

Caring &
Family
Finances

INQUIRY

UK REPORT

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Foreword

Heléna Herklots Chief Executive, Carers UK

We will all care for an ill or disabled loved one, or need care ourselves, at some point in our lives. Yet despite the fact that caring is such a normal part of life, looking after an older, ill or disabled loved one often pitches families into crisis.

For many, caring results in an income shock as they are forced to reduce working hours or give up paid work entirely, just as they face the often crippling additional costs of poor-health and disability – of care services, adaptations and equipment, higher household and transport bills. The result can be lasting debt and financial hardship, the loss of carers' careers and the risk of social isolation.

Despite these heavy costs, the number of families taking on caring responsibilities continues to rise, rapidly. The greatest increases are amongst those caring for over fifty hours a week.

These figures give lie to the myths that we are becoming a less caring society and that families aren't doing their bit.

But as greater numbers of families care for our ageing population and with the rising numbers of people living with disabilities and long-term conditions, this Caring & Family Finances Inquiry highlights very significant questions of sustainability.

Our economy cannot afford for a growing number of carers to be pushed out of the workforce – unable to earn during their working lives or save for retirement. Businesses cannot afford to lose key staff who are unable to access flexibility at work or care services at home. There are also great social costs to consigning hundreds of thousands of full-time carers to years, sometimes lifetimes, on the lowest level benefits: 'doing the right thing' for their families, but struggling to pay their basic bills as a result.

It is an indictment of successive Governments that carers' financial circumstances were not made a priority, that carers' benefits remain the lowest of their kind.

But this Inquiry has shown that a bad situation is being made far worse. In the last three years, families with such little financial resilience already, have been hit by a perfect storm of rising living costs, the withdrawal of benefits and rationed care services.

Evidence of the impact of this on carers is shocking and it is clear that the limited measures Government has put in place to protect carers from some social security cuts are failing. As a result, despite contributing more than ever in unpaid care, cuts to vital support have left many carers unable to afford basic household costs, cutting back

on food and heating, and facing long-term debt and rent arrears.

As the Government explores deeper cuts to social security, the evidence from this Inquiry strengthens our hand in fighting for further protections for carers.

These stories cannot be ignored and the Government must now act, urgently, to protect carers and their families from further hardship.

But alongside the deeply worrying evidence of families' worsening financial situation, carers' experiences also point to a more positive vision for the future.

We found strong examples of how early identification of caring responsibilities and quick intervention to guide families to advice and support as soon as they started to care, can reduce the likelihood of falling into debt in the first months of caring. Carers spoke about increasing recognition and support in workplaces and the difference that good services can make in enabling them to combine work and caring.

Our vision is for social security and care services which act as enablers, providing the support families need to balance caring responsibilities with lives of their own and paid work where possible.

Government must learn the lessons from the long struggle to establish support for childcare as an essential part of our economic and social infrastructure. Preventing carer ill-health and social exclusion is good for the NHS and social care services; supporting carers in the workforce is good for business and good for the economy. In short, giving carers the support they need isn't just morally the right thing to do, it is good for the UK - socially and economically. We need to hear 'support for carers' on the lips of senior politicians, policy-makers and business leaders, as often as we hear childcare.

Next year, marks fifty years since a woman called Mary Webster founded Carers UK and started the 'carers' movement'. Caring for both of her ageing parents had cost Mary her career and her financial independence. Isolated, and caring alone, she felt she had given up her life to care. But she spoke out and founded our charity by bringing together other carers - angry at the lack of support and determined to change things.

The carers who have contributed to this Inquiry show how the frustration and passion which drove Mary Webster half a century ago, still drives families today. At evidence sessions, through our research and in emails, letters and calls, carers have spoken with force and clarity about the financial impact of caring. This Inquiry is powered by their experiences and their resolve - not only to win a better deal for their families, but for families who will care in the future.

Carers have laid down a challenge to politicians across the UK - a challenge to which they must respond.

With thanks

Carers UK would like to thank all the carers who contributed to this Inquiry by telling their stories and submitting evidence through evidence sessions across the UK and completing our State of Caring survey.

Particular thanks to those carers who have allowed us to share their stories in detail for this report – Julie and Peter, Gill and her parents, Bushra and Talat, Graham and Lynda, Lesley and Darren, Annie and her family and all those carers who provided stories and comments anonymously. This report and Carers UK's wider policy, campaigning and research work is built on all your experiences and would not be possible without your commitment to working with us to improve the lives of all carers.

We are incredibly grateful to those individuals, local groups and networks who hosted evidence sessions, promoted our research surveys and provide local support and advice to carers year-round.

Particular thanks to the Coalition of Carers in Scotland, Carers UK Llandudno Branch, Forget Me Not Chorus – Cardiff, Merthyr Tydfil Carers Project, Red Cross Carers Project Ceredigion, Carers UK Merthyr Tydfil Branch, Voluntary Action Merthyr Tydfil, Crossroads Carers Contact Newport, the Older People's Commissioner for Wales, Carers UK Birmingham Branch, the Carers Centre Leicestershire & Rutland, Carers UK Taunton and District Branch, Carers UK Leeds Branch, Leeds Carers Centre, Islington Carers Hub, Carers Pathway Group Islington, London Fire Brigade, Carers in Hertfordshire, Carers UK Slough and District, Age Concern Slough and Berkshire East, Rosemary O'Neill and Rosie Tope for hosting and organising evidence sessions. Summaries of the evidence sessions are included in the report appendix.

Our thanks go to the All-Party Parliamentary Group on Carers, chaired by Baroness Jill Pitkeathley OBE and Rt Hon. Sir Tony Baldry MP, for hosting an evidence session in Parliament. All-Party Group members have also supported this work through evidence gathering in their constituencies and through written and oral questions in Parliament.

Carers UK is also extremely grateful to the family of Malcolm Wicks for supporting the work of this Inquiry through the Malcolm Wicks Memorial Fund. Malcolm was a great advocate for carers and is a much-missed friend to Carers UK. Much of this research has built on his work to highlight carer poverty and champion reform of support for families with caring responsibilities.

We would like to thank the Joseph Rowntree Foundation for providing additional funding which was invaluable in enabling the engagement of carers, older and disabled people in this work.

The Caring & Family Finances Inquiry was supported by an Expert Panel:

- Anand Shukla, Chief Executive, Family and Childcare Trust
- Anita Charlesworth, Chief Economist, Nuffield Trust
- Anthony Thompson, former Head of Public Affairs, Insurance & Scotland at Lloyds Banking Group
- Caroline Abrahams, Charity Director, Age UK
- Claudia Wood, Deputy Director, Demos
- Dame Philippa Russell, Chair, Standing Commission on Carers
- Don Brereton CB, former Chair, Carers UK
- Dr Michael Hirst, formerly of SPRU, University of York
- Dr Roger Wicks, Director of Policy & Campaigns, Action on Hearing Loss
- Emma Harrison, Assistant Director of External Relations, Mencap
- Dr Emma Stone, Director of Policy and Research, Joseph Rowntree Foundation
- Imelda Redmond CBE, Director of Policy and Public Affairs, Marie Curie Cancer Care
- James Lloyd, Director, Strategic Society Centre
- Liz Sayce OBE, Chief Executive Disability Rights UK
- Professor Eileen Evason CBE, Emeritus Professor of Social Administration, University of Ulster
- Professor Jay Ginn, King's College London
- Srabani Sen OBE, former Chief Executive, Contact a Family
- Teresa Perchard, former Director of Policy and Advocacy, Citizens Advice
- Vidhya Alakeson, Deputy Chief Executive, Resolution Foundation

Carers UK has been extremely grateful for their advice, support and guidance throughout the Inquiry.



About the Inquiry

The Inquiry was established to examine the costs of caring, the impact of the Welfare Reform Act and influence future policy on supporting carers

In January 2013, to examine the impact of an unprecedented combination of rising living costs and far-reaching changes to social security, Carers UK established a Caring & Family Finances Inquiry.

The Inquiry's remit was to:

- Provide a definitive study into the financial impact of caring – with carers' voices at its heart.
- Assess the impact of the Government's benefit changes on carers and their families.
- Develop future policy on reforming the financial support available to families caring for older and disabled friends and relatives.

Supported by an Expert Panel made up of older and disabled people's organisations, academia and social policy experts, the Inquiry has gathered evidence through public polling, survey data, case study modelling and evidence sessions with families across the UK.



Methodology

The main sources of data and carers' experiences for this Inquiry have been evidence sessions held across the UK, Carers UK's *State of Caring* survey and data from Census 2011¹.

Evidence sessions

Fifteen evidence sessions, attended by over 200 carers, were held across the UK in: Edinburgh, Glasgow, Aberystwyth, Llandudno, Swansea, Slough, Sutton Coldfield, Manchester, Leicester, Jarrow, Taunton, Hatfield, Leeds and in Islington, Westminster and Southwark in London.

Summaries of each of the evidence sessions are included in the appendix of this report.

State of Caring survey

A total of 3,910 carers responded to Carers UK online *State of Caring* survey between February and August 2013.

Unless otherwise stated, the data included throughout this report is taken from the results of the *State of Caring* survey.

Of respondents to the *State of Caring* survey:

Caring responsibilities

- 94% said they are currently caring, while 6% used to care for someone but don't anymore.
- Nearly 7 in 10 (69%) said that they care for 50 hours or more a week. 14% care for 35-49 hours, 8% care for 20-34 hours and 9% care for 1-19 hours a week.
- 8 in 10 (81%) live in the same house as the person they care for.
- While 77% of those responding to the survey care for one person, 18% care for two people, 4% care for three people and

¹ At the time of analysis detailed breakdowns of the 2011 Census figures were only available for England and Wales. Unless otherwise stated the quoted figures reflect this.

1% told us that they have caring responsibilities for four or more people

- Only 4% of respondents said that they had been caring for under a year, while 28% had been caring for 1-5 years, 24% for 5-10 years, 16% for 10-15 years and 28% had been caring for over 15 years.
- Over 1 in 5 (21%) also have childcare or financial responsibilities for (non-disabled) children under 18 and 13% have family responsibilities for financially dependent (non-disabled) children over 18.

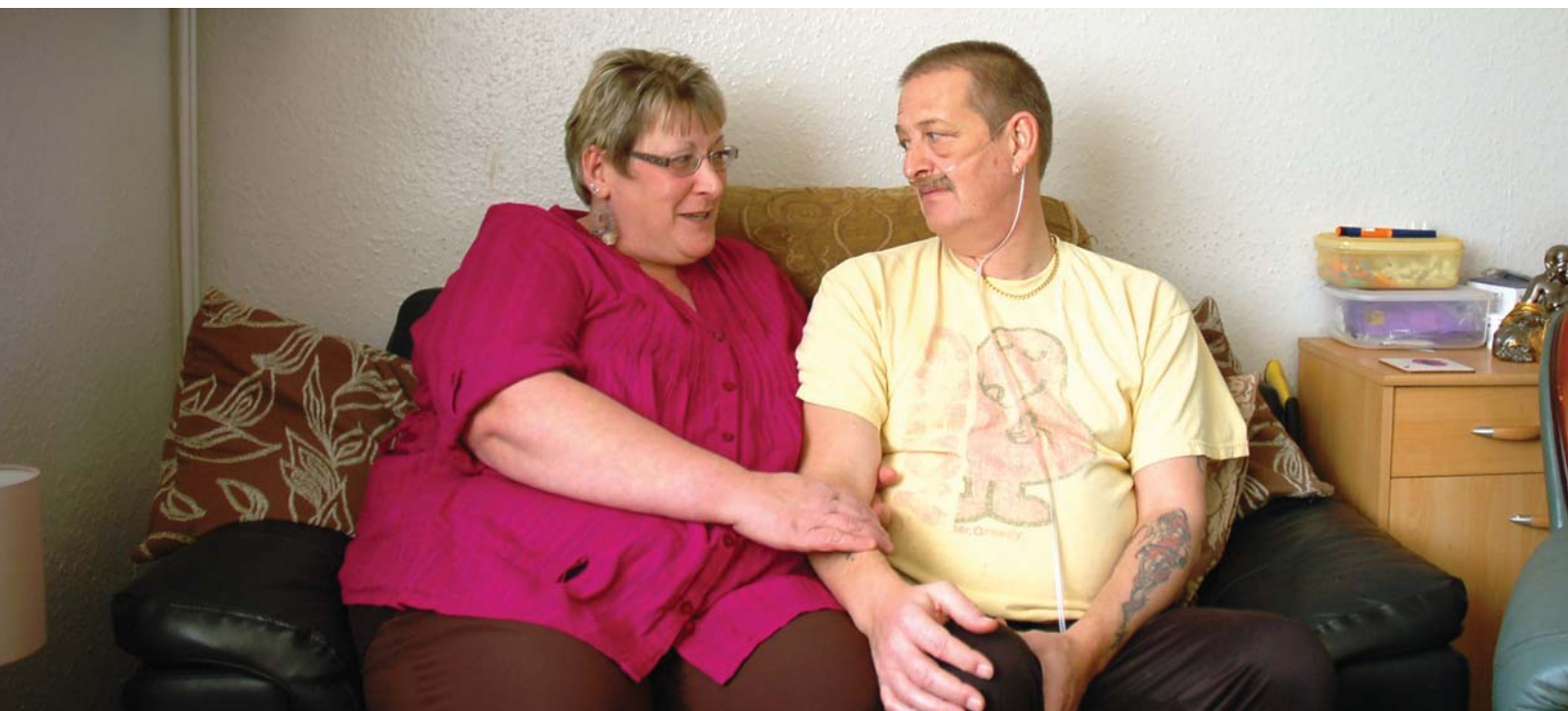
Gender, age and ethnicity

- 76% of the carers who filled in our survey are women and 24% are men. Nationally, the percentage of carers who are women is lower than this (58% of all carers are women and 42% are men). This is likely to be because, on average, women are more likely to care for a higher number of hours than men and a high proportion of our survey respondents care full-time.
- 42% of the people who filled in our survey are aged 40-54, 33% are 55-64 and 11% are 65-74. 1 in 10 (10%) said they are aged 25-39 while 3% are over 75 and 1% are aged 24 or under.
- Most (90.2%) of the carers who filled in our online survey are White British. A further 4.9% described themselves as White Irish (2.2%), White European (1.3%) or White: Other (1.4%). A small minority (1.1%) of the survey respondents were Black or Black British (Caribbean: 0.7%; African: 0.3%; Other Black: 0.1%) or Mixed: White and Black (0.2%). 1.6% said that they are Asian or Asian British (Indian: 0.8%; Pakistani: 0.4%; Bangladeshi: 0.2%; Other Asian: 0.1%; Chinese: 0.2%) and 0.3% said that they are Mixed: White and Asian. 1.1% filled in a box with a different ethnicity while 0.4% said they are Mixed: Other.

Location

- 74% of the survey respondents live in England, while 12% live in Scotland, 12% live in Wales and 3% live in Northern Ireland.
- Around 4 in 10 (41%) described where they live as a 'suburb of a town or city' and 26% said they live in a town or city centre. 13% live in a large village and a further 20% said they live in a rural area (small village or hamlet: 17%; very isolated: 4%)².

² Due to rounding, not all percentages add up to 100%.



The costs of caring

Families taking on caring responsibilities often face lasting financial pressure as a result of lost earnings and rising household costs

“We almost lost our business and our home because of the combined impact of caring for my son and my mother-in-law – the extra bills, the huge transport costs and trying to earn a living alongside it all.”

When caring affects families, the financial pressure often comes from two sides – as household income takes a hit from reduced earnings, outgoings also rise as a result of the extra costs of ill-health or disability.

For many, this dual income and household costs shock results in lasting financial hardship and debt, often exacerbated by delays in accessing financial support or advice on combining work and caring.

Carers UK’s 2013 *State of Caring* survey of almost 4,000 carers showed:

- Almost half were cutting back on essentials like food (45%) and heating (44%).
- 19% were unable to afford their rent or mortgage payments.
- One in ten carers had used up all their savings to pay basic bills and almost half (44%) had ended up in debt with a fifth using their overdraft (22%) or credit cards (20%) to make ends meet.
- 53% said their money worries were taking a toll on their health.



“We had good jobs and were doing well, but overnight it all fell apart. The impact of us both being unable to work was financially devastating. Now it is a struggle to pay our basic bills.”

Julie's story

Caring came as a complete shock to Julie. Six years ago, with no warning, her husband Peter collapsed, having suffered a brain injury and cardiac arrest. He was resuscitated on the kitchen floor by paramedics.

His brain injury resulted in him developing diabetes and experiencing significant changes in behaviour including forgetfulness, mood swings and night terrors. Weakness in his heart left him dependent on an oxygen tank.

Work was impossible for Peter, but when he came out of hospital Julie also felt huge pressure on her own career. They were offered no support from social care services at home despite Peter's need for constant care, support and supervision. Their practice nurse told Julie that Peter needed her at home and that she would have to give up her job. They were already trying to cope with the loss of one income and Julie was determined to keep her career, but in the end the pressure became too much to continue trying to combine work with caring. After initially being told by her GP that she had to take time off work with stress, Julie was forced to resign.

The loss of Julie's income on top of Peter's was devastating. It took six months for Peter to get Disability Living Allowance and by that time they already had mounting debt. With a drop in household income of over £40,000 a year, they could no longer afford their mortgage payments or even to pay basic bills. Eventually the debt became unsustainable and their only choice was bankruptcy following the repossession of their family home.

Julie says: "We had good jobs and were doing well, but overnight it all fell apart. The impact of us both being unable to work was financially devastating. Now it is a struggle to pay our basic bills. I have to choose between having the heating on, or using the tumble drier."

They moved to live in a small housing association bungalow which has been heavily adapted for their needs including ramps, a wet room and oxygen tank storage. Alongside the main bedroom there is a box room which used to be their son's room. Julie often sleeps there as Peter's own disturbed sleep, the need to use an oxygen tank overnight and Julie's worsening arthritis means it impossible for them to share.

But since April, the room has been categorised as 'spare' following the Government's change to social housing size criteria for Housing Benefit and they face a bill of over £700 a year, coupled with new Council Tax charges following the scrapping of Council Tax Benefit. They were turned down for discretionary housing payments because they both receive Disability Living Allowance and were told this should be used to pay the rent shortfall.

Julie says: "We are always in debt. We have to pay the new rent and council tax payments but that means that other debts are building up. The water company are threatening court action and I have major arrears with our gas and electric."

We have no choice of being able to get some work to pay bills, and there is nowhere to put a lodger. I just want to be able to take care of my husband because there is no way of knowing how long I will have him. We are both isolated and have no family who could help. We are desperate just to pay my bills and eat a healthy diet. I don't smoke, drink or use anything other than prescription medication, and all I want is a life where my husband and I don't have to worry about debt. My health is deteriorating and I am currently awaiting surgery for osteoarthritis myself.

I dread to think what the future holds as I truly believe that this government has no understanding of what it is really like to live on benefits long term with no other choice. I often think that we would be better off just not being here – to stop us being a further burden."

Defining disability-related costs and the costs of caring

There is a wide body of research examining the mapping and definition of disability-related costs, in particular to distinguish between what are ‘additional’ costs – for goods and services needed by disabled and non-disabled people alike but needed more by disabled people – and ‘special’ costs which are costs faced by disabled people, but not by non-disabled people,¹ which can be one-off, recurring and often daily expenses.

As Demos notes in *Counting the Costs*, deciding which costs are taken into account has a very significant impact on estimates of poverty amongst disabled people, with rates of disability poverty more than doubling when the additional costs of disability are taken into account.²

For the purposes of this report, the challenge of understanding and breaking down these costs becomes greater – in trying to understand the division between disability-related and caring-related costs. These definitional challenges were apparent throughout our evidence-gathering for this Inquiry, particularly for carers with long-term caring responsibilities who found that comparing their living costs to ‘life

Table 1: Examples of the complexity of how different costs may be both disability and carer-related.

Cost	Disability-related	Carer cost
Utility bills	More prolonged and intensive use of energy as a result of needs related to disability.	Additional usage as a result of carer being at home as well.
Personal care products	Cost of products and services required for personal care irrespective of by whom that care is provided (eg. latex gloves).	Costs of products which result from carer, rather than care services, providing personal care.
Food bills	Additional costs resulting from higher calorie intake, wastage related to appetite and food preferences; cost of specialist dietary or medical nutrition.	Higher costs of inefficient food purchasing resulting from a lack of time for food preparation – convenience foods and snacking.
Household goods and adaptations	Mobility equipment and adaptations; more frequent purchasing of white goods as a result of high usage.	Adaptations and services which enable the carer to provide care – eg. hoists, telecare services. Time-saving devices like tumble driers, dishwashers.
Transport	Costs resulting from frequent trips to access health and social care services and the need to use high-cost transport like taxis or private ambulances.	Cost of accompanying disabled or older person; costs of travel associated with ‘distance caring.’
Care services	Cost of care and support services not provided by, or where ineligible for, local authority or NHS support.	Provision of replacement care where the costs are borne by the carer in order to have time off from caring, or additional care support whilst caring.

1 *Review of Existing Research on the Extra Costs of Disability* (2005) Department for Work and Pensions

2 *Counting the Cost* (2010) Demos; *Disabled People’s Cost of Living: more than you would think* (2001) Joseph Rowntree Foundation; *Disability and the Downturn* (2009) Leonard Cheshire Disability

“We don’t go on holidays. We use the internet with a fixed fee and try to use the phone at times when it’s free. I use charity shops for clothes. We are worried about heating costs and the rising costs of food. I have no activities or hobbies, and I don’t go out with friends or family. We have no support services helping with caring. No one helps us and we are drowning.”

before caring’ was very difficult.

For example, these issues were highlighted at our Slough evidence session, which had the highest proportion of ‘hidden carers’ – people with caring responsibilities who did not recognise themselves as ‘carers’ and were not accessing support with caring. Most of the carers attending responded to questions about higher household costs related to disability but did not recognise ‘costs of caring’ as different from the costs of living as a family.

There are some easily identifiable ‘costs of caring’, for example the costs of travelling to care for someone who does not live with you. Other costs are directly incurred by the individuals as a result of being a carer but are difficult to separate from disability-related costs, for example the additional energy consumed as a result of being at home all day caring for a disabled partner. Many carers also report paying from their own income or savings for the direct costs of disability (adaptations, equipment or care services for example) because the disabled or older person cannot afford them or because the carer decides they are needed.

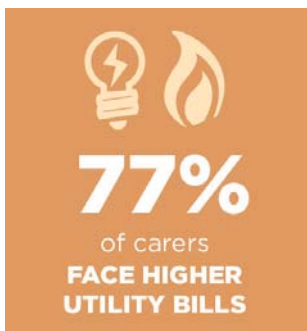
The policy response to these questions would be that benefits designed to help with extra costs (like Disability Living Allowance or Attendance Allowance) should be used to try to cover disability-related expenditure, and carers’ benefits should support carers’ incomes and costs; in reality, this is rarely how family finances work.

This chapter will examine in detail these costs, based on evidence gathered from Carers UK surveys of carers and Inquiry evidence sessions across the UK. Where possible the costs of caring and disability related costs will be distinguished, but in many cases it is more appropriate to examine the financial impact on the whole family unit of both disability and caring.

A further, very significant, ‘cost of caring’ lies in lost or reduced earnings as a result of taking on caring responsibilities. This will be addressed in section two of this report.

Figure 1: Carers UK’s *State of Caring* survey examined which extra costs carers were paying as a result of their caring responsibilities.





Key fact

► Carers of partners and disabled children were most likely to face higher utility bills.

“Compared to two loads of washing a week, it is now two a day. Every day.”

Utility bills

Higher utility bills were often the first costs identified when we asked carers about the ‘costs of caring’ at our evidence sessions and in our research surveys.

Over three quarters of respondents to the *State of Caring* survey identified higher utility bills as a cost of caring, rising to 85% amongst those living with the person they cared for.

Many pointed to higher energy bills because the person they care for needed a warmer than average house, and for heating to be used for more months in the year because they were unable to regulate their body temperature, or because they were moving around less.

Carers also noted that the perception of this as just a ‘winter bills’ problem is incorrect. If disabled or older people are unable to regulate their body temperature, then the impact of warmer weather on utility bills can be just as great.

“We seem to go straight from needing the heating on all the time to needing fans all over the place. This year I had heating on in May as my wife was still cold but then when it got just a bit hotter I had to buy fans for her bedroom and the living room and have them blowing 24/7 to keep her cool.”

Carers also reported that higher usage of appliances and equipment drove up their bills – from more intensive use of household items like washing machines and tumble driers or needing lights on during the night, to the energy used by specialist items like electric wheelchairs, hoists, adapted beds or suction pumps.

These bills were not simply increased by the needs of the disabled person. Carers often compared their energy consumption as a carer to ‘life before caring’.

Carers of partners (88%) and disabled children (79%) were most likely to face higher utility bills – reflecting likelihood of living with the person they cared for.

However additional costs were not limited to carers living with the person they cared for. At evidence sessions, carers often mentioned contributing towards the costs of utility bills of the person they cared for to ensure they could have the heating on enough, as well as the times when the person they cared for came to stay with them.

Carers who travelled to care for a loved one who lived elsewhere reported bringing home laundry for the person they cared for, and paying the costs of utility bills if the older or disabled person came to stay with them.

“Just so I get some time in my own home, I often bring Mum’s laundry back with me so I can have it running whilst I’m sorting my own things out.”

This was born out by a comparison between the costs faced by all carers and those living with the person they cared for. Almost all carers caring for partners and disabled children were living with the person they cared for, but significant proportions of carers caring for older

“I have used all of my modest amount of savings in supporting my household and paying my bills in order to care for my mother. I worry constantly and sleep very poorly.”

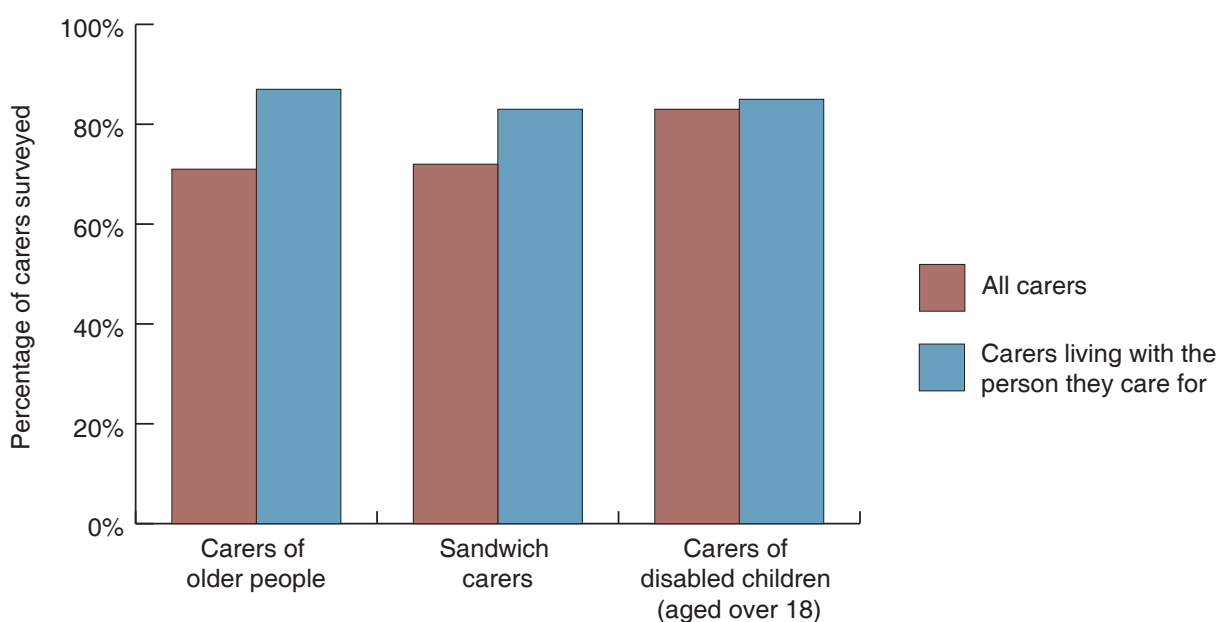
parents, sandwich carers³ and those caring for disabled children over 18 did not live with the person they cared for. As expected, higher fuel bills were more common amongst carers living with the person, and carers living with an older person they cared for were, alongside carers of partners, most likely to face additional utility bills.

The cost of utility bills was also particularly challenging for single carers – who were less likely to be in paid work or live in a household with anyone in paid work. This meant that they were more likely to be struggling with fuel bills, with half (50%) of single people saying they could not afford them. They are also less likely to be able to afford other household costs including their rent or mortgage payments and were 10% more likely than other carers to have been in debt as a result of caring.

“I am unable to leave the house to work. I have used my modest savings in supporting my household and paying my bills in order to care for my mother. We are dependent on her income and savings. I have no independence but I am responsible for all bills, financial decisions and outgoings. I worry constantly and sleep very poorly.”

An older carer in her 70s at our Llandudno evidence session in Wales noted that just the cost of the extra heating needed for her ill husband and the transport costs to take her husband and disabled adult child to medical appointments were almost the value of Carer’s Allowance each week, at almost £50. Yet as she received the State Pension she was entitled to no support from carers’ benefits.

Figure 2: Percentage of carers in different caring situations who pay higher utility costs (including for those who live with the person they care for).



Source: State of Caring survey

³ Those caring for a disabled or older adult alongside having dependent children under 18.

Lorraine's story

Lorraine from Bristol, lives with and cares for her 83-year-old mum, who has advanced Alzheimer's Disease. Five years ago, Lorraine gave up her job as an administrator to provide full-time care as her mum's health deteriorated.

"Due to mum's condition, she wants me with her 24/7 - but refuses even to let my sister help much. She gets up anything from between two and twenty times a night and needs me with her all day. I do not have a personal life. I do not go to the cinema or read. I do not get much 'me time'. I have to follow a certain routine with mum and go and do the same every day. She will not accept change in any way."

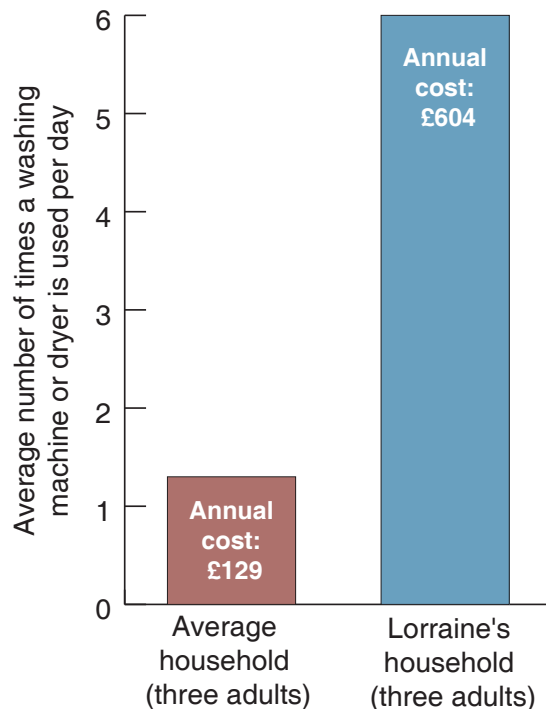
Lorraine rarely goes out beyond taking her mum to medical appointments and day centres, and does not have holidays or evenings out. They have been relying on savings to meet rising food and fuel bills. Lorraine's caring costs include:

- £4 a day to take her mum out on the bus in her wheelchair
- almost £10 a week in dietary supplements
- over £10 a week in personal care products, including a lot of antibacterial gel as her mum refuses to wash her hands.

Their washing machine and tumble drier is on at least three times a day. The additional costs that Lorraine faces as a result of this extra washing and drying alone are huge. A three person household without children (like Lorraine's but without the extra costs of caring and disability) would normally spend around £129 a year on washing and drying.⁴

In Lorraine's household, these costs would be at least £604 based on one hour cycles (which may be necessary for soiled sheets and clothing), or a minimum of £302 a year if she used shorter, half hour cycles.⁵

Figure 3: Lorraine's daily washing machine and dryer usage compared to the average household.



4 Based on figures from the Household Electricity Survey Final Report, 2012

5 This is based on appliances with ratings of 1200W (washing machine) and 2400W (tumble dryer) at a cost of 15.32p per kilowatt-hour of electricity (Energy Savings Trust). Often, washing machines and tumble dryers use more energy than this.



Key fact

► Transport costs were highest amongst parent carers of disabled children under 18 and sandwich carers.

Transport

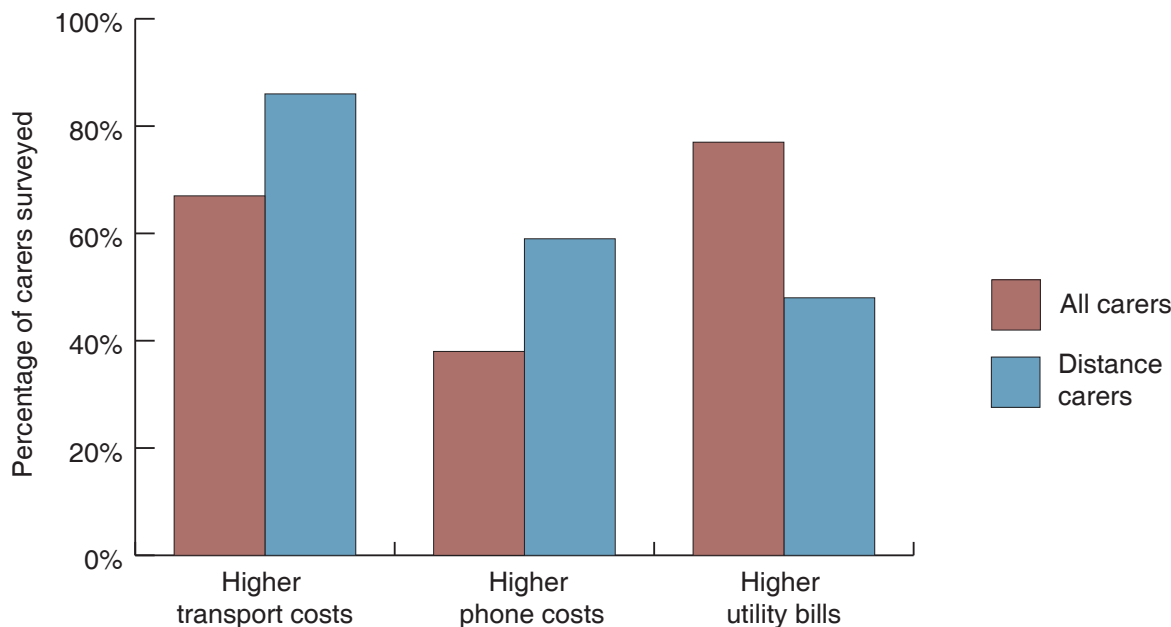
67% of carers faced higher transport costs as a result of caring, and this is highest amongst parent carers of disabled children under 18 (76%) and sandwich carers (73%).

Transport costs can be amongst the most easily identifiable ‘carer costs’ – particularly if carers travel to provide care for someone who does not live in the same household. Despite these considerable costs, distance carers⁶ are far less likely to receive financial support like Carer’s Allowance.

Those caring at a distance inevitably face lower household costs as a result of caring than carers who live in the same house as the person they care for. However, they do face very high costs in other areas. For example, only 48% of distance carers face higher utility bills because of their caring role compared with 77% of all respondents,⁷ but they are much more likely to face higher phone bills (59%, compared to 38% of all carers) and higher transport costs (86%, compared to 67% of all carers).

For example, one carer told us that she has to spend £15 on petrol four times a week to visit her loved one, in addition to buying healthy meals and driving to hospital appointments several times a year. Another carer told us that she spends £190 a month on travel and

Figure 4: **Costs faced by distance carers compared to total carer population.**



Source: State of Caring survey

6 For the purposes of this analysis ‘distance carers’ are carers caring for someone living over 30 minutes travel away.
 7 The reason that a lot of distance carers do still face higher utility bills and other household costs is because many of the carers who responded to our survey look after multiple people, so although they care from a distance they may also care for someone in their household.



38%

of carers face
HIGHER
PHONE BILLS

Key fact

- Carer companion passes for public transport may only apply when with the older or disabled person.

“After all the stress, tiredness and pain hospital visits mean for my dad, am I honestly going to turn around after I’ve dropped him home and tell him how much the bill is for using me as a taxi service?”

accommodation to visit the family members she supports.

“Fortunately my mum can cover her own costs at present. But she can’t afford to pay for us as well, for example to go out somewhere – and we can’t afford it either.”

“I travel 240 miles weekly now to visit and support two elderly people – my mum and mother-in-law. The extra petrol, tyres, insurance and the wear and tear to my car all costs me and I get nothing for it.”

Again, the policy response would be for financial transfers from disability or older people’s benefits to recompense carers for disability-related costs which they bear up-front – this is not so simple in reality. Carers at our evidence sessions noted that they felt unable to ‘charge’ an older parent, for example, for being driven to a hospital appointment.

“After all the stress, tiredness and pain hospital visits mean for my dad, am I honestly going to turn around after I’ve dropped him home and tell him how much the bill is for using me as a taxi service?”

“When my son needs to go to the doctor or hospital I have to travel to his independent living flat, then we get a taxi. He doesn’t have the money to pay it in the first place so I always pay.”

Travelling with the disabled or older person blurs what are ‘disability costs’ and ‘carer costs’ – purchasing your own ticket to accompany the disabled or older person on public transport is more easily identifiable, but the costs of driving them to a hospital appointment or day centre is less clear. Whilst some carers were able to access ‘companion passes’ for free or discounted travel when they were accompanying an older or disabled person this was far from universal. Others noted a significant flaw in many of these schemes – that the schemes often only applied when you are with the person you care for.

“So I have to go across town to get to Mum’s and then from hers to her GP, which is actually pretty close to her. The vast majority of that trip is getting to hers and back. The companion pass only saves me the costs of the middle part of the trip from hers to the doctor and back to hers.”

Parents of disabled children reported some of the highest transport costs – often from making long trips for specialist medical care. At our evidence session in Manchester, one participant noted that the need to travel for specialist hospital care meant frequent 70 mile drives. They had found rising fuel costs have had a significant impact on their ability to afford to travel. Carers in different evidence sessions noted that the rising costs of this essential travel made paying for any travel to see friends or family, socialise or take a break was becoming much harder or impossible. At the same session in Manchester, a carer described themselves as ‘virtually housebound’ as a result of not being able to pay to take the car out.

‘Costs you would never expect if you’re not a carer’ were a frequent theme at the evidence sessions. For example, a mother of a disabled son at our Edinburgh session, said that the only way they could calm

Key fact

> 'Advance Payments' of almost £2,000 can be required to access Motability vehicles.

down their autistic son when he was very upset and distressed was to take him on long drives. It soothed him and helped him to settle, but this costed a huge amount in petrol.

If carers provide transport for the person they care for to services like day centres and residential care, or to a friend or family member so that they can have a break from caring, then the carer may see themselves as 'feeling the benefit' of the replacement care. As a result they may think of these as 'carer costs' rather than seeing them as costs essential to fulfilling the care needs of the older or disabled person.

A large number of carers at evidence sessions reported depending on bus passes, particularly older carers, or on 'companion passes' which enabled them to travel on public transport for free alongside the person they cared for. However, others caring for someone with significant mobility needs, or for people with progressive conditions, noted that public transport had become unusable and that cars or taxis were unavoidable.

"Many things are more expensive as my husband cannot make use of things like his bus pass, or cheaper train travel, so we have to use the car for every journey he makes."

Regardless of their income, carers across all evidence sessions spoke about how using taxis had become a frustratingly essential part of their living costs. Reasons were varied, including: prohibitively long walks to bus stops for the person they cared for; the risk of not being able to get a seat; inaccessible buses, trains or stations; mental health conditions or learning disabilities resulting in fear, anxiety or potentially violent behaviour; unavailable rural transport; time-saving. Carers spoke about trying all alternatives but being unable to avoid high-cost taxi trips, made more expensive by some taxis charging for additional occupants and also the additional costs of accessible or larger taxis.

In Taunton, one carer said that he had no need of a car and could manage on public transport, but that to get his mother to appointments on time, he simply could not use irregular buses in rural areas which she struggled to and from. The time it would take to get to the bus-stop with her and walk at the other end, as well as the discomfort of walking for her, meant that travelling by car was their only option. As a result, he had bought a car and the total bill for him was in excess of £5,000 for the car, road tax and insurance. As he feels it is *his* car, he would not have considered asking his mother to pay.

The higher rate Disability Living Allowance mobility component enables families to access Motability vehicles. Throughout our survey work and evidence sessions families reported how essential these vehicles were in enabling them to manage essential travel related to care or medical needs and to have any independence or quality of life.

'Advance Payments' of almost £2,000 can be required up-front and a number of families were diverting income or borrowing from family members to save for this cost.

"The mobility car we have is wheelchair accessible and this time the advanced payment is £1195. We had to ask my husband's elderly

parents to use their savings for this as we do not have this sort of money. Ever.”

If they were car users, car parking charges, particularly for hospital parking, were a source of real anger amongst carers. Free in Scotland and Wales, and in certain circumstances in Northern Ireland, those carers paying for hospital parking charges in England not only pointed to the regular costs of parking for outpatient appointments but also the very high daily costs of travel and parking for inpatient stays. Many noted that, despite continuing to provide care by travelling to hospital during long hospital stays, because Disability Living Allowance is terminated for the disabled person during long hospital stays, the carer’s Carer’s Allowance is also lost – so carers lost their incomes but faced even higher transport and parking costs.

Hospital parking costs an average of £1.15 per hour, and some hospitals charge much more than this. Visitor and patient parking at some NHS hospitals costs as much as £3 per hour.⁸ While some families may be able to use public transport to avoid these charges, often the disability or mobility problems of the patient and sometimes the carer too, can mean families have no choice but to pay them.

“I ended up with huge debts by the time my late husband passed away two years ago. In the last year of his life there were very frequent trips to the hospital (including several emergency admissions), with at least one hospital admission lasting 10 days. I realised I’d incurred hospital parking charges in excess of £90 for the week when my husband was particularly poorly.”



Personal care products

Half of carers said they faced additional costs for cleaning or care products like detergents, disinfectants or disposable gloves and aprons.

“Every week it is Dettol, Savlon, Sudocrem, latex gloves, hand gel, aprons, IncoSheet, cotton buds and cotton wool, wet wipes, huge amounts of toilet tissue.”

