of the UK that can deal with our son’s condition. Our local one failed and now we have to travel. We do not get any help with train fares or hotel expenses. It is like keeping two homes going.”

A majority of respondents (54%) reported that they had given up work to care. More analysis of respondents working lives is given below, but responses to this question demonstrate that giving up work can have dire consequences on a household’s finances.

Three in ten (28%) respondents thought that charges for services are too high despite the introduction of fair charging policies in 2003.

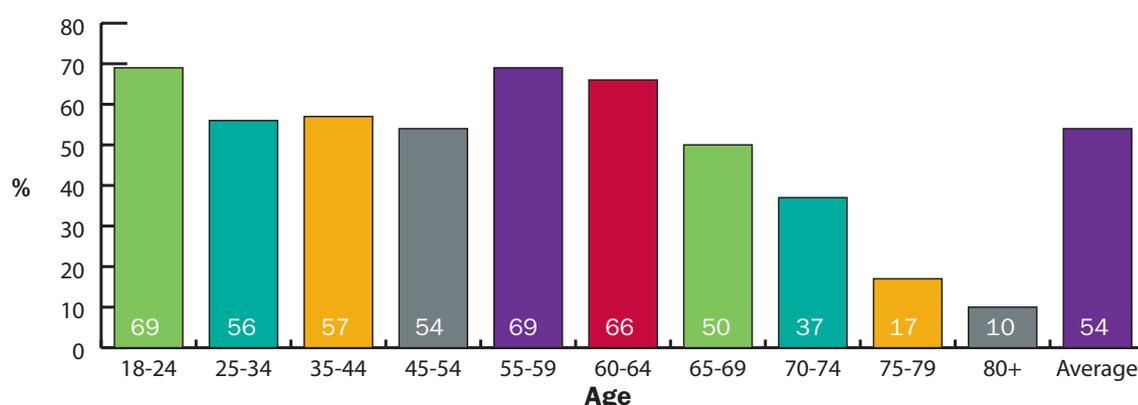
3.2 Impact on different groups of carers

When looking at the reasons for carers’ worsened financial circumstances, we found that there were considerable differences between different groups of carers. The key findings were:

- Carers in their late fifties are most likely to give up work
- Those caring long-term (10 years +) are much worse off
- A huge impact is felt in the first year
- Even those caring for fewer than 20 hours a week have had to give up work

Working age carers, particularly those nearing retirement, were most likely to say that they had given up work to care, or had reduced their hours (see Figure 4 below). Among those aged 55-59, nearly seven out of ten (69%) had given up work to care, meaning that for a large group of carers, they may be missing out on ten years of their working life. This has real implications for a future in which people will be required to work longer to counter demographic change and contribute to pensions.

Figure 4: Percentage of carers who have given up work to care, by age



Older carers were more likely than those of working age to say that the charges for services were too high. One third (33%) of those aged 60-64 thought they were, and 35% of those aged 65-69 and 75-79. Among those aged over 80, 54% thought that charges for services were too high.

As well as differences between those of different age groups, there were also differences based on who the person was caring for. Those caring for a partner were most likely to say that they had extra costs because of the disability or illness (67% compared to an overall average of 58%) whereas those caring for a parent were most likely to say that they had given up work to care (62% compared to 54% on average).

Larger proportions than average of those caring for a partner or a disabled child over the age of 18 felt that benefits did not cover the costs of disability – 57% and 56% respectively, compared with 49% overall.

In general, those caring for longer periods were more likely to face financial difficulties for the reasons suggested. For example, 65% of those caring for more than 15 years said that they have extra costs because of the disability, compared with 49% of those caring for 1-2 years. Likewise, 55% of those caring for more than 15 years said that the benefits they received did not cover all these costs, compared with 41% of those caring for 1-2 years.

High levels of hardship were reported in the first year of caring, which then fell slightly in subsequent years before increasing again. For example, 32% of

those who had been a carer for less than a year felt that charges were too high, compared with 20% of those caring for 1-2 years. This proves that carers need much more support when they first become a carer.

Those providing over 50 hours of care each week were more likely to report that they were financially worse off in all areas. Of this group, 59% had given up work to care and a further 18% had reduced their hours. Many of this group will be claiming Carer's Allowance but many will not, either because they are receiving a state pension or because they fall foul of one of the other rules for claiming it. This could be that they are caring for more than one person for a total of more than 35 hours per week, yet the rules state that it must be 35 hours for one person who is claiming the correct benefits. (see appendix B for details of Carers' Benefits.)

Among those caring for fewer than 35 hours per week, there was a marked trend towards carers not giving up work to care, but instead reducing their hours. For those caring for 1-19 hours per week, 35% had given up work and 33% had reduced their hours. In the group caring for 20-34 hours, 28% had given up work, but 39% had reduced their hours. These figures show that many carers are being forced to give up work, even though they are not eligible for Carer's Allowance. Many more are reducing their hours, suffering a lower income, working below potential⁸ and in all likelihood facing a reduced pension in retirement, yet are not receiving financial recognition of this contribution from government.

3.3 Work is not possible for many carers

Key findings:

- Carers are half as likely to be in paid work as the national average
- Those looking after a parent or partner are least likely to be in paid work
- Parents of disabled children are more likely to work, but mainly part-time
- Carers retired an average of 8 years early
- A quarter of working age carers cannot work because of their own illness or disability

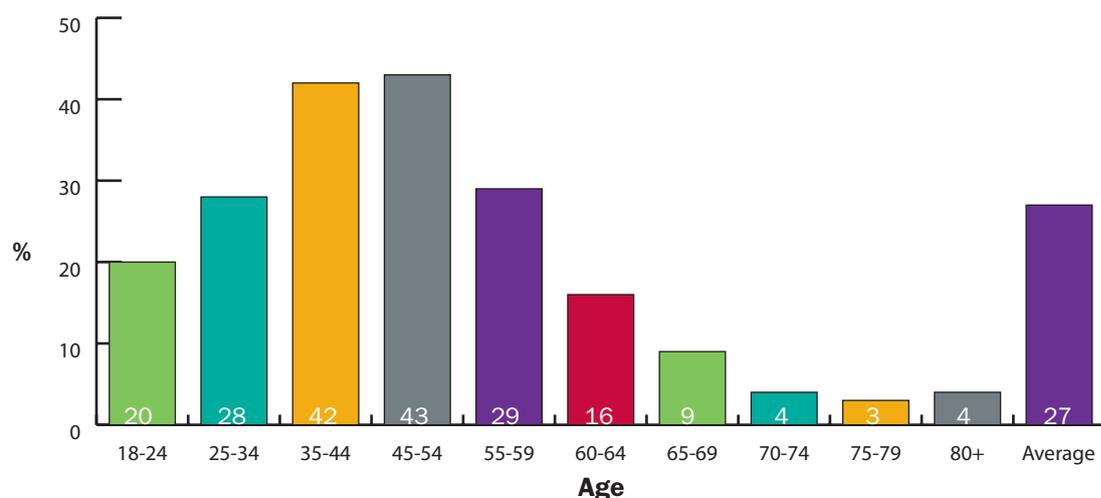
A large proportion of respondents said that they were worse off since they became a carer because they had to give up work. In fact, only just over a third (35%) of working age respondents (men under the age of 65 and women under the age of 60) were in paid work. Of these, a third (34%) were in full-time work and two-thirds (66%) in part-time work.

When compared to the overall population these figures show the huge difficulties that carers face in balancing work and care. The national employment rate for people of working age is 74%⁹, more than twice that of the respondents to our survey.

“Government should accept that carers do not choose to give up paid employment but have to because there is no alternative.”

The highest rate of employment was among the 45-54 age group (43%), followed by the 35-44 group (42%) (see Figure 5 on page 14). Similar levels of full and part-time working were found across all age groups, but the 35-44 and 45-54 age groups were most likely to work full time. In both these age groups, 35% worked full-time and 65% part-time.

Figure 5: Percentage of carers in paid work, by age



Carers looking after a partner or a parent had lower levels of employment than those looking after a disabled child - 33% and 32% respectively, compared with 44% of those caring for a disabled child under 18 and 37% of those with a disabled child over 18.

The employment rates of those looking after a disabled child under the age of 18 (42% and 43% respectively) generally correlated with those found in the 35-44 and 45-54 age groups which reflects the age group that most of these carers fall in to. However, only 16% of those working were doing so full-time, compared to 50% of those looking after a partner and 33% of working carers overall. This backs up findings from previous Carers UK research which showed that parent carers were restricting their careers because of their caring responsibilities.¹⁰

““ *My husband and I have to job share since our son left school. Our income has been halved and neither of us meet the criteria for Tax Credits.* ””

Of those who said they were not in paid work, just over half (51%) said they were retired. Men were more likely to be retired than women. Whilst six in ten men who were not in paid work had retired, only 47% of female respondents had.

More than half of those who retired early (56%) did so because of their caring responsibility. This is a staggering 878 respondents, nearly a third of the total respondents.

The average number of years early which carers retired was 8 years, meaning they have missed out on many years of both income and pension contributions.

Nearly a quarter (24%) of those of working age who were not in paid work reported that they were unable to work because of their own sickness or disability.

““ *I am now ill myself after having no help in caring. I am unlikely to find work now – I am 53 after 19 years of caring.* ””

3.4 Carers' earnings are reduced

Nearly three-quarters of respondents (72%) said that their caring responsibilities affected how much they were able to earn. Figures were much higher among working age carers, with 87% of those aged 35-44 reporting their ability to earn was impacted by their caring responsibilities. Those caring for disabled children under the age of 18 were also very likely to report that their earnings had been affected – 86% reported that they had, followed by 77% of those caring for a parent and 74% of those caring for a disabled child aged over 18.

“Don't stop me from being able to claim Carer's Allowance just because I earn over £87 per week. Provide me with alternative care so that I am able to return to work full time. I have an English Master's degree which is being wasted.”

“I earn too much to get Carer's Allowance but am too poor to survive.”

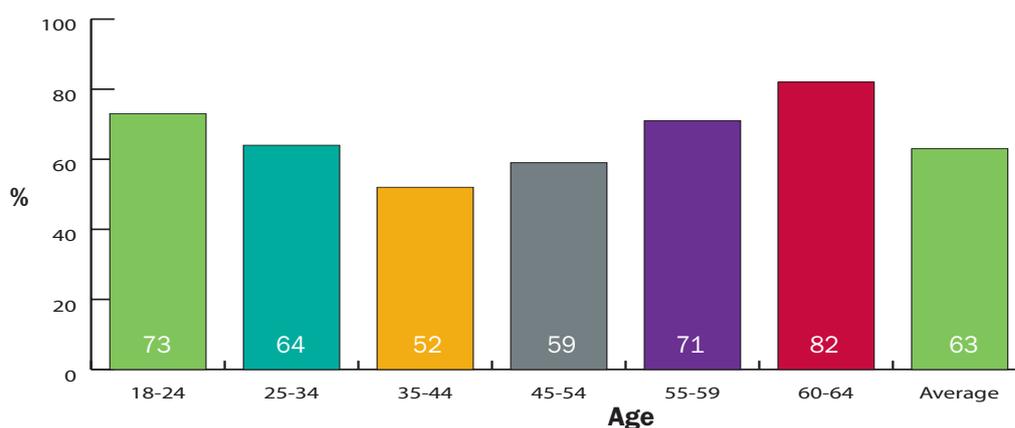
In addition, 14% of respondents said that the earning ability of others in their household had been affected by their being a carer. This may be because other people in the household are caring too, or because they have to undertake additional tasks to help the carer juggle his or her responsibilities.

