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Department
for Work &
Pensions



Household finances of Carer's Allowance recipients

July 2014

Research Report No 875

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Summary

This report presents findings from qualitative research into the experiences of people claiming or with an underlying entitlement to Carer's Allowance (CA). The findings are based on in-depth interviews with 44 people who claimed CA or had an underlying entitlement to it, in three areas of the UK in summer 2013.

The aim of the research was to better understand the following research questions:

- How is CA viewed in terms of the household budget, and does this vary by type of household?
- How do recipients use CA and what would be the impact of non-receipt?
- How does the use of CA vary depending on who is being cared for and where?
- What led to the decision to claim CA?
- Has receipt of CA had different impacts at different times of the caring career?
- What impact has caring had on labour market participation?

Main findings

For some carers, CA is a vitally important part of household income and supports both everyday expenditure and the additional costs incurred. The majority of carers do not see CA as separate from any other source of household income.

Without CA, some respondents said that they would have to cut back on food, fuel or transport costs. Some carers also suggested that without CA they would have to cut back on their caring responsibilities or give up caring altogether to seek paid work.

CA has a high symbolic value. It gives people status as a carer and reduces the stigma in terms of people who had to rely on social security benefits.

The relationship between caring and the labour market is varied and often complex. A small number of carers who had seen a reduction in their caring responsibilities were relatively close to the labour market. Many carers, however, were unable to contemplate paid work without significant packages of substitute care being put in place. Some, who were involved in high levels of caring activity, had no intention of seeking paid work while the person they were supporting was alive.

There was a large group of carers who would like to have paid work again, but could not see how that would be possible in the near future. Finding paid work that fits around caring responsibilities, and that can be flexible when unanticipated needs present themselves is essential, particularly for carers of disabled children.

The research explored a number of potential options for change in relation to CA. These included provision of a lump sum payment or providing further services for the person supported (or CA recipient). Carers were also asked how they would redesign the system.

There was no common message from carers on rolling up CA into another source of income and a one-off lump-sum payment gained very little support. Slightly more popular was the idea of a lump-sum followed by smaller, regular payments.

A quarter of carers were largely happy with the system and could not think of any ways to change it.

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Any errors of commission or omission are, of course, ours alone.

The Authors

Gillian Parker led the project, carried out interviews with carers, extracted data to the Framework used for analysis, and analysed and wrote up all the empirical material.

Caroline Glendinning was part of the planning group for the project, provided expert advice on the benefits system for carers, and wrote the background material in the first chapter.

Anne Corden and **Annie Irvine** were part of the planning group for the project, carried out interviews with carers and approved the final report.

Sue Clarke carried out interviews with carers and extracted data to the Framework used for analysis.

Executive summary

This report presents findings from qualitative research into the experiences of people claiming, or with an underlying entitlement to, Carer's Allowance (CA). CA does not form part of the 2012 welfare reforms, but the Government has announced that it will consider whether changes to CA 'will be necessary to take into account the introduction of Universal Credit and provide clearer, more effective support for carers' (DWP, 2010, para. 27). This study was commissioned to provide information to support this process of consideration.

The findings are based on in-depth interviews with 44 people who claimed CA or had an underlying entitlement to it, in three areas of the United Kingdom (UK) in summer 2013. Fifteen carers were recipients of CA and Income Support (the CA/IS group); 19 claimed CA without IS (CA only group); and 10 were entitled to the Additional Amount for Carers (AAC) within Pension Credit (the PC group).

Household finances and the role of Carer's Allowance

One of the aims of the research was to consider the extra costs faced by carers. However, in most cases, carers could not distinguish the costs that they faced as carers (such as getting to the disabled person's home when they lived elsewhere) from the general costs of disability (which would, at least partially, be defrayed by the Disability Living Allowance (DLA) and any other disability benefits received by the disabled person).

The research thus showed that most carers had difficulty separating the costs of impairment from those of caring and few felt that CA was for any specific type of expenditure. Only two in the whole sample reported spending CA on anything that was 'for' them as a carer. Despite this, however, people did differ in their views about who CA was meant to be for, with a small group feeling that CA was actually for the disabled person or for the disabled person together with the carer. Just under half were clear that CA was for the carer, though none actually used the money exclusively or at all for expenditure for themselves. The majority, however, simply saw CA as something for the household and that made a small difference to their overall budget.