These are disability related costs – but they are required because a family member or friend is providing care. If the disabled or older person did not receive personal care from a carer, the cost of these products would often be borne by the NHS or the local authority through homecare services. Families providing care are therefore penalised by bearing these costs themselves. Carers often report that the cost of these products, which enable them to provide personal care, come from their own pockets.

A minority of carers (18%) said they paid for incontinence pads, but it was significantly higher amongst people caring for someone with dementia (29%) or neurological conditions like Parkinson’s disease or Multiple Sclerosis (26%). Whilst many families reported receiving

⁸ Figures from the Health & Social Care Information Centre’s Hospital Estates and Facilities Statistics (2012/2013).



42%

of carers have to
**SPEND MORE ON
BED SHEETS**



34%

**SPEND MORE ON
CLOTHING**
because they care



49%

**PAY MORE IN
SHOPPING BILLS**
because of caring

some provision of pads from the NHS or local councils/trusts, for those who do not receive support, the cost is considerable. Even for relatively low usage, fully funding this kind of continence care would cost hundreds of pounds a year. Carers frequently reported having to supplement insufficient supplies from the NHS or local authorities or buy alternatives because those provided were unsuitable.

“We receive free pads for day use but none for night – so we have to pay for these.”

“The ones provided are too thick and they won’t change them. Because they don’t fit her properly they are useless so we have to buy our own thinner ones.”

“The incontinence pads provided are unsuitable but are the only ones on offer so we have to buy the entire lot ourselves.”

Incontinence and very frequent laundering also meant frequent replacement of bedsheets. 42% reported the need to buy additional bedsheets.

Carers reported that the clothes of the people they cared for also had a short lifespan – as a result of more frequent washing, additional wear and tear from being taken on and off several times a day, ripping and tearing whilst trying to take clothes on and off from people in bed and damage done to their clothes by people with learning disabilities.

“My daughter’s behaviour means she rips her clothes daily and her underwear needs constant replacement.”

“My son’s clothes are always getting ripped, torn, bitten – and ours are too.”

34% of carers spent additional money on clothes for the person they cared for, rising to 48% for parents of disabled children.

Clothing was also often more expensive or needed alteration to make it easier to put on and take off.

“I had to pay a lot to adapt clothes for him – £10 a polo shirt just to get a zip on them as he cannot do buttons!”

Food bills

Half of carers (49%) said they had higher shopping bills for food as a result of caring. A quarter (24%) said they were spending more on specialist foods, drinks or dietary supplements.

Disability or ill-health can increase food costs for a number of reasons:

- People with learning disabilities may have very specific and changing food preferences which result in large amounts of discarded food or a need to purchase high-cost items.
- Reduced or varying appetite may repeatedly lead to only small amounts of full meals being eaten.
- High calorie diets for older or disabled people who struggle to maintain their weight are often expensive.

Key fact

➤ 24% said they were spending more on specialist foods, drinks or dietary supplements.

Carer groups that were most likely to face high food bills were carers looking after adult disabled children (58%) and children under 18 (54%), sandwich carers (56%) and BAME⁹ carers (62%) – possibly because culturally appropriate foods can be more expensive.¹⁰

“For several days I might be making full meals but if her appetite just isn’t there, there are only so many leftovers you can freeze before it is just wasted.”

“The amount of money I spend on my son’s ‘food fads’... just to get him to eat anything I might have to cook several different things and it can change from one week to the next. Might seem wasteful to some people but it is the only way he will eat anything.”

A significant number of carers at our evidence sessions who were caring for someone who did not live with them reported having to supplement the food shopping of the person they supported. Because they felt that the disabled or older person did not have enough money to spend on quality or fresh food, a number of carers reported adding extra items, at their own expense, to the shopping lists they were given by the people they supported to ensure a full and balanced diet.

Carers also noted the impact that caring had on their own diets. Alongside widespread concern about their ability to afford or find the time to prepare good quality meals, carers noted that ‘eating on the go’ often incurred extra expense because of the cost of constant snacking and convenience foods.

“On the budget we are on I would cook every meal from scratch if I could - to save money. But the reality is often a sandwich and crisps at a service station or from a hospital shop – which costs far more than a proper meal at home would cost and is unhealthy all the time.”

“My husband’s movement and coordination leads to a high number of breakages – crockery, furniture and fittings. I constantly need to fix or replace household items.”

Furniture and white goods

One of the clear themes to emerge from discussions in the evidence sessions, which was not captured by our survey, was the cost of buying and replacing furniture and white goods.

Damage to furniture was a particular challenge for families caring for a child with autism or learning disabilities:

“My husband’s movement and coordination leads to a high number of breakages – crockery, furniture and fittings. I constantly need to fix or replace household items.”

“It is the cost of repairing damage to our house and contents. Violent temper tantrums that my son has led to replacing doors, fixing holes in walls, replacing items like the telephone, television, beds, bedding, lamps, furniture and carpets.”

⁹ Black, Asian and ethnic minority

¹⁰ Cost being driven up by culturally-specific foods being rarer - for example, needing to be ordered-in by shops or online.

“My son got through ten beds before he was 16. He would break them when he had a ‘meltdown’, or just from the daily impact of him throwing himself down on it, which we can’t stop him doing. I gave up buying good quality ones as he broke them just as fast and then the higher cost was a complete waste of money. Other parents would just have to buy one or two beds and that would last them.”

At our Leeds evidence session carers spoke about needing to replace items, not just more frequently but also more urgently. Carers are often very savvy consumers, and shopping around for appropriate and good value products is second nature. But the need to replace essential items urgently can make this impossible.

A carer at our Sutton Coldfield evidence session said:

“It sounds funny but we have spent so much on toilet seats. My wife’s mobility is bad and even with me helping get her onto the toilet she normally comes down with such a bang that they keep breaking. What ever kind we get they break. We have had to buy them again and again at £15 a time.”

These ‘distress purchases’ meant that they felt forced to spend more on buying white goods in particular. When an essential item like a fridge or washing machine broke, they needed replacements quickly as they struggled to access temporary alternatives, like laundries, but also did not have the time to ‘shop around’ or wait for longer delivery times.

“The washing machine is on every day. It isn’t designed for that sort of use and this means it breaks, but when it breaks I have piles of soiled laundry building up. I can’t leave the house to get to a laundry every day so I need a replacement as soon as. Normally I’d visit shops and look online but I don’t have time and the best deals can take longer to deliver: it comes down to whoever can get me a replacement the quickest.”

Equipment and adaptations

“The minute anything is labelled as a ‘disability’ product it suddenly seems to add 50% to the price.”


We asked carers which equipment and adaptations they paid for themselves, as opposed to costs paid for from the savings or income of the disabled or older person. 14% of carers had spent their own income or savings on equipment for the person they were caring for. 11% were spending on technology like telecare.

A number of carers at our evidence sessions noted delays meant they had felt forced to use their own savings or income to buy products which should have been provided by local authority grants or NHS funding. Others were unaware that certain benefits could ‘passport’ them to additional support so paid for services or products for which they could have received financial support.

“We paid £3,700 for a mobility scooter, £500 for ramps and £9,000 for our adapted car. Almost all of our savings have gone.”



“The minute anything is labelled as a ‘disability’ product it suddenly seems to add 50% to the price.”



“Caring has cost me my career, and my husband and I our savings, hobbies, health, opportunities, self-fulfilment, friends and quality time together. We get no respite. How can we put a value on such huge personal costs?”

Annie's story

Annie gave up her teaching career to care full-time for her son James who has cerebral palsy and suffers mental health problems. Annie is now 59 and James is 35. He lives independently, in a council house, five minutes from his parents' Yorkshire home. James needs daily care support from his mum and his step-dad, Annie's husband Peter.

Annie and Peter, who is 65 and a semi-retired lecturer, have for a number of years also cared and supported Annie's parents who until recently lived 70 miles away on the North Yorkshire coast. Aged 86 and 84, their increasing care needs have meant that both have now moved to, different, residential homes, with Annie and Peter continuing to provide considerable care and support.

James is in receipt of benefits, but increasingly these are insufficient to meet all his care and support needs and must be topped up by his parents. With the rates of cash payments for social care failing to keeping pace with price rises, Annie and Peter must also supplement devaluation of the financial support provided by the local authority.

Annie and Peter take care of their son's laundry and cleaning, they provide transport to all his medical, dental and care-related appointments, they look after his finances and paperwork, fund the upkeep and replacement of furnishings and general maintenance of his home and are on call day and night to make sure he has all the support he needs. Everyday tasks like laundry incur easily hidden costs for carers like Annie and Peter. James's condition causes frequent vomiting, with need for frequent washing, drying and replacement of bedding. Annie and Peter also do large volumes of washing for Annie's parents. As well as adding to daily utilities costs, they need to repair and replace white goods with much higher frequency than families would normally expect.

Regular long distance travel to support and care for Annie's elderly parents has also made a huge dent in the family purse. In one year they spent £1,000 on petrol alone travelling to and from the coast.

Despite Peter's pension and his continuing to work part-time in retirement, the couple have seen their savings almost totally depleted through the costs of caring for the different generations of their family. Annie has been advised that if she were to claim Carer's Allowance it would result in a deduction from her son's benefits.

"Caring has cost me my career," Annie says. "It has cost us our savings but also our hobbies, health, opportunities, self-fulfilment, friends and quality time together. We get no respite. How can we put a value such huge personal cost?"

There was a great deal of confusion, also reflected in the purchasing of care services, as to when adaptations and equipment were a ‘disability cost’ or where carers felt they were a cost for them as a carer to help them to care.

Carers often said that decisions to purchase equipment or invest in adaptations was as a result of injury or declining health on their part – as they no longer felt physically able to lift a disabled child, turn or roll a disabled adult, or help an older parent or partner climb the stairs. Similarly there can be a perception that telecare and telehealth products and services are ‘carers services’, because they can reduce pressure on carers and give them peace of mind when they are out of the house, or if they do not live with the person they care for.

As a result, some carers felt the costs of adaptations, technology or equipment were being incurred to support them and in some circumstances were paying themselves.

Care and support services

As with equipment and adaptations, carers can end up paying for care services that provide replacement care for the person they care for or which assist them, as carers, in the provision of care.

Charging for care services varies across the UK – with the provision of free personal care in Scotland and Northern Ireland, caps on home care charges in Wales, and a lottery of care charges across English local authorities.

However, carers across all parts of the UK reported paying for different kinds of care services - sometimes local authority charges, topping up cash payments or services from local authorities which were insufficient to buy-in the care needed, or privately purchasing services

Key fact

➤ 34% of carers receiving breaks were paying for them out of their own income.

“Carers are constantly told that they must ‘look after themselves’ but no assistance is given.”

Table 2: The percentage of carers that are paying for specific care services and support themselves.

Care services and support	Percentage of carers receiving specified support who pay for it themselves
Breaks from caring	34%
Occasional use of residential care	18%
Equipment and adaptations	17%
Technology like alarms or sensors	13%
Support from care workers	10%
Use of day centre	9%

Source: State of Caring survey

“In the past year we have had to pay at least 50% more for care as we simply could not manage as we had been. I was exhausted, running out of savings, and generally at the end of my tether.”

when the person they cared for was not eligible for state services or where those services were not appropriate.

Many carers were not receiving any practical support, but 13% of all carers were spending money on replacement care to get any time off from caring. This represented a third of all those receiving breaks from caring.

Paying for care was a particular discussion topic at our Jarrow session, where one carer described the often prohibitive cost of replacement care as the cost of ‘just getting out of the door’. Whether it was to enable them to have leisure activities, to spend time with friends or family, to work or even to fulfil other caring responsibilities, carers described incurring significant bills in order to access support.

“Carers are constantly told that they must ‘look after themselves’ but no assistance is given. For example, a care worker costs me on average £15 an hour so if I wanted to go to the cinema I would need to spend over £60 just to leave the house – on top of that is the cost of the travel and my cinema ticket. So going to see a film in the cinema would mean spending towards £100. It never happens. I just can’t afford it.”

“Care worker agency prices go up a little each year. It now stands at about £16 an hour and that is doubled for us as my husband needs two care workers to operate his hoist.”

In these circumstances, carers can feel that they are getting the ‘benefit’ of care services, so often end up paying for services themselves. In fact the services are fulfilling the care needs of the disabled or older person so should not, in most cases, be a cost incurred by the carer.

As part of our work on the Care Bill (England only), Carers UK has examined the implications for charging carers for care services and has been concerned about the confusion around the division between carers’ services and disabled or older people’s services. Across local providers, some carers groups and local authorities we have seen examples of practitioners who consider services which deliver support to an older or disabled person to be ‘carers services’, because those services also alleviate pressure on the person’s carer. Where there is confusion amongst social care professionals, there is little wonder that carers themselves can be confused as to whether care services should be paid for from their income or the income of the person they care for.

The cost of these services can be high. The most recent average unit cost for provision of home care in England was £17 an hour¹¹ – this means that a weekly bill for just two thirty-minute visits a day from care workers to help with washing, toileting or getting in and out of bed would cost almost £120 a week.

“I can only afford for them to come in for 30 minutes each day, when I need them to help me toilet, wash and change Mum. I get

¹¹ *Personal Social Services: Expenditure and Unit Costs England 2011-13 release* (2012) NHS Information Centre for Health and Social Care

Key fact

► Two thirds of older carers are paying towards care services, compared to half of working age carers.

“In the past year we have had to pay at least 50% more for care as we simply could not manage as we had been. I was exhausted, running out of savings, and generally at the end of my tether.”

everything ready for when they arrive. Then they are there to help me lift, turn and wash her. Sometimes it isn't really enough time and I'm left to clear everything up. But I couldn't physically do it without their help.”

During our evidence sessions and in our survey of carers, they repeatedly noted the comparison between the costs of replacement care and Carer's Allowance, which is paid at £59.75 a week for 35 hours or more of care provided.

Carers also reported that in many areas charging for care services was rising, with 31% of respondents (in England) to our State of Caring survey reporting that charging for care services for the person they care for or for carers services had increased. Although capped charges in Wales and Northern Ireland and the provision of free personal care to older people in Scotland offered some protections to carers outside England, significant proportions of respondents in these areas - 26% in Scotland, 22% in Wales and 13% in Northern Ireland. In areas where free personal care is provided, this is likely to reflect the rising cost of other (non personal care) support services which are not free and for those who do not qualify for free care (eg. working age disabled people in Scotland).

A carer at our Glasgow evidence session talked about the costs of replacement care services for her disabled daughter so she could go ‘to provide childcare for my grandchildren like other grandparents, or just spend time with them as ‘Granny’’. Others noted that taking a day off from caring, particularly if it included a night away from home, would cost more than a month's worth of Carer's Allowance.

“Services such as care would amount to around £19 per hour and this is prohibitive to me. My wage income does not stretch that far as heating costs and good nutrition have to take priority.”

Older carers were substantially more likely to be paying for care services (two thirds of older carers were paying towards care services, compared to half of working age carers) – reflecting the greater likelihood that older people will have savings exceeding the social care means-test and will not qualify for free services. In addition, compared to those working-age carers who were paying charges, older carers faced far higher charges with 32% of carers paying charges for care and support services paying in excess of £200 a month, compared to 18% of working age carers.

For others, the cost of replacement care was not the issue, it was availability. A carer in her late 70s who attended our Birmingham advice session said:

“Financially we are okay. The bills are no problem and we can afford to pay for care services, but there are no services there for him.”

Her husband, who attended the session with her, had dementia. Because he was very mobile, their local dementia day care centre had refused to give him a place as they were not geared to providing support for clients who were active and mobile. As a result, they had been placed on a waiting list for a service further away but had no

Key fact

► 18% of carers were using their own income to pay for help with household chores like cleaning or shopping, rising to 22% of carers caring for a disabled or older partner.

information on how long they would have to wait. The carer had only 3 hours' time off from 24/7 caring responsibilities per week, when her brother visited to sit with her husband. She said she was nearing breaking point.

Beyond replacement care, carers are also paying for support with other household tasks like cleaning, laundry and shopping.

18% of carers were using their own income to pay for help with household chores like cleaning or shopping, rising to 22% of carers caring for a disabled or older partner.

At our evidence sessions in Leicester, Leeds and London in particular, carers raised concerns that the value of direct payments was failing to keep pace with the costs of care services. In some circumstances, just as the costs of care were rising, families reported cuts to the amount of the direct payment. Shortfalls in the ability of direct payments to buy sufficient services were often being met by carers.

"We were told when direct payments started that it would help his choice and independence and be enough to give him what he needed. But things have changed. We're now told that travel to some things, some social activities and things he likes to do, cannot be covered by direct payments. That's the whole care plan gone. If they can't pay for it, who ends up paying?"

Alongside their own financial worries, when asked about financial concerns, significant numbers of carers across our evidence sessions raised the stress of managing direct payments, care worker payroll and compiling and submitting accounts, invoices and receipts.

Domestic support

Domestic support typically costs less than care services, so replacing these household tasks can be more cost-efficient than buying care. In addition, if families also struggle to access reliable, good quality care services, domestic support may be the only option in relieving pressure on carers. Older carers were twice as likely to use domestic services than the working age population (16% compared to 8%) and the vast majority were using their own income to pay.

Key fact

► 1 in 8 carers (13%) and 1 in 6 carers caring for over 50 hours a week have had to cut back on support services to make ends meet.

Impact of rising living costs

"The 'cutting back on essentials' happened last year. I'm NOT coping now."

In addition to coping with rapidly rising living costs, carers and disabled people have been affected by a number of changes to benefits uprating and the rise in VAT in 2011. In our evidence sessions the cost of living was a source of fear, stress and worry amongst both those struggling to make ends meet and those who were able to pay their bills. Many reported how noticeable the degradation of their buying power had been, with the message 'we were struggling already, how are we expected to manage now?' repeated across the country.

“My health suffers due to very poor diet. I am very cold in winter and summer. I live in a basement I cannot heat. I support my son to heat his flat and I cannot heat my home.”

The rise in VAT, implemented in January 2011, has had a disproportionate impact on many carers and disabled people, given their additional expenditure on VAT-rated products, like cleaning materials, detergents, incontinence pads, bed clothes and bandages.

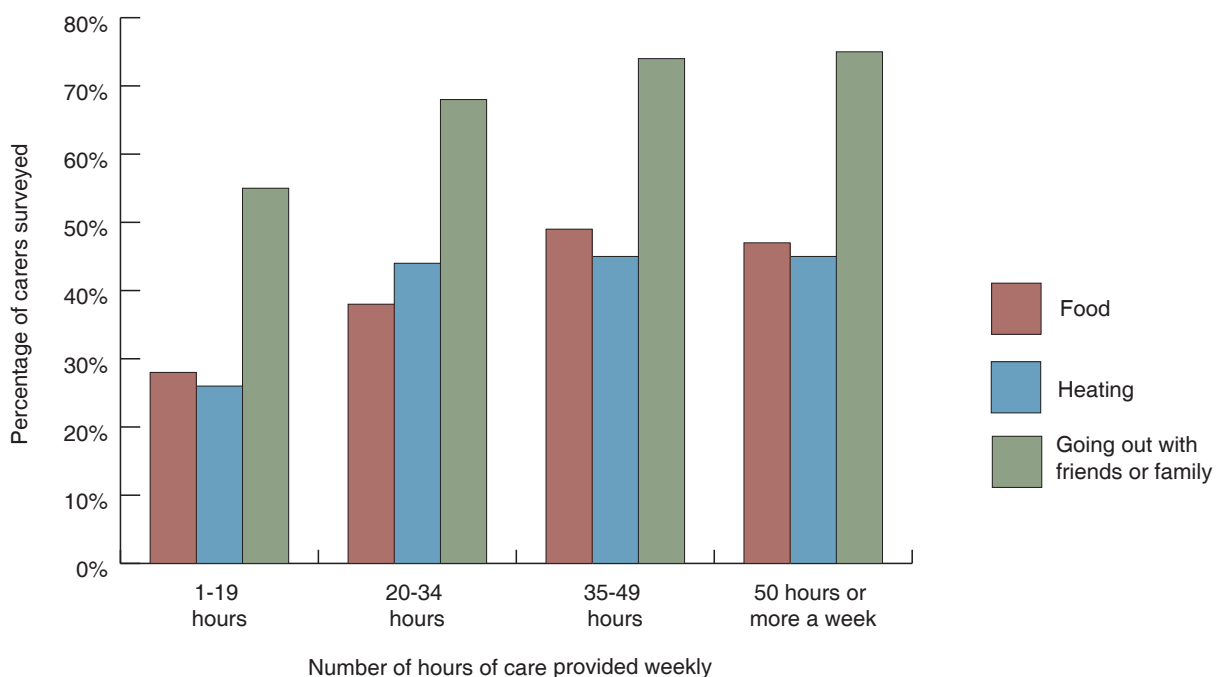
Carers reported that the only way to manage rising bills was to forgo food and heating themselves to ensure the person they care for had everything they needed – including turning off heating in their own homes in order to pay for additional energy consumption for a loved one living elsewhere, or not using heating at times when the person they cared for was at a day centre or school in the cases of disabled children.

“My health suffers due to very poor diet. I am very cold in winter and summer. I live in a basement I cannot heat. I support my son to heat his flat and I cannot heat my home.”

Whilst Carer’s Allowance and Disability Living Allowance were exempt from the Government’s freeze on benefits from April 2013, other benefits which carers and their families receive saw real-terms cuts as a result of a below-inflation rise of 1% – including Income Support, Employment and Support Allowance and Housing Benefit, the couple and lone parent elements of Working Tax Credit, and the child element of Child Tax Credit. The switch from RPI (retail prices) to CPI (consumer prices) has also significantly degraded the value of Carer’s Allowance. These changes will be explored in more detail in Chapter 4.

The impact of rapidly rising living costs and the rise in VAT is likely to be exacerbated for carers and disabled people as a result of additional expenditure on VAT-rated and high-inflation products and services, particularly food, heating and electricity bills. These multiple pressures

Figure 5: Percentage of carers cutting back on essentials (by weekly hours of care provided).



Source: State of Caring survey

have significantly undermined the ability of families, many who were already struggling to make ends meet, to afford their basic bills.

There was also significant evidence that the carers providing the highest levels of care are cutting back the most – when they are already least likely to be in employment and already facing the greatest financial hardship.

Particularly concerning was a similar correlation between hours cared for and carers being forced to cut back on care and support services because they are struggling to pay their bills. 1 in 8 carers (13%) and 1 in 6 carers caring for over 50 hours a week have had to cut back on support services to make ends meet.

For carers who are caring round the clock, and often already struggling because of a lack of support, further reductions in this support could be highly dangerous, resulting in a serious impact on their physical and mental health.

Savings and debt

Loss of savings and then debt can often result from a sharp increase in living costs at the same time as reduced or lost earnings. It can quickly become difficult to maintain existing non-disability-related household expenditure on rent, mortgage payments, existing credit payments and contracts (for example insurance, mobile phone, TV or internet packages); with the additional costs of caring as well, families can rapidly see savings dwindle and then face the risk of debt.

“We no longer have any savings or any kind of funds for later on – we have even cut our insurance.”

Of carers who had any savings:

- Over half (55%) were using them to pay their everyday living costs.
- 38% had used over half of their savings.
- 1 in 8 (13%) had used almost all and a further 10% had used all of their savings.

High and rising charges social care charges (where applicable) for people with more than a small amount of savings, leave families entirely liable for the costs of home and residential care. If they access care and support services, this can result in a rapid loss of savings until families drop down below relevant social care means-test levels.

“Hourly rates for support workers coming in have increased by 4% in the last year. This means accelerated spending of savings. Necessary expenditure, such as upgrading bathroom or kitchen facilities, cannot be made.”

- 4 in 10 (44%) carers had ended up in debt as a result of caring.
- Debt was far higher amongst families who had used up their savings or had none when they started to care, with 69% finding themselves in debt.

Key facts

Of carers who had any savings:

- Over half (55%) were using them to pay their everyday living costs.
- 38% had used over half of their savings.
- 1 in 8 (13%) had used almost all and a further 10% had used all of their savings.

Key fact

➤ 1 in 7 carers were in over £10,000 of debt.

“House was repossessed as I could not keep up the full mortgage payments. I owe £20,000 to the mortgage company plus a secured loan.”

Working-age carers caring for partners, who are most likely to see the loss of all paid household income, were more likely to fall into the red, with over half (51%) telling us they were in debt as a result of caring. They are also most likely to be using savings to meet everyday living costs or to pay for support with caring (46% were doing this, compared with 36% of all carers).

A carer attending one of our evidence session in Wales who had been pushed into debt as a result of caring talked about the ‘constant worry’ about finances. She listed costs of hundreds of pounds a month in transport costs, higher electricity and oil bills, the costs of care products, care workers and telecare equipment and talked about the frequent risk of losing her Carer’s Allowance when her husband needed to go into hospital.

Where both the carer and their partner had given up work, particularly as a result of a sudden-onset condition, carers reported struggling to adapt their finances to such a huge drop in income. Many found it impossible to quickly reassess every item of household expenditure or have the time to cancel subscriptions, change insurance policies or seek cheaper accommodation - as they were also adjusting to the physical and emotional demands of caring and the shock of a life-changing moment. Unable to reduce spending fast enough, debt was the inevitable consequence.

“House was repossessed as I could not keep up the full mortgage payments. I owe £20,000 to the mortgage company plus a secured loan.”

Parents of young disabled children and sandwich carers were also hard hit by debt, with 58% and 59% respectively facing debt as a result of caring – these are often younger families who have had less of an opportunity to build up the financial resilience that comes with savings or owning a property before caring affects them. This is also reflected in the fact that debt levels fell amongst surveyed carers higher up the age spectrum:

- 61% of 25-39 year old carers were in debt, compared to 53% of 40-54 year olds, 40% of 55-64 year olds and 18% of carers over 65.

However this does not mean that older carers escape debt – particularly those who enter retirement with caring responsibilities.

Of carers over the age of 65, 17% of those who had begun to care after they had retired were in debt, compared to 27% of older carers whose caring responsibilities had started prior to retirement and were likely to have had an impact on their earnings.

Carers also reported that the amount of debt they found themselves in was substantial.

Of those reporting they were in debt as a result of caring:

- 1 in 10 (11%) said that the debt was less than £1,000.
- 22% said they had between £1,000 - £5,000 of debt, and 13% had between £5,000 - £10,000.
- 1 in 7 (15%) were in over £10,000 worth of debt.

Key fact

► Carers who had missed out on benefits were 11% more likely to be in debt as a result of caring.

Carers who have a health condition or disability themselves were also particularly likely to find themselves in debt. Of carers who also received disability benefits, 59% had been in debt as a result of caring (compared with 44% of all carers). They were also more likely to have very high levels of debt, with 9% of these carers facing debts of more than £20,000. This may be because they face additional costs of ill health or disability – for themselves as well as the person they care for – but also because they are likely to have lower incomes. 70% of carers in receipt of one of these benefits had a household income of less than £1,500, compared with 55% of all carers, and only 27% lived in a household where someone was in paid work.

Debt is also often lasting, as families see a long-term impact on their ability to earn.

Even if benefits were sufficient to maintain household income they are rarely enough to enable carers and the people they care for to pay off debt.

“Still paying off debts incurred whilst caring for my late husband, nearly two years after he passed away.”

Often debt and financial hardship were exacerbated by the delay between the financial impact of caring starting (loss of earnings and the incurring of extra costs) and then receiving support from benefits. This can be as a result of a lack of advice and information or delays in getting the right diagnoses or assessments in order to claim disability and carers’ benefits.

Carers who had missed out on benefits were 11% more likely to be in debt as a result of caring, 5% more likely to be using their savings to pay everyday costs and 4% more likely to have no savings at all.

Carers also noted the impact of losing carers’ benefits¹² if the person they cared for spent longer periods in hospital. They lost financial support, despite the fact that they were frequently visiting and providing care to them in hospital and were continuing to incur sometimes substantial costs. This could rapidly push them into debt.

“My daughter was in hospital for months and I was with her for hours each day to provide the care she needed as her needs were so high and so specialist. The travel and having to find accommodation next to the hospital cost me a vast amount – but my Carer’s Allowance had been cut off long ago because her DLA stopped.”

A carer attending one of our evidence sessions in Wales who had been pushed into debt as a result of caring talked about ‘constant worry’ over finances. She listed costs of hundreds of pounds a month in transport costs, higher electricity and oil bills, costs of care products, care workers and telecare equipment and talked about the frequent risk of losing her Carer’s Allowance when her husband needed to go into hospital.

¹² Disability Living Allowance or Attendance Allowance are typically stopped after a disabled person has been in hospital for 28 days. This means that Carer’s Allowance is also terminated.

Key facts

- > 42% of carers have missed out on financial support.
- > 66% of those missing out did not receive advice.

Missing out

- > 42% of carers have missed out on financial support as a result of not getting the right information and advice.
- > 51% of those missing out simply did not realise that support was available.

When caring responsibilities start often the pressures of providing care, either full-time or alongside work and family commitments, mean that planning for the future and accessing advice come second to the day-to-day practicalities of providing care and support.

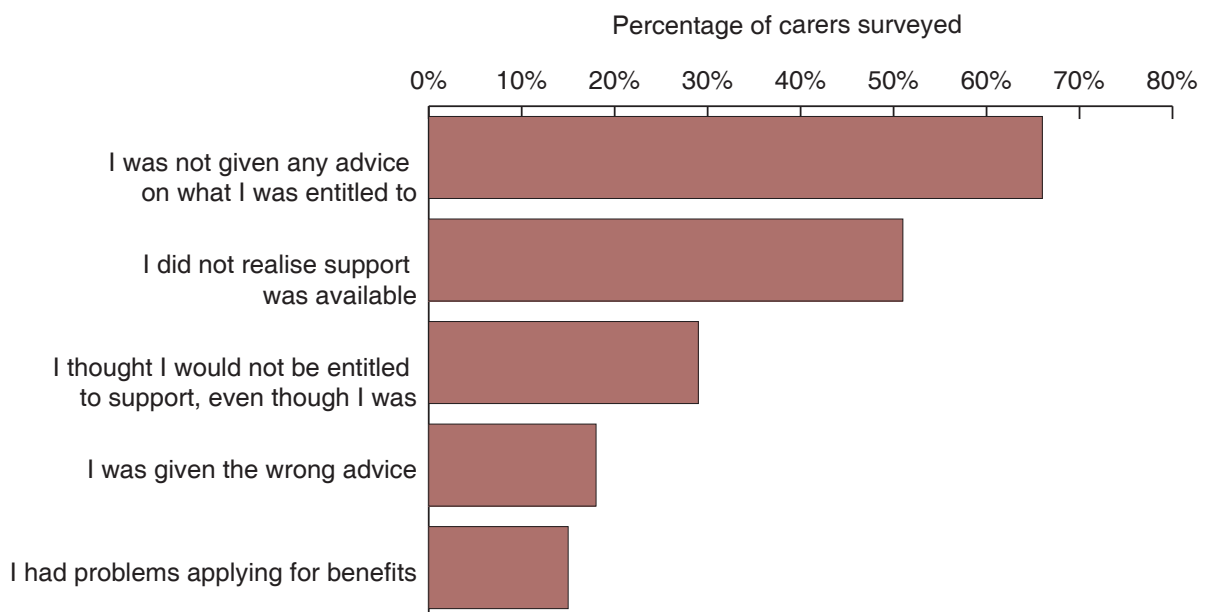
‘Carer identification’ is also a crucial issue. Many people providing care, unpaid, do not see themselves as a ‘carer’ but instead as a son or daughter, a partner, parent or friend who is supporting their loved ones. Not seeing themselves as a ‘carer’ can clearly be a significant barrier to making a claim for ‘carers’ benefits, services and support; many say that it did not occur to them that financial support was available to help them with what felt like a normal part of family life.

Research from the Centre for the Modern Family found that over a quarter of those providing care (27%) did not consider themselves to be a ‘carer’.

- > 29% of those missing out thought they would not be entitled to support even though they were.

Too often opportunities are missed to provide early advice on the right disability and carers’ benefits to claim, carers’ flexible working rights or how to access practical support with hands-on care. Key professionals like GPs or social workers can play a decisive role in

Figure 6: **Reasons why carers missed out on support.**



Source: State of Caring survey

Key fact

- 50% of BAME carers missed out on essential support because they didn't get the right advice and information.

supporting not just the person needing care, but in letting their families know how important advice on caring is. However this step is frequently missed and families can go for months or years not realising they are missing out on support they are entitled to.

- Two thirds (66%) of carers missing out on financial support attributed this to not receiving any advice on their entitlements.

“Carers should not have to go hunting for what they are entitled to. It should be like child benefit is to parents. You have a right to it and it should be flagged whenever the caring starts and put in place with no fuss. It should be flagged up by GPs, social workers and care workers and the carers should have things explained to them and have support from professionals who should work hand-in-hand.”

Our Slough evidence session demonstrated the combined impact of a lack of carer-identification (both ‘self-identification’ – recognising themselves as ‘carers’ – and identification from advice agencies and statutory services) and language barriers amongst BAME participants. None mentioned cultural barriers or unwillingness to claim entitlements - but instead lower takeup seemed to stem from the a combination of the complexity of the systems with technical social security language which was also noted by BAME carers at other evidence sessions, particularly in Islington in London.

Many participants were only receiving benefits because of intensive support from local groups like Islington Carers Hub, Carers UK’s Slough branch and the Age Concern which hosted the Slough event. Carers reported missing out for years before getting advice, but even after receiving support, their awareness of the benefits system remained low, with a number being unsure what their current package of benefits consisted of.

- Half (50%) of BAME carers missed out on essential support because they didn't get the right advice and information, compared to 42% of all carers.

At our Jarrow session, carers told similar stories which were echoed by professionals from local services who attended. The clearest illustration of this was from one attendee who did not self-identify as a ‘carer’ and had not previously sought advice or support, but had seen the session promoted in the local newspaper. She was combining full-time work with caring for her mother who had early-stage dementia. Her mother was refusing any support except from her daughter, who said that she feared the strain of work and caring would mean that work would very soon become impossible. She was at a complete loss, and had no idea that her mother might be able to access practical or financial support, or that if she did give up work to care for her mother, she may be entitled to Carer’s Allowance.

Parents of disabled children under 18 were 5% more likely than other carers to have missed out on financial support because they didn't have the right advice and information (47%, compared to 42% of other carers). Parents of disabled children over 18 were also likely to have missed out (46%) and, strikingly, 23% of these carers had gone without the support they were entitled to for over 15 years. Parent carers often attributed this to the challenges of being recognised as a

Key fact

- An estimated 360,000 carers miss out on a total of £1.1 billion in Carer's Allowance.

'carer' and 'not just a parent' - with worrying stories of health and social care professionals telling parents of disabled children that they should not expect support like carers of disabled adults, because they had 'chosen to have children.'

Even a few months of lost benefits can make the difference between families being able to adjust to the financial impact of caring and falling into lasting debt.

Of carers missing out:

- 10% missed out for up to six months and a further 10% for between six months and a year.
- 21% missed out for between one and two years and 40% missed out for between two and five years.
- 22% missed out for between five and ten years.
- 16% missed out for over 10 years.

"I had to leave work when my son came out of hospital after his accident and needed me there all the time. I just cared for him as any mother would, and we managed on my husband's wage. It wasn't until 10 years later when my son was ill and had to go into hospital that someone asked if I was getting any help and we found out he could get DLA and I could get Carer's Allowance."

This family will have lost out on a minimum of £25,000 in disability benefits and £30,000 in Carer's Allowance – £5,000 a year in income.

Updated estimates from Carers UK show that around 360,000 carers may be missing out on a total of £1.1 billion in Carer's Allowance¹³.

Not only does this mean that carers do not have the weekly income of £59.75 but they also miss out on National Insurance contributions – leaving them at risk of receiving only a reduced pension in retirement.

Cutting back

The combined impact of falling income and rising costs, rapidly dwindling savings and increasing debt is leaving substantial numbers of carers unable to afford basic bills.

- A third of carers (36%) cannot afford to pay their utility bills.
- One in five (19%) cannot afford their rent or mortgage payments.

Families providing care are facing the bleak choice of cutting back on essential expenditure to make ends meet.

A carer in her sixties at our Llandudno evidence session said:

¹³ The following figures set out the numbers of existing Carer's Allowance claimants, the existing total value of Carer's Allowance claimed, the estimated number of carers who are eligible and the total value of the estimated eligibility. In the final two columns are the estimates for the number of carers missing out (based on an estimated take-up of 65%) and the total value of Carer's Allowance missed out on, by nation, region and local authority. Based on Department of Work and Pensions Carer's Allowance take-up figures from May 2013.

“My husband and I worked slavishly to pay off our mortgage but the cost of caring for him mean that, since his death, even without housing costs, I now struggle to pay my basic bills from means-tested benefits. I am teetering on the edge by using my bank overdraft and have occasionally resorted to borrowing money from friends and family.”

- 45% were cutting back on food and 44% on heating.
- Three quarters (73%) had reduced spending on clothes.

“I can’t cut back on heating as my son will get very ill. We rely on school food and I will sometimes get by on biscuits so he can eat normally. No longer get any clothes for me and I am running out of decent clothing. My son has second hand clothing, other than shoes and coat.”

The cost of having any kind of social life was often the first to go, with three quarters (73%) of carers cutting back on spending to see friends or family, 43% reporting reducing costs by using the phone less and one in six (16%) had cut back on internet usage. One in eight were cutting back on care services to help them to care.

Unable to increase earnings to boost their incomes, carers were being forced to turn to credit.

- 22% were using their overdraft and 20% were using credit cards to cope with living costs. One in ten (9%) had taken out loans.
- Over half (53%) reported that money worries were affecting their health.

Carers who have an illness or disability themselves were most likely to say that their financial circumstances were affecting their health (71%) and this was also high among sandwich carers (70%) and carers looking after a partner of working age (60%).



Leslie and Darren's story

Lesley and Darren have four daughters – Gabrielle, 19, Olivia, 17, Fleur, 10 and Amélie, 9 who has CHARGE syndrome, a rare condition resulting in multiple and profound disabilities.

Amélie has no hearing or speech, is partially sighted, and suffers chronic lung disease and is oxygen dependent and tube fed. Amélie's disabilities mean she has very poor balance. She is now able to walk, but until the age of seven was in a wheelchair. Her health is very fragile. Winter months are a time of particular anxiety for the family. Amélie's chronic lung condition means they must heat their home 24 hours a day for at least 7 months a year. This winter Amélie has already had three emergency hospital admissions as a result of severe respiratory illness.

The costs of care associated with Amélie's health are high. Keeping the house heated year round, running oxygen cylinders and medical equipment day and night, high water usage that results from extra bathing, clothing, bedding and washing that come with being tube-fed and incontinence have resulted in massive debts for the family.

When Lesley fell pregnant with Amélie both she and Darren were in full-time employment earning a joint income of over £50,000 a year. Lesley was working as a dental practice manager and Darren was a railway engineer. When Amélie was born, family life was shaken to the core. Alongside coming to terms with Amélie's disabilities and working out how they would, together manage with their newborn daughters extra needs, Lesley and Darren also had to make difficult decisions about how they could cope financially. Shortly after Amélie was born Darren was made redundant, compounding the challenges they faced.

Inspired by the support of the midwife who helped deliver her youngest daughter Lesley decided she would retrain while Darren, who is 49, took on the role of full-time carer. As a result of the financial strain they face Lesley, 46, not only works full-time as a midwife but must also take on extra bank shifts.

“If I could change anything it would be the financial burden. Even if everything in the house is going well, there is still that financial worry hanging over us”

The family’s daily routines are relentless, with both parents surviving on but a few hours sleep a night, and the girls all playing a hands on role in helping look after their sister. Even everyday family functions like the school run, supermarket shop or dropping mum at work for an early shift are a logistic challenge, hugely stressful and exhausting.

Amélie’s health and nursing needs are high and she needs care around-the-clock. Finding any support is an ongoing battle and Lesley and Darren struggle to find care workers who are adequately trained to meet both meet Amélie’s nursing and communication needs. They qualify for 14 days respite at a local hospice which, Lesley’s shifts permitting, offers some opportunity to catch up on rest in the hospice flat.

Despite having a full-time income supported by additional hours, the family are struggling with thousands of pounds of debt. Amélie’s frail health, in particular the need to protect her from cold and damp, have led to quadrupled utilities bills. They owe £5,000 on outstanding electricity bills, £3,500 on gas, £2,000 on water bills and have accumulated council tax arrears of £2,500.

To manage the debts the family have installed a gas meter and are now paying £35 a week, £3 of which is repaying the debts. As a result of Amélie’s critical dependency on medical equipment, they cannot have an electricity meter and their provider is looking at alternative debt management measures. Their water provider has transferred the family’s debts to a scheme matching repayments of £50 a month as long as they do not default.

“Amélie is absolutely fantastic, she’s an absolute joy,” Darren says. “But stress levels are through the roof. Amélie needs care 24 hours a day, every day and because of her medical needs and the lack of professionals who also have the sign language skills to communicate with Amélie it is almost impossible to get respite care. We have battled to get direct payments from the council to buy-in care support and have been given the equivalent of 16 hours at £7.20 an hour. If we could find the right care services, I very much doubt it would be available at that rate.

“But if I could change anything it would be the financial burden. Even if everything in the house is going well, there is still that financial worry hanging over us. I think people assume that there are loads of benefits supporting families like us. But that’s not the case at all. Now Lesley works full time with extra shifts and I receive a Carers Allowance of £58 a week. I’d love to work, but show me the job I could do alongside the care Amélie needs.”



Caring and work

Caring responsibilities can result in the complete loss of carers' careers and lasting debt and financial hardship into retirement.

“My wife was in need of full-time care and no-one offered or even suggested I could get help so I had no option but to leave work.”

Whether caring is full-time and long-term, for an intensive short period or part of a stressful mix of work and childcare it can lead to permanent damage to carers' careers and earning potential.

- Over 3 million people combine paid work with caring responsibilities.
- The peak age for caring often coincides with the peak of an individual's career – 1 in 5 people aged 50-64 have caring responsibilities.
- 1 in 3 (30%) had seen a drop of £20,000 a year in their household income as a result.