Again, working age carers were more likely to report that their caring impacted on someone else's ability to earn. Among those aged 25-34 and 35-44 more than one in five (22%) felt that the earning ability of others in their household was affected by their being a carer. It was even higher for those caring for a disabled son or daughter aged under 18 (28%) and for those caring for a disabled son or daughter aged over 18 (21%). This proves that we cannot look at carers' finances and support in isolation but must address family circumstances.

3.5 A large number of households have no-one in paid work

Overall, nearly two-thirds (63%) of working age respondents said that no-one in their household had paid work. The group which was most likely to have someone in paid work was the 35-44 group: amongst these carers 48% did have someone working in their household. This fell to 41% for those aged 45-54, 29% for those aged 55-59 and just 18% for those aged 60-64 (see Figure 6 below).

Figure 6: Percentage of working age carers living in a household in which no-one has paid work



Male carers were more likely to be living in a household in which no-one had paid work. Nearly eight out of ten (78%) working age male carers reported this, compared to just 55% of working age women.

Not surprisingly, where someone was caring for their partner they were least likely to live in a household with someone in paid work – 87% of working age respondents were in this situation. Among those caring for a parent, fewer than four in ten (38%) had someone in their household in work, and of these just a third (33%) worked full time.

In families where parents were caring for a disabled child under the age of 18, in most cases (62%) someone in the family had paid work (and in 88% of cases this was full-time). This suggests that while some families have one parent in paid work and one person caring full-time, for a significant proportion of two-parent families, and in all one-parent families, the only income is from benefits. For those caring for a disabled son or daughter aged over 18, 38% of respondents had someone in their household in paid work (of which 84% were in full-time work).

3.6 Carers receive a wide range of benefits

We know that the majority of respondents are not in paid work so most of them rely on benefits of some kind, whether a State Pension, carers' benefits or means-tested benefits. See Appendix B for a brief summary of the benefits that carers and disabled people can claim.

Working age

Nearly two-thirds of working age respondents (61%) received Carer's Allowance and a further 15% received Incapacity Benefit.

“*The cost of my wife's respite care is over £1000 per week and I am expected to provide the same service for £48 Carer's Allowance. What a joke!*”

Nearly three in ten (28%) of those aged under 60 received Income Support¹¹ and 24% of working age participants received Tax Credits.

“*If Carer's Allowance was treated the same as Disability Living Allowance then I would be better off. The DLA is given to disabled people to have some degree of independence in their lives. Are carers not entitled to the same degree of independence?*”

Pension age

Just under half (43%) of respondents received a pension. Of these, more than three-quarters (77%) received a State Pension, a quarter (25%) a private pension and less than half (45%) received an occupational pension.

Of those aged over 60, 23% received Pension Credit. Considering that so many respondents reported that they struggle to make ends meet, this is a surprisingly low figure.

Carers' benefits are outdated

Carers' benefits were designed in the 1970s. When Carer's Allowance was introduced it was called Invalid Care Allowance and the world was a very different place.

Then:

- Carers had no legal status and no definition of a carer existed in legislation.
- Carers were represented by the 'National Council for Single Women and their Elderly Dependents', which later merged with the Association of Carers to form Carers UK.
- No-one knew how many carers there were: it was considered a private matter.
- Nine out of ten men and six out of ten women of working age were in employment.¹²
- Disabled and elderly people were often placed in residential, hospital or nursing homes, sometimes against their will.

Now:

- Accurate data from the 2001 Census tells us there are 6 million carers in the UK.
 - Carers' opportunities to work or undertake training are recognised in law.
- Recent changes to legislation have accepted that the benefit system is outdated. The replacement of Incapacity Benefit with the Employment and Support Allowance recognises that we should be supporting people's capacity to work, rather than embedding their incapacity.
- Whilst this research showed a large number of carers were receiving Carer's Allowance, a large number were also claiming Income Support or Incapacity Benefit which are not designed with the specific requirements of carers in mind.

3.7 Carers have a very low level of savings

Nearly half (44%) of carers said that they had no savings at all, and a further 32% said that they had savings of under £1,500 (see Figure 8 on page 18). This means that a significant number of respondents had either no buffer when they reached financial hardship or a very slim margin.

Those of working age were less likely to have savings, and those that did had a lower level of savings. The age group that was most likely to have no savings was those aged 35-44 (see FIGURE 7 on page 18). Among these respondents, just 29% have any savings. Among those that had some savings, nearly half (44%) had less than £1500.

“ I have spent all my savings and cashed in all pensions just to keep afloat. ”

Figure 7: Percentage of carers who have no savings, by age

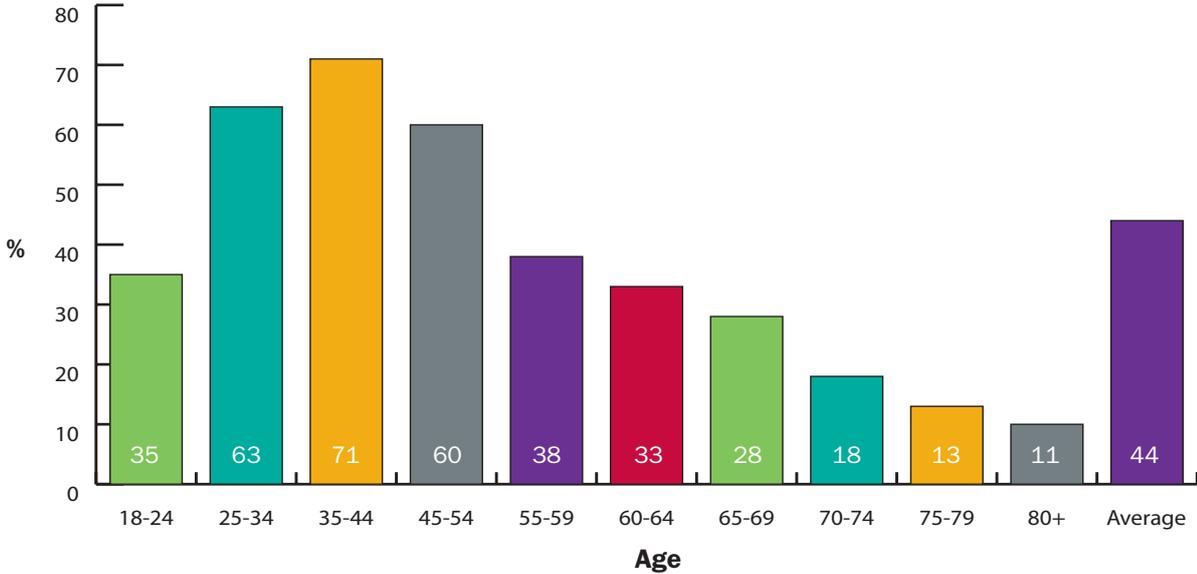
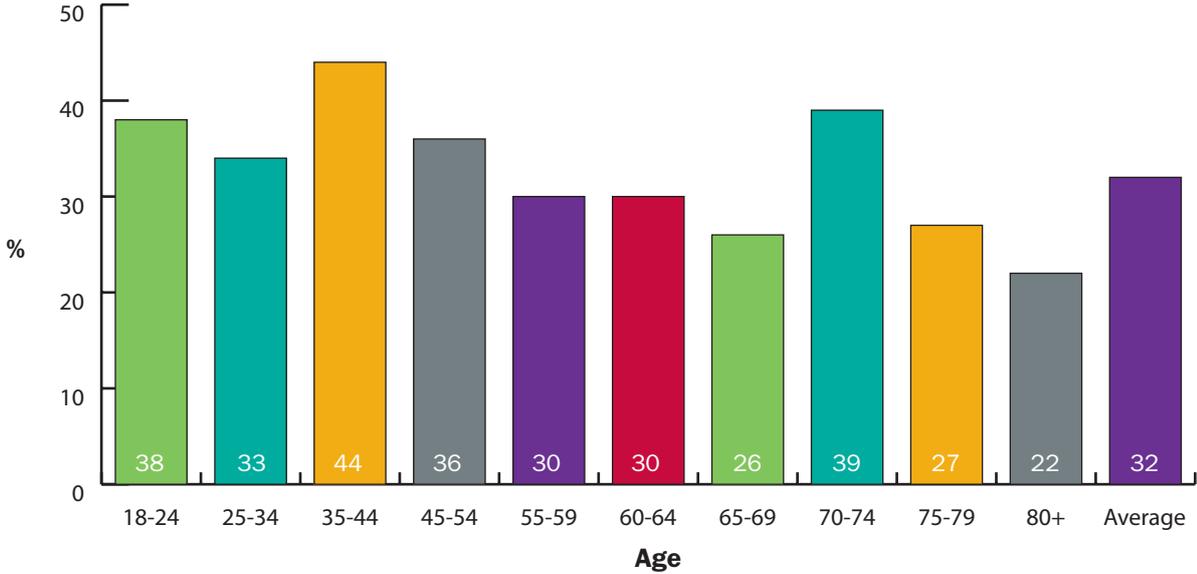


Figure 8: Percentage of carers who have savings of less than £1500, by age



4: Struggling to make ends meet

4.1 Struggling to make ends meet

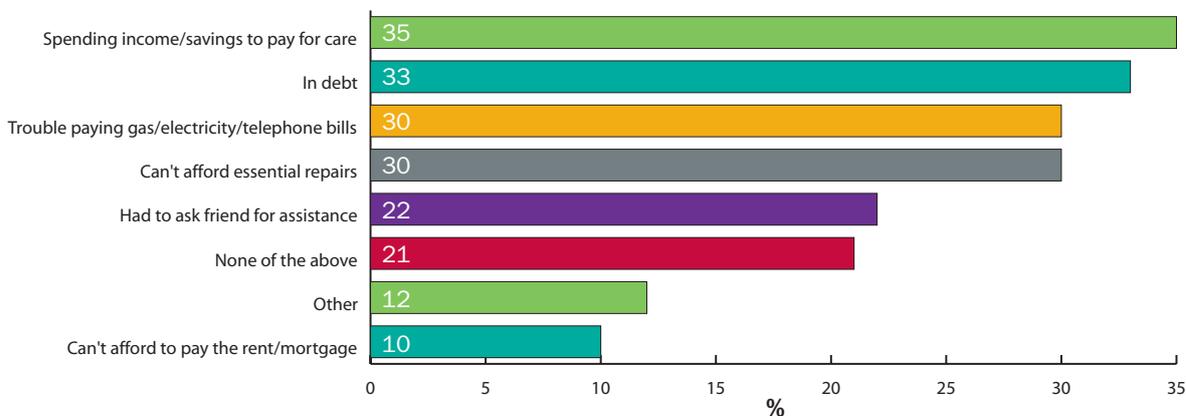
When asked about the impact of the worsening of their financial situation, carers reported that they were struggling to pay for essential services such as gas, electricity or telephone (30%), they could not afford essential repairs (30%) and were using their own income or savings to pay for care (35%) (see FIGURE 9 below).