Half of working age carers live in a household where no-one is in paid work. The Census shows that three million people manage the difficult balance of combining work and caring. Struggling to access support at home and a lack of understanding and flexibility at work

“I tried so hard to carry on working. I was told I should leave work to care for him but I couldn’t afford to. After months I was signed off with stress for two weeks and still went back, but I eventually reached breaking point.”

can lead to high levels of stress, absence, tiredness and being unable to perform well at their jobs. Caring is also a significant contributor to underemployment - with many carers reducing working hours or seeking often lower skilled work that can be more flexible.

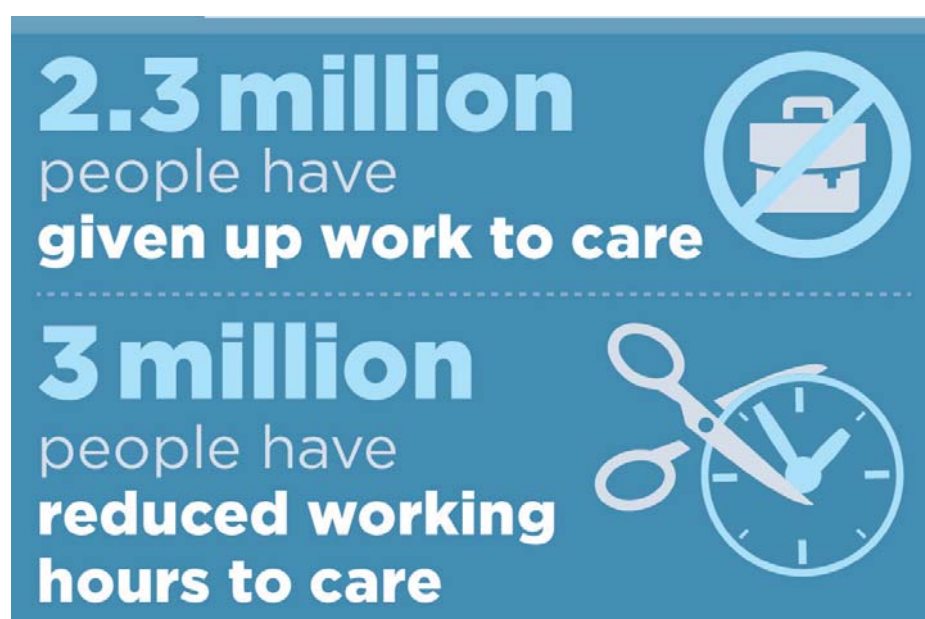
“I tried so hard to carry on working. I was told I should leave work to care for him but I couldn’t afford to. After months I was signed off with stress for two weeks and still went back, but I eventually reached breaking point.”

Public polling commissioned by Carers UK for this Inquiry further illustrates how widespread the impact of caring is on employment – with millions of workers forced to either quit work or cut hours, and one in ten of the adult population saying that caring responsibilities had a negative impact on their work through tiredness and stress.

This employment penalty has an impact across working age – from young people struggling to get into work, training or study as a result of caring for a disabled parent; through to early retirement to care for an ill partner or ageing parent. But there are also key pressure points and the peak age for caring is 45-65, resulting from the highest likelihood of needing to care for an older parent, meaning that the most intense pressure often comes at the peak of carers’ careers when the loss of employment can become irreversible.

There are also new challenges, resulting from changing family structures, with the continuing rise in the age at which individuals have children, and families living further apart, the phenomena of ‘sandwich caring’ (combining childcare with caring for a disabled adult or older loved one) and caring at a distance are bringing new pressures for work and caring.

Figure 7: **Statistics taken from *Costs of caring and impact of caring on work* (2013) Carers UK/YouGov**





“I really don’t like to look to the future at the moment. I have worked full-time all my life... I was coasting towards my retirement. Then caring came along – I’m losing all my savings and we may lose the home my parents and I bought.”

Gill's story

Gill's decision to care for her parents as they grew older has cost her career, savings, security in retirement and she now fears has led to a genuine risk of her losing her home.

Her mother, Mabel, is 97 and has vascular dementia and osteoporosis. At 92, her father, Bill, has a number of age-related health and mobility problems. An only child, she shares a home with her parents - a property which has been in the family since the 1930s. A number of years ago Gill bought into the ownership, a decision which seemed only wise at the time.

Before giving up work to care, Gill had been careful to save for her future throughout her career, which included many years as a transport manager in the shipping industry and most recently as a senior administrator in the voluntary sector.

As her parents care and support needs increased, Gill initially juggled caring with full-time work. Both home and work she was grappling with stressful compromise. When her mother contracted the potentially fatal hospital infection C-difficile, Gill reached a crisis point as she struggled to defeat the illness at home with little professional support and having reached a point of exhaustion; she felt the only option was to give up work to care full-time.

Gill has now been caring for her parents for over nine years. Providing around-the-clock care for her mother is she says "soul destroying, shattering and isolating." Her father's health needs have also increased and she has found herself on a number of occasions trying to manage care for one parent at home and spells of hospital admission for the other.

Mabel has advanced dementia, but her mobility remains good. As a result, the house must, Gill says, be 'in lock down'. The dementia also causes unpredictable and often inexplicable mood swings which can be very difficult to manage. Mabel becomes anxious if Gill is far from sight so, Gill is constantly 'on duty.' She has to sleep on chair cushions on the floor outside her mum's room to cope with Mabel's agitation at night. Gill manages to survive with between one and five hours sleep a night which leaves her permanently exhausted.

Her mother struggles to accept any care or support from strangers, but Gill and her father agreed a little while ago that they needed some help. At a cost of £16 per hour, they buy-in support from a care worker for an hour a day, three days a week. As her mother's care needs inevitably increase Gill fears the costs implications of the extra support she will need. If she continues to care for them at home she fears bills could rise to over £1,000 a week; if both parents went into residential care the bill could increase to over £2,000 a week.

The impact on Gill's personal financial circumstances has been considerable. Now 58, she feels there is no real chance she will be able to re-enter employment if her caring were to come to an end. As the law stands today, if her parents are forced to sell their share in their house to meet care costs, Gill fears she will lose a home she could now not afford to replace. She receives Carer's Allowance but no other financial support with caring.

"My future finances are a huge worry. I care a great deal about both my parents and I wanted to keep them in our home as was their wish, but we also could not afford for them to be in a care home.

"I really don't like to look to the future at the moment. I have worked full-time all my life. I'd spent a bit but I'd saved and I was coasting towards my retirement. Then caring came along – I'm losing all my savings and we may lose the home my parents and I bought."

Key fact

► 28% of carers providing 50 hours of care or more a week are in paid work.

The impact of caring on work

Census data from the 2011 Census sets out the impact on employment of different levels of caring.

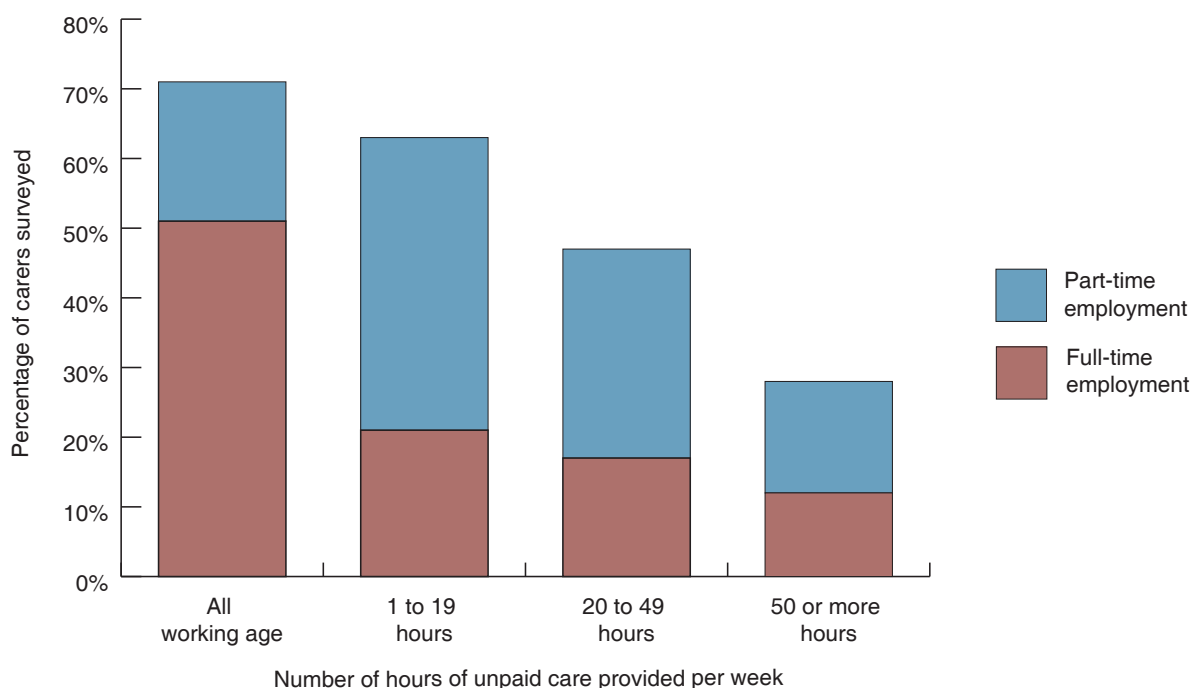
Reflecting previous work done by Leeds University¹⁴ and London School of Economics (LSE),¹⁵ and 2001 Census data, the 2011 figures¹⁶ indicate that carers providing even relatively lower levels of care are less likely to also be in paid work.

The ‘tipping point’ when levels of care begin to have a significant impact on work had previously been seen as at around 20 hours of care per week, but recent LSE research found that may be significantly lower, at around 10 hours of care each week.¹⁷

Whilst just over 70% of the total working age population were in paid work,¹⁸ the 2011 Census shows that this falls to less than two thirds (63%) amongst carers providing 1-19 hours a week in care, with 21% of those in full-time work and 42% in part-time work.

This falls again sharply for carers caring for between 20-49 hours –

Figure 8: Economic activity and provision of unpaid care (working age).



Source: Census 2011.

14 *Carers, Employment and Services (CES)* (2007) University of Leeds and Carers UK

15 *Overcoming barriers: Unpaid care and employment in England* (2012) NIHR School for Social Care Research, PSSRU, London School of Economics

16 At time of publication full Census data on caring and employment was only available for England and Wales - unless otherwise stated ‘Census 2011’ references refer to this data.

17 London School of Economics (2012)

18 This refers to the population aged 16-64, rather than the Census categories for ‘Economically active’ as the latter data excludes respondents who describe themselves as ‘Economically inactive: Looking after home or family’.

“The destruction of my own carer is probably what upsets me the most about all of this. As I know I have done my best for mum.”

with only 47% in paid work (17% full-time and 30% part-time).

Only 28% of carers providing 50 hours or more a week were in paid work alongside caring (12% in full-time work and 16% in part-time work).

“I went freelance in the 1990s when my mum was first diagnosed with dementia, anticipating I could do some work at home with my laptop. I was wrong. Mum’s needs grew rapidly but, because of her condition, she was in denial and refused support from anyone else so I had to do everything. I am having to start again from scratch at 47, after previously earning over £40,000 and see my contemporaries earning six figure salaries. The destruction of my own career is probably what upsets me the most about all of this. As I know I have done my best for mum.”

This Census data was reflected in carers’ responses to the State of Caring survey. Additional categories in this survey, for caring responsibilities between 20-34 hours and 35-49 hours a week, captured a particularly sharp fall in employment between these two categories (reducing by over a quarter) as carers cared for more than the equivalent of a full working week.

Stories captured through the Inquiry, particularly evidence sessions, also highlighted how varied and prone to change the impact of caring on employment can be. Carers spoke of the impact on employment of caring responsibilities through a spectrum, from working full-time alongside weekly visits to ageing parents, through to the lifetime loss of a career as a result of providing full-time care to a disabled child.

Some carers also described a gradual impact, typically when caring for an older parent or a partner with a degenerative condition – often starting with workplace stress, then reduction of working hours, until eventually they gave up work altogether. Others felt unable to reduce their working hours but full-time work pushed them to breaking point.

“Trying to cope with everything, mostly on my own, no unbroken night’s sleep, employers not understanding my position at all. I eventually suffered a breakdown.”

Key facts

- ▶ Parent carers of disabled children and carers of disabled partners were least likely to be in employment.

Employment across different caring scenarios

Whilst caring depressed economic activity across all caring responsibilities, there were significant differences between caring scenarios.

Carers of older people had the highest rates of employment, with 41% in paid work alongside caring (just over half in full-time work and the rest in part-time work). This remained the same even for ‘sandwich carers’ who also had dependent non-disabled children under 18 – although this latter group were more likely to be providing lower levels of care.

Parent carers of disabled children and carers of disabled partners,

were least likely to be in employment.

“I gave up work thinking that I would be able to return within a year or two years, once I got my daughter the support she needed. Little did I know how poor local services were and I am still caring years later.”

The figures in the chart above mirror patterns on the level of care provided across different carer groups.

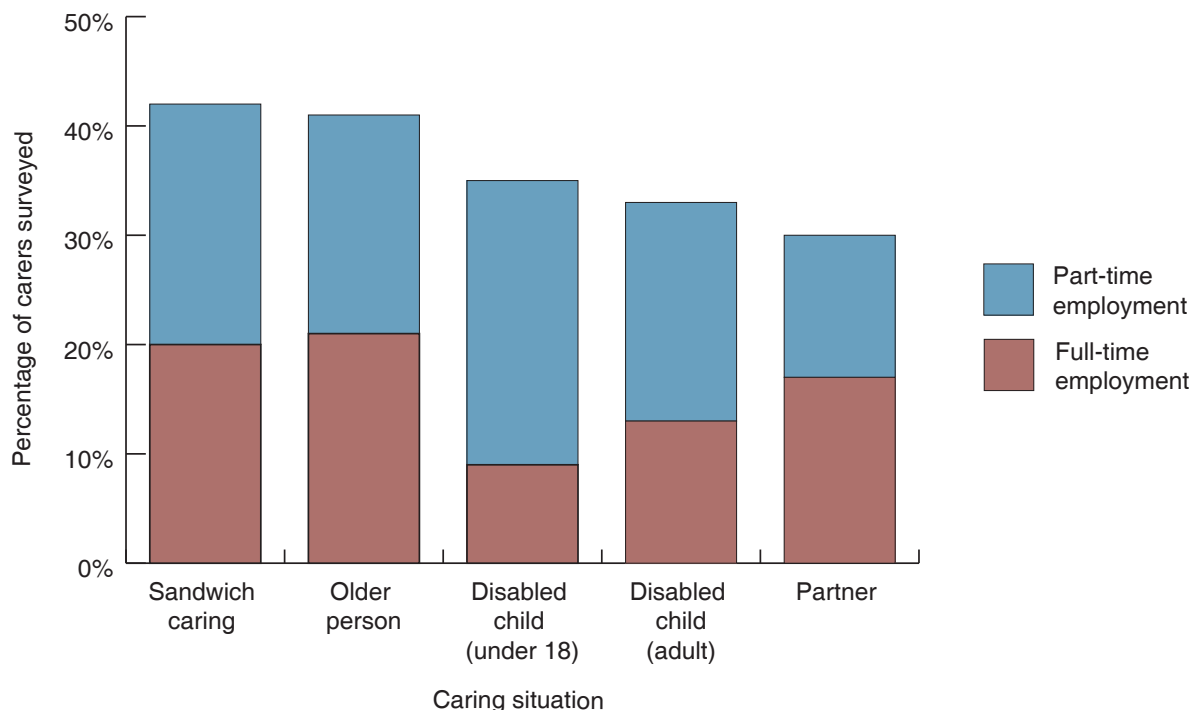
Whilst many carers care full-time for older relatives, this caring relationship is more likely to be at a distance or involve supporting a relative living in their own home to stay independent. As a result, carers of older people, including sandwich carers, are more likely to be providing lower levels of care.

Carers of older relatives, particularly their parents, often describe the ‘juggling act’ of providing reassurance and support over the phone, ‘pop-in’ visits to check everything was okay or to help at meal times and support around medical check ups or treatment. This type of support was more compatible with paid employment, even though it frequently had an impact on working hours and resulted in tiredness, stress and worry.

“Work is made harder by all the phone calls from my mother during working hours, asking why I am not there and demanding I leave work to go and help her or just for a chat because she is lonely.”

By contrast, carers of partners and disabled children were much more likely to be living with the person they cared for, and providing

Figure 9: Percentage of carers in part-time and full-time work by person cared for.



Source: State of Caring survey

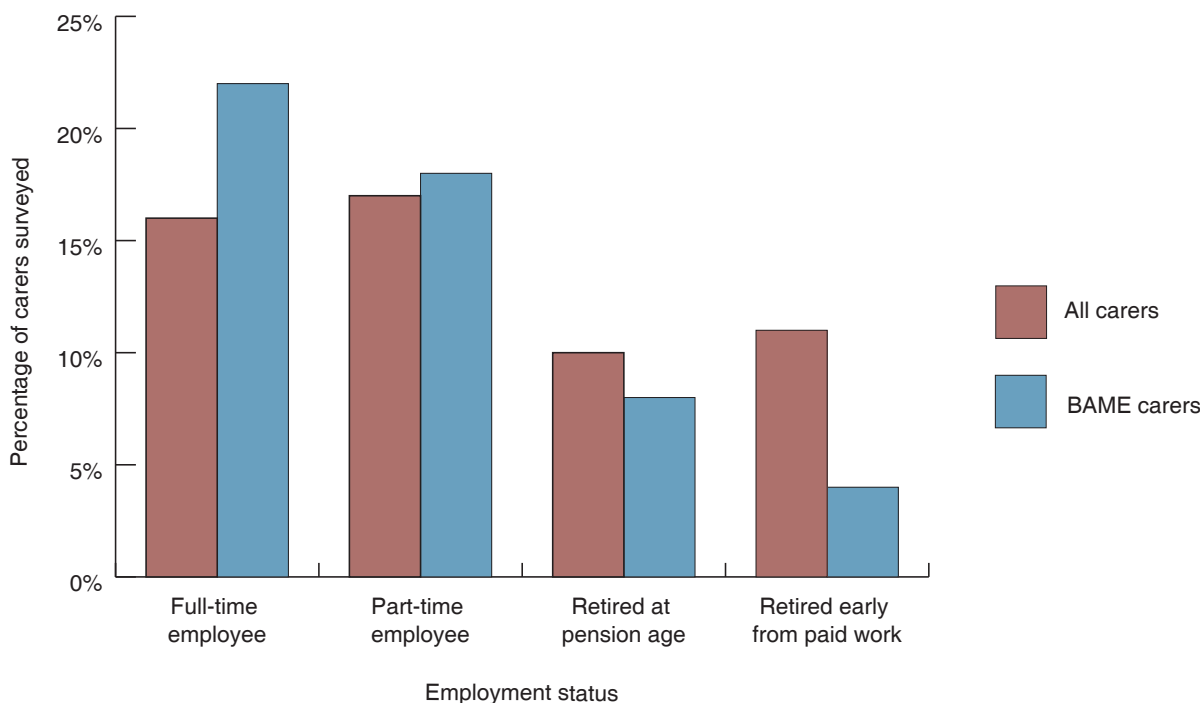
round the clock care.¹⁹ Higher levels of parent carers of adult disabled children were able to work full-time than carers of disabled children under 18, most likely because they were caring for adult children living independently but who still required some support.

“I gave up work when my disabled son was born as I couldn’t find another job that fit in with school hours. Then my husband joined the army and we moved to Germany, so I had little opportunity to find work. While in Germany, my daughter was born with severe disabilities, and as my husband was a serving soldier, the majority of caring responsibilities fell to me. As my daughter got diagnosed with more and more different conditions, the hospital appointments and time off school ill grew to the point where she’s out of school two days a week. Couple that with an autistic teenager, and there’s no time or energy to hold down a job. I already HAVE two!”

Carers from Black, Asian and ethnic minority communities were significantly more likely to be in work and less likely to be retired than the general carer population.

This reflects both that BAME carers are more likely to be of working age than other carers, but also evidence which indicates that carers from BAME communities, particularly late migrants, prioritise earning more highly even when it causes disruption to family care.²⁰

Figure 10: Paid employment status amongst all carers and BAME carers.



Source: State of Caring survey

¹⁹ Over three quarters of carers of partners/disabled children were caring for over 50 hours a week, compared to 62% of carers of older people, 46% of sandwich carers.

²⁰ Half a Million Voices (2011) Carers UK

Impact of caring on family incomes

The impact on families' incomes of giving up work, reducing hours or taking lower paid work was stark.

- 70% of carers were over £10,000 worse off.
- 1 in 3 (30%) had seen a drop of £20,000 a year in their household income as a result.

Carers who could not see the 'light at the end of the tunnel' of being able to return to work before retirement age talked about 'permanent', or 'irreversible' losses in income and frequently described this loss as 'devastating'.

A carer attending our Leicester evidence session who had given up work to care for her sister said:

"I have lost my career and my £28,000 salary – I now care 24/7 with no break or holidays for two years and no respect or support."

Some carers struggled to quantify the total, particularly those with long-term caring responsibilities or those who had been through multiple periods of caring and childcare. Carers attending our Llandudno session, alongside thinking about the value of lost earnings, also had a discussion about how the drop in income left them with a strong sense of financial insecurity as a result of not being in control of their ability to earn.

"I can't put a figure on it – caring has affected me throughout my life by changing my choices. I can't know what my life would have been like."

"How do you calculate lost earnings over 20 years of caring?"

But a deep anger at the contrast between the low level or non-existent support they received and the financial penalty they faced as a result of caring meant that many carers attending evidence sessions had already worked out the annual drop in income as a result of giving up

Figure 11: Statistics taken from *Costs of caring and impact of caring on work* (2013) Carers UK/YouGov



“I may have to start to look for work again in my 60s. Companies just don’t hire people at that age. I will never get those earnings back.”

paid work or reducing paid hours.

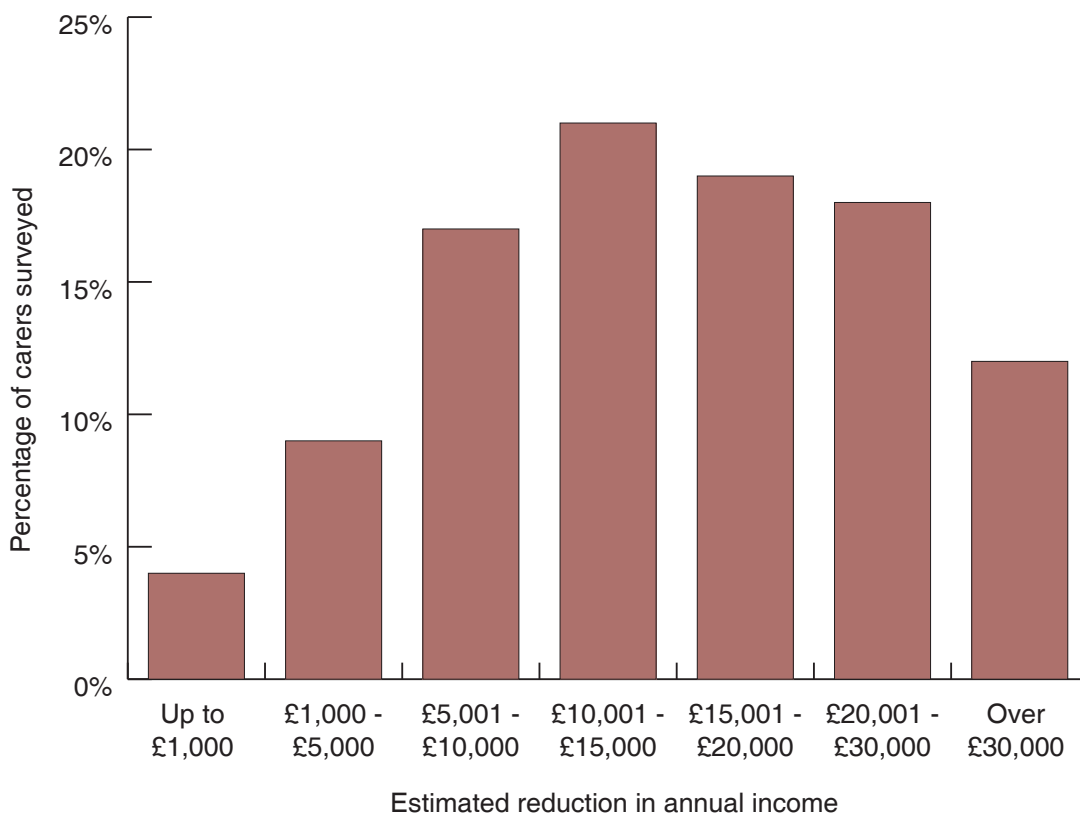
At our Glasgow session, a carer caring for his son who has Down’s Syndrome calculated that, despite managing to continue to work part-time, he had lost out on a total of £312,000 in lost earnings and a third of his occupational pension throughout the time he had cared.

Parents of disabled children under 18, are typically younger and are more likely to have seen their careers affected earlier and have given up lower salaries – but they were acutely aware that they faced cumulatively very high long-term losses. The time out of the workforce meant that many said they did not believe they could even return to work at the level of pay or seniority they had when they left, let alone the level they would have been at, at their current point in life.

Carers of older people had typically taken on caring responsibilities later and, as a result of being more experienced in the workforce and having higher earnings, their drop in income was likely to be much steeper. Whilst their caring responsibilities were likely to be shorter-term, alongside concerns that they could return to work at anything approaching the same pay level, many said that they would be surprised if they could return to work at all after several years out of employment and when they were approaching retirement age.

“I may have to start to look for work again in my 60s. Companies don’t hire people at that age. I will never get those earnings back.”

Figure 12: Reduction in annual income as a result of caring



Source: State of Caring survey

Sandwich carers were more divided at either end of the scale, with either a smaller or very high drop in income. This is likely to reflect the fact that some parents, particularly women, were already on lower earnings or not in work as a result of childcare responsibilities when they started to care so did not see as steep a fall in income. But, in line with the profile of sandwich caring, those who were in full-time work were more likely to be in more highly qualified, higher paid work²¹.

Working age carers of partners saw a similar pattern of falls in their own income as the total carer population. However this must be seen in the context of their drop in income being mirrored by their partner's loss of income, amplifying the financial impact.

Key facts

- ▶ 1/2 of working age carers live in a household where no-one is in paid work.
- ▶ Only 35% of carers of disabled partners had paid income coming into their household.

Paid income in the household

Half of working age carers live in a household where no-one is in paid work – almost triple the percentage of UK households without a paid income.²²

Unsurprisingly, carers living in households where at least one person is in paid work were noticeably less likely to be facing financial hardship.

- ▶ 72% of carers in households with paid income from work were able to afford their basic bills, compared to 57% of those where no-one was in paid work.

Whilst the loss of one income can be financially devastating for any family, when a carer's pay is the only income in the household, or if their partner has also given up work at the same time as a result of ill-health or disability, then the income shock is amplified.

"The loss of my wife's income was bad enough, but when I had to give my job we were pushed to the brink."

The experiences described by carers of partners at evidence sessions broadly fit into two different scenarios:

- ▶ A dramatic impact of a sudden-onset condition resulting in immediate exit from the workforce for both the person needing care and their partner.
- ▶ The slower impact of, for example, a degenerative condition, resulting in pressure on work and often reduction in working hours and then giving up work entirely.

The former group found it incredibly hard to adapt either work patterns or household spending, so were more likely to have to leave paid work entirely after they started to care and were particularly prone to debt. Carers in the latter group, similar to carers caring for an increasingly frail older person, had more of an opportunity to plan ahead, and reduce working hours or work flexibly and adapt household spending in anticipation of reduced income.

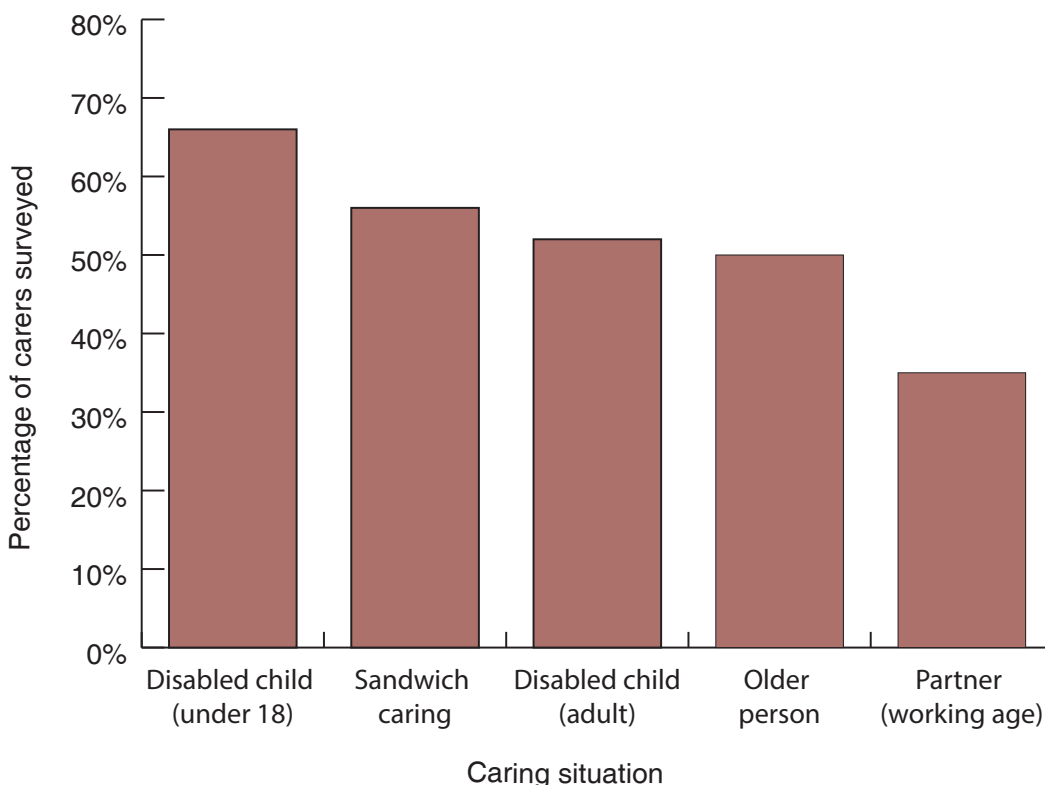
21 *Simultaneous care for parents and care for children among midlife British women and men* (2003) Agree E, Bissett B and Rendall M (2003) *Population Trends* 112 (Summer)

22 *Working and Workless Households, Statistical Bulletin* (2013) Department for Work and Pensions

Parent carers of disabled children under 18 are most likely to live in a household where someone is in paid work, typically the partner of the carer providing full-time care. Parent carers of adult disabled children were noticeably less likely to live in a household where someone was in paid work. This can be partly attributed to the increased likelihood that at least one parent is over retirement age, and to higher rates of divorce, separation and widowhood²³ – particularly given evidence from organisations like Contact a Family of the higher separation rates amongst parents of disabled children.²⁴ However this may also reflect situations where both parents of adult disabled children have given up work to manage caring between them. Parents of adult disabled children spoke powerfully at evidence sessions about the huge challenge of caring for an adult disabled child at home - as caring for them became more physically demanding compared to when they were a child, at the same time the carers’ age and the physical impact of caring over many years often left the carer less physically able to care.

“I worry about the future. If we are unable to care for our [adult] daughter, Where will she live and who will be good enough to look after her?”

Figure 13: **Percentage of carers in a household where there is paid income, by relationship to person cared for.**



Source: State of Caring survey

23 Parent carers of adult disabled children are 4% more likely to have been widowed and 6% more likely to have be divorced or separated.

24 *No Time For Us* (2003) Contact a Family

“My husband and I are arguing about the heating being on and costing too much money, but my [adult] daughter needs the house to be warm as her circulation isn’t very good.”

Half of carers for older people and 56% of sandwich carers lived in households with income from paid work, but again it was carers of working age disabled partners who were the worst off, with only 35% having income from work coming into the household.

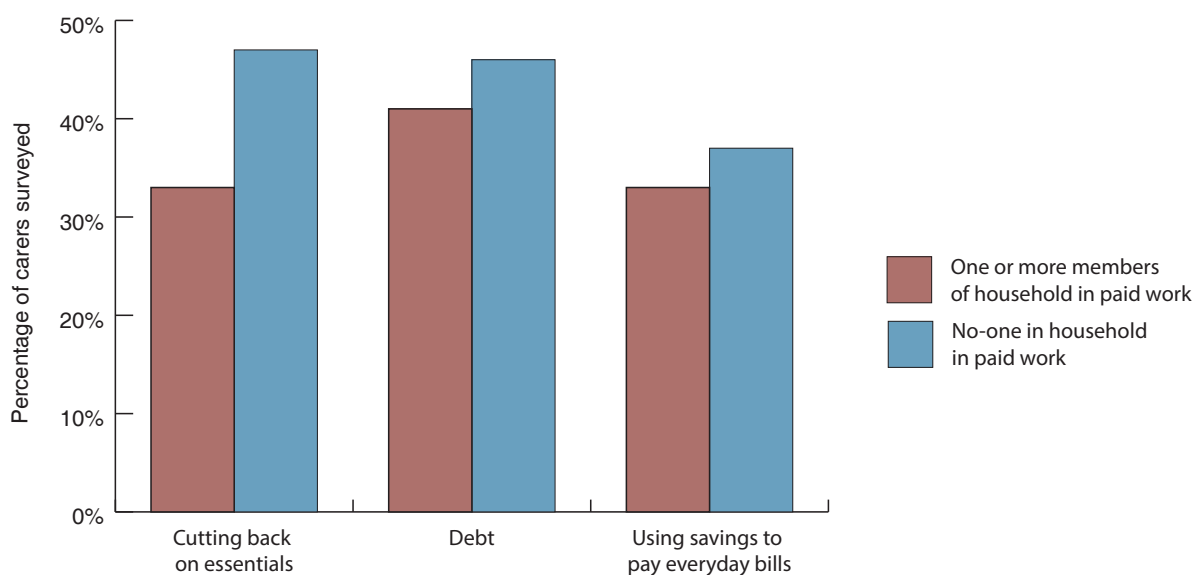
This leaves carers of disabled partners doubly disadvantaged as the group both least likely to work themselves and least likely to have anyone else in their household in paid work.

These findings reflect detailed survey work from the Centre for the Modern Family which found that carers of working age disabled adults were the least financially resilient, with household incomes on average £3,000 a year lower than carers of older people.

Clearly, if having a partner in paid work has an important effect on carers’ ability to avoid financial hardship then it is hardly surprising that single carers face a harsher financial impact – it was the ‘plight’ of this group which Mary Webster highlighted fifty years ago as she campaigned for financial support for carers.

Single carers²⁵ are more likely to have given up work to care (61%, compared with 52% of all respondents) and are more likely to be caring full-time (39% compared with 34% of all respondents). They were just as likely to say that they are in full-time employment as other carers, but less likely to be in part-time employment or self-employed - tending to have a much lower household income.

Figure 14: Financial hardship according to paid income in household.



Source: State of Caring survey

²⁵ Those who said they were single, divorced, separated or widowed.

“My son was so ill initially I had no choice but to care as I was attending hospitals every week at the start.”

“I did not have a choice as a single parent. My son was so ill initially I had no choice but to care as I was attending hospitals every week at the start.”

Although income from paid work in the household made it less likely that carers faced debt, loss of savings and cutting back on essentials, levels of these measures of hardship still remained worryingly high.

Many carers, particularly parent carers of disabled children, report that paid income coming into the household did not protect them from financial hardship – not least because paid income in carer households often comes from part-time work. In addition, because benefits are often perceived as support for people who are not in work, some carers report that as long as they remained in work they did not explore claiming disability benefits for the person they care for – so they face the extra costs of disability without support. In addition, carers who remain in part-time work alongside caring may not examine what financial support is available to them alongside it.

Carers across different evidence sessions also talked about struggling to maintain a few hours of part-time work themselves - not because it made them much better off but because it kept ‘a toe hold’ in the workforce and gave them a sense of identity outside of caring.

“I have been told on a number of occasions that if I gave up work I could have the alterations [that we need for my husband to be independent] done for free – but I refuse to give up my career that I have worked so hard for.”

Whilst parent carers were more likely to have someone in the household in paid work they also frequently spoke about losing hope they would ever return to the workforce themselves. So whilst their partner might be in work, they were conscious that long-term or even life-long caring responsibilities might leave their family cumulatively much worse off than if their caring responsibilities lasted for several years with the prospect of a return to work when caring ends.

Key facts

- ▶ 73% of ‘sandwich carers’ were using annual leave to travel.

‘Sandwich caring’

Alongside carers of older people, sandwich carers appear to be relatively better off – with both the State of Caring survey and the Centre for the Modern Family finding these groups most likely to be in work, and in full-time work and more likely to have someone in the house in paid work. Indeed the latter research found household incomes amongst sandwich carers to be almost a quarter higher than carers of working age disabled adults.

However this is also a reflection of sandwich carers as a group being more likely to hold higher level qualifications (as the sandwich caring is more likely to result from having children later, and older parents tend to be better qualified)²⁶ and attracting higher levels of pay as a result.

²⁶ ‘Simultaneous care for parents and care for children among midlife British women and men’ (2003) Agree E, Bissett B and Rendall M; *Population Trends* 112 (Summer)

“I refuse to give up my career that I have worked so hard for.”

Yet even this more economically resilient carer group is almost a third less likely to be in work themselves and 17% less likely than the average UK household to live in a household in which someone is in paid work. The pressures of sandwich caring on work are also demonstrated in our survey results.

Sandwich carers were the most likely group to be in paid work. Over a fifth (22%) were working part-time, with slightly fewer working full-time (20%) - suggesting that it is a real struggle to maintain a full-time job alongside the demanding family responsibilities of caring and looking after children. This is also borne out by the numbers of working age sandwich carers in employment²⁷ who told us that they had:

- used annual leave to care (73%)
- used sick leave to care (39%)
- done overtime to make up hours spent caring (52%).

These proportions are significantly higher than for other working age carers in employment. They were also more likely than other working age employed carers to report that, although they continued working the same hours, their job has been negatively affected by caring (for example, due to tiredness, lateness or stress), with 55% saying this. These results indicate that, although they are more likely to be providing lower levels of care to an older or disabled person and to be in work, the combination of childcare and caring for an adult had a serious impact on their working life.

Key facts

- 19% of distance carers are caring full time.

‘Distance caring’

With the rise of the so-called ‘beanpole’²⁸ families – more generations alive at once but fewer family members in each generation - combined with greater geographical family dispersal, more and more people are finding themselves needing to provide care and support to loved ones at the end of a motorway.

In Jarrow, one of the social care professionals attending the evidence session as an observer, explained how she was ‘distance caring’ for her mother in Scotland alongside working full-time. Whilst her mother did not need full-time care, she spoke about the stress, cost and disruption to her work of remotely managing her mother’s finances, making frequent phone calls to provide reassurance and travelling to Scotland for medical appointments.

Several themes were repeated by different distance carers – the cost and time taken for travel, a constant need to be on the phone to provide reassurance or organise medical appointments, and the constant stress ‘in the back of your mind’ of worrying about someone and knowing they are not nearby to pop in and check on.

“I live at a distance from my parents. I visit weekly to enable my dad to visit my mum who lives in a nursing home. On occasion I

²⁷ The statistics used here are for carers in part-time or full-time employment, excluding those who are self-employed.

²⁸ *Social Trends, England and Wales 33* (2003) Office for National Statistics

“I sometimes have to travel over two hours each way every day to care.”

also do other things [...] - helping with paperwork, shopping, etc. as necessary. My brother lives closer and we manage things between us.²⁹

“I sometimes have to travel over 2 hours each way every day to care.”

A 2011 Employers for Carers survey of ‘distance carers’ who were in work highlighted the pressures that come with caring at a distance: stress, reduced working hours, needing to change work patterns or take less senior roles.³⁰ The State of Caring survey for this Inquiry showed the impact on over two hundred distance carers both in and out of work.

Whilst carers caring at a distance³¹ were less likely to be providing higher levels of care and they were more likely to be employment that carers living closer, there was still a significant impact on their ability to work.

- 30% of working age carers who live over 30 minutes travel away from the person they care for were in full-time employment, compared to 17% of all respondents.
- 52% of working age distance carers said they were working either full-time or part-time, or were self-employed. Only 37% of all working age carers responding to our survey said this.
- 19% of distance carers were looking after dependents full-time, compared to 34% of all carers.

“We had no option but to give up both our home and our income overnight.”

Gender, caring and work

There are significant gender disparities when it comes to patterns of work and caring.

Six in ten round-the-clock carers are women, and women are far more likely to be carers at the peak age of caring, 45-64, when caring may have the most significant impact on their careers and earning power. They are also more likely to face long-term, full-time caring responsibilities for disabled children.

“When looking after my child, I was too tired to work – I was up all night.”

“I had no choice. I could not leave my daughter at home doing nothing while I worked. I had to help her learn too.”

However these female-dominated figures mask a complex picture of gender, work and caring. There is important evidence that working age men who do care, although they are a far smaller group, can face greater financial and workforce disadvantage. Whilst a greater

²⁹ *From Caring at a Distance: bridging the gap* (2011) Employers for Carers

³⁰ *Ibid.*

³¹ For the purposes of this analysis ‘distance carers’ are defined as those caring for someone who lives over 30 minutes travel away.

proportion of working age men combine full-time work and caring,³² greater incidence of ‘partner caring’ and less part-time working mean that men are more likely to give up work entirely or retire early to care and are very significantly more likely to be in a household where no-one is in paid work.

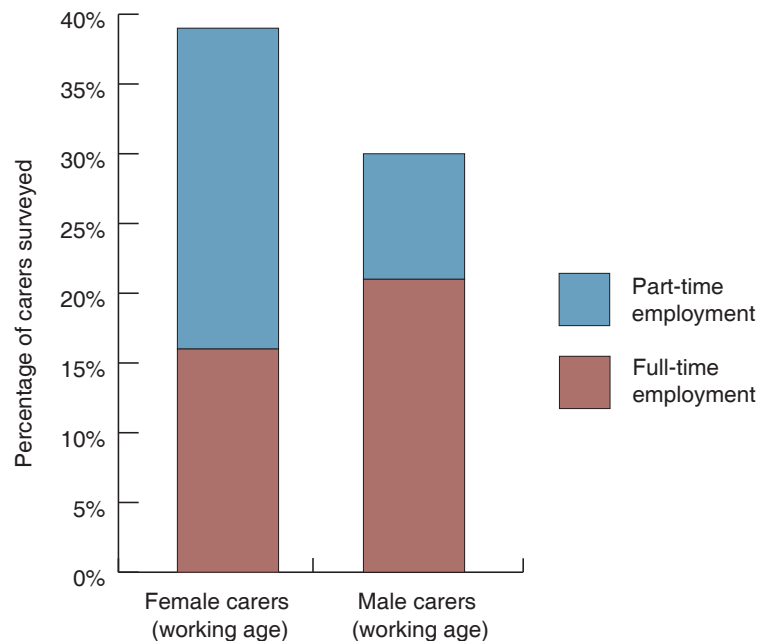
“We had to sell our farm and move to a smaller adapted place as my wife was suddenly rushed to theatre and then suffered a stroke... We had no option but to give up both our home and income overnight.”

Questions asked in Carers UK’s State of Caring survey enable a more detailed analysis of gender, caring and economic activity than current Census data.

Carers responses indicate that whilst men were more likely to be in full-time work, this was more than balanced by women being significantly more likely to be in part-time work alongside caring.

- 16% of working age female carers were in full-time work and 23% in part-time work (39% total).³³
- 21% of working age men with caring responsibilities were in full-time work and 9% in part-time work (30% total).

Figure 15: Percentage of working age carers in part-time or full-time employment, by gender.

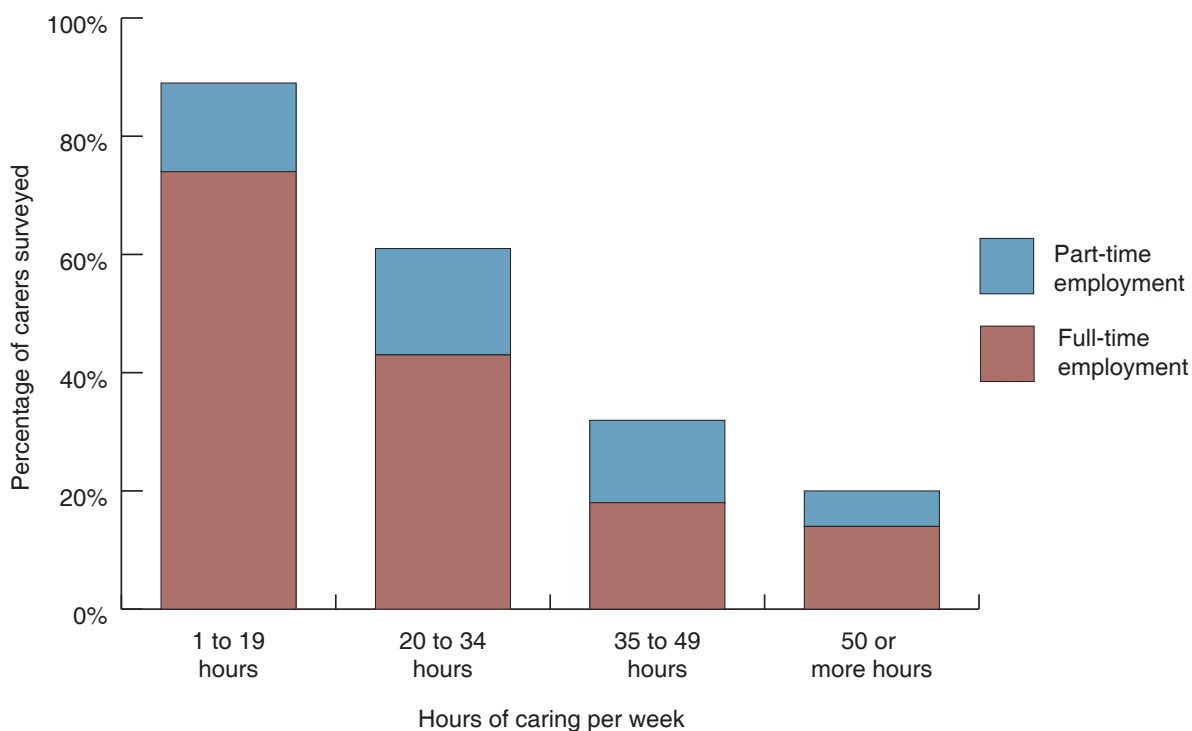


Source: State of Caring survey

32 Illustrated by Census 2001 and 2011, Family Resources Survey (2011) ONS and Department for Work and Pensions and State of Caring (2013) Carers UK

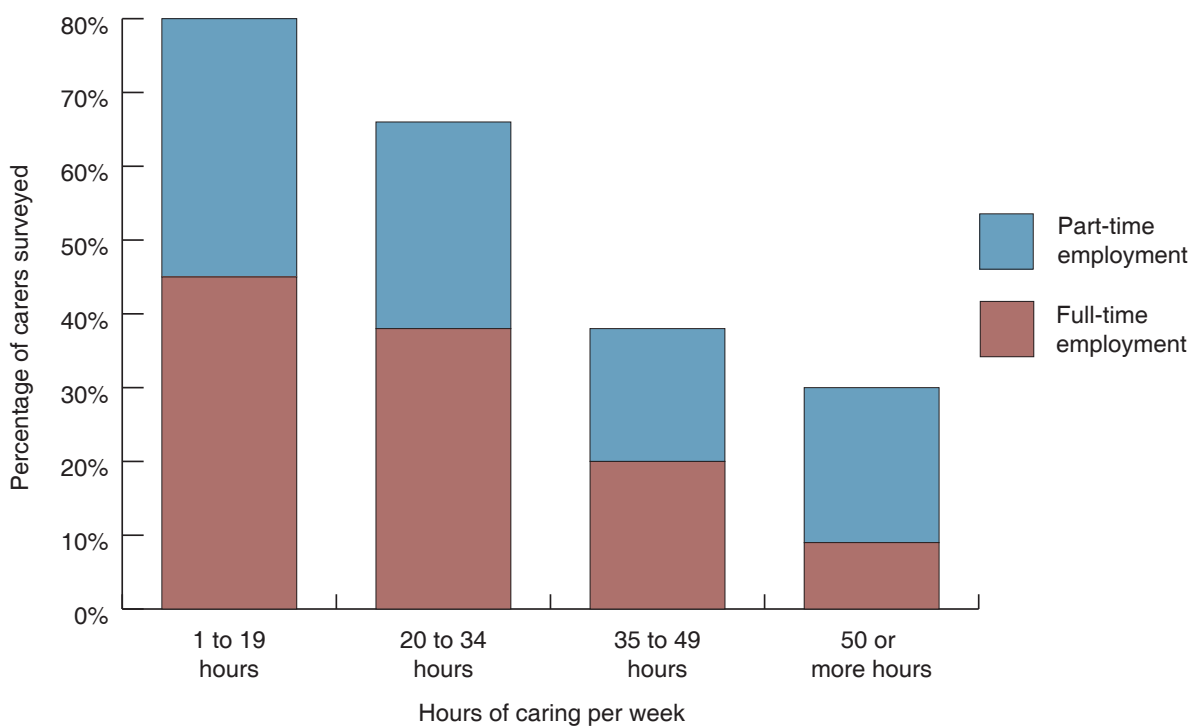
33 Unless otherwise stated, ‘full-time’ includes both full-time employees and full-time self-employed; and ‘part-time’ includes both part-time employees and part-time self-employed.

Figure 16: Percentage of working age male carers in part-time or full-time employment, by number of hours caring per week.



Source: State of Caring survey

Figure 17: Percentage of working age female carers in part-time or full-time employment, by number of hours caring per week.



Source: State of Caring survey

“Employers just don’t offer the kind of work I need, that isn’t just term-time low paid work in schools or as a cleaner which I have to take.”

There were notable differences according to the number of hours of care provided too:

- Male carers were much more likely to be able to combine full-time paid work with lower levels of care – with 74% of men providing 1-19 hours of care also being in full-time work, compared to 45% of women.
- Similarly, whilst 43% of men providing 20-34 hours of care were in full-time work, this fell to 38% for women.
- However it is the greater likelihood of part-time work at almost all levels of care which meant that overall women were more likely to be in work.
- For carers providing over 35 hours of care, 32% of women were in work but only 23% of men. Whilst male carers were 4% more likely to be in full-time work, women were 14% more likely to be in part-time work.

This greater likelihood that women are in part-time work is reflected across the economy and is understandable in the context of a wider expectation and culture around part-time working for women and the probability that working age women may have already adjusted or reduced working hours to provide childcare.

Female carers often speak about these norms not as a positive reflection on workplace flexibility but as unreasonable expectations that women will take on caring responsibilities at a cost to their careers.

“The anxiety and stress caused by caring is having a negative effect on my ability to work. If only the rest of the family would pull together there would be so much less pressure. Any problems, they are always passed onto me to sort out.”³⁴

Type of paid work

Evidence from the Carers, Employment and Services research by University of Leeds and Carers UK analysis of the last Census also highlighted the importance of the nature of paid work alongside caring.³⁵ Carers of both genders, but particularly women are likely to be in ‘elementary occupations’ – process plant and machine operative jobs, or sales, customer services or personal services.

“I was forced into a lower skilled job that was more flexible – but tiring, manual work on top of caring made my own health worse and eventually I was forced to stop working.”

This was a strong theme at our evidence sessions and through carer surveys, with predominantly women noting that the part-time work they could find was more likely to be low-skilled shift work which is local and could be flexible around caring responsibilities.

“The work I can do now is limited because of my caring

³⁴ *Caring at a distance: Bridging the Gap* (2011) Employers for Carers

³⁵ *More than a job: working carers: evidence from the 2001 Census* (2006) Carers UK

responsibilities, I cannot be away from home for long anymore.”

“I asked HR if they could transfer me to the local area and change shifts as that was the only way I could work but they said no as I couldn’t be available from 7am to 6pm.”

“Employers just don’t offer the kind of work I need, that isn’t just term-time low paid work in schools or as a cleaner which I have to take.”

Key facts

➤ 1 in 5 people aged 50-64 are carers.

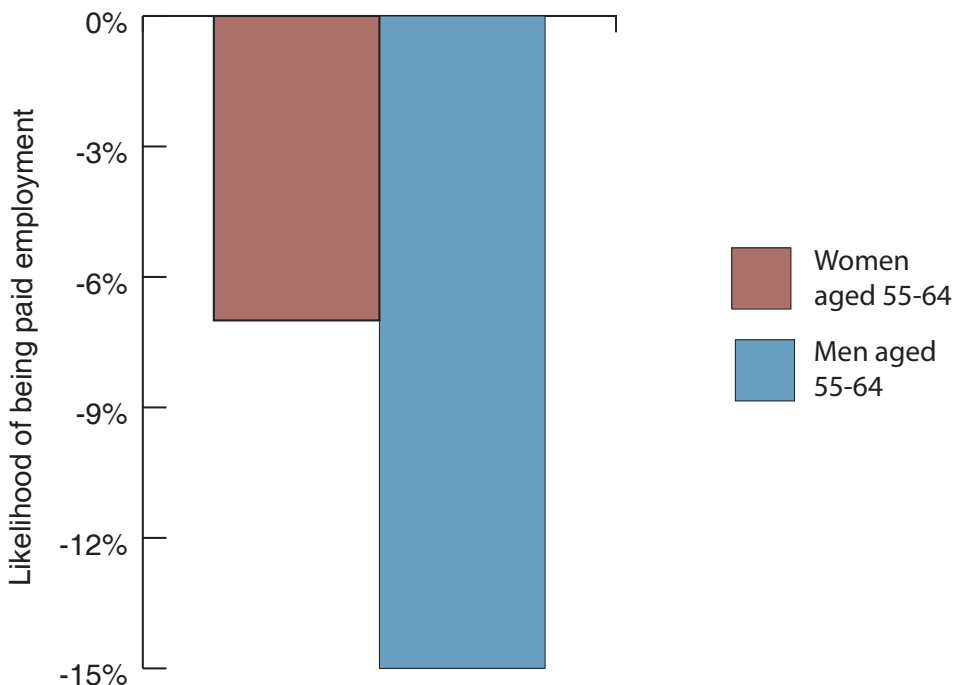
Employment at the peak age for caring

- 1 in 4 women (24%), aged 50-64 have caring responsibilities – over 1.2 million women.
- 1 in 6 men (17%) of this age have caring responsibilities – around 850,000 men.

Comparing the difference in workforce inclusion amongst ‘middle aged’ male and female carers highlights a starker disparity between genders in the 55-64 age band³⁶ – largely as a result of greater part-time working and self-employment amongst women.

Reflecting the increased likelihood of caring responsibilities at this age

Figure 18: Likelihood of carers aged 55-64 years old being in paid employment compared to all working age carers.



Source: State of Caring survey

³⁶ State of Caring survey age bands differ from Census bands – as a result this analysis uses 55-64 to analyse the peak age for caring as the alternative would be 40-64.

for both genders, men and women were less likely to be in any kind of paid work in this age bracket compared to the rest of the working age carer population (women in this age bracket are 7% less likely to be in work, and men 15% less).

The fall in full-time work amongst men over 55 is steep (-15%) whilst women's full-time working remains at a constant 16% both below and above the age of 55 (although the makeup of this shifts slightly towards full-time self-employment and away from being a full-time employee).

Women's relative position is further boosted as a result of more resilient levels part-time working, which do fall, but not as steeply as men's full-time employment.

This means there are comparable proportions of men and women aged 50-64 full-time work. Indeed the rapid fall in men's full-time employment means that this is the only age group where the percentage of women in full-time work outstrips men (16% compared to 14%). But again it is part-time working amongst women which is most significant, with women being more than twice as likely than men to be in paid part-time work.

- 16% of women aged 55-64 were in full-time work and 18% in part-time work – a total of 34% in work. This compares to 41% of the rest of the working age female carer population who are in work.
- 14% of men aged 55-64 were in full-time work and 9% in part-time work – a total of 21% in work, compared to 36% of the rest of the working age male population.

However this does not indicate that women's workforce inclusion is strong in this age band, for either part or full-time work. The 16% of women in full-time work aged under 55 is a low base compared to male carers (25%) so the fact that it does not fall further over the age of 50 is not to be celebrated. The proportion of women in part-time work falls by 7% over the age of 55 to 20% but this remains twice as high as the proportion for men, which remains constant at 9%.

In short, there is a steep fall in the proportion of men in full-time paid work over the age of 50 which outstrips the fall in the number of women in any kind of work. Men are also likely to face a greater fall in income as they appear to be more likely to have to give up full-time work entirely whilst women likely to either go from full to part-time work or be leaving part-time work.

This should not be taken as evidence to contradict the assumption that caring has more of an impact on women's careers than men's. The number of women in this age bracket affected is far greater and women are more likely to face the compound impact of a lifetime of lower pay and part-time working, childcare responsibilities, sandwich caring, distance caring³⁷ and a far greater likelihood of caring

³⁷ Female distance carers are less likely than male distance carers to be in full-time employment (25% compared to 35%) and more likely to be in part-time employment (18% compared to 10% of male distance carers). In fact, 86% of people caring for a person who lives over 30 minutes travel away are women, compared with 76% of all of the carers who responded to our survey.

throughout their working lives.

However there is some evidence that that the smaller numbers of men providing high-levels of care whilst they are of working age, may face a greater income shock as a result of caring.

This is also borne out by the fact that men responding to the State of Caring survey were over 20% more likely than female carers to live in a household where no-one is in paid work.

- 67% of working age male carers said that they in a household where no-one is in paid work compared to 45% of female carers.

This follows the pattern seen across the Family Resources Survey, which showed that middle aged and older males are overwhelmingly likely to be caring for a partner – raising the likelihood that both carers and their partners will not be in work.

“I had to stop work overnight to care for my wife. We had no income and I had problems getting any benefits through quickly enough. Had to declare myself bankrupt.”

Furthermore, the gender pay gap means that if a male carer (not in work himself) has a female partner in paid work, he is likely to have a lower household income than a female carer with a male partner in paid work.

Key facts

- 43% of carers aged 65-74 have retired early to care.
- 49% of carers were using their savings to pay everyday living costs.

Retiring early

The complexity of the impact of caring on carers' career was reflected across the evidence session sessions in ways which were not immediately evident from carers' survey responses. The issue of retirement was particularly apparent in the older demographic in Slough and Taunton. A number of participants said that they had not 'given up work to care.' However, further discussion prompted them to give examples of how their careers had, in fact, come to an end as a result of caring. These included people who had taken time out of work to care but had then decided to retire because caring made a return to work impossible.

This was reflected in responses from carers over the age of 65 who completed the State of Caring survey. Whilst 34% of 65-74 year olds said they had 'given up work to care', 43% said they had retired early to care.' Amongst 75-84 year olds the gap was similar, with 21% stating they had given up work and 33% saying they had retired early in order to care.

This is a reversal of the pattern in the preceding age bracket –of carers aged 55-64, 52% said they had given up work to care and 20% described themselves as having retired early.

This difference could be for a number of reasons. There is a degree of stigma attached to having 'given up' paid work, whilst early retirement can be seen as a more positive choice. Those still under retirement age may also hope to return to work once caring ends and before they reach pension age – an aspiration expressed by many carers of this age attending evidence sessions, although one which many

“I worked hard and I saved but I was forced to give up my career to care and now have to watch all my savings drain away to pay my bills.”

felt was increasingly unlikely. Those over retirement age may have ‘given up’ work with the hope of returning, but the length of their caring responsibilities meant that they ultimately found they would be unable to return to work, so made the decision to retire as they continued to care.

“I had to stop working in 1995 fully. I was expecting to return after a year, possibly two years – part-time at the very least. Little did I know what was in front of me.”

Men are significantly more likely to retire early to care. 26% of men aged 50-64 had retired early, compared to 17% of women – with a higher proportion of women in this age bracket (16%) working part time, compared to just 7% of men.

“I had the option of early retirement or putting my wife into residential care which I did not wish to do, having experienced care homes looking after elderly relatives.”

Women are also significantly more likely to continue working over retirement age.

- 12% of women aged 65-74 were combining work and caring (3% in full-time work) compared to just 6% of men (none in full-time work).

However there were also participants who had been made redundant and then found themselves caring and unable to return to work, and those who said they had not ‘given up work to care’, as that suggested a choice – the stress of juggling it all, or of being unable to access services, meant working lives fell apart.

“I did not give up work but was made redundant. Whilst looking for work, my mother became forgetful and got to the stage where I could not leave her alone, so I am therefore unable to go back to work.”

“I worked hard and I saved but I was forced to give up my career to care and now have to watch all my savings drain away to pay my bills.”

This feeling was reflected across other evidence sessions, particularly in Glasgow and Taunton, where carers spoke about feeling like early retirement was their only option whilst knowing that it left them with a very uncertain financial future in later life. Some spoke about taking lump-sum payments to deal with a caring-related ‘cash crisis’ in the short term, or drawing down private pensions early to provide income because they knew they would not qualify for means-tested benefits.

Carer survey data did offer some evidence of the financial impact of early retirement. Over 320 carers who responded had retired early:

- Half (49%) of carers were using their savings to pay everyday living costs (compared to 43% of other carers aged 55 or over).³⁸
- Those of working age (55-64) were 20% less likely than other carers in their age group to live in a household where someone

³⁸ 95% of those who said they had retired early were aged 55 or over.

“That is it for me now. I was never going to be able to go back to work and I have no way of climbing out of this financial hole.”

was in paid work.³⁹

There was no clear evidence of severe financial hardship amongst this group, but most were relatively recently retired - as over half were still under 65 and whilst they were using their savings up on everyday costs the majority had used less than half of their savings. But those using savings and with no other paid income in the household could expect rapidly worsening financial circumstances as they continue to care and when caring comes to an end.

“That is it for me now. I was never going to be able to go back to work and I have no way of climbing out of this financial hole.”

Key facts

- ▶ Carers who were in receipt of disability benefits themselves were half as likely to be in paid work.

The impact of carer ill-health and disability on work

In addition to people with existing disabilities taking on caring responsibilities carers frequently report developing mental and physical health conditions during and as a result of caring.

- ▶ Census data shows that carers providing over 20 hours a week were 50% more likely to be in bad health than non-carers and those caring for over 50 hours were more than twice as likely to be in bad health.⁴⁰

This pattern was mirrored by the number of carers citing ill-health as their reason for not being able to engage in paid work alongside caring, which rose according to the number of hours of care provided.

- ▶ 8% of those caring for over 50 hours a week and 9% of those caring for 35-49 hours a week said they were unable to work due to sickness or poor health.

“Due to the time taken off for either caring or sickness related to stress I was sacked.”

Carers at evidence sessions spoke about a range of health conditions, a national picture of which was given by recent publication of the GP Patient Survey⁴¹ which showed that carers are almost 10% more likely to have a long-standing health condition than non-carers, rising to 20% more likely amongst carers caring for over 50 hours a week.⁴²

Reflecting experiences related in Inquiry evidence sessions, the Patient Survey data showed carers to be more likely to have arthritis and joint problems, high blood pressure, back problems, diabetes, anxiety and depression.

“I am in the process of reducing my working hours which will have a huge impact on my income. But if I put my work commitments first

39 21% of early-retirees lived in a household where someone was in paid work, compared to 41% of all carers aged 55-64.

40 5.3% of non-carers stated they were in 'bad health' compared to 13.2% of carers caring for over 50 hours a week and 8.3% of carers caring between 20-49 hours.

41 GP Patient Survey aggregated 2012-13 wave 2 and 2013-14 wave 1 results (2013) NHS England

42 51% of non-carers had a long-term condition compared to 60% of all carers and 70% of carers caring for 50 or more hours a week.

**“I had to stop
work, or the
stress would
have killed
me”**



Graham's story

Graham, 63, cares for his wife, Linda, who is 57 and has muscular dystrophy, a condition which causes the muscles to weaken.

Graham and Linda's bungalow has, over the years, been heavily adapted to allow as much independence as possible within their own home. But muscular dystrophy is progressive and Linda has now almost entirely lost mobility in both her arms and legs and as her condition advances, she depends increasingly on Graham.

And while they have been able to afford to make changes to their own home and garden to try and maintain quality of life, getting out and about only becomes more challenging.

Eight years ago, Graham gave up work to care for his wife. He then had his own, successful business. In the end, the strain of trying to sustain work and care became too much.

"I had to stop, or the stress would have killed me," Graham says.

Graham's success in business means that the couple have been able to afford to adapt what is a lovely home. They are not, however, mortgage free and face considerable bills for care and support.

"If we die young we should be alright," Graham quips, but he and Linda are both acutely aware that, long term their financial security is at risk.

To maintain some income Graham now works from home as an independent consultant. His work must fit around caring and is also dependent on some care support.

In the past year their bill for care and support services was £22,600. Because Linda's condition means she must be kept warm, they also heat their home around-the-clock – resulting in towering utility bills.

"I was a successful businessman with a high income, good car, holidays and lifestyle. I had to sell that business and now work around my wife's care. I work seven days a week to pay for an assistant to help with my wife's care and care, gardening, cleaning and to perform the tasks I don't have time for," Graham says. *"Caring takes so much time. I care, work and sleep. I suffer stress, depression, high blood pressure and back problems. I have virtually no family or social life."*

"Though we receive some social care funding for care and support services. But care workers are not allowed to lift her - so there are many everyday things, like getting Linda in and out of bed or onto the sofa, they cannot do and I have to be there for. The budget my wife receives for care also has restrictions on how it is spent which prevent us using it to its greatest effect. In short it has to be spent on services which are of limited value."

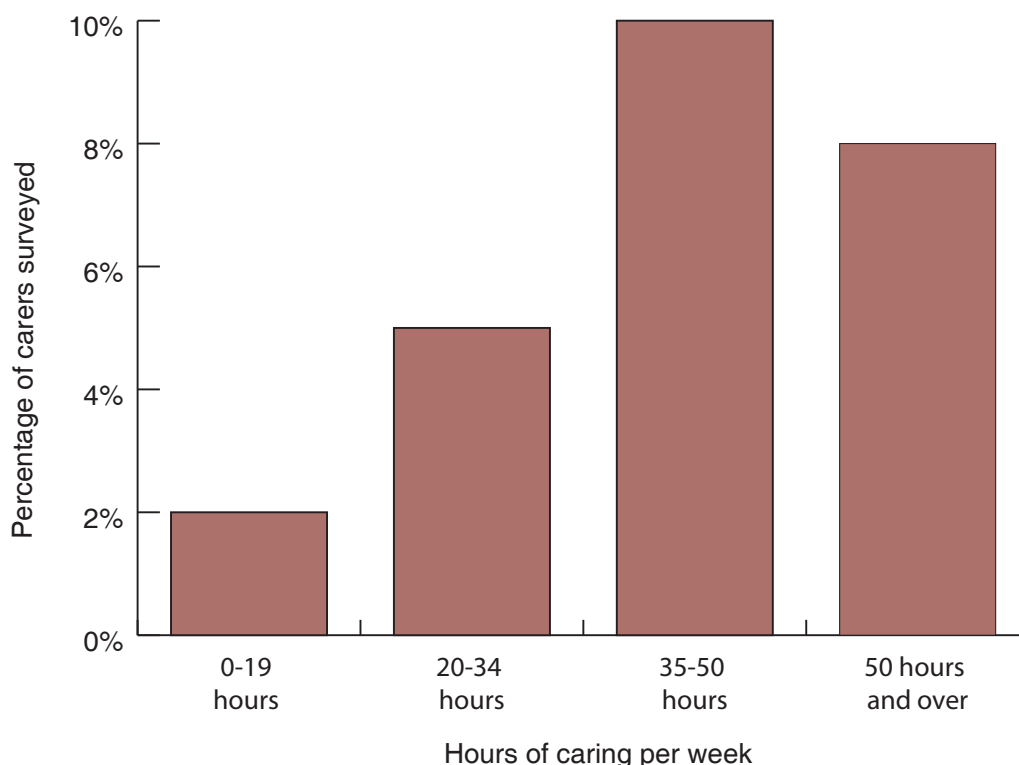
I just don't have enough time with my elderly and frail mother. My physical health and my wellbeing are suffering so much."

Government figures indicate that over 40,000 carers in receipt of Carer's Allowance also receive Disability Living Allowance.⁴³ Just under 250 carers responding to the State of Caring survey themselves received Disability Living Allowance. This group were significantly more likely to report having given up work to care – 61% compared to 52% of all working age carers. As a result they were also much less likely to be in paid work.

- Carers in receipt of Disability Living Allowance were almost half as likely to be in paid work as non-disabled working-age carers (18% compared to 33%).
- Three quarters (74%) of carers in receipt of Disability Living Allowance lived in a household where no one was in paid work, compared to 55% of all working age carers.

This points to a combination of financial disadvantage for disabled carers and those in poor health: they are significantly less likely to be in work or in a household with income from paid work, much more likely to miss out on financial support with caring and more likely to be facing greater debt and financial hardship as a result.

Figure 19: Percentage of carers reporting being unable to engage in paid employment as a result of ill-health or disability, by weekly hours of care provided.



Source: State of Caring survey

⁴³ Carer's Allowance and Disability Living Allowance recipients by local authority (2012) Department for Work and Pensions

“I have had two mental breakdowns in 16 months. I have now had to reduce my working hours on the recommendation of occupational health and my GP.”

Approaches to supporting caring and work

Experiences from evidence sessions gave lie to the myth that families were actively choosing to leave work and to claim benefits. ‘I had no choice’ and ‘I reached breaking point’ were phrases that came up time and time again.

“I have had two mental breakdowns in 16 months. I have now had to reduce my working hours on the recommendation of occupational health and my GP.”

“The day did eventually come when, even with support from work, I could not go on any longer juggling work and care. I had my own family, work, a disabled brother and my sick mum to deal with and we received no social care support. My own health was suffering massively and finally I collapsed at home. I was in intensive care for six days. I had to give up my job and my career with a good employer of 14 years.”

- 64% of carers who gave up work or reduced working hours blamed stress, and 62% said it was because they did not have time to do everything.

Alongside stress, carers were also clear about the role that inadequate support from care services and from employers could have in forcing them to give up work.

Access to replacement care services

“I gave up work because my wife needs full-time care and all I was offered was a service which was someone coming in once in the morning and once in the evening. It would have made both our lives impossible.”

Half of carers cited problems with accessing suitable care services as a reason they gave up work or reduced working hours.⁴⁴

Over a fifth of carers said that services were inflexible. Carers speak about services which simply do not fit with the working day, for example day centres which start at 10am and close at 2pm. Carers told us that, accounting for travel time, this would leave them windows of just two hours in which they could conceivably work.

Others spoke about services driven by providers’ needs and not the needs of the carers or their families. For example, care workers who would arrive in the late morning to help a disabled person get out of bed. Carers faced having to go to work and leave the person they cared for in bed until care workers arrived even if they wanted to get up. Carers and disabled people were told that the only option was for care services to provide bedtime support as early as 7 or 8pm.

Key facts

- 51% of carers cited problems with accessing suitable care services as a reason they gave up work or reduced working hours.
- A fifth of carers said care services were too unreliable to allow them to work alongside caring.

⁴⁴ The total of carers who stated that they had given up work or reduced working hours because they person they cared for didn’t qualify for social care (15%), or because care services weren’t flexible (22%), affordable (24%), suitable (25%) or reliable (19%) enough.

Key fact

► 25 hours of childcare costs £106.50 a week. The same amount of care for an older or disabled person would cost £425.

“It is as simple as this: the cost of care means that going to work would cost me more money than I earn.”

Carers themselves drew comparisons between this ‘out of date’ approach to care services and with childcare services, which are designed around working days.

Carers at evidence sessions were very aware of the impact of tightening eligibility criteria for social care services.

“Social care is never going to help me work. The point at which my husband has got to a stage where he qualifies for social care will be long after I’ve had to give up work.”

Social care services were viewed by many as crisis care which would only step in if burn-out left the carer unable to care or when the disabled or older person needed the highest levels of 24/7 care.

“I have had to stop working as social services couldn’t provide care for the hours I worked even though I reduced my hours. This has resulted in us now having no money to live on and I am facing financial ruin. I already have debts piling up and I can’t pay as just surviving is a struggle.”

With an average cost of replacement care of £17 an hour⁴⁵ this means that the cost of care services for older or disabled people dwarf childcare costs. According to the Family and Childcare Trust’s 2013 Childcare Costs Survey the average cost of per hour for a childminder for a child under two is £3.93 an hour.⁴⁶

“I had intended to work shorter part-time hours when Mum moved in but the cost of providing the care to enable me to work would be too much. I can afford small pockets of time off caring but nowhere near long enough to work on a regular basis.”

In the previous chapter carers comments about the ‘cost of getting out of the door’ focussed on taking just a few hours a week off for a break. Given this level of costs, it is hardly surprising that carers across different evidence sessions scoffed at the prospect of buying in replacement care to enable them to work.

“It is as simple as this: the cost of care means that going to work would cost me more money than I earn.”

“Part-time self-employed is the best I can manage alongside caring for my 93 year old mother with dementia. But I’m often paying more to a care worker than I earn for the same number of hours.”

Almost a third (29%) of carers also said the charges they paid for care services were increasing.

However even for carers who could afford services or who qualified for social care support there were serious concerns about quality and suitability.

- A fifth of carers said care services were too unreliable to allow them to work alongside caring.

They spoke about transport services which would arrive within a two

⁴⁵ *Personal Social Services: Expenditure and Unit Costs England 2011-13 release* (2012) NHS Information Centre for Health and Social Care

⁴⁶ *Childcare Costs Survey* (2013) Family and Parenting Trust

“We have care workers coming in. But it isn’t ‘replacement’ care – they can’t do it without me as they don’t have the skills.”

hour window in the morning to collect the person they cared for, or which were frequently late – preventing them from leaving home for work.

“My ability to work is driven by what I call my curfew. I have to be back home to be there for my wife starting from 3pm and then be at home until care starts again in the morning at 9:30am.”

Others described a ‘lottery’ in paid care staff – a caring, trained care worker might be followed the next day by someone without the experience or skills needed. This can leave carers with little confidence that services will provide the levels or quality of care necessary.

“We have care workers coming in. But it isn’t ‘replacement’ care – they can’t do it without me as they don’t have the skills. They are basically there as my assistants so they provide me with no time off from caring. They just make the most physically difficult parts more possible for me to do.”

Home care services being consistently late or even not turning up was a huge source of stress, with carers having to leave work to deal with this or coming home to find the person they cared for distressed or confused by the expected services not arriving on time or at all.

“Replacement care is a problem even if you can afford top rates. There are too few reliable agencies and reciprocal care with friends – for example those with disabled children – doesn’t work for husbands or often for adult children.”

A quarter of carers said that they simply could not access any suitable services.

“The services for children with learning disabilities simply do not exist.”

“We pay through the nose for services which don’t offer me any additional freedom. I still have to be there with the care workers because they don’t know what they are doing.”

Carers from BAME communities were surprisingly both less likely to be accessing practical support with caring and more likely to be in work.

The reduced levels of support amongst BAME carers may result from the evidence seen earlier around a lack of advice and information on rights and entitlements, but also from a lack of culturally appropriate services. Echoing the findings of a Joseph Rowntree Foundation study on the availability of culturally sensitive services⁴⁷ a higher proportion of BAME survey respondents stated that a lack of suitable services were a contributing factor to them giving up work or reducing hours to care (33% of BAME carers compared to 25% of all carers). BAME carers attending evidence sessions commented in particular on struggling to find services where care workers spoke the mother tongue of, for example, an older parent. They were understandably unwilling to use replacement care provided by people who could not effectively communicate with the person they cared for.

⁴⁷ *Equality and diversity and older people with high support needs* (2010) International Longevity Centre

As seen earlier, BAME carers' higher levels of employment, despite lower levels of support, can be attributed to a lower age profile but also an apparent prioritisation of paid work alongside caring. Carers from BAME communities may also be more likely to be living in multi-generational households, with greater availability of other family members living in the same house to provide care or domestic support.

Key facts

- ▶ 21% of carers have given up work because of workplace issues around caring.
- ▶ 38% of working carers use annual leave to care.

Flexibility, understanding and support at work

- ▶ 21% of carers said they had given up work because of workplace issues around getting flexible hours or a lack of understanding from their employer.

Although far fewer carers raised workplace problems as a factor, compared to issues with services, a significant proportion felt that a lack of support or flexibility or disputes at work had forced them out of paid work.

Echoing issues around accessing benefits entitlements, many carers hadn't asked for support at work and had never been told about what support might be available.

As part of the Inquiry, Carers UK hosted workplace based evidence sessions, including one at the offices of major public sector employer, including both administrative staff and frontline staff. At this session, there was a clear split between participants who had discussed their caring responsibilities with their employer and were accessing support including more suitable shift patterns, and those who had combined work and caring for years without mentioning it and were completely unaware of their employer's progressive carers' policies.

These carers commented on the stress not just of the practicalities of juggling work and caring, but also of trying to ensure it didn't affect their work.

Working carers attending several of the evidence sessions said they were worried that telling their employers they were carers would damage their careers.

A carer at our Edinburgh evidence session said:

"When the jobs situation is like it is, you just don't want to put your head above the parapet and make yourself a problem person at work. Like me, I know others don't tell anyone about caring responsibilities - they just try to make sure it doesn't affect work. But it is hard."

Almost one in five (17%) carers said that they had fallen out of work or cut their hours because they were unable to get flexible hours.

"It took me 15 years to find term-time work which fits in with caring for my daughter."

Alongside these challenges for carers in work, flexibility of hours was repeatedly raised by carers as an issue for returning to or getting into

“You just don’t want to put your head above the parapet and make yourself a problem person at work.”

paid work alongside caring. A significant number were aware that the right to request flexibility took time to kick in and that, unless flexible working was available from the start – work would be impossible.

“After being made redundant I have not been able to find a similar part-time job as I need flexible hours. I cannot apply for flexible working until I have been employed for months and I cannot work that long before applying for flexible working. I am therefore taking temporary employment, as and when it comes, meaning no financial security.”

In an extremely difficult jobs market, carers who were seeking work alongside caring often felt they were looked on as ‘difficult cases’ so were very reticent to mention to potential employers their caring responsibilities.

There were extremely positive accounts of support at work. Carers often said they went ‘the extra mile’ for employers who had supported them. They described developing relationships with employers and managers over time which led to flexibility, sometimes beyond organisational policy. This built loyalty, not least because carers were concerned about how difficult these arrangements would be to establish in a new job.

“I had a brilliant job and employer which worked well with Mum but then I was made redundant and now I could never get that flexibility from a new job. I have started my own business but at the moment I only have 5 hours of work a week.”

However these positive accounts were balanced by some extremely negative experiences. There was also some frustration that organisation policies on flexibility or support for carers could only work if line managers followed them or were aware of them.

“Although my organisation provides support for carers, my head of department was not supportive, and most of my colleagues don’t seem to have a clue, and this is in a hospital.”

- 11% said they had given up work because of difficulties or disputes with their employers.

A man with a long-term condition requiring frequent hospital visits and operations told us:

“On one occasion last year my wife had agreed a work plan with her manager to come in early, ensuring there was no loss in output for the department and then be able to leave work and pick me up from hospital. She was told to confirm this by phone when I had been taken to theatre for my operation just in case of any problem. When she did so her department deputy stated on the phone that she knew nothing about it, my wife was shirking and not pulling her weight and letting the company and her colleagues down.”

“My employer doesn’t like it if caring duties clash with work. I have now used up all my sick days and unpaid leave allowance – what happens when the next thing happens which means I need to be at home?”

One of the most frequent issues raised around difficulties with

employers was carers' access to leave. Many working carers reported struggling to take time off work to respond to the needs of the person they cared for, particularly to attend frequent medical appointments but also when they had a health crisis and needed greater support at short notice.

Using up annual leave was common, and almost a quarter of carers reported taking sick leave to manage caring responsibilities.

Carers spoke about feeling like they were 'operating on the edge' of using too much leave and risked disciplinary action.

"I'm on two strikes because of the amount of sick leave I take. But if I've used up most of my holiday and need to keep some back for hospital appointments later what choice do I have?"

This was illustrated by the experiences of parent carer in Leicestershire, who cared for his disabled daughter. He who was forced to take seven weeks off work when his wife, who cared full-time for his daughter, fell seriously ill. He was very grateful to his employer for keeping him on, but noted that whilst his manager was understanding and supportive this absence would have been noted as part of his employers HR electronic rating system – meaning it would have an impact on his future likelihood of being selected for promotion.

Of working carers responding to the *State of Caring* survey:

38%	Use annual leave to care
27%	Do overtime to make up hours spent caring
22%	Take sick leave to care
12%	Take leave for carers
7%	Take dependents leave to care
4%	Take parental leave to care
20%	None of the above

This reflects evidence from Employers for Carers on employers' own concerns about extent to which caring responsibilities drive up sickness absence and absenteeism.

- 12% of carers reported having access to some kind of 'care leave' specifically for carers.⁴⁸

Alongside flexibility of working hours, home working, self-rostering and shift swapping carers also reported the difference that carer-specific policies made. Over two thirds of Employers for Carers members, for example, reported having a 'care leave' policy of time off for caring responsibilities. Whilst the forum now represents over 1 million employees across over 70 employers, data from our carer survey indicates they remain in the minority of employers – only one in eight carers said access this kind of leave.

⁴⁸ *Supporting Working Carers* (2013) Employers for Carers and HM Government

Key facts

- ▶ 61% of carers said additional support from care workers would have made the biggest difference in enabling them to stay in work.

How to better support work alongside caring

With failures in care and support services a key factor in pushing carers out of the workforce, respondents were asked what would make the biggest difference to enabling them to stay in work.

Carers were asked what would be their top three choices and these answers were compiled to examine which options were most popular across all three choices.

- ▶ 61% of carers said additional support from care workers would have made the biggest difference in enabling them to stay in work.

Unsurprisingly, the top choice of most carers was replacement care provided in the home by care workers. As seen earlier in carers' comments on the accessibility, reliability and flexibility of care services, many could only have the confidence to consider working alongside caring if they had good quality services they could rely on.

“When I was able to find and purchase care services myself through direct payments it made a huge difference. The care workers from the agency were rubbish, whereas personal assistants, who knew what they were doing and who I paid for from the direct payment, were miles better.”

- ▶ The second most popular choice was for services to help with domestic chores like shopping or cleaning.

Over a quarter of carers reported being unable to access support like homecare from care workers or day centres because the person they cared for did not want to use those services. This may have partly resulted from poor experiences of care services and, in the event of being able to access affordable, personalised and good quality services this number may reduce. However in circumstances where replacement care services cannot be used then domestic services can take the pressure off carers in different ways.

Domestic services should also not simply be seen as alternatives to care and support services. Carers often report that, on top of providing hands-on care, it is the domestic tasks which take so much of their time – including repeated loads of laundry, cleaning and sanitising, stripping beds, finding and buying specialist foods and collecting medicines. Support to carry out these tasks could both free up carers to spend more quality time with the person they care for and make work alongside caring possible.

- ▶ The third most popular choice was help with managing or co-ordinating care (32%).

Carers at evidence sessions repeatedly told stories of the time-consuming nature and complexity of managing and co-ordinating care services – from dealing with the complex payroll and budgeting tasks that come with buying in care with direct payments from local councils, to managing and buying private care services.

“The admin for his direct payment alone is a part-time job. I’m not just his carer, I am his care manager.”

“The admin for his direct payment alone is a part-time job. I’m not just his carer, I am his care manager.”