“We cannot afford some of the basic things that normal people have and take for granted. We feel that we are treated as second class citizens.”

A third (33%) also reported that they were in debt or had been in the past. This is extremely worrying given that we know many respondents were on a very low income and therefore have little chance of repaying the debt. A further one in five (22%) of respondents reported asking friends for assistance, meaning that more than half of respondents have not been able to survive on their own income.

“We depend on family and friends for everything – its so embarrassing to admit that I can't afford to provide my wife with the basics.”

Figure 9: The financial impact of being a carer



Respondents were asked to tick as many as applicable.

4.2 Impact on different groups of carers

Key findings:

- Working age carers are worst off
- Parents of disabled children struggle more than most - this persists as the child becomes an adult
- Carers find it hard to manage in the first year of caring

The data shows that there is a significant difference between carers of working age and older carers. Carers of working age reported more difficulties with financial problems and hardship than older carers.

The group aged 35-44 reported the highest levels of hardship in many areas. For example this group was most likely to have been, or be in debt (53%), most likely to have trouble paying gas, electricity or telephone bills (40%) and most likely to have asked friends or relations for assistance (35%). The group aged 45-54 was most likely to be unable to afford essential repairs to their house (38%) and those aged 25-34 were least likely to be able to afford the rent or mortgage (16%).

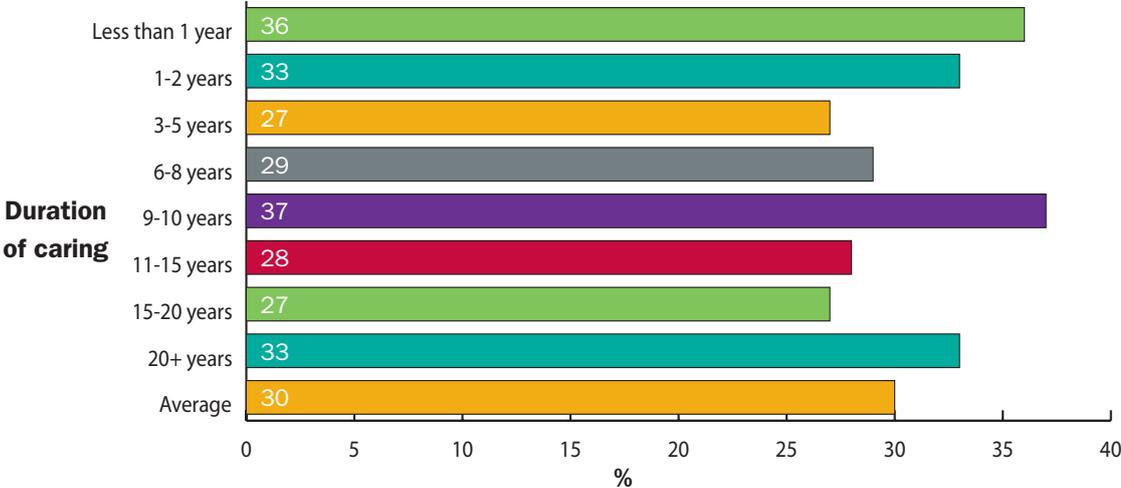
“It is constant scrimping and living hand to mouth. If something goes wrong in my house I have to ask favours of friends – I am sick of feeling like a charity case.”

Those caring for disabled sons and daughters under the age of 18 seemed to be struggling more than others. They were most likely to be in debt (48% compared to 33% of respondents overall) and 13% could not afford to pay the rent or mortgage. Problems seem to persist when these children become adults, however, as those caring for a disabled son or daughter over the age of 18 also showed higher than average levels of debt and trouble paying bills. This group was least likely to be able to afford repairs (35% could not). This highlights the impacts of additional costs and low income faced by those caring long-term.

“With every year it gets worse, partly because benefits are not keeping up with the cost of inflation which is much higher for essentials like food, gas, electricity, water etc.”

The survey also found that carers tended to struggle in their first year of caring, when they may have lost a household income or had to give up work. Their finances then stabilised slightly for the next few years before problems started to creep up again over the next ten years. This pattern can be observed for several categories and demonstrates the importance of early support for carers to avoid them getting into serious debt or other financial problems. However it also highlights that those caring for long periods of time (ten years seems to be a threshold) can find their finances deteriorating sharply. Figure 10 demonstrates this for those carers who reported that they have trouble paying gas, electricity or telephone bills.

Figure 10: Percentage of carers who have trouble paying gas, electricity or telephone bills, by duration of caring

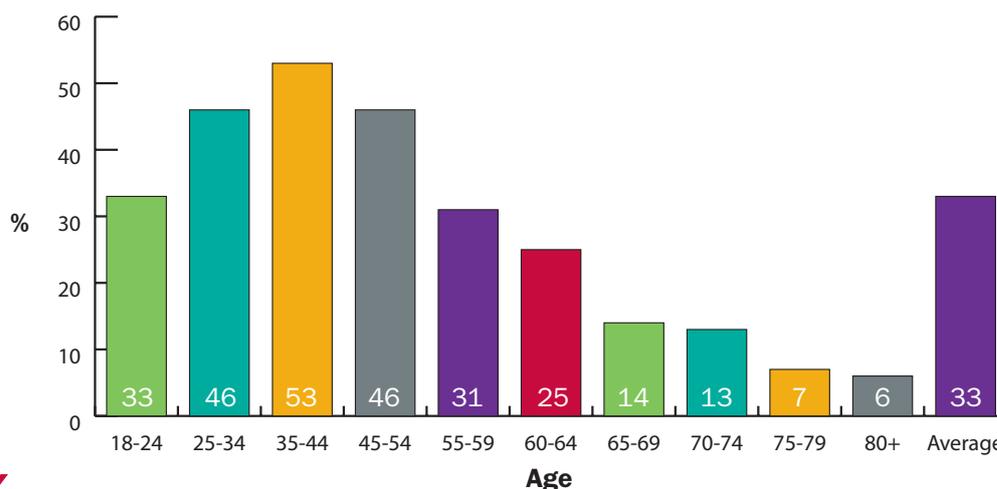


4.3 In debt

Working age carers were most likely to be in debt, with the group aged 35-44 most likely (53%) (see FIGURE 11 on page 20.) In addition, more than a third (35%) of this age group had asked friends for assistance.

“*I am gradually over time running up more and more debt and I don't see a way out of this situation.*”

Figure 11: Percentage of carers who are, or have been, in debt, by age



“*The effect on our lives is total devastation. We no longer go on holiday, we do not go out, my kids have not had the things they deserve. They have had to go without so much. We are now bankrupt, just because I tried to do the best for my family.*”

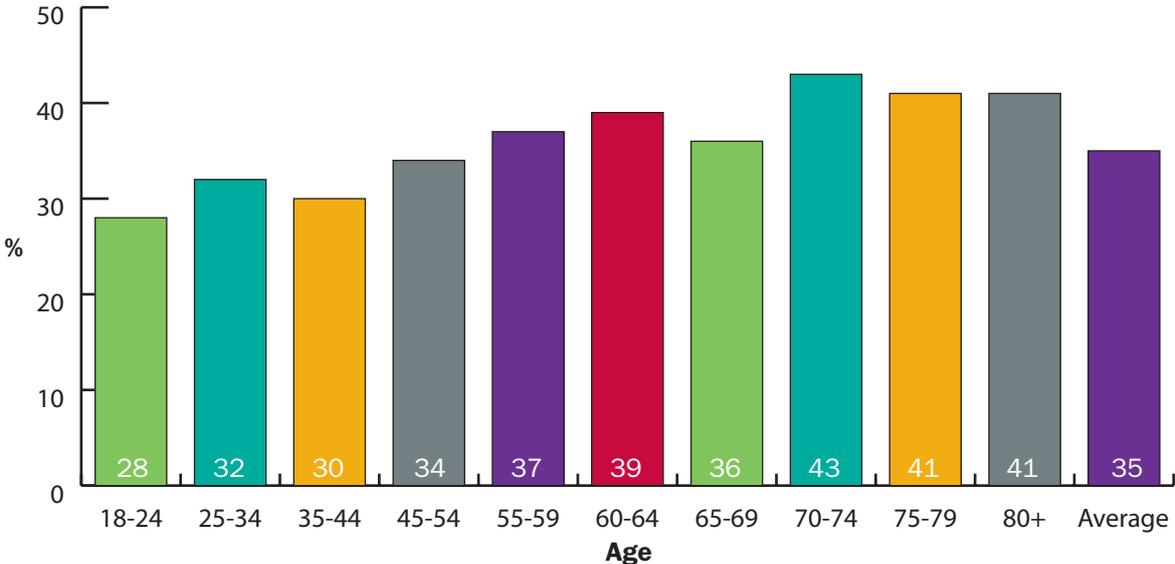
A worrying 61% of carers on Income Support and 50% of those on Incapacity Benefit said they were in debt. These are the people who are least likely to be able to pay off any debt.

4.4 Spending savings on care

Carers approaching or over retirement age were most likely to be spending their income or savings on paying for care, at a time when many would wish to be building up (or indeed spending) their pension. More than a third (37%) of the 55-59 age group reported they were, along with 39% of the 60-64 group. These percentages are even higher for those over the age of 75 (see Figure 12 on page 22).

Those caring for a partner were most likely to be spending their income or savings paying for care (38%). Whilst it might be expected that these carers will pool their income with the person that they care for, the same cannot be said for those caring for a parent. Yet among this group, 36% were spending their income or savings paying for care.

Figure 12: Percentage of carers who are spending their income or savings paying for care



4.5 Unable to pay rent

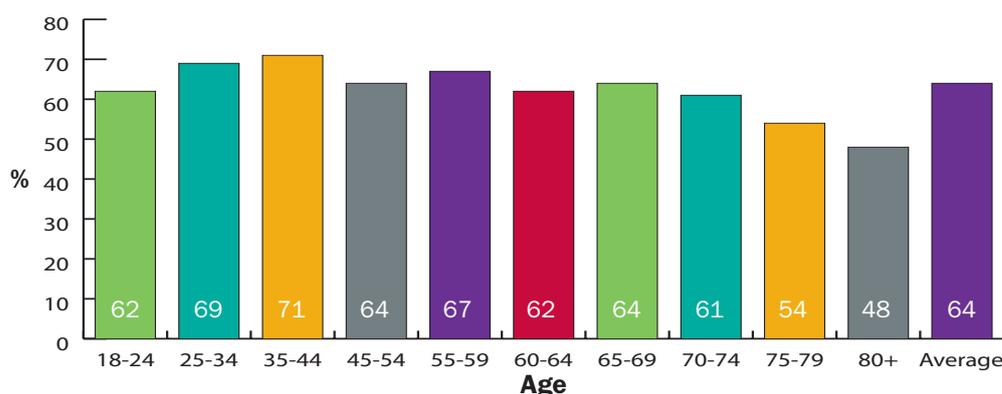
A worrying one in ten respondents could not afford to pay their rent or mortgage, with the 25-34 age group most likely to be in this situation. One in six (16%) of this group could not afford their rent or mortgage. This sort of financial worry can have a serious impact on carers’ mental and physical health and often means that entire families are at risk of homelessness.

4.6 Struggling to pay fuel bills

Nearly two in every three respondents spent more than 10% of their household income on fuel bills.

The group most likely to be in this position were those aged 35-44 (71%), followed by 25-34 (69%) and 55-59 (67%) (see Figure 13 on page 23). Whereas many questions seem to show an improvement after the age of 60 or 65, this question only showed a noticeable difference over the age of 70, where it dropped to 54% for those aged 70-75. This is surprising given that carers aged over 60 will receive a winter fuel payment. These figures suggest that fuel poverty is a serious problem both amongst working age people but also amongst younger pensioners. Whilst many utility companies offer discounted rates for carers, these are not well publicised and are sometimes only available for a limited number of people.

Figure 13: Percentage of carers who spend more than 10% of their household income on fuel bills



There were not huge differences based on who the respondent was caring for, but the likelihood of spending more than 10% of income on fuel bills increases with the number of hours care per week. For those caring for 1-19 hours a week it was 40%, for those caring for 20-34 hours it was 53%, for those caring for 35-50 it was 67% and for those caring for 50+ hours it was 66%.

“Due to my daughter’s disability she has to be kept very warm all the time. It would help if we got some help towards fuel to alleviate some of the worry of the huge debts.”

There was also a significant problem in the first year of caring. Amongst these respondents, 71% reported that they spent more than 10% of their income on fuel bills. This then fell to 64% in the second year, and again to 60% between three and five years. However, for those caring for 9-10 years it had increased again to 69%.

4.7 Cutting back on essentials

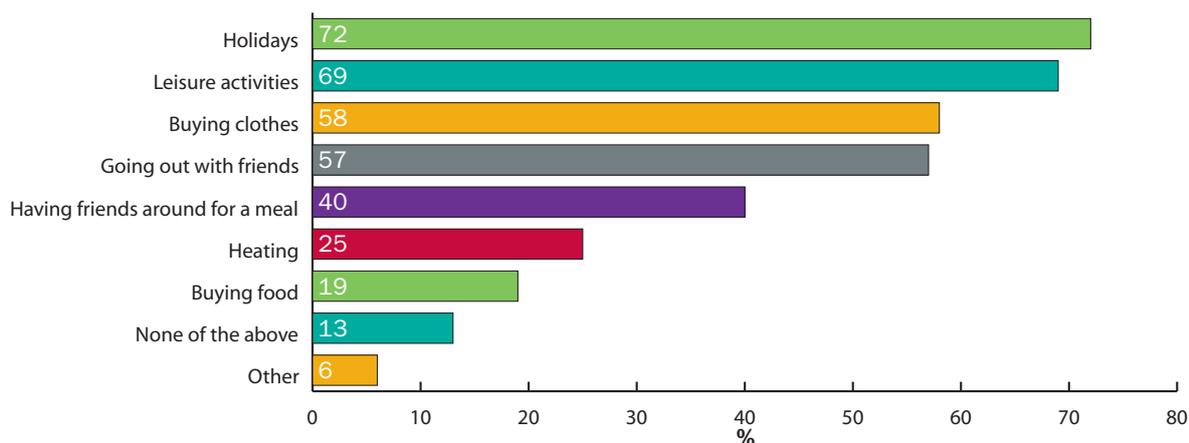
Carers were asked whether, as a result of their financial circumstances, they had given up or cut back on a range of activities. Worryingly, 19% have cut back on food and 25% on heating. Altogether, three in ten (30%) respondents told us they have cut back on either food or heating, or both. This might have a knock on impact on their health which could have lasting effects.

“In winter I have to choose between heating or food. I need a car to carry out my caring duties as the public transport is virtually non-existent.”

Larger proportions have cut back on ‘non-essential’ spending, which nonetheless marks a reduction in their ability to enjoy a quality of life which most people take for granted. Nearly three-quarters (72%) had given up or cut back on holidays, with nearly seven in ten (69%) cutting back on leisure activities and nearly six in ten cutting back on going out with friends (57%) and buying clothes (58%) and 25% on heating (see Figure 14 on page 24).

“Luxuries – what luxuries! I haven’t had a holiday for 20 years!”

Figure 14: Areas in which carers are cutting back



Carers of all ages are cutting back as a result of their financial circumstances, although those in their thirties and forties were more likely to report that they had given up things or cut back than those of other ages. More than four out of five (81%) had cut back on holidays – compared to 72% overall – and nearly three in ten (29%) had cut back on food – compared to 19% overall.

“*I have to make do with what I have as I can no longer save up and replace anything that wears out. I shop for clothes in second hand shops and buy value brands in the supermarket.*”

Cutting back on heating did not vary as much as some of the other categories – the 18-25 age group actually showed the highest result with 38%, although this was from a fairly small sample. However it is worrying that 24% of those in their sixties and 21% of those in their seventies had cut back on heating.

Again, those hardest hit are those caring for a disabled child who are more likely to report cutting down on things like holidays (78%), buying clothes (69%), leisure activities (75%), but also worryingly buying food (22%). Again, this persists into adulthood with 29% of those caring for an disabled child over the age of 18 cutting back on heating.

4.8 Health affected by money worries

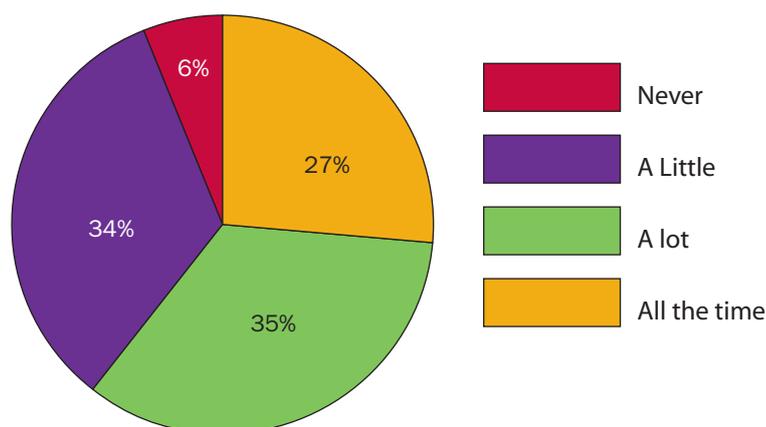
As suggested above, carers' health is considerably affected by worsening financial circumstances and cutting back on essential expenditure.

More than six in ten carers (62%) said that they worried about their financial circumstances a lot or all the time. A further one in three (34%) (see Figure 15 on page 25) said they worried a little and just 6% reported that they never worried about their finances.

“*It has at times driven me to deep depression and thoughts of suicide.*”

“*Since my husband's illness, juggling caring responsibilities with trying to earn money has led to a total breakdown in our marriage. We separated in May.*”

Figure 15: I worry about my financial circumstances...



Whilst there was a small difference in terms of gender – with 53% of men worrying a lot or all the time compared with 63% of women – the difference between different age groups was very marked.

“ I am so stressed I do not sleep at all some nights.”

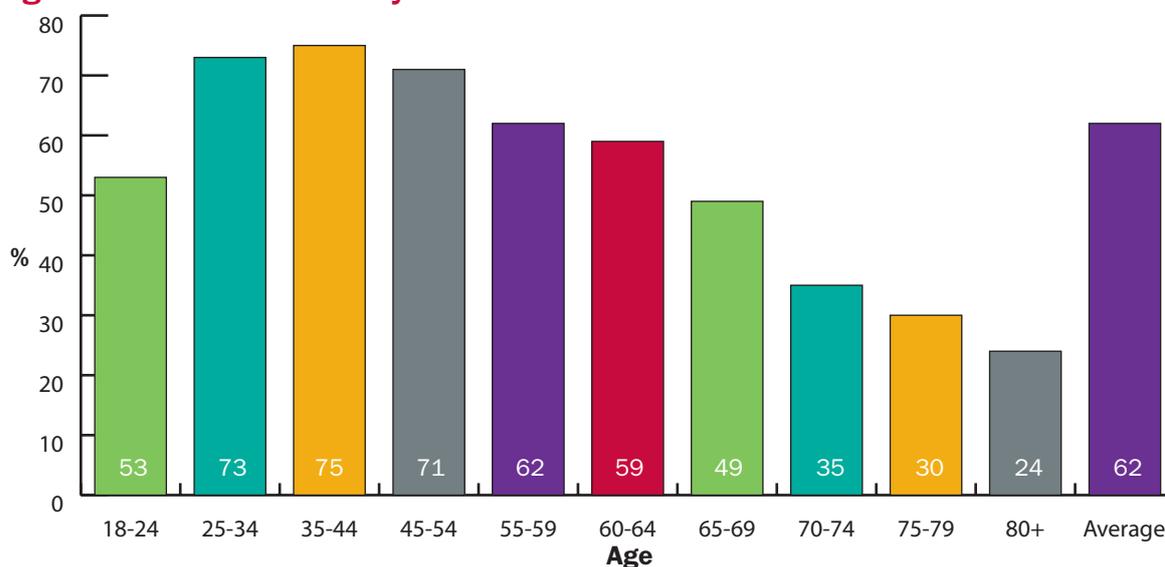
4.9 Impact on different groups of carers

The age group which worried most about its finances was the 35-44 group, in which three-quarters (75%) (see Figure 16 on page 25) worried a lot or all the time about their finances. Just two percent never worried and 23% worried a little.

This is compared to just one quarter (24%) of the over 80s who worry a lot or all the time about their finances. Among this age group, 58% worry a little and 18% never worry.

The reason for this difference may well be because of the additional responsibilities of those in their thirties and forties who may have children and mortgages. It also highlights the extent to which Government’s focus has been on reducing poverty among pensioners and children, rather than creating policies to support those of working age.