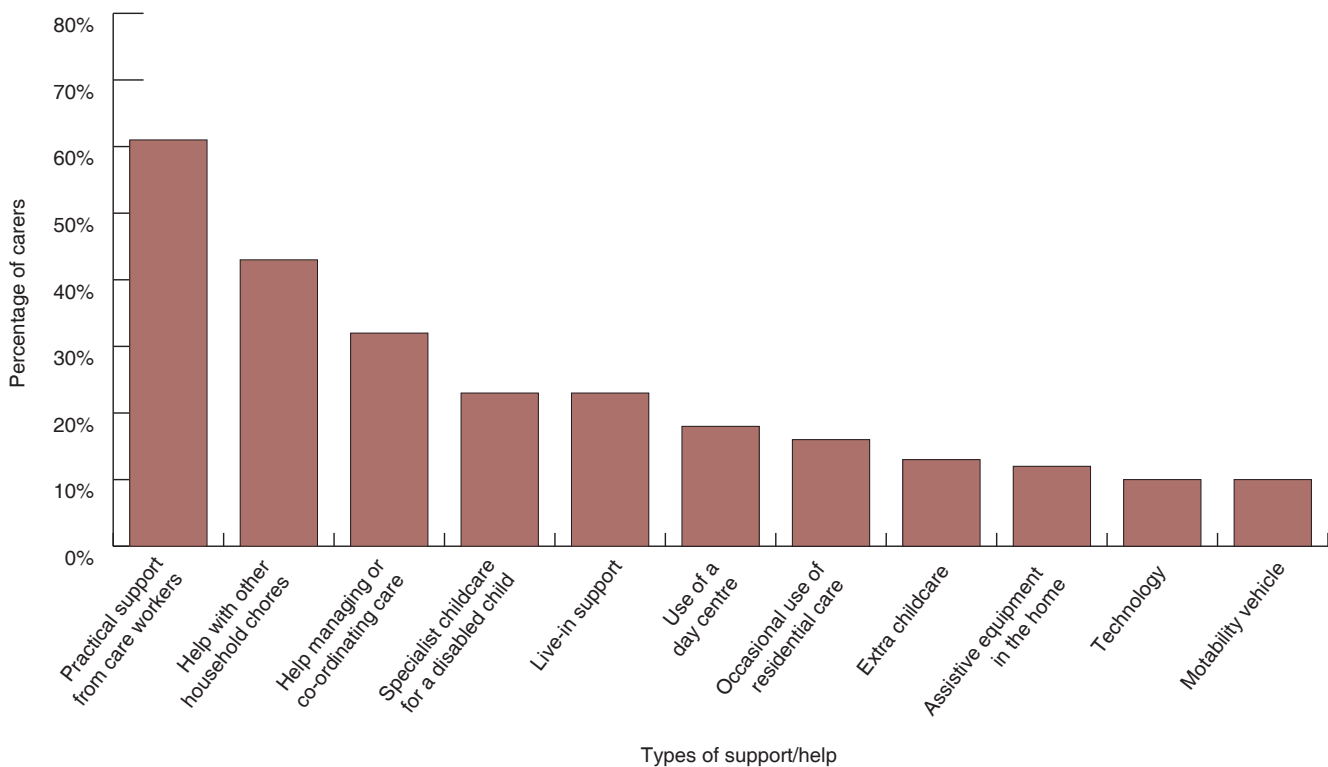
Few had access to tools or services which helped them to find, compare and buy care and support and they often felt overwhelmed by the amount of time that sourcing, purchasing and managing care services took them.

Amongst parents of disabled children the vast majority selected the need for support from specialist childcare as one of their top requirements for supporting them to work. At evidence sessions parents of disabled children frequently spoke about the unavailability or cost of suitable childcare making work simply impossible. Whether it was services which could provide the skilled and one-to-one support needed by children with learning disabilities or specialist medical care for children with profound physical disabilities, parents reported struggling to access support even to take short breaks from caring, let alone the support they would need to work. Residential colleges for adult disabled children and supportive living had some impact on the ability of carers of adult disabled children to work but many carers said that they still often faced having to step in at short notice to provide more care themselves during health crises or when services were struggling to cope.

- One in ten carers said further support from technology could support them to work alongside caring.

A carer caring for a disabled partner at our Edinburgh evidence

Figure 20: Percentage of carers who identified specific types of support/help as making the most difference in supporting work alongside caring.



Source: State of Caring survey

session spoke about how telecare had given him and his partner the confidence for him to go out to work – reflecting the findings of wider Carers UK research into the capacity for health and care technologies to make carers' lives easier and support employment.⁴⁹ However polling has also highlighted significant barriers in public awareness of assistive technologies which prevents wider adoption.⁵⁰

Key facts

- ▶ Only 49% of former carers are in work.

When caring ends

Carers often report a real lack of understanding from others when caring comes to an end. The expectation can be that carers will feel a sudden sense of freedom and will quickly want and be able to return to work. However this is often not the reality of life after caring.

The end of caring responsibilities can be an extremely difficult time for carers. They often report very mixed emotions – alongside grief if the person they care for has died, they also often talk about feelings of emptiness or a loss of identity, including when the person they care for has recovered from poor health or has moved into residential care or supported living.

Just as with carers currently caring, the loss of skills, knowledge and confidence as a result of time spent out of the workforce can pose considerable barriers to returning to work. Former carers also talk about how caring is not understood or respected as a reason to be out of the workforce.

“I have had employers not understanding what caring is – just asking me why I’ve been unemployed for so long and just thinking I’ve been sitting around all these years.”

“I know that my application will go to the bottom of the pile as soon as they see I haven’t been in work – it doesn’t matter that I have been caring.”

Whether their caring responsibilities were short or long-term carers report simply not having the time, money or the support to plan or prepare for what would happen next – through, for example, studying, training or volunteering alongside caring. Complex rules around benefits and work also act as barriers to this kind of preparation, which will be addressed in the next chapter.

Those with very long-term caring responsibilities said that they thought employers would see them as ‘completely unemployable’. A carer at our Edinburgh session talked about having given up a skilled, professional job over fifteen years ago, and knowing from former colleagues just how much his workplace had changed he said he would have to start from scratch with learning systems, technologies and practice.

Equally, short-term caring responsibilities were often the most intensive and offered the least opportunity to prepare for life after

⁴⁹ *Carers and Telecare* (2012) Carers UK

⁵⁰ *Potential for Change: Transforming public awareness and demand for health and care technology* (2012) Carers UK

“Now I am no longer caring but have been unemployed for over three years and cannot even find part-time work now.”

caring – for example end-of-life care, providing care during recovery from an accident or stroke, or caring for someone going through cancer treatment.

Of over 230 former carers who completed the State of Caring survey, those of working age were significantly more likely to be in work than current carers of working age (49% compared to 37%). However there is evidence that caring has had a significant ongoing impact on their earning potential and long-term capacity to work, even after their period of caring has come to an end.

- With only half of working age former carers responding to the survey saying they were in work, this group was significantly lower than the wider employment rate of over 70% of UK adults.

Amongst those in work, almost a third (29%) were in full-time work and a further fifth (20%) in part-time work – reversing the pattern for current carers who were more likely to be in part-time work.

“I reduced my hours, and then had to quit my job with my understanding and flexible employer to care for mum full-time. Now I am no longer caring but have been unemployed for over three years and cannot even find part-time work now.”

Former carers in and out of work still reported high reductions in their income as a result of the legacy of caring. Even amongst former carers in work, almost two thirds (63%) said the losses exceeded £10,000 a year. Although lower than the 70% of current carers saying they were over £10,000 a year worse off, this remains stubbornly high.

The loss in income of former carers not in work appeared to be even worse than current carers, with over 80% saying their income was over £10,000 a year less than it would have been as a result of caring. Financial hardship also appeared to continue after caring ended, with similar numbers reporting measures of financial hardship and debt as amongst the group currently caring, and the situation of former carers in work was only slightly better.

The end of caring responsibilities can also cause complete disruption of family finances, as a result of the likely loss of disability or older people’s benefits and a relatively short, 8 week, ‘run-on’ of carers’ benefits once caring has come to an end. Indeed some carers who were still providing care, but who were not entitled to Carer’s Allowance, expressed deep concerns about what would happen to them if the person they cared for died – they would not even have the brief run-on period of benefits and felt completely dependent on the income coming into their household from disability benefits

If carers are not able to quickly move into work then this period of readjustment may contribute to further and ongoing financial hardship.



Carers' benefits

Carers' benefits are failing to recognise the contribution carers make or protect families with caring responsibilities from financial hardship

“We are saving the Government thousands of pounds in care home fees by looking after our elderly or disabled at home. But in return they allow us a pittance in Carer’s Allowance.”

Carers UK fought for and won the first ever social security support for carers in the 1970s, when Invalid Care Allowance – the forerunner to Carer’s Allowance – was introduced.

The benefit was designed to address the situation highlighted by Mary Webster in the previous decade – that the impact of caring on carers’ ability to earn could result in lasting financial hardship and carers’ complete financial dependence on others.

Yet despite some changes in the last three decades to widen eligibility and enable small amounts of paid work alongside caring, many of the features of Carer’s Allowance have increasingly become seen as outdated.

Restrictions in eligibility and the level of the benefit provoke deep anger amongst carers, and Carers UK has called on successive UK Governments to implement reform to modernise and improve it. These calls have been echoed by reviews of Carer’s Allowance in the last

“The level of Carer’s Allowance is an insult and it makes me so angry. I would just like Government ministers to look me in the eye and tell me £59 a week is all I am worth.”

decade, including by the Work and Pensions Select Committee⁵¹ and Child Poverty Action Group.⁵²

Many of these flaws in the benefit have also been acknowledged by Government, most recently in the Universal Credit White Paper in which the current Government stated that it was *‘neither effective in poverty prevention nor in meeting the wider needs of carers’*.⁵³

As the number of full-time carers continues to rise rapidly and the body of evidence of the financial impact of caring grows, there is an ever-strengthening case for urgent reform of Carer’s Allowance.

Yet as unprecedented cuts to social security are made by the Coalition Government, alongside identifying the flaws of Carer’s Allowance it is vital to identify the principles which underpin the benefit and which must be retained in any reform proposals.

The following analysis of Carer’s Allowance highlights some of the most frequently reported flaws in financial support for carers; however, this list is not exhaustive and a more detailed review of carers’ benefits will be conducted by Carers UK later in 2014.

The level of Carer’s Allowance

- ▶ 77% of the public say they would struggle to or be unable to pay their household costs if they had to give up work to care and had to live on the current level of support for carers from the benefits system.⁵⁴

Many carers are not entitled to Carer’s Allowance at all, a situation which will be explored in subsequent sections. However, for carers who do receive it, the level of the benefit is one of the greatest sources of anger and frustration.

“The level of Carer’s Allowance is an insult and it makes me so angry. I am not angry at having to care; she is my wife and I am doing my duty by her. But I was forced to give up my job and we are in huge financial difficulties as a result. We feel unprotected by the benefits system. Carers are saving the country a lot of money and I would just like Government ministers to look me in the eye and tell me £59 a week is all I am worth.”

Figure 21: Taken from a YouGov and Carers UK survey.



51 *Valuing and Supporting Carers* (2008) Work and Pensions Select Committee

52 *Paying the Price* (2001) M. Howard/Child Poverty Action Group

53 *Universal Credit: welfare that works* (2010) Department for Work and Pensions

54 YouGov/Carers UK (2013)

“Basically the Government is saying we are worth less than everyone else. We are told we do so much and we are heroes, but then they turn around and pay us so much less than every other type of person receiving benefits.”

This anger stems both from Carer’s Allowance’s failure to protect many carers from severe financial hardship, as seen in Chapter 1 of this report, but also from carers’ keen awareness that Carer’s Allowance remains significantly lower than all other ‘income replacement’ benefits.

“Carer’s Allowance is lower than Jobseeker’s Allowance. But you are doing at least a full working week.”

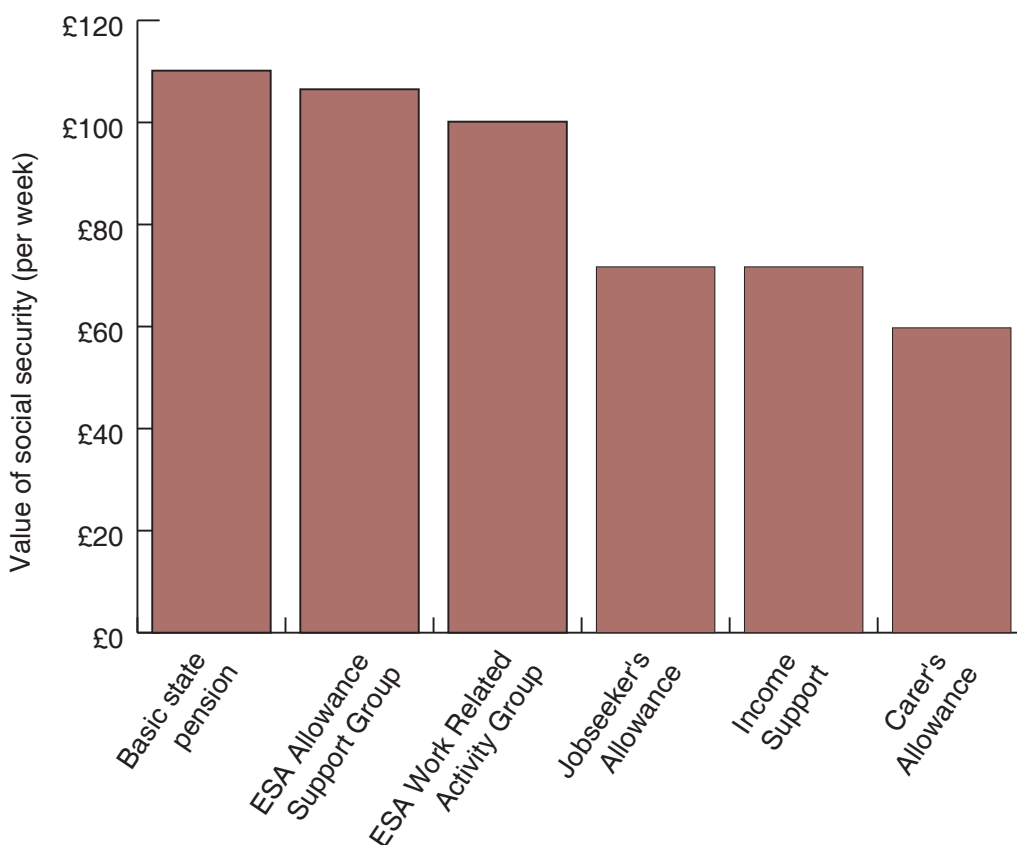
At £59.75 a week (2013/14 rate), Carer’s Allowance is considerably less than Jobseeker’s Allowance, Employment and Support Allowance and Income Support and almost half the value of the basic State Pension (see figure 22).

Carers are very alive to these comparisons and Inquiry evidence sessions again highlighted a degree of incomprehension from carers as to why benefits which recognise other individuals’ limited ability to work, being out of work or needing an income in older age, are set at higher levels.

“Basically the Government is saying we are worth less than everyone else. We are told we do so much and we are heroes, but then they turn around and pay us so much less than every other type of person receiving benefits.”

Carer’s Allowance is often described by Government as a recognition of carers’ contribution. Yet carers frequently say that receiving the

Figure 22: Comparison of levels of social security support (per week).



“I am saving the Government a fortune and with Carer’s Allowance as my only source of income I feel diminished and insignificant as a person.”

lowest benefit of its kind reflects very badly on how their contribution is viewed. Time and time again the word used is ‘insulting’ – because their situation is seen to merit the least financial support and recognition.

Carers feel this is a major contributor to them feeling completely invisible and unrecognised.

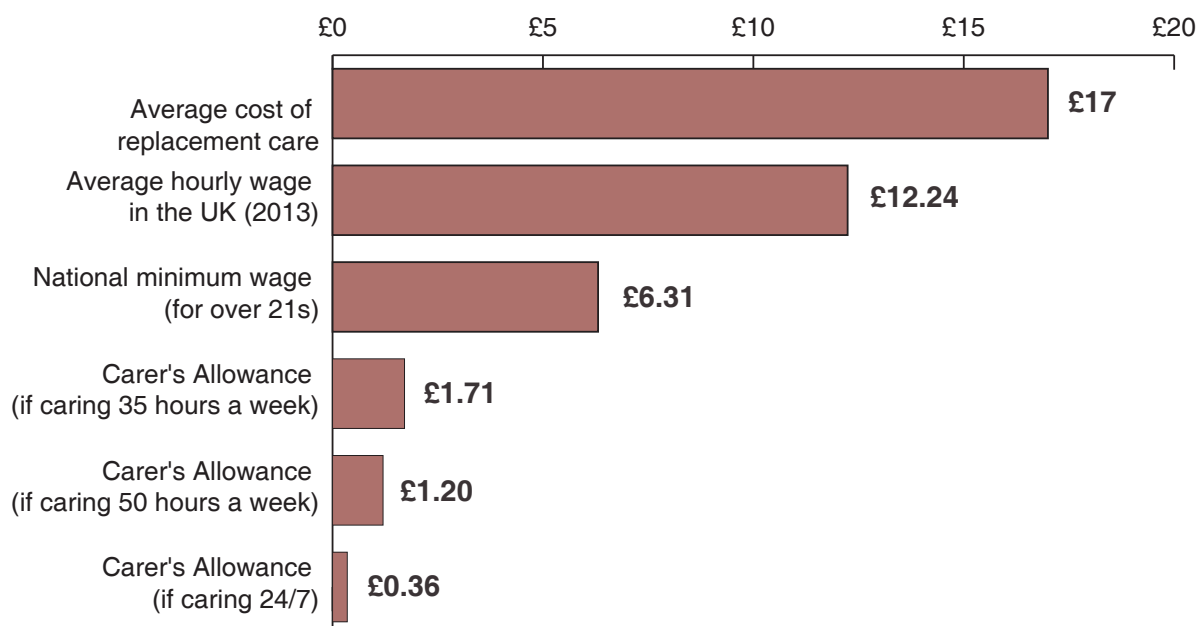
“I am saving the Government a fortune and with Carer’s Allowance as my only source of income I feel diminished and insignificant as a person. I have really negative thoughts about the fact that I am caring, which make me feel guilty and ashamed because Mum needs me – she is 83 with advanced dementia and heart failure.”

Carers very frequently comment on the value that Carer’s Allowance attributes to the care they provide per hour (see figure 23). Carer’s Allowance is paid to carers caring for a minimum of 35 hours or more each week – the equivalent number of hours to a full-time paid job. This inevitably begs the comparison between the amount carers receive in benefits and the number of hours they care for.

- If carers are providing even the minimum level of care required to qualify for Carer’s Allowance (35 hours a week) this means that they receive the equivalent of just £1.71 per hour of caring.
- Those providing 24/7 care – caring throughout the day and ‘on duty’ and often providing care throughout the night – receive what amounts to 36p an hour.

Carers are acutely aware that the financial support they receive is far below the minimum wage and just a fraction of the cost of replacement care services – not least because when they use their Carer’s Allowance to pay for care services they find that a full week’s benefits buys only a few hours of a paid care worker’s time to provide the same

Figure 23: Comparisons with the value of Carer’s Allowance (per hour).



“It was recommended that we have care workers come in to get my husband up five mornings a week. However this would cost £17. It makes the 36p an hour of Carer’s Allowance I get seem insulting to say the least.”

care.

On top of all of the emotional turmoil of caring for a loved one, day-to-day caring feels like work, and amongst the hardest work you can do. Carers often care alone, providing care they know agencies would require at least two paid care workers to provide. Carers often get no training, no time off and no health and safety protection from physical strain and constant stress. When caring feels so much like work, many carers simply do not understand why it is not paid like work.

“I care for my husband 24/7 – he cannot be left alone and I am on duty all night and all day. I have no money of my own coming in except the Carer’s Allowance. It was recommended that we have care workers come in to get my husband up five mornings a week. However this would cost £17. It makes the 36p an hour of Carer’s Allowance I get seem insulting to say the least.”

“Caring is work. Minimum wage is what we should get. Simple as that.”

Carers on the lowest incomes can claim some means-tested benefits.

- ▶ Approximately half of carers in receipt of Carer’s Allowance – around 320,000 people – also claim Income Support.

This results in complex interactions between the two benefits which will be examined later in this chapter. However, the fact that half of those entitled to Carer’s Allowance are not entitled to low-income benefits does not mean that they are isolated from financial hardship.

For example, the following groups of carers may live in households with very low incomes but would not be entitled to Income Support:

- ▶ Carers who have a partner who works for 24 hours a week or more, even on minimum wage.
- ▶ Carers who have more than £16,000 in savings, even if they have no other income in their household.

Many carers in this situation reported loss of savings, debt and struggling to pay basic bills.

Carers in households on the lowest incomes and who have little or no savings are able to receive Income Support (single person rate of £71.70 in 2013/14) – an income-related benefit designed to support people who do not have enough money to live on. If they fulfil the eligibility criteria for Carer’s Allowance they may also be entitled to receive a ‘carer premium’ (£33.30 at the 2013/14 rate) on top of the Income Support rate.

The status of these benefits can feel like ‘adding insult to injury’, as carers often say that having to claim ‘low income’ benefits along with other, very different, groups of claimants fails to recognise their unique circumstances and contribution.

“I am unable to work because I am caring. Carer’s Allowance is not enough to live on, so I have to claim Income Support. Having to receive poverty benefits in return for what I do makes me feel like my role is not valued. I have to run a car because the person I care

“Having to receive poverty benefits in return for what I do makes me feel like my role is not valued.”

for cannot use public transport, but then I cannot afford to heat the house, have a break or even a day out.”

Furthermore, carers are often shocked to find that they do not receive Income Support on top of Carer's Allowance. Instead the amount of Income Support they receive is reduced by the amount of their Carer's Allowance, because Income Support is means-tested and Carer's Allowance is treated as income.

“It is awful. I get Carer's Allowance but this is taken off my husband's Income Support. I lie awake at night worrying how the bills will get paid and how much further into debt we will have to go.”

For example, Barbara is 55 and cares for her mother who has dementia. She is entitled to Carer's Allowance (£59.75) and Income Support with the Carer Premium (£105.00). However, because Carer's Allowance is treated as income her Income Support is reduced by that amount meaning she only receives £45.25 in Income Support.

“I feel it is paltry what you get. I'm on Income Support but even that has been reduced due to the Carer's Allowance. I'm no better off from claiming it.”

Carers say they feel they are penalised and short-changed because they are caring for a loved one. They feel it is perverse that their financial recognition from carers' benefits is reduced because caring has pushed them into financial hardship and into means-tested benefits.

“Carer's Allowance is derisory and doesn't recognise the true cost of caring.”

Carer's Allowance is seen as giving carers financial recognition for their caring contribution and for many it is their only income. Yet carers often talk about using all or part of their Carer's Allowance to pay for things for the person they care for.

- ▶ 75% of carers in receipt of Carer's Allowance said it was used it to pay everyday living expenses.
- ▶ 46% said they used it for caring-related expenses like travel costs or replacement care to take a break from caring.

In discussions at evidence sessions, carers gave a wide range of examples of how Carer's Allowance is not sufficient even to cover these extra costs of caring – let alone provide them with any income for themselves:

“I receive just Carer's Allowance to look after my mother full-time. She lives with us and therefore our bills are higher. The allowance hardly covers these costs.”

“I have to spend it on nappies and gluten-free food, extra sheets and bedding and destroyed furniture.”

“My Carer's Allowance is combined with the pension of the parent that I care for and used to fund combined living expenses, the cost of running a car for essential hospital visits, energy costs and ever increasing care costs including the funding of home adaptations.”

“My Carer’s Allowance is not enough for my own day-to-day living costs. I would challenge anyone to live on £59.75 a week.”

“I gave up my job to care so we lost my salary. My husband’s pay is enough for him to live off but my Carer’s Allowance is not enough for my own day-to-day living costs. I would challenge anyone to live on £59.75 a week.”

Bearing out the Government’s own recognition that Carer’s Allowance fails to prevent carers from falling into poverty,⁵⁵ working-age survey respondents in receipt of Carer’s Allowance were more likely to be in financial hardship across a whole range of measures, including more likely to be in lower income households, in debt, struggling to pay housing costs and cutting back on essentials.

Retaining Carer’s Allowance

Despite carers’ anger and frustration at the level of Carer’s Allowance and the restrictions on eligibility (which will be explored in this chapter), they also fiercely defend their right to it.

At a number of evidence sessions, carers were aware of the possibility of Carer’s Allowance being drawn into the means-tested benefits system,⁵⁶ potentially as part of Universal Credit, something which had been actively under consideration by the Government. Even carers who would retain the benefit under a means-tested system expressed their strong opposition to any measures to further restrict the benefit to a smaller group of carers, as they believed it already fails to recognise the contribution of so many families providing care.

There was strong support for the central principle of an independent, non-means-tested carers’ benefit which recognised carers’ unique position in the benefits system. This echoed Carers UK’s position – expressed during the development of Universal Credit – that means-testing Carer’s Allowance would return hundreds of thousands of carers to the ‘*patterns of economic dependency*’ described in 1964 by the *National Council for the Single Woman and her Dependents*.⁵⁷

Carers who have given up work to care but who have partners in work would not qualify for support and would depend on their partners’ income. The gender implications are inescapable. To apply the household means-test to Carer’s Allowance would be to strip an estimated 220,000 women (who make up 74% of the Carer’s Allowance caseload) of any right to an independent income or recognition of their contribution in unpaid care.

Caring and the State Pension

One of the issues which, both historically and throughout this Inquiry, has been the source of the greatest resentment and incomprehension has been the treatment of carers in receipt of the State Pension.

⁵⁵ *Universal Credit: welfare that works* (2010) Department for Work and Pensions

⁵⁶ Whilst Carer’s Allowance does have a restrictive ‘paid income’ limit for the carer themselves, it is not means-tested according to savings or household income.

⁵⁷ *The History of the Carers Movement* (2007) Carers UK, p.14

“Just because I am now over 65 does this make my caring worthless? Don't I still face the same bills, the same pressure and the same stress on me?”

The ‘overlapping benefit rule’ means that Carer’s Allowance and the basic State Pension cannot be paid simultaneously, as the Government argues that it should not provide more than one ‘earnings replacement’ benefit and only the highest will be paid even if all the eligibility conditions for both are met.

With larger numbers of older carers at our Taunton, Slough and Glasgow sessions, this anger was particularly apparent. Carers felt it is ‘disgraceful’ that people in receipt of the State Pension cannot receive Carer’s Allowance and argued it fails to give any recognition of their caring and means they get no help to cover the extra costs.

A carer in her 70s who attended one of our Welsh evidence sessions had cared for three different members of her family since she retired 10 years ago and was still providing full-time care. She estimated that she faced an additional £40 a week in household and transport bills, yet received no financial support related to caring because of the ‘overlapping benefits rule’. She said:

‘I am getting older and I need financial support now with caring, I have never got any recognition for what I do.’

Indeed many commented that their caring responsibilities were growing at the same time as support from carers’ benefits stopped because they started to receive the State Pension – as partners or older parents needed increasingly higher levels of care as they got older.

Their income from the State Pension by no means guarantees any significant level of disposable income, yet they face many of the same costs as, and often greater costs than, working-age carers.

Older carers at our evidence sessions in particular noted that, as they themselves got older and physically found caring more challenging, they needed to spend more on care and support services to help them to care. This was borne out by our *State of Caring* survey which showed that:

- 30% of carers over the age of 65 were accessing support from domiciliary care workers which they or the person they cared for were paying for, compared to 20% of working-age carers.⁵⁸
- 51% of older carers were using paid-for domestic cleaning support to help them to care compared to 29% of working age carers.
- 13% of working age carers paid for breaks for caring from their own income, compared to 21% of older carers.

“It makes no sense. I paid into my State Pension all my life – I am entitled to it. I care for 35 hours a week – I am entitled to Carer’s Allowance. That should be that.”

In addition to being without financial support for the extra costs of caring, carers receiving their State Pension also feel that, because they cannot receive Carer’s Allowance, their contribution to society

⁵⁸ This could also be attributed to older carers having greater financial means to purchase care and support services.

goes unrecognised.

Older carers are also the fastest growing group, rising by 35% to 1.28 million from 2001 to 2011.⁵⁹ With the most recent estimates showing the average saving to the state per carer to be £18,471 each year⁶⁰ this would mean that the contribution of older carers is over £23.6 billion a year. Yet they are denied entitlement to £3,107 a year in Carer's Allowance.

- Department for Work and Pensions figures show that over 340,000 carers over the age of 65 have an entitlement to Carer's Allowance but cannot receive it – almost all will be prevented from doing so because of this 'overlapping benefits' rule, despite fulfilling all the criteria by providing full-time care to an ill or disabled loved one.

If they are entitled to Pension Credit because they are on a low income, then older people may be entitled to receive a top-up payment called the 'carer addition'. But this means that carers with modest savings or private or occupational pensions do not qualify for any financial support with caring.

At our evidence sessions carers commented that they were 'doing the right thing' twice over – having saved for retirement and now caring for their loved ones – but felt penalised for doing both.

Carer's Allowance and earnings

The Carer's Allowance £100 a week earnings limit makes it an anomaly in the benefits system. As the Government moves to introduce a system-wide earnings taper under Universal Credit to facilitate paid work amongst people in receipt of benefits, it further exposes how outdated this rule is for carers' benefits.

Carers are able to earn up to £100 a week⁶¹ but if they earn more they lose Carer's Allowance in its entirety. This 'cliff-edge' means that carers often face a range of absurd situations as they try to retain entitlement to Carer's Allowance and engage in paid work.

"If I work more than a certain amount of hours I am penalised by losing Carer's Allowance. If I earn just one penny over the allowed amount, Carer's Allowance stops entirely. Why doesn't the system look after those of us who need our jobs not just for the money but for self-worth and pride in ourselves?"

At the evidence session in Islington, London, carers who had lost Carer's Allowance but only earned slightly over the earnings limit spoke about all the extra costs of caring they still faced, but which they get no financial support for. Carers in Jarrow, Leicester and Hertfordshire described the earnings limit as a 'barrier' to them being able to build any kind of career alongside caring.

59 Census Data Update (2013) Carers UK

60 *Valuing Carers* (2011) Carers UK and University of Leeds

61 The earnings limit applies after deductions relating to Income Tax, National Insurance and half of any contributions towards an occupational/personal pension.

“My life has been torn to pieces and it is very stressful. I could not work as I cared for my family and now I don’t have enough of my own income to live on.”



Bushra's story

Bushra cares for Talat, her sister. Talat is in her fifties, has learning disabilities and a number of physical health issues, including a thyroid condition, kidney failure, epilepsy and a hearing impairment.

Talat says: *"Bushra is my sister, my mother, she's everything to me."*

Bushra, 65, became her sister's full-time carer following the death of their mother in 2011. Bushra has also cared for her husband since he suffered a heart attack in the 1990s followed by a stroke 8 years ago. Towards the end of her mother's life, Bushra cared for all three of them at once.

Despite her multiple and prolonged caring responsibilities, Bushra receives scant support.

Like so many older carers, in normal circumstances Bushra would be denied Carer's Allowance because she receives the State Pension.

However, the long period she has cared for her family means Bushra does not even receive a full State Pension, as a result of not having a full National Insurance record. In addition to her very low pension she does also receive a small top-up from carers' benefits – but this still leaves her with a total income of less than £300 a month as she cares for two people.

Even worse, the £98 a month carers top-up she receives counts as income and is deducted from her husband's benefits, entirely negating the benefit to the family.

"I am just expected to survive on virtually nothing. I don't have anything for myself," Bushra says.

Talat's care needs meant that when their mother died, Bushra had to make some incredibly difficult decisions.

Her sister has lived in the home she shared with her mother for more than 20 years. It is a familiar and secure place for her. Leaving would be hugely unsettling and upsetting.

Bushra's marital home is about 10 minutes drive away, but Talat cannot live alone. Neither is Bushra's home suitable for Talat's needs.

So Bushra has moved in with Talat, and because her husband's needs remain she spends her days travelling to and fro, juggling both their care needs.

She is caring round the clock and running two households. The only help she gets is from social services care workers who help take Talat to dialysis appointments three times a week and a day centre for two days each week.

"My life has been torn to pieces and it is very stressful. I could not work as I cared for my family and now I don't have enough of my own income to live on. My married life is destroyed but my sister cannot live alone. I must be here for her every day and I must stay with her at night. I could not think of my sister going into a care home – I could not leave her in strangers' hands."

“As my husband’s condition deteriorated it was harder to work and it was more and more difficult to find any job that would give me the right number of hours. I haven’t found the right work in two years. I doubt I will ever work again.”

The previous chapter explored how caring often forces carers to take lower paid, flexible work to fit around caring. The Carer’s Allowance earnings limit adds further restrictions to the kind of paid work carers can find. Many carers said that their caring responsibilities meant they were unable to work enough hours to make up for the loss of Carer’s Allowance - as on minimum wage this would involve working over nine more hours a week. As a result, they were left hunting for local work for a certain number of hours that paid no more than £100 a week, from employers willing to be flexible around caring responsibilities but who did not anticipate any fluctuation in hours that might risk losing the benefit. Many carers reported that this, particularly in the current jobs climate, is an almost impossible task.

Carers with seasonal or fluctuating work patterns often find it incredibly hard to manage hours and earnings to retain Carer’s Allowance – for example, parents of disabled children who could manage term-time jobs when their children were at school or college, or carers who could take on seasonal jobs when a partner can take time off over Christmas to provide care.

“I face a complete catch-22. If I work Sundays or over Christmas or Easter and get higher pay rates I get pushed over the earnings limit. But if I refuse I feel like I’m letting my colleagues down, so end up doing it and losing Carer’s Allowance and then having to reapply. I’ve had a total of £2,000 in overpayments of Carer’s Allowance because of my changing work patterns and have to repay it. It is a mess.”

Many had given up trying, but for those who did persist, it often means repeatedly reapplying for benefits when temporary periods of work come to an end, incurring unnecessary administrative burdens for both families and the Department for Work and Pensions.

“I have only worked a few hours a week for the last twenty years to keep within the limits of Carer’s Allowance. I have done low paid menial work to fit in with the earnings limit and as the years passed, employers were willing to pay me less and less because they said I wasn’t working enough hours to have proper experience in the jobs I was doing. As my husband’s condition deteriorated it was harder to work and it was more and more difficult to find any job that would give me the right number of hours. I haven’t found the right work in two years. I doubt I will ever work again.”

Other carers at evidence sessions reported that higher hourly pay for professional work meant they could only work a very minimal number of hours in order to stay under the earnings limit.

- If they are earning minimum wage carers have to work less than 16 hours a week to stay under the earnings limit.

“What I need is to keep up my skills in my old job. But if I worked at that pay rate I’d lose Carer’s Allowance. It is a catch-22.”

“I’ve had to take a part-time shop job on minimum wage, but I’m capable of being a high earner. Doing this job, my hours are inconsistent and differ every week from 16 hours to 24 hours, so

I'm not entitled to any Carer's Allowance. It is absolutely destroying me financially. But at 57 years old I need to work to stay in the jobs market and for other adult company, selfish as it sounds."

It is also a very significant barrier to progression in the workplace, and carers report perverse outcomes including having to refuse promotion, greater responsibility or additional working hours as these things would entail an increase in earnings or longer working hours. However, the increase in pay would be more than cancelled out by the resulting loss of Carer's Allowance.

"From having a career, I now have a job. I have had to turn down promotion as it would have meant working more hours. There is no advantage to me working any overtime, as I lose all my Carer's Allowance."

Running counter to many of the core principles of the Government's approach to reforming the benefits system, this 'cliff edge' earnings limit traps carers in low-paid, limited-hours jobs – unable to progress at work, accept overtime or be flexible with their hours, or to engage in more highly paid, skilled work alongside caring.

Carers at evidence sessions spoke about the earnings limit preventing them from preparing for the future. A carer in her 50s caring for a disabled child who attended one of our evidence sessions in Wales said:

"Carer's Allowance doesn't allow me to work enough hours to achieve promotion, or ever earn enough to have savings or accrue a good pension. It prevents me having any financial security."

Furthermore there has been an annual problem caused by the increase in the minimum wage as the Carer's Allowance earnings limit has remained at £100 since 2010.

Carers earning just under the earnings limit on minimum wage have been pushed over the £100 level, even though their working hours remain exactly the same. Carers described 'ridiculous' situations where they had to ask for a cut in hours in order to stay in work, or face a decision between quitting their jobs or being almost £60 a week worse off.

The situation was worsened in 2013 when the increase in the minimum wage rose to £6.31. This meant that it was no longer possible to work 16 hours, even on minimum wage, and remain below the earnings limit. However, 16 is the minimum number of hours of paid work needed for entitlement to Working Tax Credit, meaning carers faced a 'no-win' situation:

- If they continued to work for 16 hours to keep their tax credits, their earnings on minimum wage would be £100.96 – 96p over the Carer's Allowance earnings limit – so they would lose £59.75 a week (or £3,107 a year).
- If they were able to reduce working hours by just one hour, they would lose Working Tax Credit of up to £36.92 a week (or £1,920 a year), and any additional elements (top-ups) or support with childcare costs they receive as part of Working Tax Credit.

“I have had to turn down promotion as it would have meant working more hours. There is no advantage to me working any overtime, as I lose all my Carer’s Allowance.”

- Giving up work, at 16 hours a week on minimum wage there would be a loss in earnings of over £5,250 a year.

Study rule

Carer’s Allowance eligibility also means that carers are unable to combine studying for 21 hours a week or more with claiming Carer’s Allowance.

However, Department for Work and Pensions guidance indicates that the definition of 21 hours is flexible and can extend far beyond ‘contact time’ of lectures and seminars to ‘any involvement in [an] exercise, experiment or project’. This guidance is often applied to any course that is termed ‘full-time’ by an educational institution.⁶²

The Carers UK’s Adviceline has heard from carers whose Carer’s Allowance has been removed on the basis of studying for a course termed ‘full-time’ by a college, but which amounts to only 14 hours of study a week.

Carers at evidence sessions who had tried to study alongside caring, particularly in Hatfield, Leeds and Edinburgh, commented that Government ought to be finding ways of incentivising carers to study, through reduced fees and greater access to student finance. But instead they felt were being penalised for studying and had found themselves at risk of losing what was often their only source of income if they engaged in any structured study programme.

“My daughter spends a few hours a day at a day centre. Why wouldn’t the Government want me to use that time to learn new skills or train to try to get a job which I could do along with caring?”

Whilst committing to a set pattern of working hours or even volunteering may be impossible for many carers, fitting studying at home around caring may be achievable. Completing assignments or online courses whilst a disabled child is asleep or an older parent is watching TV may be possible, and carers find it perverse that they are prevented from doing so.

Carers of all ages reported the study rule acting as a barrier to studying and training. However, it is particularly concerning given the rapid increase in the number of young adult carers. The number of carers aged 18-24 has risen by 28% in the last 10 years, far faster than the increase in the total carer population of 11%⁶³.

62 Paragraphs 60,068 – 60,072 in Decision Maker’s Guide Volume 10, Chapter 60, DWP

63 Census 2011 compared to Census 2001

Multiple caring responsibilities

Carer's Allowance is payable at a flat rate either as a standalone benefit or as part of a package of means-tested benefits. Carers frequently argue that this fails to fully reflect different caring scenarios.

"I only receive Carer's Allowance once. But I care for an adult and a child. They each get disability benefits to cover their extra costs, but I only get one lot of Carer's Allowance, even though I have twice the caring costs."

Carers caring for more than one person receive the same level of support as someone caring for one person. Our Leicester evidence session included a number of carers of disabled children who were also supporting an older parent. They expressed their frustration around two different scenarios of multiple caring responsibilities:

- ▶ If they were providing high levels of care to both, Carer's Allowance only recognised one of their caring responsibilities and did not increase to respond to 'double the amount of caring'. A number of carers said that they easily provided 35 hours of care each to two people and questioned why this wasn't recognised with additional support from Carer's Allowance.
- ▶ If carers were providing a cumulative total of 35 hours of care a week but divided between two people they were not eligible. For example, one carer was caring for her own mother and her mother-in-law who lived in their own homes. This was 'more than a full time job' but because she didn't care for any one person for 35 hours or more a week she would not qualify for Carer's Allowance.

There was also disbelief among carers, particularly parent carers of disabled children at our Leeds and London sessions, that only one person could receive Carer's Allowance for each disabled person in receipt of a relevant disability benefit. For children with extremely high level needs, there were examples of parents who both had to give up work to provide round-the-clock and often complex medical care, but only one could receive Carer's Allowance:

"When we have short breaks from caring, our daughter's care assessment says there always have to be two care workers looking after her. Yet between me and my wife only one of us can get Carer's Allowance. Is a parent carer of a disabled child supposed to be superhuman, doing the work of two paid staff?"

Severe disability premium

Carers in different evidence sessions, particularly parent carers of disabled adults in Leeds, Leicester and Edinburgh, expressed anger that they could not receive Carer's Allowance because the person they cared for, who lived independently, received the severe disability premium to means-tested benefits.

This premium is awarded on top of other disability premiums for

disabled people who technically live alone (anyone under 18, or who is severely disabled themselves, or who is not a close relation who lives in the same household may be ignored) and if no-one receives Carer's Allowance for caring for them.

However there were numerous examples of parents of adult disabled children who lived independently in supported living and where the severe disability premium was essential to them for living costs, but where their parents continued to provide high levels of support 'at a distance.' Carers spoke about providing at least 35 hours of care a week, for example covering for care workers who did not arrive or doing shopping, cleaning or laundry, but who could not claim Carer's Allowance as it would result in a fall in the income of the person they cared for.

Application and assessment processes

In addition to anger at the eligibility criteria and level of carers' benefits, carers also frequently expressed frustration that applying for their entitlements felt like a battle.

This contributes not only to substantial numbers of carers, disabled and older people missing out, as seen in Chapter 1, but also to stress, worry and frustration for families already struggling with the fears and pressures of caring.

"We faced a huge combination of factors. The person cared for was reluctant to share information, professionals did not want to liaise with me, I didn't know what benefits were being applied for, or what was being paid until recently, and Disability Living Allowance was not paid at the appropriate level to claim. Carer's Allowance stops at pension age and actually just Carer's Allowance per se – even if I could have claimed – would not have been enough for my living needs."

Typically, when they take on caring responsibilities carers may need to complete application forms for:

- Attendance Allowance or Disability Living Allowance/Personal Independence Payment with or for the person they care for.
- If they are caring for someone of working age, they are also likely to apply for Employment and Support Allowance with or for the person they care for.
- Carer's Allowance.
- Currently they may also be applying for Housing Benefit and Income Support – which will later be subsumed into Universal Credit, requiring a further application.
- Discounts or reductions in Council Tax.
- A Community Care Assessment.
- A carer's assessment.

Even after getting over the hurdle of understanding which of these

things are related to their situation, carers then describe facing a 'maze' of complicated, confusing and time-consuming processes and application forms.

Carers express considerable frustration at having to tell different agencies, or often the same agency, the same information over and over again and do not understand why it is not possible for data to be shared to reduce this. Opportunities are also missed to ensure that contact with one agency triggers advice, information or sign-posting to others.

- ▶ One in seven carers say that they missed out on benefits because of problems applying for them.

As explored earlier in this chapter, significant barriers exist specifically related to eligibility rules and application processes for Carer's Allowance. However carers often first cite concerns about applying for benefits for the person they care for.