Figure 16: Carers who worry about their finances a lot or all the time

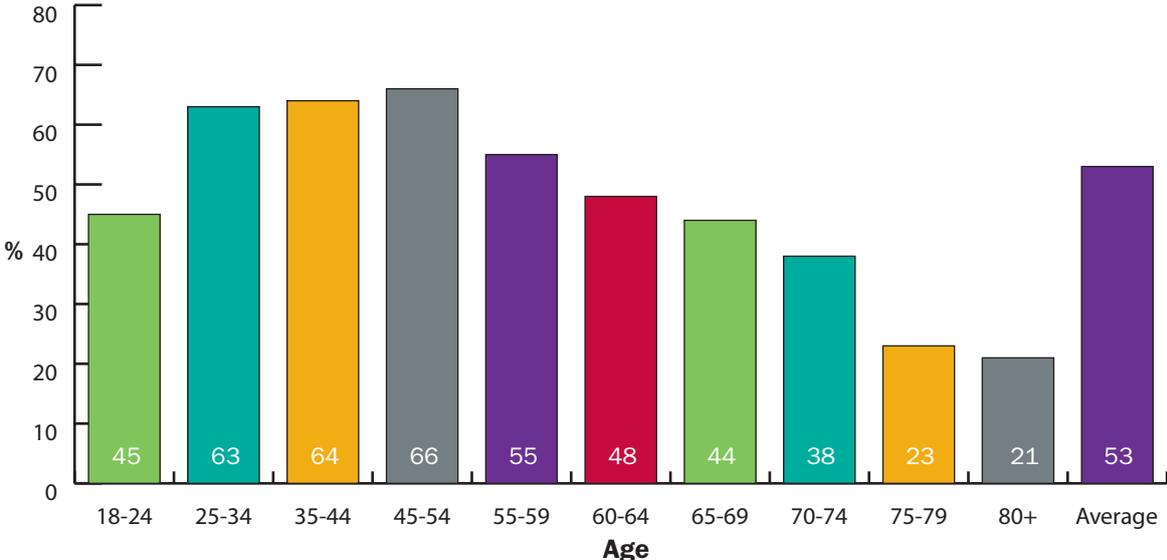


Worry about finances was particularly severe amongst those carers on Income Support. Of these, 84% worried about their finances a lot or all of the time and 80% thought their health had been affected.

In terms of caring relationships, those caring for disabled children under the age of 18 were most likely to worry about their finances. Seven in ten (70%) of this group worried all or a lot of the time.

More than half (53%) of all respondents said that their financial circumstances were affecting their health (see Figure 17 below). Therefore worry about finances alone risks carers' ability to continue caring, not to mention additional costs for the health service. A belief that financial circumstances were affecting their health also varied considerably with age. The 45-54 age group was most likely to believe their health was suffering because of worry over finances: 66% of this group answered yes to this question. The 35-44 age group was close behind with 64% believing their health was affected. This compares with 21% of over 80s and 23% of those aged 75-79.

Figure 17: Percentage of carers whose financial circumstances are affecting their health



Very high figures were also found among those caring for a disabled child over the age of 18: 60% of this group reported that their financial circumstances were damaging their health. The next highest figures were found among those caring for a disabled child under 18 or a parent (both 54%).

5: Results from around the UK

England – based on 2097 responses

- 74% of respondents have found that their financial situation has worsened since becoming a carer.
- 31% of carers are having trouble paying gas/electricity or telephone bills; 32% are, or have been, in debt.
- 69% of carers have had to cut down on leisure activities because of their financial circumstances; 19% have had to cut down on buying food.
- 59% of respondents worry about their finances either a lot or all the time; 52% report that this worry is affecting their health.
- Looking into the future, 55% of carers expect their financial situation to become worse.
- 43% of carers in England have no savings at all.

Scotland – based on 232 responses

- 71% of respondents have found that their financial situation has worsened since becoming a carer.
- 32% of carers are having trouble paying gas/electricity or telephone bills; 36% are, or have been, in debt.
- 66% of carers have had to cut down on leisure activities because of their financial circumstances; 22% have had to cut down on buying food.
- 62% of respondents worry about their finances either a lot or all the time; 54% report that this worry is affecting their health.
- Looking into the future, 53% of carers expect their financial situation to become worse.
- 50% of carers in Scotland have no savings at all.

Wales – based on 191 responses

- 74% of respondents have found that their financial situation has worsened since becoming a carer.
- 27% of carers are having trouble paying gas/electricity or telephone bills; 28% are, or have been, in debt.
- 72% of carers have had to cut down on leisure activities because of their financial circumstances; 16% have had to cut down on buying food.
- 61% of respondents worry about their finances either a lot or all the time; 55% report that this worry is affecting their health.
- Looking into the future, 58% of carers expect their financial situation to become worse.
- 41% of carers in Wales have no savings at all.

Northern Ireland – based on 45 responses

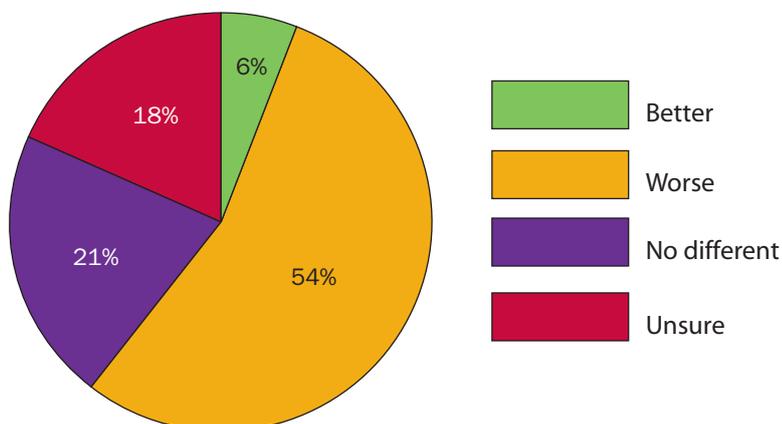
- 93% of respondents have found that their financial situation has worsened since becoming a carer.
- 48% of carers are having trouble paying gas/electricity or telephone bills; 48% are, or have been, in debt.
- 70% of carers have had to cut down on leisure activities because of their financial circumstances; 27% have had to cut down on buying food.
- 77% of respondents worry about their finances either a lot or all the time; 72% report that this worry is affecting their health.
- Looking into the future, 44% of carers expect their financial situation to become worse.
- 64% of carers in N. Ireland have no savings at all.

6: Facing the future

6.1 Most carers expect things to get worse

More than half of all carers responding to the survey felt that their future financial situation would be worse (54%). Only 6% felt it would be better, 21% felt it would be no different and 18% were unsure (see Figure 18 below).

Figure 18: Looking into the future, I think my financial situation will be..

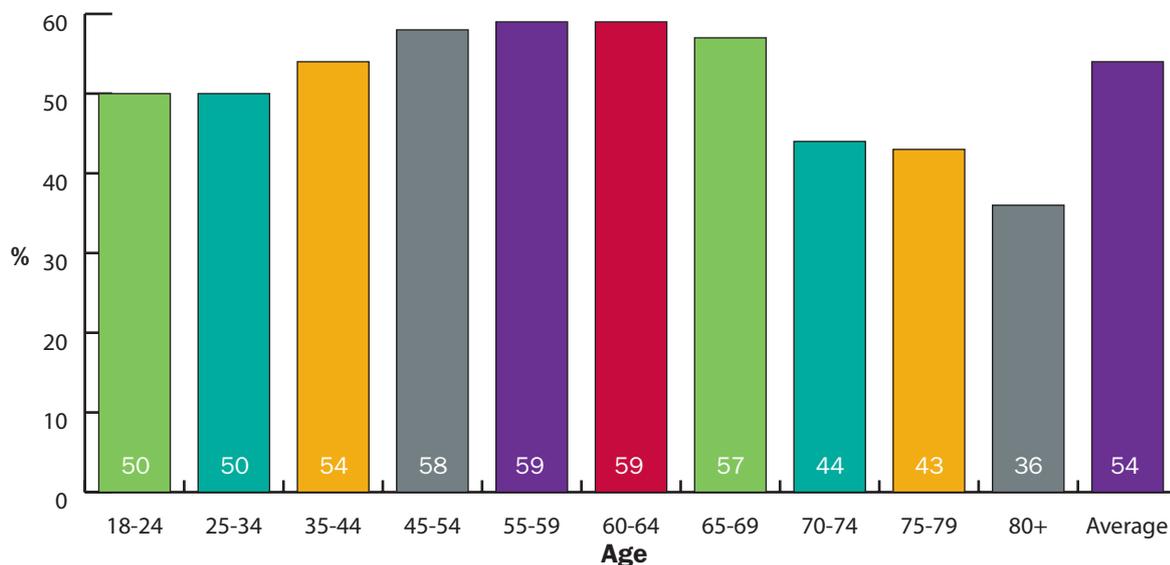


“At 36 I have very little chance of getting on my feet if anything happened to my mum. I would have no home, no immediate liveable income, no ability or right to be re-housed or get extra help to find employment or even take up further training.”

Those approaching retirement were most pessimistic about the future with 59% of those aged 55-65 believing that their financial situation would get worse (see Figure 19 below). This may reflect concern about their pension entitlement if they have had long periods out of the labour market.

“I am unlikely to work again. My wife is 60 and is disabled. I am 63 and it looks like I will be caring for her indefinitely.”

Figure 19: Percentage of carers who expect their financial situation to get worse in the future



“It’s too late ... my health and age would make it impossible for me to work”

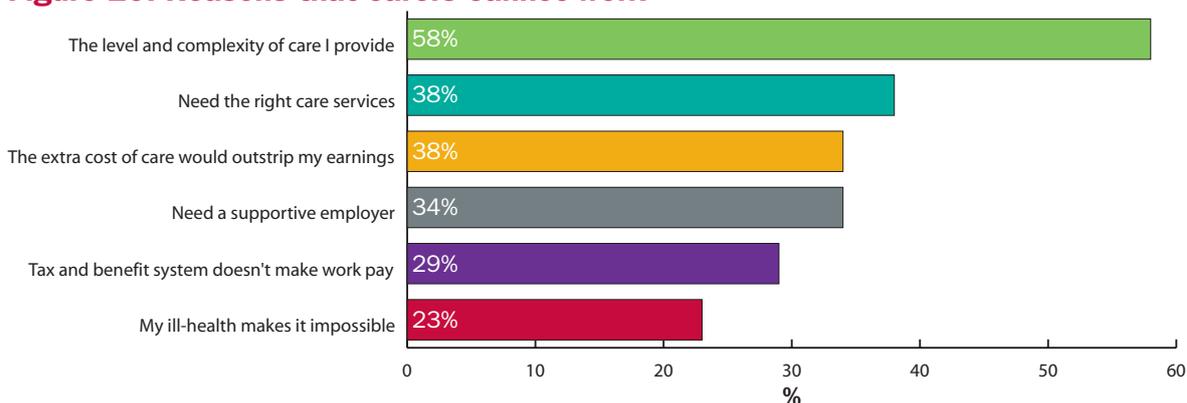
6.2 Carers want to work, but there are many barriers

Nearly half (45%) of working age carers reported that they would like to work – of these 41% would like to work now and 59% after their caring role had ended.

Nearly six in ten (58%) said the introduction of a financial incentive for carers to return to or remain in work would make them more likely to seek employment, with 42% saying it would not. This proves that for many carers the main barrier to returning to work is financial.