"My son has just been through an Employment and Support Allowance assessment. Took two and a half hours to fill in, and then two months of stress and worry for me as his carer."

Many carers, particularly parents of disabled children and those caring for working-age disabled partners, had experienced significant difficulties in applying for disability benefits for the person they cared for. This was a particular theme in Leeds and Leicester, where most participants had examples of the complexity and inaccessibility of the benefits system. In particular, participants raised the challenges of accessing support for children with learning disabilities which are hard to diagnose. They spoke about the frustration of explaining their situation multiple times to different agencies and reapplying for disability benefits even when circumstances have not changed.

The stories were again of feeling like they were 'fighting the system' – being turned down first time then reapplying or appealing decisions, sometimes with support from an advice agency but often without, before eventually establishing an entitlement.

"We were turned down because I did not make our case clearly enough on the application form. Had to start all over again - by the second time I knew the right way to say why he needs help. A waste of everyone's time and even longer without that money coming in."

Carers with longer-term caring responsibilities talked about becoming experts in the language needed to express the conditions of the person they care for in a way which correctly fits with how the eligibility criteria works. At evidence sessions in Glasgow, Edinburgh, Leeds, Leicester, Hertfordshire, Birmingham and London carers reported huge anger about Employment and Support Allowance in particular.

"I am currently fighting for Employment & Support Allowance as I have been told my son is 'fit to work'. He had been awarded it but then it was taken away. He has severe cerebral palsy in all four limbs, is registered blind, has scoliosis, reflux, epilepsy, is a wheelchair user, doubly incontinent and more. Our local MP is now involved and eventually it looks like we will get it reinstated."

“ESA has caused my health and that of the person I care for to relapse, necessitating a call to the emergency mental health team.

Unbelievable that our health can be worsened by a system and an assessment which removes legal benefits from genuinely sick people. How can it be right that this system plunges people into a need for acute services and poverty and despair?”

Carers of disabled partners were most likely to report problems with applying for disability benefits, including Disability Living Allowance and particularly Employment and Support Allowance. Carers' experiences indicate that people with acquired health conditions or disabilities in particular struggled to access advice and information and establish entitlements to disability benefits. One in four (25%) carers of working-age partners reported missing out on benefits as a result of problems making a claim, 10% higher than the average amongst carers.

Across all caring scenarios carers gave examples of inadequate, inappropriate and, on occasion, absurd assessments for Employment and Support Allowance, particularly cursory face-to-face interviews overriding long-established evidence from clinicians, specialists and social work professionals, and the application of unrealistic proxies for disability and capabilities.

“My wife was asked if she could walk down a corridor outside the assessment room to test how far she could get. With her walking frame, in a long, flat, carpeted corridor she can get around. Apparently that means she is fit and able. The test assumes the rest of the world is all carpeted corridors. But in reality she couldn't get 10 metres beyond our front gate.”

This Inquiry has not examined in detail experiences of claiming either Disability Living Allowance or Employment and Support Allowance. However carers' experiences of the ongoing failures of the Employment and Support Allowance Work Capability Assessment echo the wide and growing body of evidence gathered by disabled people's organisations, the Disability Benefits Consortium and disabled people themselves, particularly through the We are Spartacus group.⁶⁴

- ▶ Disability Benefits Consortium notes that 30% of all 'fit for work' decisions appealed to date have resulted in the initial decision being overturned and that 200,000 disabled people have only accessed the appropriate Employment and Support Allowance, Work Related Activity Group support via appeals and reconsiderations (36% of the entire group).⁶⁵

Carers describe frustration, fear, despair and exhaustion at the cycle of applications, assessments and repeated appeals often needed to establish entitlement to support, or which still end up with them being turned down for financial assistance.

“My husband and son get ESA and DLA. My son is in the support group but my husband is in the work-related activity group. There is no way my husband can work and he should not be in this group, but I was too exhausted to appeal against it on his behalf.”

Our evidence sessions also highlighted how these experiences have also led to a rising fear that new assessments for working-age people being moved from Disability Living Allowance to Personal Independence Payment would have a similar, destructive impact on their lives.

⁶⁴ WCA People's Reviews (2012 and 2013) We are Spartacus

⁶⁵ WCA still failing disabled people (2013) Disability Benefits Consortium



The impact of the Welfare Reform Act

As a result of the Government's changes to benefits, carers will see a cut of over £1 billion to their incomes between 2011 and 2018

“I couldn't pay the bills already. How am I supposed to pay £900 more a year, when I've got less coming in?”

On top of often decreasing support from social care services, carers face significant cuts to disability benefits, the introduction of Universal Credit and changes to support with housing costs and Council Tax.

They feel like they are being hit by a perfect storm of cuts when they were already struggling.

- Hundreds of thousands of carers will face cuts to vital support, additional charges for Council Tax or shortfalls in their rents.
- Families are already facing costs in excess of £1,000 a year as a result of cuts to support with housing costs and Council Tax.⁶⁶
- The cumulative total of cuts to carers' incomes will reach over £1

⁶⁶ The localisation of Council Tax support currently only applies in England and Wales.

“I used to just feel ignored. Now I feel persecuted.”

billion by 2018.

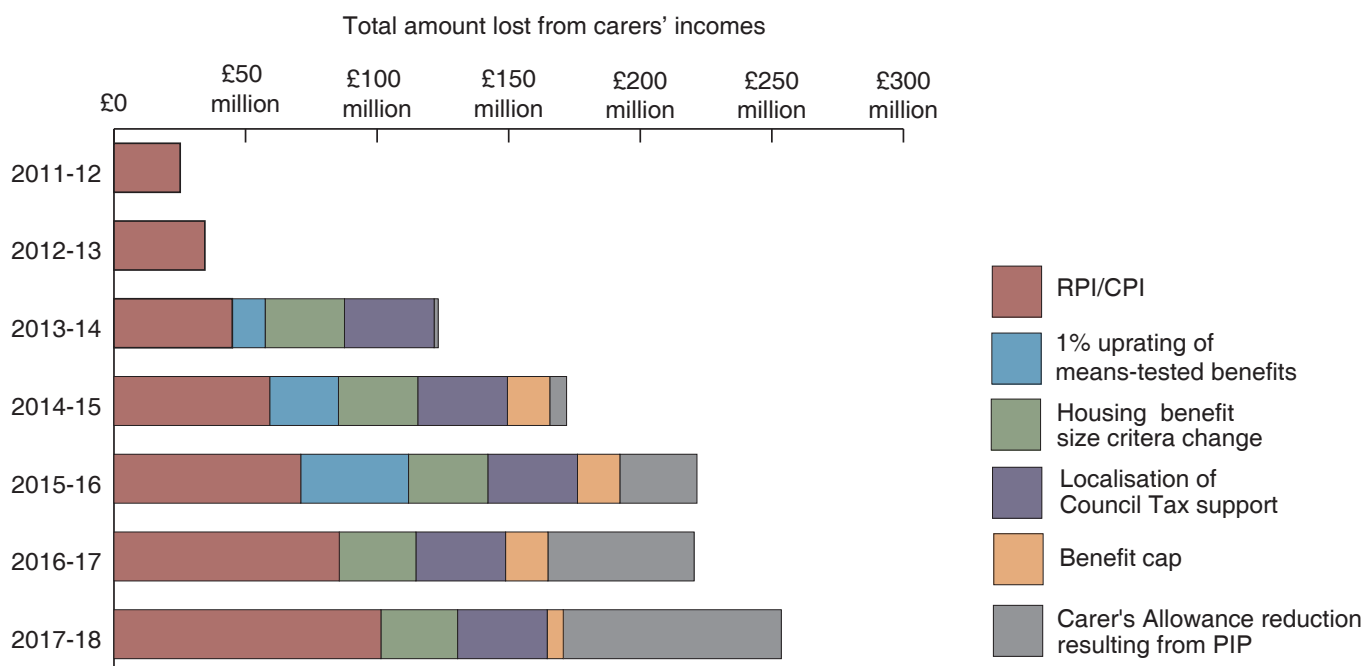
Across all the evidence sessions, in survey responses and frequently in calls to Carers UK’s Adviceline carers reported feeling not just unrecognised and unvalued but that they are also now also being publically criticised for claiming their social security entitlements.

Carers spoke in particular about the treatment of families receiving benefits in the press. There were also numerous stories of hostility and even abuse from other members of the public who they did not know.

“We receive a pathetic, insulting amount of money to pay for providing 24/7 caring for another. I have no quality of life because we are told that we shouldn’t receive enough to have a ‘life on benefits’. Well sorry, but for some people it has to be. And now it is awful that we are being seen as ‘benefits scroungers’ when we actually work for our money.”

Carers reported feeling ‘degraded’ or ‘insulted’ by media reporting on benefits claimants and particularly accusations of fraud. Families talked about having ‘benefits cheat’ shouted at them when they were seen with someone with a visible disability. Others talked about being reported to benefits fraud agencies by neighbours who thought that people receiving benefits should not be able to afford Motability vehicles or trips away from home to, for example, visit family members. At evidence sessions this was demonstrated by carers feeling they needed to explain and apologise for their receipt of benefits, even to

Figure 24: Cumulative cuts to financial support for carers 2011-2018.



Source: See Appendix 2 for original Carers UK analysis.

“This ‘bedroom tax’ has put so much stress on me. I am scared for the future.”

other carers.

Carers were also clear that they felt that the Government was contributing to this with a very negative narrative of ‘cracking down’ on benefits claimants and ‘benefits dependency’. This added to their feelings of exclusion, invisibility and insult – demonstrating a lack of public understanding of how caring and disability often make social security support both vital and unavoidable.

They said they never heard the reality of benefits being talked about: carers and their families are not part of a minority - caring and disability could happen to anyone and every family needs social security to be ready when it does.

The Welfare Reform Act 2012

“We already couldn’t afford our bills. We can’t afford this cut. It now just feels like kicking us while we’re down.”

The following analysis largely focuses on the Housing Benefit and Council Tax support changes, as these changes have been most widely implemented and evidence on impact is more readily available.⁶⁷ Whilst it is possible to forecast and model the impact of Universal Credit and Personal Independence Payment, limited and delayed roll-out makes any evidence gathering extremely challenging.

Carers UK has called for an urgent cumulative impact assessment of the Government’s benefits changes, alongside disability organisations and groups of carers and disabled people like the Pat’s Petition group.⁶⁸ Carers UK has consistently argued that siloed impact assessments of the different changes are completely inadequate for capturing the combined impact of the changes on families, disabled people’s independence or carers’ ability to continue to provide care.

- Across six of the major changes to benefits the Government will cut support for carers by over £1 billion over the period of implementation 2011-2018.

However it is possible to begin to calculate the scale of some of these changes and the cumulative national impact as the Welfare Reform Act 2012 is implemented, in particular the following six measures:

1. The Housing Benefit size criteria changes for the social rented sector, described by the Government as the ‘spare room subsidy’ and known by many as the ‘bedroom tax’ (only currently implemented in England, Scotland and Wales).
2. The localisation of Council Tax Support (affecting England and Wales).
3. The household Benefit Cap which places a limit on the weekly

⁶⁷ The Housing Benefit size criteria changes have been implemented in England, Scotland and Wales.

⁶⁸ Pat’s Petition was organised by a group of women with disabilities and/or caring responsibilities including Rosemary O’Neill, Frances Kelly, Pat Onions, Karen Machin and Rachel Gladwin, alongside similar work by disabled people from the WOW Petition and the We are Spartacus groups.

amounts households can receive from social security (only currently implemented in England, Scotland and Wales).

4. The impact of switching from the Retail Prices Index to the Consumer Prices Index as an inflation measure for uprating benefits (all of the UK).
5. The impact of the 1%, below inflation, yearly rise to most means-tested benefits (affecting all of the UK).
6. The impact of the introduction of Personal Independence Payment on the number of people entitled to Carer's Allowance (across the UK).

The majority of the evidence from carers for this Inquiry focuses on the first two changes on this list, which have been fully implemented and are having a significant effect on very large numbers of carers.

Key facts

- Essential accommodation is being treated as 'spare' and carers are being hit by a rent shortfall of £14 a week.

Housing Benefit social sector size criteria changes

"This 'bedroom tax' has put so much stress on me. I am scared for the future."

Implemented in April 2013, changes to the 'size criteria' for Housing Benefit for social housing tenants mean that those who are considered to have 'spare' rooms are seeing their Housing Benefit reduced by an average of £14 a week. They either have to make up this shortfall in rent themselves, or move to a smaller property. The policy is currently being applied in England, Scotland and Wales, but implementation in Northern Ireland has been delayed for at least four years.

Since the proposals were initially debated in Parliament, Carers UK has expressed deep concerns about the impact on carers and their families. Whilst limited exemptions have been put in place for families affected by disability, Carers UK identified several groups of carers and disabled people who are still affected, despite the accommodation being essential:

- Carers caring for disabled partners who are unable to share a room as a result of the condition of the person requiring care and support, because of medical or assistive equipment – for example oxygen tanks or hospital beds.
- Families where adaptations or equipment are installed or stored in an additional bedroom, making it unusable as a bedroom. For example 'through-floor' lifts being installed in a bedroom to enable access to an upper floor, or the storage of equipment like dialysis machines or motorised wheelchairs.
- Families who have been assessed as needing additional space unrelated to equipment or adaptations – for example, 'quiet' or 'safe' rooms which may be free of furniture on which people with learning disabilities could injure themselves.
- Parents of disabled children who split overnight care between them, so that one parent can sleep uninterrupted and the other

Families feel like they are being penalised for providing care.

uses a room to try to sleep but is available to provide care throughout the night.

- Families who need overnight accommodation for a non-resident to provide overnight care for disabled children, disabled siblings, older parents or other disabled relatives of tenants who live with the tenants.

The principle of the change was to reduce support for people living in accommodation which is considered too large for their needs, yet in the circumstances set out above, the accommodation is essential, not spare.

In addition, there are families who may have 'spare' space but moving home makes no sense for the family and would be counter-productive for the local authority – for example where homes have been heavily adapted or where the families lived close to friends and family who provide support which enables them to continue to care. The costs or the risk to the health of the disabled or ill person may also be too high.

The Government has acknowledged that there are some circumstances where families have needs which require an additional room. For example there are exceptions if tenants or their partners need 'non-resident overnight care' (care overnight from someone coming in from outside the home) and, following a legal battle by families of severely disabled children, the Government granted exemptions for disabled children who cannot share with their siblings.

Carers express their shock that these needs-based exemptions are so limited and do not recognise very similar situations. There are a number of perverse contradictions which arise:

- If rooms for 'non-resident' care are recognised as being necessary, why are rooms for carers who are resident not permitted?
- If a 'cannot share a room' exemption exists for disabled children who are unable to share with siblings, why does this not exist for disabled people unable to share with their partners?
- If an extra room is permitted for a tenant or their partner to receive 'non-resident overnight care' then why is this not allowed if it is the tenant's children or other older or disabled relatives living with them who need care?

Families feel like they are being penalised for providing care.

If a single disabled person were to need overnight care they would be permitted an additional room for care workers to stay in, but where that care is provided by a partner there is no provision for their accommodation if they cannot share. Where a young disabled adult lives on their own they are similarly permitted an additional room for someone to stay in to provide overnight care; but were they to live with and be cared for by their parents, no additional room would be allowed for a care worker to stay to give the parent carers a break from providing overnight care.

Zara's story

Zara, 58, cares full-time for her husband Chris, who has Huntington's Disease. Chris was 40 years old and working as a mechanic when he was diagnosed. The symptoms of Huntington's meant he had to give up work immediately. Zara and Chris had met later in life, were only recently married and had just bought a home, their small but "dream cottage", together.

At first Zara was able to continue to work and care for Chris, but as his health deteriorated he needed more support and Zara's struggle to maintain their income alongside caring grew ever harder. Six years ago Zara gave up her job in education to care full-time for her husband. The drop in income meant they simply couldn't afford a mortgage and they sold up their home and moved to Local Authority accommodation.

Their home has two bedrooms. Chris's illness means his sleep is constantly disturbed. The second bedroom in their home allows Zara the space to get the respite she needs, but it is now considered to be 'spare'. As a result, they face a £15 a week shortfall in their rent on top of £2 a week more in Council Tax following the loss of full support from Council Tax benefit – together this means finding £884 more a year.

Zara and Chris have now received two Discretionary Housing Payment awards to cover the cost of the 'bedroom tax' until April 2014. When they first applied for a Discretionary Housing Payment to cover the shortfall in their housing benefit as a result of the bedroom tax they were told that daily necessities did not include stamps, spectacles, or saving for household repairs. They were left paying the shortfall in rent.

They successfully appealed and were awarded discretionary payments for three months and have since made a second successful application for discretionary payments, which was awarded for six months. It has been a battle - and there is no guarantee the discretionary support will be re-awarded when they must apply again in April 2014.

Zara says:

"I have been my husband's full time carer for twelve years now, without a break, and fulfil the roles of several health and social care professionals, yet I feel we are being penalised for this. We cannot sleep in the same bed, let alone the same room. Like many others, as a married couple we would dearly love to share the same bed but it is impossible and one of the sacrifices we have already had to make.

I want to do the best for my husband but the government has brought this policy in and they do not see the effect on the people concerned. When I see my husband deteriorate day by day it makes me angry. When a person is diagnosed with Huntington's they say you have between 15 and 20 years until they are wheelchair bound, lose use of limbs and their speech. Already 12 years have gone by and we just want to enjoy what time we have left together and not have to fight for every little crumb the government or local authority throws our way."

Zara's own health has also suffered and she has had two strokes in the past ten years. Zara and Chris have faced a huge struggle with rising costs of living - especially energy and food prices. To keep Chris warm and healthy the heating needs to be on day and night. Zara cannot reduce the bills by cutting down on food for her ill husband - his condition means he loses weight rapidly and to maintain his health he must have a high calorie diet. Zara is trying to manage to make ends meet by saving money on her own food bills, restricting herself to one small meal a day.

Discretionary housing payments create a cycle of long-term insecurity and stress.

Discretionary housing payments

In response to widespread concerns about the impact on carers and disabled people, the Government set aside £25 million in additional funding for councils to distribute in discretionary housing payments. This was part of a wider package of additional funds for local authorities to respond to the need generated by several benefits changes, including both the size criteria change and the introduction of the household benefit cap.

The Government argued that if families affected by disability were hit by the policy but felt the accommodation was essential, they could apply to their council for payments to cover the shortfall in their rent.

Appropriateness

This approach was challenged by Carers UK, other disability and care organisations and housing providers, led by the National Housing Federation. Concerns centred on both the sufficiency of the funding and on the appropriateness of discretionary relief to respond to disabled people and carers' needs.

Carers are furious at what they feel is a complete lack of understanding of the reality of disability and caring. They are being told accommodation is spare and presented with a range of unsuitable solutions by their councils in line with Government guidance. Carers are being told their options are to find work, move to smaller accommodation (which would be too small for the needs of their family), take in lodgers (for rooms that are already in use or where it would be inappropriate to have strangers in their home) or apply for short-term discretionary payments.

Carers themselves are quick to question the appropriateness of discretionary, short-term payments and point out the 'complete failure in common sense' of families being affected by a policy on 'spare rooms', if they need the space.

James cares for his wife Dana, 57, who was diagnosed with MS in 1982. Her condition has gradually deteriorated and after juggling work and care, he eventually had to give up his job to care full-time ten years ago. They have lived in their three bedroomed family home for thirty years and their three grown-up daughters have moved out. Their home has been heavily adapted by their local council to support them – including by installing a full lift from the ground floor into one of the bedrooms - and James uses the third room to catch up on sleep as Dana's sleep is often very disturbed because of her condition. They were informed in April they would be charged £24 a week because they were considered to have two 'spare' rooms.

They were told they would either have to pay the shortfall or downsize, find the extra money or consider other options like finding a lodger or moving. Not only would they have to move out of their family home and potentially further away from their daughters – who support James to care – but it would involve moving out of a home which the council has spent substantial amounts on adapting for Dana. If they had to move they would also have to move away from Dana's frail mother who lives

Focusing discretionary funds only on those with adapted homes fails to recognise the impact of many health conditions and disabilities.

a few doors down and who they support. John found the idea of taking in a lodger laughable, saying *'we could barely fit a bed into the room next to the lift, and who would want to live in a lift shaft anyway?'*

Carers cannot understand the logic of central Government cutting support for essential accommodation, and then telling families to apply to local Government to get the money back.

Uncertainty about the long-term stability of funding for discretionary housing payments from central Government to councils has also meant that councils have not committed to making discretionary housing payments for any longer than a year.

Evidence from Carers UK Adviceline queries, Inquiry evidence sessions and Carers UK's research interviews with families affected, indicated that no payments had been guaranteed for over a year and over half were for less than 8 months.

From an administrative perspective this would also seem bureaucratically wasteful – if a local authority identifies long-term need, this approach does not enable them to put in place a long-term solution. It creates a cycle of long-term insecurity and stress every few months or each year for families already often struggling with the mental and physical pressures of caring, ill-health and disability, as they need to reapply for funding to stay in their own homes.

Whilst the Government has not given specific guidance on which disabled people should receive discretionary support, the *Discretionary Housing Payments Guidance Manual* states that *'the extra funding is intended to provide additional help to disabled claimants living in properties where significant adaptations have been made.'*⁶⁹ However the rationale for using 'significant adaptations' as a proxy for needs related to poor health or disability has not been set out.

This criteria does not provide for circumstances where an additional room is needed as result of ill-health or disability but unrelated to adaptations. For example, carers of partners with early-onset dementia or post-traumatic stress disorder who wake up not recognising their partners, and who can lash out; safe rooms, free of furniture, for children with learning disabilities; or additional rooms needed by parents of disabled children who share night-time care and sleep in separate bedrooms to enable one parent to sleep through the night whilst the other can get up to provide care. A fund targeted at homes with adaptations further reflects a lack of understanding of the impact different health conditions, disabilities and caring responsibilities can have on carers' lives.

Sufficiency

Whilst the Department for Work and Pensions has stated that *'the allocation of the additional funding for disabled people broadly reflects the impact of this measure and the additional funding needed*

⁶⁹ *Housing Benefit: Under occupation of social housing – Impact Assessment* (June 2012) Department for Work and Pensions

Key facts

- Of 660,000 people affected by the 'spare room' cuts, 420,000 are disabled.

to support this group',⁷⁰ the formula for determining this level has not been published and it is unclear what definition of 'significant adaptations' was used to calculate it.

The Department has 'purposefully not provided a definition of significantly adapted accommodation' in guidance to local councils, in order, it argues, to allow for 'decisions based on local knowledge and individual circumstances'.⁷¹ However, the *Discretionary Housing Payment Guidance Manual* does state that payments should be considered even if the criterion of adaptations has not been met. For example where a long term medical condition 'creates difficulties in sharing a bedroom'.⁷² However if the value of the discretionary housing payments funding has been calculated in relation to the number of people with adaptations, then extension of the payments to individuals with different needs will result in a shortfall amongst those with adaptations.

It has been argued that this £25 million fund for disabled people affected can be supplemented from elsewhere. The wider discretionary funding pot is much larger (£155 million)⁷³ but is designed to respond to a variety of need, including the Local Housing Allowance reforms and the introduction of the household benefit cap – supporting tenants with transitional payments, the costs of moving, rent advances or deposits.⁷⁴

Whilst local authorities have the power to use the funding according to local needs the remainder of the discretionary payments pot has been allocated to deal with other needs and to use it for disabled tenants would likely leave other need unfulfilled – for example supporting non-disabled tenants to transition to smaller properties.

Councils also have the limited power to divert spending from other areas of local authority expenditure to discretionary housing payments. But in the current local authority funding environment this would also necessitate, in most cases, cuts to other local authority services in order to supplement the discretionary pot.

The Government announced further in-year funding for discretionary housing payments of £35 million in July 2013. None was set aside for disabled people. £20 million of this appears to be available for councils to use flexibly but can only be accessed from February 2014. The remaining £15 million was earmarked to respond to rurality and for transitional payments and is not for responding to long-term need.

As a result, the total amount local authorities have available specifically for disabled people, intended for those with 'significantly adapted accommodation'⁷⁵ is £25 million, with limited ability to supplement this if they apply for additional funding or draw funding from other parts of

70 *Discretionary Housing Payments Guidance Manual* (April 2013) Department for Work and Pensions

71 Ibid.

72 Ibid.

73 *DWP response to the consultation on the Discretionary Housing Payments guidance manual* (December 2012) Department for Work and Pensions.

74 *Housing Benefit Circular* (March 2013) Department for Work and Pensions

75 *Discretionary Housing Benefit Guidance Manual* (December 2012) Department for Work and Pensions

Key fact

- In the first six months councils have spent 93% of discretionary funds designed to cover a whole year.

their budgets.⁷⁶

However this earmarked fund is not ring-fenced and the *Discretionary Housing Payment Guidance Manual* also states that, whilst the funding is aimed at disabled people in adapted accommodation, it '*is for LAs [local authorities] to determine how they use their DHP [discretionary housing payment] allocation... [and they] should not exclude any groups affected by the social sector size criteria or any other welfare reform*'.⁷⁷

Analysis of the size of the fund compared to a variety of measures of needs related to disability has also indicated insufficiency. With an average shortfall of £14 a week, £25 million would enable local authorities to cover the shortfall for 34,341 households.

There are a number of metrics by which the scale of need can be assessed:

- The Government's impact assessment indicates that of 660,000 claimants affected, 420,000 would be disabled according to the Disability Discrimination Act's definition of disability. By this measure, fewer than 1 in 10 (8%) of disabled people affected would be able to access discretionary housing payments.
- The National Housing Federation also estimates that 230,000 people affected claim Disability Living Allowance so the discretionary pot would not cover even this smaller group. This would leave only 15% of those tenants affected, who were receiving Disability Living Allowance, able to access discretionary payments.⁷⁸
- Estimates from the National Housing Federation showed that around 100,000 disabled people affected have home adaptations.⁷⁹ According to this measure, which is closest to the Government's intended target for the funding, just over a third

Figure 25: Impact on carers of the Housing Benefit cuts



Source: Hansard (21 Nov 2013 : Column 1021W)

76 The The Scottish Government also provided an additional £20m for local authorities in Scotland.

77 *Discretionary Housing Benefit Guidance Manual* (Decembe 2012) Department for Work and Pensions

78 *Bedroom Tax: Some Home Truths* (2013) National Housing Federation

79 Ibid.

Key fact

- Only 23% of carers were receiving a discretionary payment to cover their rent shortfall.

(34%) of disabled people with adaptations could be supported.

- In response to a written parliamentary question the Government has stated that 60,000 carers entitled to Carer's Allowance will be in households affected.⁸⁰ Even without accounting for disabled people who do not live with a family member providing full-time care, and using entitlement to Carer's Allowance as a limited proxy for caring responsibilities, only just over half (57%) of carer households could access discretionary funds.

These figures assume that councils make full-year awards to cover the shortfall. If, instead, the funding was used to provide some mitigation for all those affected, the levels of support would be minimal. For example, the National Housing Federation estimates that, if split amongst Disability Living Allowance claimants, individuals facing the average £14 a week shortfall would receive just £2.09 a week.⁸¹

There is also emerging evidence of spending on discretionary payments since implementation of the policy which adds considerable weight to concerns about the sufficiency of the fund.

Mid-year returns from local authorities have been used to indicate that the discretionary housing payments pot is sufficient, as only 40% has been spent, halfway through the year (April to September 2013).⁸² However, simply looking at this topline figure gives an incomplete picture of the funding breakdown:

- The 40% figure applies to the total discretionary housing payment pot, which includes funds for Local Housing Allowance reforms and the benefit cap implementation as well as the size criteria changes. However the benefit cap was only implemented nationally in September 2013 following some local trials, so it would be entirely expected that the funding earmarked for the implementation of this policy would be largely unspent.
- The figures from local authorities who responded to the Government (85% of local authorities in Great Britain) show that, when looking specifically at the money earmarked for the size criteria changes, 93% of their total year allocation has in fact been spent.

Frequently quoted figures indicating that local authorities have returned as much as £11 million in discretionary funding to Government have been used to suggest that the funding levels exceeds need. However these apply to the financial year 2012-13, the year prior to the implementation of the size criteria changes.

To use these figures from 2012-13 or the data for the total discretionary payments fund to respond to questions of sufficiency related to the size criteria changes would be disingenuous and misleading.

80 Figures on number of people eligible for Carer's Allowance were provided by the Government in response to written question from Barbara Keeley MP (House of Commons, 21st November 2013, c1021W).

81 *Bedroom Tax: Some Home Truths* (2013) National Housing Federation

82 *Use of Discretionary Housing Payments Analysis of mid-year returns from local authorities* (2013) Department of Work and Pensions

Key fact

- 75% of carers hit by a shortfall in their rent were cutting back on essential spending.

Key fact

- 240,000 carers face additional Council Tax payments.

In order to assess the impact of the policy since April 2013, Carers UK conducted 101 interviews with carers affected in June and July 2013.⁸³ Of the 101 carers interviewed:

- 56% had applied for discretionary payments from their local council to cover the shortfall.
- 8% had been exempt from the changes because, since they had been informed they would be affected, exemptions had been added to allow for extra rooms for disabled children who cannot share with siblings and for tenants or tenant's partners who need a room for someone to come in to provide overnight care.
- Only 22% of those interviewed had received a discretionary payment – of those, 10 were receiving support for a full year (when they would have to reapply), and a further 12 had received temporary support for between 3-8 months, which had already ended for some.

"I was told by a social worker not to bother to apply for the money to cover the cost – they said there wasn't enough and I'd only be wasting my time filling in all the forms."

"They said I could apply but would only get a few months. With everything I have on my plate I just couldn't face all the forms, just to get a few payments."

With just 8% exempt and a further 22% receiving any support from discretionary payments, applying the breakdown from this sample to the national figures would leave at least 40,000 of the 60,000 affected paying the shortfall.

- Even accounting for support from discretionary housing payments⁸⁴ at least 40,000 carers will be paying an average of £14 a week and over £720 a year. Assessing the total impact of this from implementation in 2013 until the completion of the Welfare Reform Act implementation in 2018, this represents at least a £150.7 million cut to support for carers.

Laura's family has accumulated serious debt as a result of seeing a shortfall in their rent. Her daughter Rachel has cerebral palsy and is unable to walk or talk and has very disturbed sleep. Their home has been adapted to provide Rachel with an accessible downstairs bedroom. Upstairs the family have a further two bedrooms and a boxroom.

One bedroom is for Rachel's non-disabled twin, who is in the middle of her school exams. The second is Laura and her partner's room and the boxroom provides the couple with space for respite, which is frequently needed as they take it in turns to provide night-time care.

⁸³ Carers UK interviewed 101 carers affected, between 28 June and 9 July 2013. A sample of 258 households were identified in advance of the implementation of the policy via Carers UK online surveys and case study interviews. Members of the Carers UK policy team systematically rang each contact on the list and ran through a set series of questions with each carer interviewed. A total of 101 carers were successfully interviewed.

⁸⁴ Even though many in this group will just be receiving temporary payments and will end up paying the shortfall in rent.

Key fact

► 29% of carers affected by the 'bedroom tax' were also paying additional Council Tax payments.

One bedroom was exempt from the changes, but they are still being charged for one 'spare' room, backdated to April. It's a bill they cannot afford and they fear the consequences of the arrears that have already built up. They fear eviction.

- Of those not receiving discretionary payments and having to pay the shortfall, 75% were cutting back on essential spending like food and heating, 17% were in arrears and 8% were paying by getting into debt.

Localisation of Council Tax Support

- An estimated 240,000 carers are paying an average of £138 a year in additional Council Tax Payments as a result of the abolition of Council Tax Benefit.

"We're paying an extra £1,000 a year because of the 'bedroom tax' and in Council Tax. We do not have that kind of money."

Since April 2013, English and Welsh local authorities have had responsibility for providing support with Council Tax costs through local reductions schemes following the abolition of Council Tax Benefit.

In England and Wales, Councils have received a grant from central Government to pay for their local schemes, and these are calculated based on forecasts of what would have been spent on Council Tax Benefit for 2013/14 minus 10%. The Scottish Government has protected support in Scotland for 2013-16 so households will not be left worse off. The UK Government has also reduced the funding available for support with rate rebate (the equivalent of Council Tax Benefit) in Northern Ireland, but the impact will not be felt until April 2014.

In England and Wales older people in receipt of the State Pension were the only group protected under national rules to ensure they continue to receive the support they would have received from Council Tax Benefit.

To support others in need of help with Council Tax payments, councils can design their own local schemes and decide which groups should be entitled to reductions in their Council Tax payments and at what level those reductions should be set. However the protection of older people means that the impact of the reduction in funding will fall more heavily on the working-age population.

The Government guidance issued to councils on 'vulnerable groups' notes that local authorities should take account of disabled people's needs and any 'limited ability to work or likely higher-level disability-related living expenses.'⁸⁵ It does not contain any reference to carers, the impact of caring on work or additional household costs as a result of caring.

The Government also drafted a 'default scheme' for local authorities, which mirrored existing provision including support for carers in receipt of the carer premium to means-tested benefits. The default scheme

⁸⁵ *Localising Support for Council Tax Vulnerable people – key local authority duties* (2012) Department for Communities and Local Government

Key fact

➤ The localisation of Council Tax support will result in a cut of at least £170 million in support for carers.

effectively committed local authorities to the level of expenditure which would have been required to maintain Council Tax Benefit, however with the 10% reduction in the grant they received they would be liable for the difference.

Carers are being affected differently depending on the scheme adopted by their local authority. Some councils are proposing to recognise carers as a vulnerable group and to protect them when deciding who will pay more.

As a result of this local variation, understanding the impact on carers across the country is challenging. However the Inquiry evidence sessions and calls to Carers UK's Adviceline have highlighted both that carers are being significantly affected and there is some confusion from families as to why they have to make additional payments.

Significantly, there was clear evidence of carers being affected by the withdrawal of support with both housing costs and Council Tax.

- 29% of carers affected by the 'bedroom tax' changes were also paying additional Council Tax as a result of the loss of Council Tax Benefit.
- Families who face a rent shortfall of as much as £1,200 a year as a result of the Housing Benefit size criteria changes are also having to pay as much as £300 a year in new Council Tax charges as a result of the localisation of support.

Just as 'spare room' cuts were affecting essential accommodation, the rationale set out by Government for this policy is contradictory when applied to carers. The Department for Communities and Local Government consultation papers and impact assessments on the change state that moving people into work is a major driver of the changes, but also note the importance of protecting those who cannot work.

"Unlike most other groups, pensioners cannot be expected to seek paid employment to increase their income. The Government therefore proposes that as a vulnerable group, low income pensioners should be protected from any reduction in support as a result of this reform."

The same justification is clearly applicable to carers. Yet the UK Government did not respond to Carers UK's calls to give carers the

Figure 26: Number of carers paying additional Council Tax as a result of the localisation of Council Tax support.

240,000
CARERS PAYING
EXTRA COUNCIL TAX
 following the scrapping of Council Tax Benefit

Key fact

► Despite their contribution of the equivalent of £119 billion in unpaid care, carers are being hit by a benefit cap designed for households described as 'workless'.

same protections as older people, or indeed, as noted above, provide any guidance to local authorities on protecting carers in local schemes.

Whilst some carers were aware that the new payments resulted from the abolition of Council Tax Benefit, others did not realise that the change was due to a Government policy shift, rather than rises in local Council Tax rates.

However it is possible to develop a national picture. Analysis of the Family Resources Survey within the Government's equality impact assessment⁸⁶ demonstrates that disabled people and carers were overrepresented the Council Tax Benefit caseload and are, as a result, likely to be disproportionately affected:

- 48% of Council Tax recipients lived in a 'benefits unit' (individual recipients and any partners or children under 18) including at least one disabled adult or child.
- 18% included at least one adult with caring responsibilities.

Work by the Joseph Rowntree Foundation and the New Policy Institute examined the schemes drawn up by English and Welsh local authorities⁸⁷ and categorised the different approaches local authorities were taking.

Only 18% of councils were retaining the levels of support provided by Council Tax Benefit. This means that the majority of councils are asking some or all of their working age population, who had previously received Council Tax Benefit, to pay additional amounts towards their Council Tax. 71% of local authorities were requiring all working-age adults to pay at least some Council Tax, many had no protections for vulnerable groups and only 35% of councils protected certain vulnerable groups.

Carers UK used this data to assess the number of local authorities implementing a blanket policy of minimum Council Tax payments, where no protections for vulnerable groups were in place. Whilst 95 had some protections for specific 'vulnerable groups', 133 local authorities were imposing minimum payments on all working-age former recipients of Council Tax Benefits.

Whilst the minimum amounts will be different according to each local authority, the Joseph Rowntree Foundation/New Policy Institute analysis indicated that the average cost was £138 a year per household affected.

Whilst the schemes in the 95 local authorities that are protecting some vulnerable groups may protect some carers, it is clear that carers across the 133 local authorities imposing blanket minimum payments will be paying additional amounts following the scrapping of Council Tax Benefit.

Applying the Family and Resources Survey data on the number of carers in relevant households to Department for Work and Pensions figures on the numbers of working-age Council Tax Benefit recipients

⁸⁶ Ibid.

⁸⁷ *The Impact of Localising Council Tax Benefit* (2013) Joseph Rowntree Foundation and New Policy Institute

allows for an estimate of the number of carers in these areas who will now be paying an average of £138 a year: 246,865.

- A minimum of 246,865 carers will lose a total of £170.34 million in Council Tax support from 2013-2018.

However this is likely to be an extremely conservative estimate as many carers living in local authorities with some protections for 'vulnerable groups' will still remain unprotected.

Key fact

- The benefit cap will cut at least £72.4 million from carers' incomes by 2018.

Benefit cap

Since April 2013 in pilot areas, and across England, Wales and Scotland since September 2013, a household benefit cap has put a limit on the total amount in benefits households can receive. The cap has been set at £500 a week for couples and £350 a week for individual claimants. Exemptions from the cap were put in place for households including claimants of some benefits, including Disability Living Allowance and Attendance Allowance. However other benefits, like Carer's Allowance, do not exempt a household from the cap.

This means that, whilst the majority of carers are protected because they live within the same benefits 'household' as a Disability Living Allowance claimant, certain groups of carers are not. This is because 'households' in the benefits system are considered to include children under 18 and partners, but not adult children or other adult relatives – even if they live under the same roof.

So, whilst carers looking after disabled partners and disabled children under 18 would be exempt from the cap, those caring for adult disabled children, elderly parents or other adult relatives would not.

In addition to these arbitrary inconsistencies, it is unclear how placing Carer's Allowance under the remit of the benefit cap is compatible with the Government's aims for the cap. The Government has stated that the cap is designed to:

- Improve work incentives and tackle 'worklessness'⁸⁸ - yet carers in receipt of Carer's Allowance are caring for a minimum of 35 hours a week, many for 50 or more hours. It would be impossible for many to juggle work with such heavy caring responsibilities and carers are insulted to be described as 'workless.'
- Promote behaviour change and discourage long-term benefit claims - yet in response to an amendment at Report Stage in the House of Lords, Lord Freud said that 'the one thing we are not looking to encourage is a change in the carer's behaviour so that they stop caring. That is absolutely not where we want to go.'⁸⁹
- The Secretary of State for Work and Pensions stated, when he introduced the Bill in the Commons, that the benefit cap was: '*A matter of fairness, so that those who are working hard and paying their taxes do not feel that someone else will benefit more*

88 *Benefit Cap (Housing Benefit) Regulations 2012: Impact assessment for the benefit cap (2012)* Department for Work and Pensions

89 Lords 23 Jan 2012: Col. 893

Key fact

► As a result of the change in the inflation rate used to increase benefits each year, Carer's Allowance will be worth £132.60 less a year by 2018.

by not playing a full part in society'.⁹⁰ If this cap is designed to be fair to individuals who are working hard and playing a full part in society, then it cannot be right that it applies to carers who save the UK an estimated £119 billion a year with the care they provide.

The updated impact assessment released in January 2012 showed that the Government predicts that around 5,000 households including a Carer's Allowance claimant will have their benefits capped, with a mean reduction in income of £105 a week.⁹¹ Needless to say this loss in income could be devastating for families who may be unable to increase their income from paid work, or reduce housing costs by moving to smaller properties or to a different area away from support networks which enable them to care.

Latest indications are that the total numbers affected by the benefit cap are lower than expected at 33,000 as opposed to the 56,000 predicted in the initial impact assessments.⁹² However no updates on numbers of carers affected have been published.

If the Government's initial impact assessment were correct this would mean a total loss of £27.3 million a year from carer households. The decrease in the number of households affected predicted in the impact assessment may be attributable to some people moving into paid work. Given that this is not an option for most carers, the number of carers affected may have remained as high as the original estimates as carers have been unable to increase their income or move into cheaper, smaller accommodation to avoid the impact of the cap.

However, if the number of carers affected fell by the same proportion as the total number of households affected then 2,946 carer households would have seen their benefits capped. Using this conservative estimate indicates a total cut of £16.1 million in carers' incomes per year. Carers' barriers to work will mean those affected are also unlikely to be able to move into paid work in the future, so this cost is likely to be ongoing for carers.

The cap was rolled out fully nationally from September 2013 so will have been in place for four and a half years across Great Britain by April 2018 - this will mean a total of £72.4 million cut for carers affected by the benefit cap.

Changes to the uprating of carers' benefits

The Government has implemented two key measures to change the way in which benefits across the UK are increased each year in line with inflation:

- From 2011, the Government has moved from using the Retail Prices Index to the Consumer Prices Index to increase benefits

⁹⁰ Commons 9 March 11: Col. 922

⁹¹ *Figures from Benefit Cap (Housing Benefit) Regulations 2012: Impact assessment for the benefit cap* (2012) DWP

⁹² *Benefit Cap – number of households capped, data to November 2013* (2014) Department for Work and Pensions

“I am already on the edge. How can we be expected to get by with less?”

each year.

- From 2013 to 2016 most working-age benefits will receive only a 1% annual rise regardless of the level of inflation.

Despite some exemptions for carers, analysis indicates that these changes will have a very significant downward pressure on carers' incomes.

In 2010, the Government announced benefit uprating would move from using the Retail Prices Index (RPI) to the Consumer Prices Index (CPI) as a measure of inflation.

To understand the impact this is having, Carers UK has modelled the effect on Carer's Allowance.

However the impact will be far wider as many carer households will see this change have an effect across a number of the benefits they receive, including means-tested support and disability benefits.

For Carer's Allowance, the difference from 2011 to 2018 has been as follows:⁹³

- In 2013-14, the Carer's Allowance rate if the Government had continued to use RPI would have been £61.10 a week compared to the rate set by Government using CPI, £59.75.
- If future years are forecast, using an optimistic measure for inflation and the smallest gap to-date between RPI and CPI then, by 2018 Carer's Allowance will be £65.15 a week compared to £67.70 under RPI uprating – a difference of £132.60 a year.

Using Department for Work and Pensions figures on the Carer's Allowance caseload since 2011 and assuming an average increase in the caseload year-on-year from 2013 onwards⁹⁴ it is possible to estimate the total over the period 2011-2018.

- Beginning with a £25.16 million deficit in 2011-12 created by the switch from RPI to CPI uprating for the 569,240 carers affected, this rises to £101.45 million for an estimated 765,080 carers in 2017-18.
- The cumulative financial cut between 2011 and 2018 mean that carers over the period will receive £421.91 million less in support from Carer's Allowance as a result of the change in the measure of inflation used for uprating.

In the 2013 Autumn Statement, the Chancellor also announced that from 2013-2016, most means-tested benefits will rise by only 1% (including Jobseeker's Allowance, Employment and Support Allowance work-related activity group, Income Support and applicable amounts for Housing Benefit).

Some benefits, including Disability Living Allowance, the support component of Employment and Support Allowance, Carer's Allowance

⁹³ Inflation rates for both RPI and CPI were taken from September each year – the figure used to uprate benefits for the following year - to model what the rates of Carer's Allowance would have been under RPI compared to the rates set using CPI.

⁹⁴ Based on the average increase from 2004 – 2013.

“I’m unclear, uninformed and very scared about what will happen.”

and the carer premium to mean-tested benefits will rise with inflation. However many carers receive means-tested benefits as a significant or majority part of their benefits package, and, as a result, will not be protected from the real-terms cut which a 1%, below-inflation rise entails.

Half of carers receive Income Support⁹⁵ and, even if they received no other means-tested support, the 1% uprating of the Income Support section of their benefit would have a significant impact on their family finances, even though their carer premium top-up rose by 2% (the current rate of inflation).

So a carer receiving Income Support could have received, in 2012-13, the Income Support personal allowance of £71.00 and the carer premium of £32.60.

Whilst the carer premium rose 2.2% in April 2013 to £33.30, the Income Support part rose by just 1% to £71.70. So the total package of the two rose from £103.60 to £105.00 – a 1.35% rise, which is significantly below the level of price rises. This means that half of carers entitled to carers’ benefits would have seen a real-terms cut to their benefits.

- Forecasting the impact for the duration of the policy (2013-16) indicates that the deficit created will result in carers in 2015-16 receiving Income Support at £73.10 rather than £75.30, which they would have received if the benefit had kept pace with inflation.
- So these carers are over £117 a year worse off by 2015-16. That amounts to a cumulative total £234 over the period of the policy.

In national terms, by 2015-16, an estimated 350,015 carers in receipt of Income Support will have seen a cumulative £79.56 million gap develop between the support they would have received if benefits had risen with inflation and what they will receive with just a 1% annual increase.

These figures also just represent the impact if carers only received Income Support and the carer premium – many receive a wider set of means-tested benefits in their households and will feel a deeper real-terms cut as a result.

- Already 52% of carers think their quality of life will get worse in the next year. Only 6% think it will improve.

As both the 1% freeze and the switch from RPI to CPI act to suppress the value of the allowances received by carers and their families relative to prices it is likely the measures of severe financial hardship set out in Chapter 1 will rise.

“I am already on the edge. How can we be expected to get by with less?”

⁹⁵ *Developing a clearer understanding of the Carer’s Allowance claimant group* (2011) Gary Fry, Benedict Singleton, Sue Yeandle and Lisa Buckner; commissioned by Department for Work and Pensions.

“Are they honestly going to check my son still has Down’s Syndrome?”

If, as some commentators are predicting,⁹⁶ wages begin to rise faster than prices in 2014, then there is a risk that these families – already vulnerable to severe financial hardship – will be left behind as benefits lag behind both wages and prices.

The impact of the introduction of Personal Independence Payment on carers

“Hanging over us is what happens when we’re reassessed for Personal Independence Payment. God knows what we will do if we don’t qualify.”

Alongside the more visible and more widely implemented changes to Housing Benefit and Council Tax support, carers were also keenly aware of the forthcoming introduction of Personal Independence Payment which will replace Disability Living Allowance for all working-age disabled people by 2018.

“I’m unclear, uninformed and very scared about what will happen.”

Following the announcement of delays, the implementation of reassessments of working-age Disability Living Allowance claimants for the new benefit has started in Wales, the Midlands, East Anglia, Edinburgh, Dumfries and Galloway and the Borders, after initial trials in Greater Manchester. Roll-out across the rest of the UK is planned to progress during 2014 with full UK implementation in place in 2015. Apart from anecdotal evidence from the early implementation areas which indicates there are some long delays in decision-making following assessments, delays in the roll-out of Personal Independence Payment mean it is not yet possible to establish a clear picture of the impact on carers and their families.

As a result, this Inquiry is not able to examine Personal Independence Payment implementation in detail⁹⁷. However there are number of areas of particular concern which were expressed by carers at Inquiry evidence sessions which can help to guide ongoing work to understand the impact of implementation on carers.

Assessments

The Government describes the assessments for Personal Independence Payment as ‘involv[ing] a more objective assessment, with a face-to-face consultation with an independent health professional for most people’ and ‘includ[ing] regular reviews so that individuals continue to get the right support’.⁹⁸

96 ‘UK real incomes to rise at last in 2014, says Bank of England official’ (17th January 2014) The Guardian; ‘Wages WILL rise faster than prices this year admits Ed: Labour leader concedes average pay will outstrip inflation’ (17th January 2014) Daily Mail

97 Existing Carers UK modelling on the impact of PIP and responses to Government consultations on the implementation are available at www.carersuk.org/professionals/resources

98 *Simplifying the welfare system and making sure work pays* (2013) Department for Work and Pensions

Reflecting carers' experiences of Work Capability Assessments for Employment and Support Allowance, there was widespread worry at Inquiry evidence sessions about the nature, conduct and need for the new Personal Independence Payment assessment.

With strong similarities between the Work Capability Assessments and the proposed Personal Independence Payment model there were understandable fears about the risk of poorly conducted assessments resulting in the loss of support and the need to go through a series of appeals to establish entitlement:

“After years of filling in Disability Living Allowance forms every three years and last year being given a letter saying my daughter is entitled to the benefit indefinitely, I now expect a letter saying that we will have to go through all this again. It is unbelievable that doctors, specialists and teachers can give their professional view and some DWP worker will have the final say. Unbelievable.”

- Carers, particularly of people with lifelong or degenerative conditions, did not understand why the person they cared for should need to go through a further assessment when they had clearly established entitlement to Disability Living Allowance. They also expressed concerns about the need for more frequent assessments, which were likely to cause both them and the person they care for a great deal of stress and worry.
- There was worry that face-to-face assessments presenting only a narrow snapshot of a disabled person's condition could be given equal or even more weight than extensive evidence from specialists established over years.

“Are they honestly going to check my son still has Down's Syndrome?”

“It is like we are being told we should be kept in a constant state of worry that we are always at risk of losing the benefits. That is no way to live a life.”

“My wife has MS and she gets the highest levels of both DLA components. She isn't going to get better and our best hope is that she only gets worse slowly. Why would anyone need to make us go through a new assessment to prove this all over again?”

Key fact

- By 2018 over 600,000 fewer disabled people will be entitled to disability benefits as a result of the implementation of Personal Independence Payment.

Reduction in entitlement

- The Government estimates that, by 2018, approximately 607,000 fewer people will receive Personal Independence Payment than would have received Disability Living Allowance – a 28% reduction.⁹⁹
- This represents a £2.5 billion cut in spending compared to forecasts of spending if Disability Living Allowance remained

⁹⁹ *Draft Social Security (Personal Independence Payment) Regulations 2013* (2013) House of Common Library

Key fact

➤ Over 24,000 fewer carers will be entitled to Carer's Allowance as a result of the introduction of Personal Independence Payment.

unreformed.¹⁰⁰

Since the Chancellor first announced the intention to significantly reduce spending on disability benefits, Carers UK has expressed fundamental disagreement with the rationale for funding cuts. The Government has consistently failed to set out a justification for the withdrawal of support at this scale.

Given that the fraud rate for Disability Living Allowance is 0.5%,¹⁰¹ it is clear that a 28% reduction in the number of people entitled to support will result in the removal of disability benefits from very high numbers of legitimate recipients.

"How can they remove legal benefits from very sick people? It will plunge them into a need for more acute services and for some, into poverty and despair."

Again and again carers have spoken about their shock, anger and fear at the possibility of the person they care for losing support. At evidence sessions, carers described how a loss of support would have devastating consequences for the dignity and independence of the person they care for and for wider family finances.

The Government has sought to reassure families that Personal Independence Payment will 'support those facing the greatest challenges to living an independent life'.¹⁰² Some carers at evidence sessions were confident that the person they care for will continue to receive a similar level of support because their needs are well-evidenced by specialist diagnoses, for example. However the majority of carers, in particular those who had experience of Work Capability Assessments, were sceptical about even those with very high needs being 'safe.'

It is clear from the Government's impact assessment that the losses in support will occur at all levels of the existing Disability Living Allowance caseload including substantial reductions in support to the number of people receiving currently the highest levels of support.

- Without the introduction of Personal Independence Payment, in 2015 519,000 people would be entitled to the highest level of the Disability Living Allowance care component. As a result of the implementation of Personal Independence Payment, this will fall to 281,000.¹⁰³

These figures show that families' fears are well founded, and that there is a risk that any disabled person of working age, however severe their disability, could see support reduced or removed following a reassessment for Personal Independence Payment.

Carers are extremely worried both about the loss of financial support for the person they care for and the consequences for their ability to

¹⁰⁰ Ibid.

¹⁰¹ Fraud and Error in the Benefit System: 2011/12 Estimates (Revised Edition) (2012) Department for Work and Pensions

¹⁰² *Government's response to the consultation on Disability Living Allowance reform* (2011) Department for Work and Pensions

¹⁰³ *Draft Social Security (Personal Independence Payment) Regulations 2013* (2013) House of Common Library

Thousands of families will be hit by the 'double whammy' of losing carers' and disability benefits simultaneously.

afford living costs and buy or maintain essential care services or aids and adaptations. In addition, those in receipt of Carer's Allowance feared the 'double whammy' of a loss of disability benefits causing a simultaneous loss of Carer's Allowance.

In order to claim Carer's Allowance, carers currently need to be caring for someone in receipt of a 'qualifying benefit,' including Disability Living Allowance. This link will be replicated as Disability Living Allowance is replaced by Personal Independence Payment. Carers UK welcomed the Government's decision not to dramatically narrow entitlement to Carer's Allowance by only linking it to the highest level of the Personal Independence Payment 'daily living' component.¹⁰⁴

However despite linking Carer's Allowance to both levels of the Personal Independence Payment daily living component, impact assessments indicate that, as the Government reduces spending on disability benefits as Disability Living Allowance is replaced by Personal Independence Payment, carers will also lose entitlement to Carer's Allowance because the person they care for loses disability benefits. Crucially, there are no transitional protections, so those who do not qualify under the new system will be offered no protection of their current level of income.

The Government's impact assessment¹⁰⁵ shows that, in the period 2013-15, 75,000 carers will see the person they care for reassessed for PIP and that that 5,000 carers will lose Carer's Allowance as a knock-on consequence of the person they care for losing disability benefits. This is a net figure - the Government predicts 25,000 carers will lose Carer's Allowance and 20,000 will gain entitlement as a result in changing eligibility as Disability Living Allowance is replaced by Personal Independence Payment - so the net figure masks far greater numbers losing support, for whom expanded entitlement for other carers will offer cold comfort.

In addition, over 4,000 new claims carers who would have made successful claims under Disability Living Allowance will not be able to claim Carer's Allowance under Personal Independence Payment.¹⁰⁶

However these figures only represent the first tranche of Personal Independence Payment implementation and the Government impact assessment on Carer's Allowance does not extend beyond 2015. Carers UK modelling indicates that if the same patterns of attrition amongst the Carer's Allowance caseload are maintained for the rest of the Personal Independence Payment implementation then it can be

¹⁰⁴ Currently Carer's Allowance is linked to the middle and higher rates of the Disability Living Allowance care component, and not to the lower rate. In Personal Independence Payment, these three rates are being replaced by two, the standard and enhanced rates, of what is called the daily living component. Carers caring for someone on either of these rates will be able to make a claim for Carer's Allowance (if they fulfil the other conditions).

¹⁰⁵ *Personal Independence Payment and Carer's Allowance briefing note* (2013) Department for Work and Pensions

¹⁰⁶ 'New claims' refers to future forecasts of claims for Carer's Allowance which would have been made and been successful under Disability Living Allowance but which would not be possible under Personal Independence Payment as no entitlement to the 'gateway' disability benefit would be established, so no claim for Carer's Allowance could be made.

“If we do not keep getting the money we get now I just have no idea what I will do.”

anticipated that 24,457 fewer carers will receive Carer’s Allowance as a result.¹⁰⁷

In estimating the value of support lost it is important to recognise that the losses will not all occur at once. By 2018, carers who lost Carer’s Allowance in 2013-14 or could not establish entitlement as a result of Personal Independence Payment will have missed out on five years of support.

Our modelling indicates:

- Assuming a low-end estimate of inflation to uprate the value of Carer’s Allowance each year, the cumulative value of decreasing entitlement amounts to a cut of £175.63 million between 2013-2018.
- For a family currently receiving Carer’s Allowance alongside Disability Living Allowance at the middle rate care component and the lower rate mobility component, if the disabled person did not qualify for Personal Independence Payment the financial loss in carers’ and disability benefits would be just under £7,000 a year.

Taking into account the existing low financial resilience, highlighted in Chapter 1 by the loss of earnings and savings and high levels of debt, carers struggled to respond to questions about what the financial impact of this level of loss would be. Most concerning was the fact that the groups highlighted as facing the greatest financial hardship, carers of working age disabled partners and parents of adult disabled children, will be the groups most affected by the cuts to disability benefit spending. Many simply said they ‘could not cope.’

“I am so worried about the new Personal Independence Payment. The money we get now pays for so much of what enables me to care for my son full-time. I would love to go to work but cannot due to his needs. If we do not keep getting the money we get now, as a single mother looking after a soon to be 20 year old, with no support, I just have no idea what I will do.”

The biggest concerns centred on:

- The ability to pay household bills which many were already struggling with.
- Affording vital care and support services, not least because of reducing levels of local authority provision and rising care

24,000 FEWER CARERS
WILL GET CARER’S ALLOWANCE
 when Personal Independence Payment is introduced

¹⁰⁷ This does not account for an annual growth of around 30,000 in the Carer’s Allowance caseload and as a result the actual losses are likely to be higher.

- charges.
- What financial support would be available to carers if they lost Carer's Allowance. Many were deeply concerned that they would need to claim Jobseeker's Allowance – bringing the risk of sanctions and further loss of support as they would be unable to seek work given an ongoing need to provide high levels of care.

In addition to the financially devastating consequences, a key worry for many was the risk of losing support which Disability Living Allowance provides a 'gateway' to, including eligibility for Motability vehicles, disability premiums to means-tested benefits, blue badge schemes and exemption from road tax.

For example, if an assessment for Personal Independence Payment resulted in a reduction from the higher rate mobility component for DLA to the standard rate for PIP, then this would mean a reduction in support of £34.25 a week, almost £1,800 a year. Many families would lose financial support essential to pay for transport costs including adapted taxis or the high cost of frequent trips to hospital.

Access to a Motability vehicle is linked to receipt of the DLA higher rate mobility component and the enhanced PIP mobility component. The loss of what is typically the only family vehicle, when families would often have no savings to afford to buy the vehicle independently, demonstrates the wider impacts of the loss of disability benefits. Carers said that the loss of this support would result in social isolation, struggling to access even basic health and social care services or breaks from caring and the potential loss of paid work.

Universal Credit

This Inquiry had originally set out to examine the impact of the first stages of Universal Credit implementation on carers. However both the planned approach to implementation and delays announced by Government in the course of this Inquiry in the roll-out of Universal Credit, mean that very little evidence is available.

The total numbers of claimants receiving the new benefit remain very limited and the Government had also intended to limit applications in the first stages of implementation to claimants with simpler claims. As a result, even setting aside delays in implementation, claims by disabled people and people with caring responsibilities were not planned to be accepted until further into the implementation process – potentially as late as 2015.

Many of the systems and processes for these more complex claims are yet to be developed or published – for example the processes for exempting carers from work-related conditionality within Universal Credit. This means it is not possible to conduct a meaningful assessment of either the structure of the new benefit for or the impact on carers within the current caseload.

Carers UK will continue to assess the roll-out of the benefit, in particular:

- Whether Universal Credit can offer greater opportunities for

carers on means-tested benefits to combine work and caring. The earnings taper and the removal of the Carer's Allowance cliff-edge for carers in receipt of Universal Credit may smooth the interaction between carer's benefits and work. However Carers UK has concerns about the treatment of housing support, particularly support with mortgage payments, in relation to the Universal Credit work allowances.

- The impact of aligning the disability premiums for disabled children with those for disabled adults. Whilst the most severely disabled children will see a similar level of support - children with slightly lower level, but still very substantial, needs will be entitled to significantly less support under Universal Credit.
- The absence of a replacement for severe disability premium within Universal Credit – the knock-on impact this will have for carers of disabled people living independently, and the implications for the children of single disabled parents where a loss of financial support may put pressure on the children to provide care and support.
- Carers UK has heavily criticised the decision to make the carers and disability premiums exclusive within Universal Credit. This fails to recognise that many disabled people have caring responsibilities and that many carers are made ill or become disabled as a result of long periods spent caring.

Whilst transitional protections are available for existing claimants, these are extremely fragile and there is no guarantee that carers or disabled people whose circumstances change will receive the same level of income.

Results from across the United Kingdom

Scotland

There are 481,579 carers in Scotland (Census 2011). However, the Scottish Household Survey puts the figure for the number of carers in Scotland at a significantly higher level of 657,000.

A YouGov poll showed:

- 65% of Scottish adults would be worried about the financial impact if they had to care for a loved one.
- 1 in 10 adults in Scotland (11%) said their work has been negatively affected by caring for an older or disabled loved one.
- 4% of Scottish adults, the equivalent of 170,112 people, have given up work to care for a loved one at some point.

Of State of Caring survey respondents in Scotland:

- 37% were unable to afford their utility bills.
- 47% had been in debt as a result of caring.
- 38% were cutting back on essential spending like food and heating to make ends meet.
- 46% had missed out on financial support as a result of a lack of advice and information.
- 47% were in a household where no-one was in paid work.
- 46% had given up work to care, 22% had reduced working hours, 17% had taken a less qualified job or turned down a promotion to care and 10% had retired early to care.
- 19% were in full-time work and 19% in part-time work.
- 43% had used annual leave and 25% sick leave to care.

Northern Ireland

There are 213,980 carers in Northern Ireland (Census 2011).

A YouGov poll showed:

- 82% of Northern Irish adults would be worried about the financial impact if they had to care for a loved one.
- Over 1 in 7 adults in Northern Ireland (15%) said their work has been negatively affected by caring for an older or disabled loved one.
- 11% of Northern Irish adults, the equivalent of 151,811 people, have given up work to care for a loved one at some point.

Of State of Caring survey respondents in Northern Ireland:

- 42% were unable to afford their utility bills.
- 46% had been in debt as a result of caring.
- 45% were cutting back on essential spending like food and heating to make ends meet.
- 42% had missed out on financial support as a result of a lack of advice and information.
- 45% were in a household where no-one was in paid work.
- 48% had given up work to care, 31% had reduced working hours, 20% had taken a less qualified job or turned down a promotion to care and 8% had retired early to care.
- 19% were in full-time work and 22% in part-time work.
- 43% had used annual leave and 33% sick leave to care.



England

There are 5,430,016 carers in England (Census 2011).

A YouGov poll showed:

- 76% of English adults would be worried about the financial impact if they had to care for a loved one.
- 1 in 10 adults in England (10%) said their work has been negatively affected by caring for an older or disabled loved one.
- 4% of English adults, the equivalent of 1,667,020 people, have given up work to care for a loved one at some point.

Of State of Caring survey respondents in England:

- 37% were unable to afford their utility bills.
- 45% had been in debt as a result of caring.
- 41% were cutting back on essential spending like food and heating to make ends meet.
- 42% had missed out on financial support as a result of a lack of advice and information.
- 56% were in a household where no-one was in paid work.
- 55% had given up work to care, 19% had reduced working hours, 15% had taken a less qualified job or turned down a promotion to care and 13% had retired early to care.
- 13% were in full-time work and 17% in part-time work.
- 38% had used annual leave and 22% sick leave to care.

Wales

There are 370,230 carers in Wales (Census 2011).

A YouGov poll showed:

- 79% of Welsh adults would be worried about the financial impact if they had to care for a loved one.
- 1 in 10 adults in Wales (11%) said their work has been negatively affected by caring for an older or disabled loved one.
- 6% of Welsh adults, the equivalent of 145,803 people, have given up work to care for a loved one at some point.

Of State of Caring survey respondents in Wales:

- 32% were unable to afford their utility bills.
- 33% had been in debt as a result of caring.
- 37% were cutting back on essential spending like food and heating to make ends meet.
- 41% had missed out on financial support as a result of a lack of advice and information.
- 56% were in a household where no-one was in paid work.
- 45% had given up work to care, 19% had reduced working hours, 14% had taken a less qualified job or turned down a promotion to care and 15% had retired early to care.
- 17% were in full-time work and 18% in part-time work.
- 38% had used annual leave and 18% sick leave to care.

Conclusions and recommendations

Families are giving more and getting less

The evidence from this Inquiry shows an increasingly divergent picture of families' increasing contribution in unpaid care and diminishing support from Government. As the number of carers, the amount of care they provide and the disadvantage they face continue to grow, the support they receive from benefits and social care is either failing to keep pace or being reduced.

This is unsustainable. Demographic pressures already indicate that we are approaching a 'tipping point in care' where the number of older people needing support will begin to outstrip the number of working age family members able to care for them.¹⁰⁸ Further reductions in support for families who are often already struggling to cope will push many into crisis.

On top of the devastating personal consequences of families reaching breaking point and being unable to care for their loved ones, the costs to the Exchequer of local authorities and the NHS having to replace family care are extremely high.

Carers UK estimates that the number of carers will increase to 9 million by 2037 and Census analysis indicates that the proportion of carers caring round the clock continues to rise. With full-time carers facing the greatest financial penalties, this gives rise to serious questions of economic sustainability as growing numbers of carers are forced to give up work or reduce working hours, facing long periods out of the workforce, lasting debt and an inability to save for retirement.

Carers' experiences highlight how cross-cutting the issue of caring is – as their financial resilience can be affected by issues as diverse as the advice provided by their GP, the local supply of care services, the availability of flexible working hours and their access to assistive technology. Alongside highlighting specific policy areas in need of review, this Inquiry shows that there is a worrying absence of a strategic approach from across Government to tackling the unsustainable lack of support for carers.

A strategic approach to alleviating carers' financial hardship

Carers UK strongly endorsed the vision in the 2008 National Carers Strategy which set out core objectives which we believe broadly set the right blueprint for the future. Although specific strategies have also been developed in Scotland, Wales and Northern Ireland, many of the key aspects of carers' finances are affected by tax and benefits decisions made at a UK

¹⁰⁸ *A growing care gap? The supply of unpaid care for older people by their adult children in England by 2032* (2013) Pickard, L. London School of Economics

Government level.

The 2008 Strategy's vision was that, by 2018:

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role
- carers will be able to have a life of their own alongside their caring role
- carers will be supported so that they are not forced into financial hardship by their caring role
- carers will be supported to stay mentally and physically well and treated with dignity
- children and young people will be protected from inappropriate caring

In refreshing the Strategy in 2010, the Coalition Government set four priority areas for future work: carer identification and involvement, fulfilment of educational and employment potential, personalising support and mental and physical health. Carers' strategies in Scotland, Wales and Northern Ireland set similar priorities on health, care and work.

Whilst the additional focus on education and employment was welcome, Carers UK was deeply disappointed that these new priorities both excluded carers' finances and failed to retain the 2018 commitment. The Strategy simply stated that the Government would consider 'whether changes to Carer's Allowance will be necessary to take account of the introduction of Universal Credit.'

Given the long-established and growing evidence of the financial challenges of caring, further shown by this Inquiry, the failure of Government to have any strategic approach to alleviating carers' financial hardship demonstrates a serious failure to both understand and respond to carers' needs.

Furthermore, instead of having a clear plan to improve carers' financial resilience and prevent caring from pushing families into financial crisis, the Government has implemented a package of benefits changes which is undermining families' ability to care. Instead of committing to tackling carers' financial hardship by 2018, the Government will in fact leave carers over £1 billion worse off by 2018.

A central recommendation of this report is that the UK Government must urgently make alleviating carers' financial hardship a core priority of the National Carers Strategy.

The Government has also consistently failed to recognise or assess the impact on carers of wider changes to the benefits system.

Impact assessments have also been limited individual measures - for example, there have been separate impact assessments for the Housing Benefit social sector size criteria changes and the localisation of Council Tax support. The evidence from this Inquiry of the early impact of these measures shows that carers are already being affected by multiple changes and cuts to support. Many of these families will also be affected by the implementation of Personal Independence Payments, yet combined impact of these different changes is not shown in siloed impact assessments for each measure.

Delays in assessing the impact on carers, their absence from key analysis

and the lack of a cumulative impact assessment ignores the crucial role carers play within families and how their income, family finances and ability to provide care are closely tied to the support and benefits received by the person they care for.

Also missing is analysis of the wider knock-on social or economic consequences, or the impact on other parts of social security, health and social care services if carers are: left unable to continue to care, or are pushed into poor health or out of paid work as a result of losing support for them or the person they care for.

To prevent these serious omissions in the future and to identify opportunities for co-ordinating different policy agendas to deliver better support for carers, the National Carers Strategy should also include a cross-Government and cross-nation commitment to ensuring that future policy, particularly on benefits and social care, is 'carer-proofed' to examine the likely impact on carers.

The UK Government must publish a cumulative impact assessment of the impact on carers of the Welfare Reform Act 2012.

The UK Government and, where relevant, in partnership with the Governments in Scotland, Wales and Northern Ireland, must commit to 'carer-proofing' future social security and (in each nation) social care policy and legislation, to ensure it does not negatively affect families' ability to care.

The cost of living and the costs of caring

Many of the issues relating to the cost of living are caused by restricted access to carers' benefits, their low level and their failure to keep pace with the cost of living, and will be addressed through recommendations on reform of carers' benefits.

- The UK Government should implement a 'carer income guarantee' to ensure carers' benefits do not fall further behind in value. This should be similar to the 'triple lock' for the State Pension: pegging the uprating of carers' benefits to whichever is the highest increase between wage, prices or 2.5%.
- The UK Government must also ensure that disability and older people's benefits rise with inflation.
- The UK Government should work with energy companies to improve carers' access to reduced energy tariffs by:
 - Developing carer-specific energy tariffs alongside existing tariffs for disabled and older people.
 - Implementing a joint annual awareness campaign starting in 2014 to ensure carers and their families access existing discounted energy tariffs.

Carers' and disability charities should also review advice and information on energy tariffs to ensure signposting to tariff information is embedded across all advice resources.

- Each Government across the UK should work with local authorities,

other key public bodies and transport providers to develop a template ‘Carer transport card’ scheme to provide discounted or free public transport for carers visiting loved ones in hospital, and extend companion cards to cover all care-related travel, not only when accompanying the person cared-for.

- NHS England should consider a template for an NHS ‘passport-style’ scheme to provide carers with a resource to inform them of their rights within the NHS, to assert their role as ‘expert partners in care’ and gain access to support including discounted or free hospital car parking. The Scottish, Welsh and Northern Irish Governments, with the NHS and other key public bodies, should consider how legislation and policy in their areas can be shaped to deliver a similar commitment.
- Each Government across the UK and debt advice providers should review support, advice and information for families in debt to provide tailored support for carers facing long-term debt as a result of caring.

Missing out

- In responding to the new duty in the Care Bill (England only) and proposals in the consultation on Carers Legislation (Scotland only) to provide information and advice, local authorities should ensure that advice on social security, housing and support with employment is provided alongside information on care services.
- The UK Government should amend the Care Bill to place a duty on NHS bodies to identify and support carers (England only). This already applies in Scotland and may be further enhanced by Carers Legislation to identify and provide information and advice. The Welsh Government should ensure that the existing duties on NHS bodies to identify and support carers are wholly transferred into the Social Services and Wellbeing (Wales) Bill.
- Governments across the UK should also implement a duty on educational bodies to identify and support young and student carers, following the lead taken in Scotland through the Children & Young People Bill. The Governments in Wales and Northern Ireland should ensure that similar duties are being effectively implemented.
- Governments across the UK should work in partnership to examine how different parts of Government can make automatic referrals between agencies – for example a Carer’s Allowance claim should trigger a check on whether a carer has received a carer’s assessment.
- Governments across the UK and carers’ and disability organisations should look at targeted information and advice for specific carer groups – particularly parent carers of disabled children, BAME carers, carers who are themselves disabled and male working age carers.
- All Governments across the UK should work with employers and carers’ charities to develop resources for exit interviews for carers leaving the workplace to signpost to advice and support.

Work

- The Government should legislate to give carers the right to between 5-10 days of paid care leave from paid work.
- Government should open a debate on longer term leave from work to enable carers to care for seriously or terminally ill or significantly disabled loved ones.
- Government should examine the option of ‘day one’ rights to request flexible working.
- Government should work with employers to implement the recommendations of the joint report, Supporting Working Carers, in particular: stimulation of the care market with an explicit focus on services to support carers to work and the promotion of workplace good practice via Employers for Carers.
- Travel costs should be added to the list of deductible costs from weekly earnings for the purposes of Carer’s Allowance.
- Governments across the UK and employers should work together to share and develop good practice on:
 - ‘Carer passports’ in the workplace, so that carers can ‘carry’ flexible working arrangements into different posts in the same organisation and that agreed flexibility can be easily demonstrated to different line managers, supervisors or colleagues.
 - Changing workplace culture to ensure support for carers is embedded throughout workplaces.
- Government should use procurement policies to encourage carer-friendly workplace practice amongst suppliers.
- The UK National Carers Strategy should include cross-Government work (including between the UK and nation governments) to develop support for carers to return to work when caring comes to an end: reviewing the role of Care Partnership Managers in job centres and the availability of funding for replacement care and training to enable carers currently providing care to retrain and engage in study.

Care services

Access to good quality care and support services is a key determinant of carers’ ability to stay healthy, live their own lives, study and combine caring with paid work.

- Reducing resources at a time of growing demand is unsustainable. Governments across the UK must deliver a long-term settlement for social care to fulfil existing unmet need and keep pace with demographic change.
- Each of the Governments across the UK and their respective local authorities and health and care bodies should review support provided to families for managing and co-ordinating care – including the best approaches to care service brokerage and tools for care co-ordination.

- Each of the Governments across the UK and their respective local authorities and health and care bodies must realise the potential for health and care technologies through awareness raising and measures to stimulate supply and access to technological care support.
- Carers report growing concerns about the sufficiency of support provided through direct payments and lack of support with their management. Governments across the UK should evaluate the impact of personalisation on carers, including:
 - Assessing the support provided for the management of direct payments.
 - Analysing comparative levels of support following transition to direct payments.
 - Assessing sufficiency of direct payment funding and the extent to which families are forced to subsidise care.
 - Assessing access to direct payments by different groups of carers and in different parts of the UK.

Carers' benefits

- The UK Government must commit to no further cuts to carers' benefits.
- Carer's Allowance:
 - Government must implement an urgent review of the level and structure of Carer's Allowance, in particular to examine the application of an earnings taper and support provided to older carers. This should report by the end of 2014.
 - In the short-term the Government should urgently raise the earnings limit for Carer's Allowance to at least £105 (and update it each year in line with the minimum wage until a taper is implemented) and remove the study-rule from Carer's Allowance.
- As part of a new National Carers Strategy, and in partnership with Governments across the UK, the UK Government should conduct a wider review of supporting families with caring responsibilities into work alongside caring – examining how to better integrate benefits, services and employment.

The impact of the Welfare Reform Act 2012

Alongside specific measures to mitigate the impact on carers and their families, Government must also show leadership in changing the public discourse on social security, particularly around disability benefits. Ministers must take action to put an end to divisive and damaging rhetoric about benefits recipients and play an active role in demonstrating the importance of social security and the social and economic contribution made by carers and disabled people.

- Government should urgently implement the following changes to mitigate the impact of the benefits changes on carers:

Means-tested benefits and Universal Credit

- Within Universal Credit the Government should reverse its decision to make the carers' and disability elements exclusive.
- Households including someone entitled to Carer's Allowance should be exempt from the household benefits cap.
- Carers and disabled people should be exempt from the change to the Housing Benefit social sector size criteria (in England, Scotland and Wales).
- Alongside older people, carers and disabled people should be identified as a priority group for local support with Council Tax bills (in England and Wales).

Personal Independence Payment

Carers UK fundamentally disagrees with the Government's decision to make sharp cuts to spending on disability benefits as Personal Independence Payment is implemented. We continue to urge the Government to reconsider a decision which will cause very significant hardship and distress and will push many families into financial crisis. However if the Government continues to implement Personal Independence Payment as it stands, it is essential they consider the impact on carers.

- Carers UK is concerned that full details of the PIP evaluation have not yet been published and that this work will come too late for families who lose support from disability benefits. Alongside medium and long-term reviews the Government must conduct early evaluation of PIP implementation, in particular to examine whether the current descriptors are appropriate, particularly given widespread concerns raised by disability organisations.
- As previously recommended by Carers UK, Government must ensure carers are fully embedded in the evaluation of PIP implementation – by assessing the impact on and number of carers losing Carer's Allowance, the impact on the level and nature of care provided by carers caring for someone who sees a change in the level of support they receive and the sustainability of caring responsibilities as a result (including carer health and wellbeing and carers' ability to work).
- Carers who lose Carer's Allowance as a result of the person they care for not qualifying for Personal Independence Payment should be entitled to an eight week run-on, as when caring comes to an end.

Appendix 1:

Evidence sessions

Carers UK worked with local groups and community organisations to run Caring & Family Finances Inquiry evidence sessions between May and September 2013.

Ten sessions were initially planned, however these were extended to sixteen to ensure engagement in every English region and across the nations.

Sessions were led by Carers UK staff members and each followed a similar format, adapted for group size which has ranged from three to forty. The sessions were based around a short written survey and a series of small and larger group discussions. Carers were asked to provide demographic information and details about their caring responsibilities and then complete questions and contribute to facilitated discussions on:

- Identifying ‘costs of caring’
- The impact of caring on carers’ ability to work and earn
- Experiences of the benefits system.

Sessions were promoted through Carers UK’s membership and affiliates and by asking local carers and older and disabled people’s groups to promote to their members, some sessions were also promoted in local media.

In total, 212 carers attended the evidence sessions:

- Just under three quarters of attendees were women, reflecting the fact that the majority of those attending sessions had more intensive caring responsibilities, a group dominated by women.
- Representation from older carers was strong – over a third of attendees were over 65.
- The largest group of attendees was amongst 55 to 64 year olds (just under 40%)
- Attendance from younger carers was much lower, just under one in five were aged 40-54 and only 2% were under 40.
- There was a relatively even split between the types of carer according to their relationships with the person being cared for - this means that parent carers of disabled children were overrepresented compared to the total carer population.
- Whilst six in ten attendees were caring for over 50 hours a week – more than in the wider carer population – over one in five cared for less than 35 hours a week.
- A quarter were combining caring with paid work.
- 9% reported receiving a disability benefit themselves.
- Black, Asian and minority ethnic (BAME) communities represented over 10% of session participants.
- Whilst over three quarters lived in a town or city, just under 1 in 5 described the place where they lived as rural (very isolated), a small village or hamlet or a large village.
- Whilst significant numbers of attendees were connected with Carers UK or affiliated local groups, half of attendees were not Carers UK members.

Summary of evidence sessions

London: Parliament

The All Party Parliamentary Group on Carers hosted a two hour evidence session in Parliament for carers to give evidence, and for Parliamentarians to contribute evidence from their constituencies and casework, on the financial impact of caring. Three carer ‘witnesses’, recruited by Carers UK, gave evidence in facilitated discussions and answered questions from Parliamentarians: Gill, who retired early to care full-time for both of her older parents – her mother has dementia and contracted C-Difficile and her father is very frail and recently suffered a broken leg; John, who, along with his wife, cares for his son who has severe learning disabilities and also took on caring responsibilities for his wife’s mother who has dementia; and Louise, who cares for her disabled husband and has two autistic sons, and is also disabled herself, following a stroke, and needed round the clock care from her husband in the period immediately following the stroke. Early analysis by Carers UK and evidence submitted in advance by carers affected by the Housing Benefit changes (known as the ‘bedroom tax’ or ‘spare room subsidy’) was also set out at the session.

Dame Anne Begg MP, Chair of the Work and Pensions Select Committee, presented evidence on the impact of the changes in the Welfare Reform Act on disabled people and their families.

Key themes

- Caring is often unpredictable – families often do not plan to care and when it affects them, they have no time to manage the change to family finances or work.
- Access to support from care services – charges for care services are rising, particularly the costs of transport to day centres, and carers are often unable to find good quality, reliable and appropriate support.
- The ‘costs of caring’ include both direct costs, of care and support services, and a wide variety of costs which increase families’ cost of living – higher household bills resulting from greater energy usage, the cost of specialist equipment and foods and greater wear and tear on items ranging from clothes to washing machines.
- Carers often face compound barriers to work – a combination of poor understanding and recognition of caring in many workplaces and families’ difficulties in accessing affordable, good quality care services that are appropriate for high-level and complex needs.
- A lack of early advice and information – carers feel that they need to ‘fight’ for support and often miss out on financial and practical support for months or years.
- Widespread anxiety amongst families about benefit changes – already carers were seeing sharp cuts to their income as a result of changes implemented in April. More families will be affected following the changes to disability benefits and a significant number of families are seeing a greater fall in income as a result of being affected by more than one change in the benefits system.
- Evidence from both carers and Parliamentarians gave early indications that discretionary relief was both inadequate and failing to reach disabled people and their families affected by Housing Benefit changes.

Scotland: Edinburgh

The Coalition of Carers in Scotland hosted a session in Edinburgh attended by 34 carers and 9 professionals who provide local support to carers. The Coalition is a group of over 80 local, independent, carer-led groups and centres, and carers from these groups are supported and given bursaries to attend Coalition meetings several times a year. This meant that attendees were from across Scotland, including carers from Argyll and Bute, Dundee, Fife and Stirling as well as from Edinburgh and Lothian.

Almost half were aged 55-64, a fifth were between 40 and 54 years old and a third were over 65. They had a range of caring responsibilities and included parent carers and those caring for partners and parents. The group were overwhelmingly White British. Just over a third of participants were male.

Almost 40% were combining work and caring, the majority in part-time work, and almost a third reported having retired early as a result of caring.

Key themes

- The cost of living is rising faster than carers' family incomes, making it even harder for carers to make ends meet – attendees reported rapidly rising energy and petrol bills which they felt they were being disproportionately affected as a result of higher consumption related to disability and poor health. Both for working carers and those whose income was based on benefits, incomes had not kept pace with increasing bills.
- The inadequacy of Carer's Allowance was a consistent theme. The majority of those who were receiving it did not feel it protected them from financial hardship; other carers expressed frustration that they were not entitled to Carer's Allowance as a result of the 'overlapping benefit rule', particularly those in receipt of the State Pension, or that they did not receive the full amount as a result of the interaction with means-tested benefits.
- There was widespread anxiety about the forthcoming changes and cuts to benefits – in particular the Housing Benefit size criteria (the 'bedroom tax') and reductions in spending on disability benefits. Five reported that they had already been affected by one or more of the changes already implemented, including changes to Housing Benefit size criteria and the time-limiting of contributory Employment and Support Allowance.
- A significant proportion of attendees stated that they did not believe they would be able to continue to pay basic bills if their rising living costs were overlaid with reductions in support from benefits. Several repeated the message 'I don't know how the Government expects us to manage if we receive less than we need to live on and cannot work.'
- A number of attendees felt that the rationale and justification for changes to benefits failed to recognise carers' circumstances – particularly messages around work and benefits dependency. Expressing a feeling echoed by others, one participant said, 'we are always being told we ought to go out to work and we shouldn't be getting benefits – they just don't understand what caring is like.'

Scotland: Glasgow

Carers Scotland hosted a session at the offices of Crossroads Caring Scotland, inviting local carers and members of the Carers Scotland Committee.

The majority of the thirteen attendees were from the Glasgow area but also the session included those from rural Ayrshire, Kilmarnock and the Isle of Lewis. All were Carers UK

members.

Participants' ages were relatively evenly split with approximately a quarter each aged 25-39, 40-54, 55-64 and 65 and over. A quarter were men. Four were juggling work and care and one was in full-time education.

Key themes

- The notable proportion of younger adult carers, including one student carer, gave an emphasis on consequences on carers' long-term employability of being unable to work in your 20s as a result of caring. Carers of all ages noted the challenges of trying to study alongside caring – the lack of support with education costs and the fact that Carer's Allowance not payable to students in full-time and many part-time courses.
- Other frustrations were raised about Carer's Allowance – there was widespread anger about the level but also restrictions on pensioners receiving it and the fact that Carer's Allowance is not payable in full for those receiving means-tested benefits.
- Several carers attending had themselves put together estimates of lost earnings over years spent caring – which totalled tens or even hundreds of thousands of pounds, particularly for parent carers of adult disabled children. It was also noted that this meant an inability to contribute to a private pension or save, or drawing down pensions early, sometimes in lump sums which were used up to cover care costs or adaptations.
- Several attendees had grandparenting responsibilities as well as other caring responsibilities. One commented that, 'for time to be Granny or to provide the childcare my children need for the grandchildren, I have to find the money to buy replacement care for my other daughter who is disabled.'
- Carers were both anxious and confused about the forthcoming benefits changes – those with experience of Work Capability Assessments for Employment and Support Allowance were concerned at the extension of similar assessments to the replacement for Disability Living Allowance; others reported that existing financial pressures meant they did not know how they could cope with any reduction in income.