This is especially the case for those caring for a disabled son or daughter under the age of 18. Among this group, 70% said that a financial incentive would make them more likely to return to work, compared with 45% of those caring for a partner, 48% of those caring for a disabled child over the age of 18 and 56% of those caring for a parent.

Figure 20: Reasons that carers cannot work



These figures show that whilst many carers do want to work, there are a number of barriers that prevent this from becoming a reality. As well as a lack of alternative care services, the system of financial support does not make it easy for carers to combine work and care. For example the earnings limit for Carer’s Allowance (currently £87) means that even at a fairly low hourly rate, a carer cannot work many hours. For highly skilled carers or those who worked in a high paid profession, it may simply be impossible to work even very short hours without losing Carer’s Allowance. Although carers feel that it is paid at too low a level, for many it is a lifeline and a guaranteed source of income. The risk of losing it is too high to take the chance of going a few pounds over the earnings threshold.

“I may have to give up work in summer as the person I look after leaves school and social services will not cover the time I need to keep working.”

6.3 For some carers, it is impossible to work

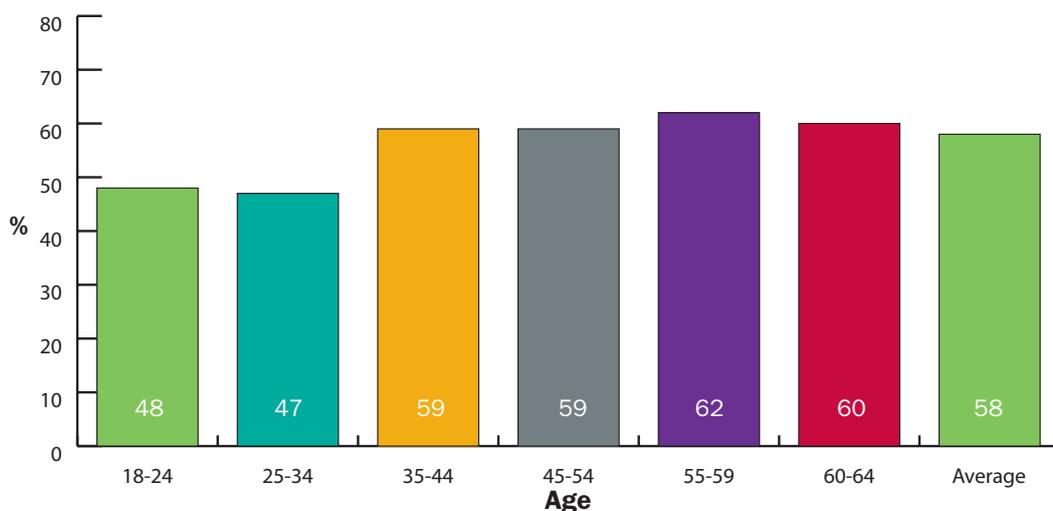
Nearly six in ten carers (58%) believe that the level and complexity of care they provide means that it is impossible for them to work (see Figure 20 above). For this group of carers, who have no alternative but to provide care, there should be better

support from the benefit system. There was some variation by age (see Figure 21), with those carers nearing retirement age more likely to report that it was impossible for them to work. Among the 55-59 age group, 62% reported that this was the case, compared with 47% among those aged 25-34 (see Figure 21 below).

“After 16 years of caring I feel out of touch with the world of work and unconfident going back to my previous job. I feel humiliated by being on benefits.”

Figure 21: Percentage of carers for whom it is impossible for them to work because of the level and complexity of care they provide.

Respondents were able to choose more than one category.



6.4 Impact on different groups of carers

The group aged 35-44 reported the highest percentages for four of the six options in this question. This group was most likely to report that they could not work unless they got the right care services (47% - see Figure 22 for a full breakdown), that the extra costs of care would outstrip their earnings (47%) and that they need a flexible employer (49%) and that the tax and benefit system does not make work pay (37% - see Figure 22 for a full breakdown). Older carers were more likely to suffer from health problems which prevent them working: this was the case for 32% of those aged 60-64.

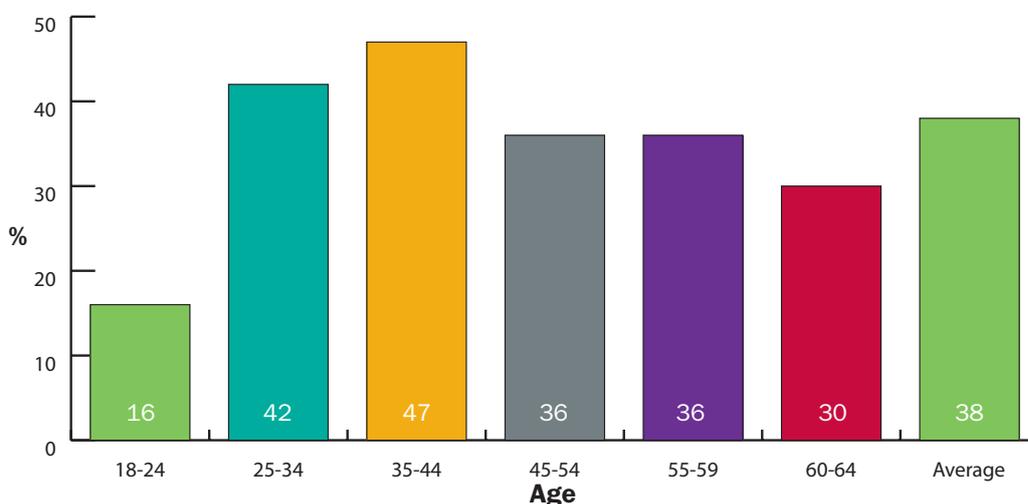
Similar, extremely high figures are found for those caring for a disabled child under the age of 18. Among this group, 46% cannot work unless they get the right care services (compared with an average of 38%), 45% cannot work because the extra costs of care would outstrip their earnings (compared with an average of 34%), a staggering 55% need a flexible employer (compared with an average of 34%) and 40% believe that the tax and benefit system does not make work pay (compared with 29%). As with other indicators, it is parents of disabled children who find it hardest to overcome barriers to work.

“Government should accept that I have to stay at home and facilitate and enable my daughter’s care and education and that I’m not work-shy – but no employer will fit around my child’s needs. I would then get benefits sufficient to live on.”

A couple of other details stand out, however. Among those caring for a disabled son or daughter aged over 18, 65% believe that the complexity and level of the care they provide makes it impossible to work. A third of this group (32%) also suffer from ill-health that makes it impossible for them to work. Similar levels of ill-health are found in those caring for a partner (30%). These findings show that for these carers, many years of caring for someone who is likely to be severely disabled has taken a heavy toll both on their health and also on their belief that they will ever be able to return to work. This is backed up by the finding that 37% of those who have been caring for more than 20 years report that their ill-health prevents them from working.

“I need more respite care for my daughter so I can commit to working without worrying about her.”

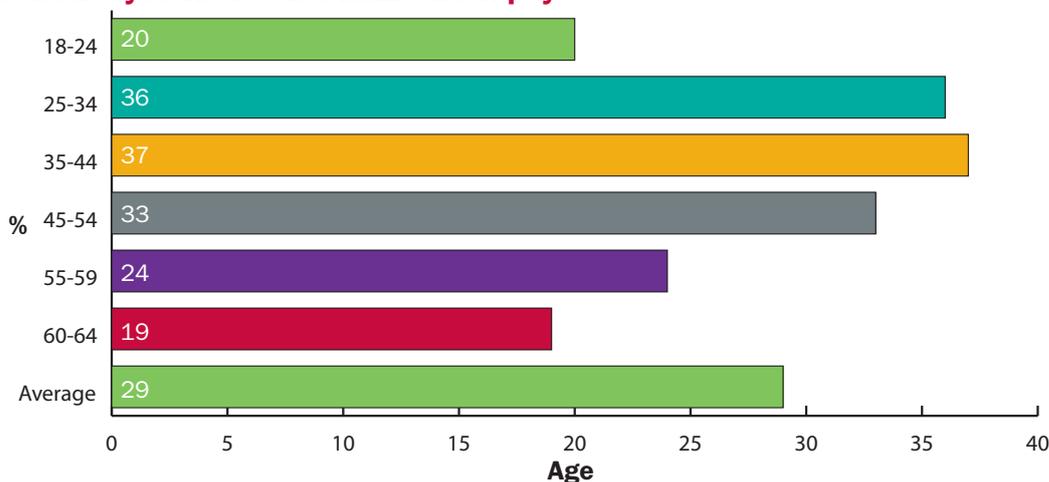
Figure 22: Percentage of carers who cannot work unless they get the right care services



Respondents were able to choose more than one category.

“If I manage to secure paid employment I shall be no better off because of the benefits I would lose and needing to pay another carer.”

Figure 23: Percentage of carers who would like to work but find that the tax and benefit system doesn't make work pay.



Respondents were able to choose more than one category.

7: Conclusion

This report demonstrates decisively that the benefits and tax system for carers is not fit for purpose to prevent financial hardship and the worry associated with it.

The tax, benefit and support system should be radically reformed so that it:

- **helps carers stay in work**

Having to give up work is a direct cause of carer poverty. Carers lose income and through a loss of pensions are storing up future poverty. Even when caring ends it can be difficult to get back into work and regain skills. There are carers who are currently unable to work who would love to be able to get back to work, but cannot because the right support is not available.

- **helps carers who are unable to work**

For some carers work is not an option. The level of skill and care they provide simply cannot be replaced. For example many carers provide complex medical nursing care which would never be provided by the state outside of a hospital setting. The benefits system needs to recognise who these carers are and reward them accordingly.

- **helps older carers enjoy a decent retirement**

For many people their long dream of retirement never appears. Older carers continue to provide high levels of care into their retirement. The benefits system is not geared up to recognise this. Carers lose their Carer's Allowance when they reach retirement as the benefit is seen simply as an income replacement. Yet they continue to provide care with little or no recognition.

Key findings

1. Most carers have faced a severe financial penalty since they started caring, which has affected their health and quality of life.
2. Those of working age are far more likely to report financial hardship compared to those receiving pensions.
3. Those caring for disabled children – both under the age of 18 and over the age of 18, and those caring for partners – are worst off.
4. Caring over time seems to have a huge impact – it is critical to mitigate the financial impact of caring in the first year.
5. After the first year of caring, carers get more used to their financial situation but it steadily gets worse over the next decade of caring.
6. Those caring at the heavy end (particularly the large group caring for more than 50 hours per week) face more hardship.
7. The levels of hardship remain unacceptably high amongst carers providing full-time care. Some areas of hardship have decreased since the Government brought in a few changes to carers' benefits. This demonstrates that more change could be positive in reducing these indicators.

Our conclusions show not only what carers want to see changed, but also how these changes must fit into the new social, economic and demographic agendas in our changing world.