South East: Slough

This session was organised by Carers UK's Slough branch and Age Concern Slough and Berkshire East.

It was hosted in an Age Concern Community Centre in Cippenham, a suburb of Slough. Those attending were mostly from Slough itself, but with a significant proportion from Cippenham and other suburbs and some from surrounding villages and small towns in Berkshire. Those not able to travel to the centre themselves were collected by Age Concern staff.

The 17 participants (15 carers, two of whom attended with the person they cared for) were largely recruited by the local Age Concern and only a minority were familiar with Carers UK or were Carers UK members.

All those attending were over 50, and, reflecting Slough's ethnic diversity, 60% of attendees were from BAME communities, including British Indian, Pakistani and Black Caribbean participants. Just under a quarter of participants were male. Four reported that they combined work and caring – two part-time and two full-time.

Many of the participants were 'hidden carers' who would not identify themselves as 'carers.' As a result, the session posed a number of challenges for evidence gathering which also

highlights some of the core issues the Inquiry is examining:

- Some participants did not separate their caring role from their relationship with the person they cared for. This meant they struggled to identify specific costs of caring, or isolate the impact on them as ‘carers’ as opposed to the impact on their family.
- Awareness of the benefits system was low. Some had received advice, information and support in claiming benefits which meant they could access their entitlements, but were unsure what their package of benefits consisted of.
- A number of participants did not speak English as a first language so understanding some survey questions and communicating complex benefits entitlements and the details of family finances proved challenging, even with support from Carers UK or Age Concern staff.

Key themes

- Even where carers do not immediately identify additional ‘costs of caring’, they are often able to quickly identify additional expenditure which they ‘end up’ paying themselves.
- For example, one participant spoke about ‘quality of life’ purchases for her son who has learning disabilities. For her, buying a large number of games and DVDs is essential to give him stimulation. In the group discussion other participants quickly identified other examples from their own caring scenario – including activities for older parents or subscribing to additional TV channels which carers were using their own incomes to pay for.
- The session was conducted on one of the hottest days of the year and participants noted that higher heating bills in the winter months could be matched with higher electricity bills in summer months from needing multiple fans or air conditioning units for disabled, ill or older people who struggle to regulate body temperature when ambient temperature moves outside average room temperature.
- Several participants said that they had not ‘given up work to care’ but discussion prompted examples of how their careers had, in fact, come to an end as a result of caring. These included people who had been made redundant and then found themselves caring and unable to return to work, and those who did not identify with the description ‘given up work to care’, as that suggested a choice – the stress of juggling it all, or of being unable to access services, meant working lives fell apart.

North West: Manchester

This evidence session was organised by Carers UK staff. Carers UK members in the Manchester area and North West branches of Carers UK were invited alongside key organisations affiliated to Carers UK within Manchester.

Seventeen people accepted, however only seven attended on the day: six current and one former carer. Four of those attending came from within the city of Manchester, two from Preston and one from Bury. All the participants were Carers UK members and most were over 50 years old. The majority were White British, one was British Asian and one was Chinese.

Because it was a small group, the session was mostly focussed on discussion, with less detail included on survey forms.

Key themes

- Almost all participants said public transport was not really accessible to them because of the disability of the person they look after, often because of behavioural issues as much as physical access. This leads to extra costs in petrol and sometimes taxis. One participant noted that the need to travel for specialist hospital care meant frequent 70 mile drives which is extremely expensive. They have found rising fuel costs have had a significant impact on their ability to afford to travel. The majority reported this and so they are becoming more isolated, some saying 'housebound', as a result of not being able to take the car out.
- Parents of disabled children reported that the cost of specialist playschemes was high - resulting in particularly expensive bills over the summer. However they felt these costs were essential, not just for respite but for the child do something fun and engaging. However several said that they have been forced to stop their child going because of the cost.
- There was widespread frustration at the 'exorbitant cost' of anything labelled as a 'disability' product – attendees described how they felt it was taken by providers as a 'licence to print money' – examples included specialist sleep suits, special swimming costumes, special needs toys – which all cost much more than equivalent clothing or toys.
- Attendees spoke of the costs of challenging behaviour or accidental damage to household items, including children with learning disabilities damaging furniture and mental health conditions resulting in costly 'obsessive behaviour' like high phone bills or overspending on food.
- The costs of incontinence were a theme throughout. Carers reported the high costs of latex gloves, wet wipes and incontinence pads as NHS supplied pads were frequently insufficient. One carer noted that their water meter made their water bills extremely high as a result of the need to constantly wash bedding due to incontinence.

West Midlands: Sutton Coldfield

This session was held as part of an informal carers' coffee morning organised by Carers UK's Birmingham branch and held in a church hall in the centre of Sutton Coldfield. Those attending were from Sutton Coldfield itself and surrounding suburbs including Erdington and Walmley.

Approximately 20 people attended the coffee morning, including several couples where both the carer and the person they cared for attended. Most were Carers UK members and regular attendees at carers' events.

Rather than hold a formal session, Carers UK staff took attendees through the survey questions and facilitated some small table discussions.

Full survey responses were gathered from 9 participants. Over half were aged 65 or older and the remainder were between 40-64. Participants were evenly split between caring for partners and parents, with one caring for an adult daughter with a mental health condition.

Key themes

- There was a clear split of issues between the working-age and older carers. Those of working age reported significant financial difficulties resulting from a loss of earnings and extra costs of disability and caring.

- However, all but one of the older carers were ‘self-funders’ whose income or savings meant they did not qualify for social care services or means-tested benefits. Most of these said that their finances were not a major concern, but they were concerned about the availability of affordable and good quality care services.
- For example, one carer in her late 70s said: ‘Financially we are okay. The bills are no problem and we can afford to pay for care services, but there is nothing there for him’. Her husband, who attended the session with her, has dementia. He is frequently unable to carry out daily living tasks, often has poor short term memory and frequently ‘wandered’ - letting himself out of the house and on one occasion walking into a road causing him to be injured in a road traffic incident. Because he was very mobile, their local dementia day care centre had refused to give him a place as they were not geared to providing support for clients who are active and mobile. As a result, they had been placed on a waiting list for a service farther away but had no information on how long they would have to wait. The carer had only 3 hours’ time off from 24/7 caring responsibilities per week, when her brother visited to sit with her husband. She said she was nearing breaking point.
- This experience was mirrored by other participants, who could not find suitable private purchase care and support services that were appropriate for people with a mental health condition or could provide the right care for a stroke victim.

South West: Taunton

Carers UK’s Taunton & South Somerset Branch organised an evidence session attended by 29 participants – 25 current or former carers, one support worker and three disabled people who attended with their carer.

Those attending came from Taunton and surrounding villages in Somerset; 40% described the area they lived in as a village or rural area.

The majority of the participants were Carers UK members. All were White British, a quarter were aged 40 – 54, three quarters were over 65 and almost a third were over 75. A significant proportion reported having retired early to care and only one attendee was juggling work and caring.

Key themes

- A significant proportion of attendees reported that, as a result of savings or income, they were ‘self funders’ who did not qualify for means tested support or social care support.
- Several felt that they were being penalised for having modest savings or pensions (e.g. a teachers pension) that meant that they did not qualify for means-tested benefits or, for example, free dental care. Due to the high costs of caring, many do not have any significant disposable income despite these sources of income.
- The difficulty of accessing good quality, reliable care was identified as a more major issue than financial pressures by a number of participants. Others noted that deterioration in their own health and mobility was also bringing additional costs as they have to buy in additional support for strenuous caring activities like showering and bathing.
- Given the large proportion of older carers, the issue of Carer’s Allowance and the State Pension arose frequently during the session. Carers felt it is ‘disgraceful’ that people in receipt of the State Pension cannot receive Carer’s Allowance and argued this fails to

give any recognition of their caring or help cover the extra costs.

- Significant one-off costs were a theme throughout the session – carers reported paying very high costs from savings or loans, or through debt, to adapt their homes or buy mobility equipment for their loved one. Examples given by carers were: mobility scooters, bathroom adaptations and wet rooms, a house so that an adult child could live independently and a home conversion so that an adult child could live semi-independently.
- One carer, who had previously only used public transport and had an older person's bus pass and discount card for train travel, was forced to buy a car to take his older mother to essential appointments and to enable her to get out of the house at all, as she lived in a very rural area. He estimated the cost of the car, insurance and road tax was over £5,000 which he had paid entirely himself.

East Midlands: Leicester

The Carers Centre (Leicestershire & Rutland) (CLASP) organised an evidence session held in a community centre in Leicester city centre.

The organisers targeted carers who they thought would be most likely to attend and engage with the issues, resulting in a high level of engagement.

A total of 15 carers attended the session, most of whom were from the centre of Leicester, though some travelled from the city's suburbs and surrounding towns such as Market Harborough.

The session had a high proportion (almost two thirds) of parent carers, the majority caring for teenage or young adult children with learning disabilities, and the remainder were caring for partners or older parents.

Apart from two attendees over 65 all those attending were aged 40-64.

Two were British Indian and the rest were White British. Over two thirds of participants were female.

Two attendees were able to work alongside caring: one worked part-time and the other reported being only able to do occasional work when it could fit in with caring. A quarter reported that poor health or disabilities alongside caring responsibilities meant they were unable to work.

Key themes

- Most participants commented on the complexity and inaccessibility of the benefits system, in particular the challenges of accessing support for children with learning disabilities which are hard to diagnose and the frustration of explaining your situation multiple times to different departments and agencies and reapplying for disability benefits even when circumstances have not changed.
- Attendees identified a large number of costs which are picked up by carers themselves, in particular the frequent and costly impact of damage to household goods and furniture from children with learning disabilities.
- Several said they had found themselves in poor health or with a disability as a result of their caring role, which means they then face the extra costs of their own poor health as well as of caring.
- As parents of disabled children, several carers expressed frustration at the changes to benefits and services that happen when disabled children transition to adults, even

though their needs remain the same.

- During discussions one carer commented that their direct payments (cash payments to buy services), are often not enough and families have to make up the shortfall. Several other carers said they were experiencing the same issue and that this had worsened since they had initially started receiving direct payments.
- Carers reported being made to feel like ‘scroungers’ because they have no choice but to rely on benefits.
- Several attendees had multiple caring responsibilities or were one of two carers providing full-time care to one person (most commonly a disabled child) – they noted that carers can only receive Carer’s Allowance at £59.75 a week, even if they care for two or more people; and that, if two people care full-time for one disabled person, only one of the carers can receive Carer’s Allowance.
- Carers who were also working or who had tried to work reported that the costs associated with replacement care can mean that work doesn’t pay.

North East: Jarrow

Carers UK organised a session in Jarrow Community Centre promoted by local carers groups and centres across Tyneside, to Carers UK’s local members and through the local press.

Of 20 attendees, 15 were carers, 4 were voluntary sector or local authority professionals working to support carers (one professional was also a carer) and one carer came with her disabled son.

Participants were from across Newcastle and Tyne and Wear, including several from other towns and villages such as Hebburn, Brunswick Village, and from as far as Newbiggin-by-the-Sea in Northumberland.

They were aged between 40 and 84 with the majority at the lower end of this range. A fifth were male. Carers for parents, partners and disabled children each represented around a third of participants, but over a quarter were also multiple carers – with two reporting three different caring responsibilities.

Just over a quarter were combining work and caring and the same number reported that they were unable to work as a result of both caring responsibilities and their own poor health.

Key themes

- Attendees had a wide-ranging discussion on the costs of caring, emphasising the changing year-round costs – heating through most months of the year was replaced by needing a number of fans on throughout the day and night during the summer. Several highlighted the need to supplement food shopping of older parents living independently by constantly ‘sneaking in’ things to their cupboards and fridges because they were concerned about their diets – as a result, carers were bearing the costs.
- Travel costs, including the frequent necessity of taxis, and hospital parking were raised repeatedly. Two carers were caring at a distance, one juggling work with caring for a parent in Scotland, and pointed to substantial travel costs. Several older carers noted that their travel costs would be unaffordable without their rail or bus passes.
- Amongst those who were working, three were working full-time. The group discussed how, whilst many full-time carers were struggling to make ends meet, those who had slightly higher incomes, often from paid work, still saw a significant financial impact. Some in this situation were reticent to talk about the financial impact because they

realised there were others struggling more. One carer juggling full-time work and caring said: 'It isn't like we're struggling to pay our bills for the house, like I know other people here and other carers are. But we can't afford to do the things we want. Any breaks or holidays – when we have the energy to try – cost so much to set up, we often don't bother.'

- This was reflected in discussions around the costs of caring. Carers described the 'cost of setting foot out of the door' for carers – which included a series of phone calls to arrange care, the cost of replacement care and potential travel costs to residential or day care, even for carers to take a few hours off from caring.
- Several carers noted that a lack of early advice and information often led to carers missing out on support and this was echoed by professionals supporting carers. One attendee did not self-identify as a 'carer' and had not previously sought advice or support, but had seen the session promoted in the local newspaper. She was combining full-time work with caring for her mother who had early-stage dementia. Her mother was refusing any support except from her daughter, who said that she feared the strain of work and caring would mean that work was impossible very soon – but she had no idea what to do.

Yorkshire and the Humber: Leeds

This session was organised by Carers UK's Leeds branch and held at Leeds Carers Centre. It was attended by 14 people – 12 carers, two of whom came with the people they cared for.

Most were already Carers UK members or in contact with the Carers Centre, however several had been 'hidden carers' and recently been identified at outreach events by Carers UK's branch.

Those attending were all from Leeds apart from one couple from Wakefield. Three quarters were aged 55-64, with the remainder evenly split between the 40-54 and over 65 brackets. 17% were from BAME communities.

One attendee was able to combine part-time paid work with caring and the rest had given up work or retired early to care. Over 80% were female.

Caring scenarios ranged from caring for adult children with care needs resulting from drug and alcohol dependency, to disabled siblings, older parents and a partner with a mental health condition.

Unusually, the majority currently had, or previously had, multiple caring responsibilities – combinations of disabled children, partners and older parents.

Key themes

- Parents of adult disabled children spoke about growing concerns about the adequacy of direct payments and the necessity of carers 'topping up' care packages. Annie and Pete, who care for their son who has learning disabilities, highlighted the financial impact of direct payments failing to meet needs. Annie said: "We were told when direct payments started that it would help his choice and independence and be able to give him what he needed. But things have changed. We're now told that travel to some things, some social activities and things he likes to do cannot be covered by direct payments. That's the whole care plan gone. If they can't pay for it, who ends up paying?"
- Numerous examples of the high cost replacement of broken furniture and household goods were given, including a carer whose adult son, who has learning disabilities,

broke more than ten beds during his childhood and teenage years.

- At the end of discussions on the costs of caring, one carer noted that it was not simply a question of replacing household items more frequently, but also more urgently. For example, they did not have time to shop around for a good deal or wait for longer delivery times for broken washing machines – the need to replace these items instantly brought higher costs. The majority of attendees then spoke up to echo this.
- Attendees pointed to the costs of not eating properly or being able to plan meals – a cost to their health, but also convenience foods and ‘quick sandwiches at service stations and hospitals’ are often more expensive.
- Missing out as a result of a lack of identification and advice was a key issue for a number of attendees. One carer who had only recently been identified by Carers UK Leeds branch, and who was supporting a son in his 20s with drug and alcohol addiction, said, ‘I’m just a Mum, I don’t even know if I should be answering questions about being a carer’. John and Jean, who came to the session with their daughter Jo, who has Down’s Syndrome, demonstrated the impact of a lack of early advice and support. Only when John’s job resulted in a move from the South of England to Leeds did they access formal support. ‘We just coped as Jo grew up and relied on friends and family. Only when we had to move away from that and had to think about where to find support. We wouldn’t have known what social services were for until that moment.’
- Carers also discussed the premium put on products and equipment related to disability. David, who cares for his disabled wife who has specialist and often changing dietary needs, said: ‘It seems that whenever disability or specialist health needs are involved companies’ approach is to ‘add a nought’ to the price.’

London: Islington

Islington Carers Hub (ICH) organised an evidence session to take place during a Carers Pathway meeting. The Carers Pathway group meets every two months to inform local authority commissioners of carers’ needs. 36 people attended. The majority were carers, and four were ill or disabled family members of carers.

The majority of the carers at the session were members of the BAME Support Group which is chaired by ICH. The rest of the carers were either members of the Carers Pathway group or had been invited by members of the Carer Provider Forum, a forum of voluntary organisations that is chaired by ICH, including parent and older carers groups.

Attendees were ethnically diverse. Less than half were White British – over 40% were from BAME communities including Black African, Black Caribbean, Korean, Chinese and British Pakistani; almost a fifth were White Irish or White European. Over 60% were of working age, including two carers under 40, and the remainder were over 65. Attendees covered a wide range of caring scenarios. 10% were working alongside caring and over two thirds were female.

Key themes

- Dissatisfaction with Carer’s Allowance was a significant theme. Many attendees commented on its low-level and felt eligibility was restrictive. In particular a number felt that it is unfair that they do not receive Carer’s Allowance because the person they care for does not receive a qualifying benefit, despite the fact that they care full time. A number also said that if more than one carer is caring for a person full time, they should both/all be able to claim the benefit. Comments were also made about the fairness of the earnings limit, as people earning over £100 per week and caring full time still face

the additional costs of caring.

- Several attendees had experienced problems with work-related conditionality, and argued that it is unreasonable to ask a carer to look for work if the reason they do not qualify for Carer's Allowance is because their loved one does not get the middle or higher care rate of DLA.
- Many felt that the benefits system is too complicated and dealing with it is too time-consuming, especially for people who care full time and don't have time to spare. There is a lot of repetition in the forms they have to fill in, which seems unnecessary. Language barriers make it very difficult to fill in complicated forms. There are voluntary services in Islington that can help, but people are not always aware of them.
- A large number of additional costs of caring were identified, notably 'hidden costs' (i.e. not day-to-day costs) like hospital parking but also generally higher living costs like food, utility and phone bills. Some carers talked about how they stay at home all day, with the television and other appliances on, to care for their loved one so bills can be very high.
- Several carers at the session said that direct payments are often inadequate. For example, one carer is given only 18 pence per mile for petrol which is far below the actual cost, and he has to cover the shortfall. Other participants said that their direct payments have been reduced but the goods or services they are supposed to be used for have stayed the same price, or become more expensive.

Wales

Carers Wales held three evidence sessions across Wales: in Llandudno, Aberystwyth and Swansea in community venues. Attendees were drawn from Carers UK's local members and carers supported by local carers groups and projects. There was strong representation from rural areas, with over half of the carers attending saying they lived in villages or isolated rural areas.

Almost all attendees were White British/Welsh. Half were over 65 with a quarter aged 75 or over. A third were aged 50-64, with the remainder aged 40 – 54 and one attendee was under 40. Over 80% were female.

Key themes

- As a result of the high proportion of older carers at all three sessions – there was widespread discussion of the treatment of Carer's Allowance in relation to the State Pension. Participants over pension age commented on the unfairness of Carer's Allowance stopping at pension age – arguing that the fact that they were older did not diminish the caring role and that caring actually gets harder because of limitations that ageing places on their own health. One attendee said 'I feel that I am not recognised for my caring role because I get no Carer's Allowance because I am over pension age, I am getting older and need it now more than ever.' Participants over pension age commented that they felt that losing their Carer's Allowance reflected their not being valued or recognised by society for the care that they provided - it made them feel 'invisible' and 'worthless.'
- Older carers also spoke about the challenges of meeting the costs of caring on a pension. Cars, particularly in rural areas are a necessity – as they find it hard to manage basic chores like food shopping using public transport.
- For those participants who were under pension age, they felt that Carer's Allowance was too low and restrictive. In particular they argued that the earnings limit is too low and inflexible – resulting in the complete loss of the benefit even if they earn 'one

penny' over the £100 a week earnings limit. They argued that Carer's Allowance should be reduced only by the amount they had earned over the limit and that the earnings limit should be increased to enable people to have a reasonable living wage. One participant said: "Allow me to earn more and get Carer's Allowance so I can secure a better financial future. I save the taxpayer a lot of money. I feel abandoned by the Government"

- Participants also raised concern about the costs associated with disability and the rising costs of utility bills and petrol. Most said that they had to cut back on other things to meet these rising costs and that they felt trapped because they had no option other than to heat the home because they were invariably there all day.
- Some participants felt that they had missed out on benefits and practical help because of a lack of appropriate information and advice. This meant that for some, they had been paying for equipment and things like incontinence pads when they could have been provided elsewhere. One commented: "Throughout my dad's dementia, we felt isolated, we did not know what we were entitled to so we just had to get on with things. The only way Mum eventually got Attendance Allowance and Council Tax Benefit was through a relative's advice, so despite all the medical and social services care, there was no joined up thinking in terms of telling us how and what benefits we may have been able to claim."
- A number of participants have been affected by the Housing Benefit 'bedroom tax' changes and were trying to secure discretionary housing payments – they said that as well as being a drain on their finances, it was 'draining their ability care' and causing high levels of stress.

Hatfield, Hertfordshire

Carers in Hertfordshire hosted an evidence session in a community centre in Hatfield in Hertfordshire. They had recruited a varied group of participants from St Albans, Hertford, Hatfield and their suburbs and surrounding villages.

Participants were all White British or Irish and almost all of working age. Unusually, the majority had multiple caring responsibilities – most for both a disabled child and an older parent, but one attendee was caring for two disabled children and another carer was caring for a disabled child, an ill partner and a parent-in-law.

Key themes

- Participants discussed the impact of caring on their mental and physical health: of tiredness, exhaustion and social isolation which, although not immediately linked to finances, had a significant impact on their ability to work or was worsened by money worries.
- With the majority of attendees being of working age, work, studying and skills were a recurring theme.
- Whilst just under half were also in paid work, for most this was limited part-time work. They discussed the different ways in which caring had affected their work, in particular the drop in income from going part-time but also the need to often take on lower paid, flexible work to fit around caring.
- Participants also discussed in detail the challenges of finding appropriate replacement care services and the paucity of specialist services for certain conditions, in particular for children with learning disabilities and people with early-onset dementia.

- There were strong examples of how early identification, advice and information, provided by Carers in Herts had made a difference to carers accessing support.
- The number of attendees with multiple caring responsibilities, often with at least one example of 'distance caring,' led to discussions on travel costs, 'caring down the phone' and the challenges of managing hospital and doctors' appointments at a distance.
- One carer, caring for a disabled child, who was trying to study to develop a career alongside caring and manage seasonal working spoke about the frustration of the Carer's Allowance restrictions around work and studying.
- Concerns were also raised about support with managing direct payments and the value of the payments relative to the rising costs of care services.

Evidence was also gathered from working carers including a workplace evidence session, however attendees requested that the session remain confidential.

Appendix 2

Detailed calculations of cumulative impact of benefit reductions on carers

Carers UK has assessed six of the major changes the Government is making which affect carers. These changes are being rolled out in different parts of the UK at different times:

- **Carer's Allowance and Personal Independence Payment (PIP):** PIP will be UK-wide but delays in the original 2013 roll-out for Great Britain mean that it is currently only operating in Wales, the Midlands and East Anglia and implementation in Northern Ireland is due to begin in Spring 2014. The UK Government intends for implementation to be progressing UK-wide by 2015. The analysis in this paper is based on available data from the UK Government which applies to Great Britain only.
- The **Housing Benefit size criteria changes for the social rented sector**, described by the Government as the 'spare room subsidy' and known by many as the 'bedroom tax'. This has only currently been implemented in England, Scotland and Wales and has been delayed in Northern Ireland for at least four years. This analysis is also based on figures for Great Britain only.
- The **localisation of Council Tax Support**, following the scrapping of Council Tax Benefit, was implemented in April 2013 and is currently affecting only England, Scotland and Wales. Data to analyse the impact was only available across English local authorities so this analysis applies to England only.
- The **household Benefit Cap** which places a limit on the weekly amounts households can receive from social security, was trialled in pilot areas before being rolled out across England, Scotland and Wales in September 2013. This analysis is based on Government impact assessment across Great Britain.
- The **impact of the introduction of Personal Independence Payment on the number of people entitled to Carer's Allowance** – this will affect carers across the UK, but our analysis is based on the only available data from Government, which applies to Great Britain.
- The **impact of changes from Retail Prices to Consumer Prices for uprating benefits** and the impact of the **1%, below inflation, rise to most means-tested benefits** will also apply to carers across the UK. However the analysis below is based on Department for Work and Pensions figures for Great Britain only.

Cuts to the numbers receiving Carer's Allowance by 2018

In order to claim Carer's Allowance, carers currently need to be caring for someone in receipt of a 'qualifying benefit' including Disability Living Allowance. This link will be replicated as Disability Living Allowance is replaced by Personal Independence Payment. However, impact assessments indicate that, as the Government reduces spending on disability benefits as Disability Living Allowance is replaced by Personal Independence Payment, carers will also lose entitlement to Carer's Allowance because the person they care for loses disability benefits.

The Government's impact assessment¹ shows that, in the period 2013-15, 75,000 carers will see the person they care for reassessed for PIP and that that 5,000 carers will lose Carer's Allowance as a knock-on consequence of the person they care for losing disability benefits.

The period 2013-15 accounts for the first 33% of the total reassessment caseload. The rest of the reassessments will take place between 2015 and 2018 - but Government impact assessment relating to carers does not extend beyond 2015.

If the attrition of existing claimants follows the same pattern in the second tranche of reassessments, then a further 10,190 carers will lose Carer's Allowance. This comes to a total of 15,190 existing claimants losing Carer's Allowance by 2018.

The Government impact assessment also shows that reduced eligibility amongst new claims for PIP (new claimants who would have received support from DLA but will not from PIP) will mean that, by 2015, a further 4,000 carers whose new claims have been successful under DLA would not have entitlement under PIP.

Again, the period 2013-15 accounts for just the first tranche of PIP implementation – 43% of the total new claims for PIP to be processed by 2018. So if 4,000 new claimants will be disentitled between 2013-15, then this would indicate that a further 5,267 carers would be disentitled in the following three years. This results in a total of 9,267 carers from 2013-2018 who would have been entitled to Carer's Allowance under DLA but will not be when new claims are made under PIP.²

In total, as a result of the introduction of PIP, it can be anticipated that 24,457 fewer carers will receive Carer's Allowance.³

However the losses do not all occur at once, and by 2018 carers in 2013 who lose Carer's Allowance or cannot establish entitlement as a result of PIP will have missed out on five years of support. The loss is cumulative.

The Government's impact assessment forecasts that by 2015 the losses will be 9,000 but this will be backloaded as a result of delays in the implementation in 2013-14 and 2014-15.⁴ However post-2015 forecasts envisage a steady rise in assessments from 2015-18. With these assumptions, a forecast pattern of losses in Carer's Allowance could be as follows (see *overleaf*):

1 *Personal Independence Payment and Carer's Allowance briefing note* (2013) Department for Work and Pensions

2 The briefing note above also showed that, when new claims were taken into account, the total reduction in claims was between 9,000 – 10,000 adding a further reduction of least 4,000 in new claims to the loss of Carer's Allowance by 5,000 existing claimants.

3 This does not account for an annual growth of around 30,000 in the Carer's Allowance caseload.

4 However the Government has said that they intend to reach the same forecast by 2015 as they had originally forecast.

Year	Value of Carer's Allowance (assuming 2% inflation)	Cumulative reduction in Carer's Allowance entitlement	Value lost per year
2013-2014	£59.75	500	£1.55m
2014-2015	£61.35	2,000	£6.38m
2015-2016	£62.60	9,000	£29.30m
2016-2017	£63.85	16,729	£55.54m
2017-2018	£65.15	24,457	£82.86m
		Total	£175.63m

These estimates have been made assuming a rise in the value of Carer's Allowance of 2% each year – a low-end estimate of inflation.

Total cut of £175.63 million as, by 2018, 24,457 fewer carers are entitled to Carer's Allowance as a result of the implementation of Personal Independence Payment.

Housing Benefit ('bedroom tax') changes (All Great Britain)

In a response to a written Parliamentary question the Department for Work and Pensions stated that 60,000 carers entitled to Carer's Allowance would be affected by the change to the size criteria for Housing Benefit in the social sector.⁵

The Government's impact assessments indicate that the average reduction in support will be £14 a week per household affected, adding up to £728 a year.⁶ This would mean that those affected have seen a total reduction in support of £43.68 million a year.

The Government has put in place a limited discretionary fund which is providing some temporary support to disabled people and carers. However, our research with carers⁷ indicates that only 31% of carers affected were exempt or had access to discretionary payments, which would leave over 41,000 paying the shortfall – a total of £30.14m cut per year. This is likely to be a significant underestimate of those affected as over half of those receiving discretionary payments had only been awarded temporary support – however the figures below treats this group as not being affected as we do not know the proportion who are receiving ongoing support.

Carers UK's evidence also does not indicate that carers are able to respond to the reduction in support by downsizing, taking in a lodger or increasing income through paid work⁸, so it is reasonable to assume no behaviour change which will reduce the numbers affected. As a result, the recurring cost will remain at a similar level.

Implemented in 2013, a total cut for five years 2013-18 would be £150.70 million, as at least 40,000 carers see support with their rent cut.

5 Figures on number of people eligible for Carer's Allowance were provided by the Government in response to written question from Barbara Keeley MP (House of Commons, 21st November 2013, c1021W)

6 Housing Benefit: Size Criteria for People Renting in the Social Rented Sector: Equality Impact Assessment (2012) DWP

7 Housing Benefit 'bedroom tax' research (2013) Carers UK

8 None of the carers surveyed had taken in a lodger and just 1% had increased income through paid work.

Benefit cap (all Great Britain)

Since April 2013 in some areas, and fully implemented nationally in September, a household benefit cap has been in place to limit the total amount in benefits households can receive. The cap has been set at £500 a week for couples and £350 a week for individual claimants. Exemptions from the cap were put in place for households in which someone is in receipt of benefits including Disability Living Allowance and Attendance Allowance. However Carer's Allowance is included under the cap.

The Government's impact assessment in 2012 showed that 5,000 carers would be in households affected, losing an average of £105 a week.⁹

Latest indications are that the total numbers affected by the benefit cap are lower than expected, at 33,000¹⁰ as opposed to the 56,000 predicted in the initial impact assessments. However no updates on numbers of carers affected have been published.

If the Government's initial impact assessment were correct this would mean a total loss of £27.3 million a year from carer households. The decrease in the number of households affected compared to the impact assessment may be attributable to some moving into paid work. Given that this is not an option for most carers, the number of carers affected may have remained as high as the original estimates as carers have been unable to adopt 'behaviour change' to escape the impact of the cap.

However, if the number of carers affected fell by the same proportion as the total number of households affected then 2,946 carer households would have seen their benefits capped. Using this conservative estimate indicates a total cut of £16.1 million in carers' incomes per year. Carers' barriers to work will mean those affected are also unlikely to be able to move into paid work in the future, so this cost is likely to be recurring.

The cap was rolled out fully nationally from September 2013 so will have been in place for four and a half years across Great Britain by April 2018 - this would be a total of £72.4 million cut from carers affected by the benefit cap.

⁹ *Figures from Benefit Cap (Housing Benefit) Regulations 2012: Impact assessment for the benefit cap (2012) Department for Work and Pensions*

¹⁰ *Benefit Cap – number of households capped, data to November 2013 (2014) Department for Work and Pensions*

Change in uprating from RPI to CPI (All UK)

In 2010 the Government announced benefit uprating would move from using the Retail Prices Index (RPI) to the Consumer Prices Index (CPI) as a measure of inflation. This is having a significant downward pressure on the uprating of Carer's Allowance. The difference from 2011-2013 has been:¹¹

Year	CPI rate*, previous September	RPI rate*, previous September	Actual level of Carer's Allowance, uprated by CPI	Level of Carer's Allowance if uprated by RPI (to nearest 5p)**	Difference
2010/11	n/a	n/a	£53.90	n/a	n/a
2011/12	3.1%	4.6%	£55.55	£56.40	£0.85
2012/13	5.2%	5.6%	£58.45	£59.55	£1.10
2013/14	2.2%	2.6%	£59.75	£61.10	£1.35
2014/15	2.7%	3.2%	£61.35	£63.05	£1.70

* Percentage change over 12 months

** The Government rounds to the nearest 5p when setting the level of Carer's Allowance

If current rate of inflation (2%, using CPI as a measure) and the smallest difference between RPI and CPI in this period (in 2012-13 RPI was 2.6% and CPI was 2.2%, a 0.4% difference) were used to forecast the divergence over the next five years the trend would continue. This is an optimistic forecast for inflation, but which represents the Bank of England's target rate.

Year	CPI rate	RPI rate	Level of Carer's Allowance if uprated by CPI (to nearest 5p)	Level of Carer's Allowance if uprated by RPI (to nearest 5p)	
2015/16	2.0%		£62.60	£64.55	£1.95
2016/17	2.0%		£63.85	£66.10	£2.25
2017/18	2.0%		£65.15	£67.70	£2.55

¹¹ Inflation rates for both RPI and CPI have been taken from September each year – the figure used to uprate benefits for the following year.

Using DWP figures on Carer's Allowance caseload since 2011 and assuming an average increase in the caseload¹² year-on-year from 2013 onwards, it is possible to estimate the total deficit:

Year	Number of carers in receipt of Carer's Allowance (historic caseload and forecasts)	Total Carer's Allowance budget under RPI uprating	Total Carer's Allowance budget under CPI uprating	Difference
2011-12	569,240	£1,669,467,072	£1,644,306,664	£25,160,408
2012-13	603,770	£1,869,634,182	£1,835,098,538	£34,535,644
2013-14	640,520	£2,035,060,144	£1,990,095,640	£44,964,504
2014-15	669,620	£2,195,416,132	£2,136,221,724	£59,194,408
2015-16	700,030	£2,349,720,698	£2,278,737,656	£70,983,042
2016-17	731,840	£2,515,480,448	£2,429,855,168	£85,625,280
2017-18	765,080	£2,693,387,632	£2,591,938,024	£101,449,608

This is a total of £421.91million less being spent on Carer's Allowance by the time the Government's Welfare Reform Act is fully implemented as a result of the switch from RPI to CPI.

1% uprating for most means-tested benefits (all UK)

From 2013-2016, most means-tested benefits will rise by only 1% rather than with inflation (including Jobseeker's Allowance, Employment and Support Allowance WRA group, Income Support and applicable amounts for Housing Benefit). Some benefits, including Disability Living Allowance, the support component of Employment and Support Allowance, Carer's Allowance and the carer premium to mean-tested benefits will rise with inflation.

However many carers receive means-tested benefits as a significant or majority part of their benefits package, and as a result will not be protected from the real-terms cut which a 1% rise, which is below inflation, entails.

Half of carers receive Income Support¹³ and, even if they received no other means-tested support, the 1% uprating of the Income Support section of their benefit would have a significant impact on their family finances, even though the carer premium added on top rose by 2% (the current rate of inflation).

So a carer receiving Income Support could have received, in 2012-13, the Income Support personal allowance of £71.00 and the carer premium of £32.60.

Whilst the carer premium rose 2.2% in April 2013 to £33.30, the Income Support part rose by just 1% to £71.70. So the total package of the two rose from £103.60 to £105.00 – a 1.35%

¹² Based on the average increase from 2004 – 2013.

¹³ *Developing a clearer understanding of the Carer's Allowance claimant group* (2011) Gary Fry, Benedict Singleton, Sue Yeandle and Lisa Buckner; commissioned by Department for Work and Pensions.

rise, which is significantly below the level price rises and means that half of carers entitled to carers' benefits would have seen a real-terms cut to their benefits.

Year	Income Support rate in previous year (uprated by 1%)	Income Support after uprating at 1% (to nearest 5p)	Income Support if uprated at 2% (to nearest 5p)	Difference
2012-13	£67.50*	£71.00*	n/a	n/a
2013-14	£71.00	£71.70	£72.40	£0.70
2014-15	£71.70	£72.40	£73.85	£1.45
2015-16	£72.40	£73.10	£75.30	£2.20

*Actual rates, uprated by more than 2% prior to implementation of 1% rise

So these carers are over £39 a year worse off in 2013-14 and over £117 a year worse off by 2015-16. That amounts to £236 over the period of the policy.

In national terms this amounts to a very substantial cut to carers incomes.

Year	Number of carers in receipt of Carer's Allowance	Estimated number in receipt of Income Support	Total annual cost of benefit under 1% uprating	Total annual cost of benefit under 2% uprating	Difference
2013-14	640,520	320,260	£1,194,057,384	£1,205,714,848	£11,657,464
2014-15	669,620	334,810	£1,260,492,688	£1,285,737,362	£25,244,674
2015-16	700,030	350,015	£1,330,477,018	£1,370,518,734	£40,041,716

These figures just represent the impact if carers only received Income Support and the carer premium – many receive a wider set of means-tested benefits in their households and would feel a deeper real-terms cut as a result.

Over the period of the policy (2013-2016) this represents a cut of a minimum of a £76.94 million cut to carers' incomes.

Localisation of Council Tax Support (England only)

Since April 2013, local authorities have had responsibility for providing support with Council Tax costs through local reductions schemes following the abolition of Council Tax Benefit.

Councils have received a grant from central Government to use to pay for their local schemes, and these are calculated based on forecasts of what would have been spent on Council Tax Benefit for 2013/14 minus 10%.

Older people in receipt of the State Pension were the only group protected under national rules to ensure they continue to receive the support they would have received from Council

Tax Benefit.

To support others in need of help with Council Tax payments, councils have the discretion to design their own local schemes and decide which groups should be entitled to reductions in their Council Tax payments and at what level those reductions will be set. However the protection of older people means that the impact of the reduction in funding will fall more heavily on working age groups.

The Government guidance issued to councils on ‘vulnerable groups’ notes that local authorities should take account of disabled people’s needs and any ‘limited ability to work or likely higher-level disability-related living expenses’.¹⁴ However, it does not contain any reference to carers, the impact of caring on work or on additional household costs.

The Government also drafted a ‘default scheme’ for local authorities, which mirrored existing provision, including support for carers in receipt of the carer premium to means-tested benefits. The default scheme effectively committed local authorities to the level of expenditure which would have been required to maintain Council Tax benefit. However, with the 10% reduction in the grant they received they would be liable for the difference.

Carers are being affected differently depending on the scheme adopted by their local authority. Some councils are proposing to recognise carers as a vulnerable group and to protect them when deciding who will pay more.

As a result of this local variation, understanding the impact on carers across the country is challenging. Analysis of the Family Resources Survey within the Government’s equality impact assessment¹⁵ demonstrates that disabled people and carers were overrepresented in the Council Tax Benefit caseload and were, as a result, likely to disproportionately be affected by the changes:

- 48% of Council Tax recipients under 65 lived in a ‘benefits unit’ (individual recipients and any partners or children under 18) including at least one disabled adult or child.
- 18% of Council Tax Benefit recipient households included at least one adult with caring responsibilities.

Work by the Joseph Rowntree Foundation and the New Policy Institute examined the schemes drawn up by English local authorities and categorised the different approaches local authorities were taking.¹⁶

As all councils decided how to meet the 10% shortfall in budgets passed on as the Council Tax Benefit budget was passed to local authorities – only 18% were retaining the levels of support provided by Council Tax Benefit.

This means that the majority of councils were asking some or all of their working age population who had previously received Council Tax Benefit to pay additional amounts towards their Council Tax. 71% of local authorities were requiring all working-age adults to pay at least some Council Tax, many had no protections for vulnerable groups, and only 35% of councils protected certain vulnerable groups.

Carers UK used this data to assess the number of local authorities implementing a blanket policy of minimum Council Tax payments and where no protections for vulnerable groups are in place. Whilst 95 had some protections for specific ‘vulnerable groups’, 133 local authorities were imposing minimum payments on all working-age former recipients of Council Tax Benefits.

¹⁴ *Localising Support for Council Tax Vulnerable people – key local authority duties* (2012) Department for Communities and Local Government

¹⁵ *Localising Council Tax Equality Impact Assessment* (2012) Department for Communities and Local Government

¹⁶ *The Impact of Localising Council Tax Benefit* (2013) Joseph Rowntree Foundation and New Policy Institute

Whilst the minimum amounts are different across different local authorities, the Joseph Rowntree Foundation/New Policy Institute analysis indicated that affected households will pay on average £138 more a year from 2013-14.

Significant numbers of carers live in local authorities which have some protections for vulnerable groups but which may offer no protections for carers.

But whilst the schemes in the 95 local authorities protecting some vulnerable groups may protect some carers, it is clear that carers across the 133 local authorities imposing blanket minimum payments will be paying additional amounts following the scrapping of Council Tax Benefit.

1,371,471 working age people who were in receipt of Council Tax Benefit live in local authority areas where minimum payments were being implemented and no protections were in place for vulnerable groups.

The Department for Communities and Local Government Impact Assessment also cites data from the Family Resources Survey showing that 18% of working age households in receipt of Council Tax Benefit included someone with caring responsibilities.¹⁷ This allows for an estimate of the number of carers in these areas who would now be paying the average of £138 a year: 246,865, the equivalent of a total loss of £34 million a year.

By 2018, the localisation of Council Tax support will have cost carers a minimum of £170.34 million.

¹⁷ *Localising Council Tax Equality Impact Assessment* (2012) Department for Communities and Local Government

A tribute to Rt Hon. Malcolm Wicks MP

Carers UK is immensely grateful for the support of the Wicks family and the Malcolm Wicks Memorial Fund for making this Inquiry possible.

Malcolm Wicks approached social policy and social security reform from the simple standpoint of making a better life for everyone, not just the few.

As well as bringing in the landmark Carers (Recognition and Services) Act 1995 at a time when carers felt overlooked and forgotten, Malcolm also played a very significant role in the development of policy which has touched so many aspects of carers' lives - from influencing the introduction of Child Benefit, to reforming pensions and improving access for adults to education.

The support of his Memorial Fund has enabled this Inquiry to dig deeply into carers' experiences of isolation and hardship as they provide vital care to disabled and older relatives.

As Malcolm did throughout his career, it develops the evidence needed to bring about change. We need creative solutions and action that help build a better world for carers – a cause so close to Malcolm's heart.



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