Carers UK believes that the solution to the financial hardship facing carers lies not just with the benefits system, but across several policy areas. How we deliver and

fund social care services, how disabled people are supported to live independently, the use of assistive technology and telecare, the campaign to end discrimination and promote equality and human rights, the need to help vulnerable people pay for fuel: these are all areas in which carers' needs must be addressed. The review of the National Carers Strategy is an ideal place to start addressing this broad agenda.

Carers UK also believes that the debate about carers needs to shift until it is treated like the childcare debate. It is now broadly accepted that the state has an extremely important role to play in supporting families in work when they have childcare responsibilities. It is critical that we change the agenda so that we recognise the contribution that carers give to society in the same way as we do work. Carers do not understand why there is a distinction between the contribution provided by parents with regard to childcare and the contribution that carers provide with regard to disabled, elderly or frail people.

This report also shows that the system needs flexibility and diversity if it is successfully to target those most in need and properly recognise those who face the greatest financial challenges.

Future policy agenda

This research highlights a number of policies that could be changed to ensure that support systems address carers' financial hardship and deliver the outcomes that carers most want – to be recognised for what they do and to have choices and opportunities in their lives.

The Leitch report, which reviewed the UK's skills agenda, recommended an urgent rise in the level of the UK's skills if it is to become a world economic leader by 2020.¹⁴ Carers need to be part of this agenda and the benefits system needs to promote their inclusion, rather than prevent it. At present, someone studying more than 21 hours cannot receive the main carer's benefit, Carer's Allowance. This acts as a barrier to many vocational as well as non-vocational courses. Equally, more could be done to ensure that carers have greater access to learning and education opportunities. One way that Government intends to promote this is through a new training programme – the Expert Carers Programme – for which £5 million has been pledged.¹⁵ However, beyond training aimed at individuals' caring role, there should be training aimed at carers who want to return to work after a period out of the labour market or who want to pursue a change of job role to enable them to juggle work and care. These carers need tailored advice and guidance and access to funding or concessions for training.

Government has set ambitious new targets to get another 1 million people back into work – looking at both older people and those in receipt of Incapacity Benefit in its welfare-to-work strategies. Equally, in its new review of welfare reform conducted by David Freud, a new vision is suggested whereby there would be more tailored support around return to work.¹⁶ The Freud Review, however, does not sufficiently address carers' needs. The evidence provided by carers in this report highlights that many of those people will be carers, either because statistically they will fit into that age category, having taken early retirement, or they have some kind of disability or chronic illness that prevents them from working. All of these issues are

complicated by caring. Rather than discount carers entirely from this agenda, it is critical that carers are treated sensitively, but also given opportunities to engage in similar back-to-work policies. For those carers who want to work, Government will need to address these issues in its response to the Freud Review.

The UK is also facing an economic challenge brought on by the demographic changes within our population. In the next twenty years, the number of people aged 85 and over will increase by two-thirds, compared with a 10% growth in the population as a whole¹⁷. We will need an extra 3.4 million people caring, if services still stay at the same level. Future workforce predictions tell us that in 20 years time we will need an additional 2 million new workers, only a quarter of whom will be school leavers¹⁸. Employers will be widening their recruitment pool and carers could be part of that pool if care services and the pathway back to work are improved.

With this changing demographic situation, there is also an increasing need to ensure that there is a robust public health agenda that prevents ill-health from arising or tackling it early on. From the 2001 Census, we know that carers are twice as likely to suffer ill-health as non-carers.¹⁹ Many of the reforms Carers UK recommends would help give carers independence and choice for their families, which will have a positive impact on their health.

There are wider benefits to many reforms that would support carers. For example giving carers access to energy saving programmes would reduce fuel poverty and at the same time contribute to measures to prevent climate change. It is also critical that carers and disabled people have access to tariffs that allow discounts on fuel bills.

Finally, if Government is to implement its own equalities and human rights agenda then it needs to recognise that carers are in danger of suffering disproportionately because of their situation. We know that those with the worst incomes and those most likely to give up work are women.²⁰ We know that young Bangladeshi and Pakistani men and women are up to three times more likely than their white counterparts to combine work and care.²¹ This report shows that those caring full time for disabled children are more likely to suffer hardship, as are those caring long term. The new Commission for Equalities and Human Rights must take steps to understand and address the multi-layered disadvantage faced by carers.

Carers UK recently asked carers what their future priorities were for change. Their top choice was recognition for their role from professionals. This applies as much to the policies of Government as it does to a local health worker. Carers see the value of Carer's Allowance, at only £48.65, as an indication of what Government thinks they are worth. The second most important issue was improvement of carers' benefits for the under 65s, third was services for disabled people and fourth was income in retirement, including those who do not receive Carer's Allowance because they receive a pension. For those carers who cannot work and those aged over 65 who both feel particularly undervalued, it is critical that Government reviews how the benefits system values these carers.

This survey repeats one carried out by Carers UK in 2000. Comparing the two, it is clear that some improvement has occurred and that by some indicators, carers are struggling less than they were previously (see Appendices for a comparison with the survey in 2000). This clearly demonstrates that where Government does invest in carers (for example the £1.1 billion allocated to carers' breaks through the Carers Grant since 1999) it does bring benefits to those that need them most. However, as this new research shows, there are still unacceptably high levels of hardship.

In order to make carers feel valued and prevent the excessive levels of hardship reported in this research, Government needs to address the following areas:

1. The low level of Carer's Allowance – the lowest benefit of its kind
2. Financial barriers to work – we currently have a system that does not promote work or help carers move in and out of work
3. Carer's Allowance – a benefit which does not help those caring long-term.
4. Carer's Allowance – a benefit which does not value the contribution carers make to the provision of care
5. Carer's Allowance – a benefit which does not recognise a person's inability to work in the same way as other benefits do
6. Carer's Allowance classed as an overlapping benefit – a benefit that leaves older carers feeling they are not valued because many cannot receive it.
7. A complicated application process for older carers for Carer's Allowance which leaves them confused, angry and with little faith in how the system works, with advisers caught up in complicated advice.
8. The lack of funding of social care – from equipment to practical help – places a financial strain on carers by making caring harder and by giving carers no choice but to give up work when services are not available or accessible.
9. A system that does not help those in the first year of caring come to terms with the extreme challenges of their new financial and personal situation.

Carers UK's tests for a new system of financial support for carers:

- a system that is based, not on what carers have given up, but on what their contribution is to society
- financial support for carers which is equitable and fair
- financial support which promotes carers' opportunities for work, leisure and learning, building in flexibility to move in and out of work
- financial support which recognises and values care
- simpler procedures for accessing financial support
- less bureaucracy, particularly the need to provide information time and time again
- a system which considers the wider impact of carers' financial hardship on other family members
- solutions which look at short and long-term financial improvement for carers, including pension provision
- solutions for improving carers' incomes which are cross-Governmental and joined up
- a system which takes into account the long-term impact of caring
- a system which takes into account the impact of caring for more than one person

8. Recommendations

Strategic

1. Government should undertake a wholesale review of the income that carers have, whether it be through employment, tax credits, benefits or pensions in order to provide financial support that is fit for purpose. This should fit the tests that carers have identified (see box on page 35). This needs to be addressed through the National Carers Strategy.
2. The Scottish Executive, Welsh Assembly Government and Northern Ireland Assembly all contribute to this agenda within their devolved powers and share a common vision to improve carers' financial situation.
3. A question on carers must be included in the 2011 Census to mark progress, to aid local planning, but also to target particular support for employment, housing and services.
4. There should be targeted solutions which recognise carers' diversity, for example the different needs of carers from Black and Minority Ethnic (BME) groups and those caring long-term.

Employment services

5. Carers should have access to one-on-one support from employment services which recognises the complexity of their situation, without the threat of excessively punitive sanctions which can increase stress.

Health and social care services

6. The UK and devolved governments should develop new strategies to look at how services, including social care services, can help carers stay in or take up employment. This would also aid independent living for disabled people.
7. The UK and devolved governments should look at developing a long-term strategy for funding social care in the context of improving carers' financial situation.
8. All health and social care bodies throughout the UK should review their policies and procedures to make sure that carers are able to better combine work and care, for example recognising that the timing of hospital appointments and social care services impact on carer's ability to work.

Benefits and pension system

9. The UK Government should include carers' benefits as part of its work on simplifying benefits
10. The UK Government should continue to build on and implement policies to help carers gain access to the Basic State Pension, State Second Pension and to build up Personal Accounts.

Information and advice

11. The Welsh Assembly Government should introduce a specific duty on health bodies to inform carers about support services and their rights and the Scottish Executive should ensure that NHS Carer Information Strategies are fully implemented.
12. The UK Government should implement its pledge to fund a national helpline to help guide carers through advice and entitlements, particularly in the first year of caring.

Social inclusion

13. Carers should have wider access to schemes to help them pay fuel bills
14. The UK and devolved governments should improve carers' access to learning opportunities.
15. The UK Government should continue to fund the Carers Grant in England.

Appendices

a) Impact on carers: Comparison with the survey from 2000

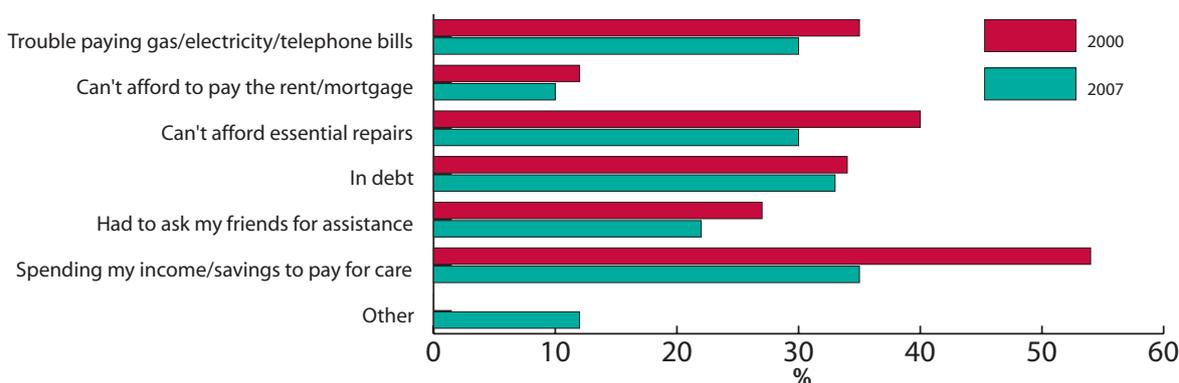
Carers UK undertook a similar survey in 2000. Many of the questions were repeated in this survey. The survey in 2000 was undertaken as part of Carers UK's Fair Deal Campaign. This campaign was successful in persuading Government to announce a package of financial support for carers that would benefit around 300,000 carers over three years, costing in the region of £500 million. The changes included:

- a £10 increase in the Carer Premium (almost doubling it at the time) – helping those on Income Support
- an increase in the earnings limit for Carer's Allowance from £50 to the Lower Earnings Limit for National Insurance – which in 2007/8 is £87
- A change to allow carers over the age of 65 to claim Carer's Allowance, although the majority of carers did not receive the Allowance, thousands gained access to Carer Addition (same as Carer Premium) on top of their Pension Credit.

Whilst caution must be exercised in comparing the surveys from 2000 and 2007, as they do contain some differences and did not use controlled samples, there are some useful comparisons which can be made as indications of trends. When we compare the results from the two surveys, we find that there is still a very high proportion of carers facing hardship and who struggle to make ends meet. However, we also find that some of the changes made by Government may have made a difference as hardship in some areas is slightly reduced.

For example, in 2007 nearly three-quarters of carers (72%) said that their financial situation had got worse since becoming a carer. This figure was 77% in our last survey in 2000.

Figure 24: Financial impact of caring: a comparison between 2000 and 2007

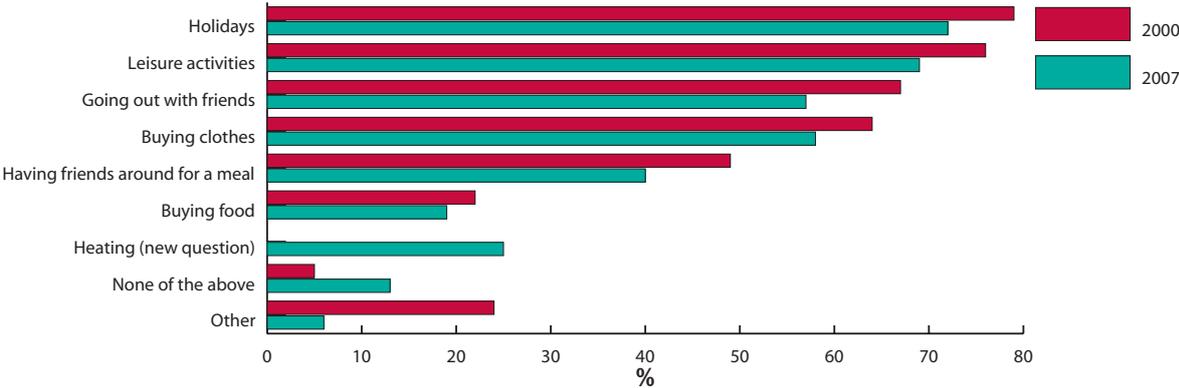


Cutting back on essentials

Similarly, the proportions of carers cutting back on things that most people find essential or take for granted remain extremely high – one in five carers is still cutting back on buying food. However, as this table shows, the proportion of carers cutting back has fallen slightly between 2000 and 2007. In 1999, Government gave

its first grant of £20 million to local authorities to provide breaks for carers so that they could have holidays, a break, or have leisure activities. In 2007 the Grant is worth £185 million and since 1999 around £1.1 billion has been invested in breaks. Many local authorities provide these breaks free or with a very low charge. This investment in breaks, and the fact that many are free, could be a reason why there is a decrease in certain hardship indicators by carers. For example in 2000, 67% of carers had to cut back on going out with friends compared with 57% in 2007.

Figure 25: Areas in which carers are cutting back: a comparison between 2000 and 2007



In 2007 more than six in ten carers (62%) said that they worried about their financial circumstances a lot or all the time. This is down a little compared with 2000, when 68% of carers said the same thing.

Likewise, in 2007 53% of all respondents said that this worry was affecting their health. This is down from nearly six out of ten (61%) in 2000.

This suggests that, should Government invest in more support for carers, it could have a direct impact on those who face hardship. It also demonstrates that the solutions to financial hardship for carers and their families lies not just with the benefits system, but with a whole range of other solutions – such as better social care services to help carers live a normal life with choices and opportunities.

b) Carers' Benefits – a short guide

Carer's Allowance

Carer's Allowance is the main benefit for carers. It is paid at a basic rate of £48.65 a week.

You can get Carer's Allowance if:

- you look after someone for at least 35 hours each week, and
- the person you look after gets Attendance Allowance or the middle or higher rate of the care component of Disability Living Allowance, and
- you are aged 16 or over, and
- you are not studying for more than 21 hours a week, and
- you don't earn more than £87 a week from work (after some deductions).

If you are getting State Retirement Pension, Incapacity Benefit, Bereavement Benefit or any other 'earnings replacement' benefit of more than the rate of Carer's Allowance, you cannot be paid Carer's Allowance.

Income Support

Income Support is a means-tested benefit paid to people on a low income (or with no other income) aged under 60 who do not have to sign on to look for work. The amount of Income Support you get varies according to your family circumstances, income and age. You cannot get Income Support if your savings are higher than £16,000.

Pension Credit

Pension Credit is a benefit for people aged 60 or over on a low income. It is split into two parts; Guarantee Credit and Savings Credit.

- Guarantee Credit can be claimed by people aged 60 or over. The Guarantee Credit is means-tested, so your income and savings will affect the amount you get.
- Savings Credit rewards pensioners who have a second pension or modest savings. It is paid as part of a claim for Pension Credit to pensioners who are 65 or over.

Carer premium/addition

The carer premium and addition are extra amounts used in the calculation of some means-tested benefits. The carer premium is used in Income Support, Jobseeker's Allowance, Housing Benefit and Council Tax Benefit and the carer addition is used in Pension Credit. The carer premium/addition is worth £27.15 a week and is included in your benefit calculations if you get Carer's Allowance or if you have 'underlying entitlement' to Carer's Allowance (see above).

Incapacity Benefit

Incapacity Benefit is for people who are unable to work because of illness or disability and is paid if:

- you have paid enough National Insurance contributions
- you cannot get Statutory Sick Pay from your employer
- you are under State Pension age

To qualify for Incapacity Benefit, you must also prove your incapacity for work. It is paid at three rates: short-term lower rate (£61.35), short-term higher rate (£72.55) and long term rate (£81.35).

From 2008, the Employment and Support Allowance will replace incapacity benefits for new claimants and in time all existing claimants will also be brought onto the new system.

Disability Living Allowance

Disability Living Allowance is a benefit paid to help with the extra costs of long-term illness or disability. To qualify for Disability Living Allowance, you must make a claim before your 65th birthday. Your income and savings do not affect whether you can get Disability Living Allowance, or how much you get. Disability Living Allowance is split into two parts; you can claim for either or both these components:

- care component – this is for the help someone needs to look after themselves and can be paid at one of three rates (lower, middle and higher)
- mobility component – this is for the help someone needs getting around and can be paid at one of two rates (lower or higher).

Attendance Allowance

Attendance Allowance is a benefit paid to people aged 65 or over to help them with the extra costs of a long-term illness or disability. Your income and savings do not affect whether you can get Attendance Allowance or how much you can get. Attendance Allowance is paid at two rates (lower or higher); the amount you get depends on the amount of help you need. There is no amount for mobility needs in Attendance Allowance.

Tax Credits

Child Tax Credit and Working Tax Credit are paid to top up the incomes of families or workers with a low income. The amount you get of either/both is affected by your household income and savings. Child Tax Credit is paid if you have a child(ren) under 16 (or 19 if they are in full time education). You may be able to get extra credit if you have a disabled child. You do not have to be in work to get Child Tax Credit. Working Tax Credit is paid if you are working. You may be able to get extra credit if you work for more than 30 hours a week, are aged over 50, or are disabled.

Council tax benefit

Council Tax Benefit helps people to pay their council tax. The amount you can get depends upon your family circumstances, income, savings and the level of your council tax. You cannot usually get Council Tax Benefit if you have savings of £16,000 or more.

c) About the respondents

A total of 2950 responses were received, with 1597 responses being collected on-line.

The vast majority of respondents had a long-term caring commitment. Nine out of ten of them had been caring for three or more years. Just 3% had been caring for less than one year whilst 20% had been caring for over 20 years. One in ten (9%) were former carers.

The respondents were mainly full time carers with three-quarters (77%) caring for 50 hours or more per week. This level of care has a huge impact on carers' lives. For example, these carers are twice as likely to suffer from poor health than those who are not carers²². A further 16% were caring for between 20 and 50 hours a week. Evidence shows that those caring for more than 20 hours each week have significantly lower employment rates²³. These carers will find it more difficult to combine work and care. The remaining 6% were caring for fewer than 20 hours each week.

The majority of respondents (84%) cared for only one person, but 12% cared for two. As people live longer, multiple caring responsibilities will become increasingly common, particularly among middle-aged carers who may have a disabled child and an elderly parent. This 'sandwich generation' faces a particularly tough challenge.

The largest single age group was 45 to 54 (17%). We know from the 2001 Census that this is the peak age for becoming a carer. However nearly four in ten (39%) were over the age of 65.

Two-thirds of respondents (67%) were female with just a third male, however the people they were caring for were more evenly split: 49% were male and 51% were female.

Respondents were caring for a wide range of people, but the single largest group being cared for were aged over 80 (30%). Nearly half (46%) of respondents were caring for a partner and a quarter (24%) for parents. A further 13% cared for a disabled child and 15% were caring for an adult disabled son or daughter.

Out of those who answered the question, 89% were White British. The remaining 246 respondents were from a wide range of backgrounds including white European, black British, Asian, Caribbean, African or Chinese backgrounds. Given the small numbers in some of the Black and Minority Ethnic (BME) groups, we have not conducted an analysis of responses based on ethnic origin. We know from other research that there is a huge diversity between different BME groups and analysing them as one group would have little relevance.

2097 respondents lived in England, 232 lived in Scotland, 191 lived in Wales, 45 lived in Northern Ireland and 385 did not give a location.

d) Methodology

The survey was carried out between December 2006 and January 2007. For purposes of comparison, the same questions were used as in 1999, however additional questions were added.

The questionnaire included both open and closed questions and was available to complete on-line or on paper. The questionnaire was distributed in several ways:

- it was included in Caring magazine
- it was included in Carers UK's mailing to nearly 700 local carers and other organisations throughout the UK
- it was circulated by the National Black Carers Workers Network and the London Black Carers Workers Network
- it was emailed to key contacts and promoted on our website.

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Carers UK

20/25 Glasshouse Yard
London EC1A 4JT

Telephone 020 7490 8818
Fax 020 7490 8824
Email info@carersuk.org
Website www.carersuk.org

CarersLine 0808 808 7777
Open Weds and Thurs 10-12 and 2-4pm

Carers Wales

River House
Ynys Bridge Court
Gwaelod y Garth
Cardiff CF15 9SS

Telephone 029 2081 1370
Fax 029 2081 1575
Email info@carerswales.org
Website www.carerswales.org

Carers Northern Ireland

58 Howard Street
Belfast BT1 6PJ

Telephone 028 9043 9843
Fax 028 9032 9299
Email info@carersni.org
Website www.carersni.org

Carers Scotland

91 Mitchell Street
Glasgow G1 3LN

Telephone 0141 221 9141
Fax 0141 221 9140
Email info@carersscotland.org
Website www.carersscotland.org



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