The most commonly reported extra costs across all groups were for transport, whether due to running a car or having to depend on taxis for routine journeys. Household fuel costs also played a large part in additional expenditure, for keeping houses warm for disabled or ill household members who were vulnerable to cold, for extra laundry associated with incontinence, dribbling and feeding difficulties, and running medical equipment such as feeding pumps and oxygen masks. More rapid replacement of furniture, clothes and household equipment, associated with wear and tear, and extra expenditure on food were also commonly reported.

Struggling to get by or 'only just' managing was a common feature of CA-only and CA/IS group carers' lives. In all groups, if there was any money left over after having met essential expenditure, this was put away to cover future bills or unplanned or emergency expenditure. A significant minority spontaneously mentioned significant debts, and pre-payment meters for fuel expenditure figured largely in their lives. The complexity of households and patterns of ill-health and impairment influenced whether people were 'getting by' or struggling, with the five who had taken on responsibility for the care of grandchildren seeming particularly vulnerable.

Findings showed that, perhaps unsurprisingly, the CA-only group were the most concerned about the potential absence of CA. For some in this group, CA was their only independent source of income.

Cutting back on food, household fuel and transport costs was seen as the only possible response, with two CA-only carers feeling that they would have to stop caring altogether and find paid work if CA was not paid. Even in the CA/IS group, the relatively small amount of additional income was important enough for some to feel that they also would have to cut back on food or fuel if the Carer Premium was not available.

The research showed that while all carers appreciated CA because it enhanced their income directly or, for the PC group, indirectly (via enhanced entitlements to other benefits), other reasons for appreciating it varied between the groups. For the CA-only and PC groups, the role of CA in supporting income was predominant. For the CA/IS group, however, the recognition of their role and the appreciation of this that CA seemed to confer were more important. For some, this was closely tied to the reduction of stigma that might otherwise come with benefit receipt and having to attend Jobcentres as a condition of receipt. Some in the CA/IS group also explained that CA 'allowed' them to be carers and to provide the support that they wanted to provide to family members. However, there were carers in all three groups for whom CA's symbolic value – as a recognition of, or 'payment' for, caring – was very important.

As part of the research, carers were asked whether some other form of support would be better than receiving CA. Money was the main issue for most and few could see anything else that would help. People also pointed out the remote possibility of services being able to replace what they did for the person they supported. Neither continuous care nor that which was episodic and reactive in nature was seen to fit with the resources available to, or the timetables of, conventional services. Even in the very few cases where the disabled person was receiving a substantial package of support from elsewhere, this did not mean that the carer was free to do other things. The quality of services and the views of the disabled person were also issues that carers spoke about, as well as, simply, their love for the person they were supporting.

However, carers did point to things that would make their lives a little better, over and above CA, mentioning a more proactive approach to providing information, carer training, the company of others outside the household and domestic help. Only two carers reported employment as a better option for them than CA; we deal further with this issue in the next section.

Carers and employment

Only three carers in the whole sample were in paid work – all in the CA-only group, as might be expected. All were also in part-time work, again as would be expected. In all cases, caring and CA played a role in their decisions about employment and seemed to hold them from more, or more rewarding, work.

The majority of carers were not in paid work, but for reasons that, initially, had nothing to do with caring. This pattern was most likely in the CA/IS group and least likely in the PC group.

The main reason for these carers not being in the paid labour market was marriage, family and childbirth, and this group was exclusively female. This was followed by redundancy and job loss, which was more common in the CA/IS and CA-only groups. Finally, there was a small group of carers where their own ill health had prompted leaving paid work. Although

Household finances of Carer's Allowance recipients

caring was not the initial reason for these carers having left paid work, it did play a role in their subsequent engagement in the labour market, making it more difficult or impossible for them to return to paid employment.

Most of the remainder of carers (under a third of the total), and mostly in the CA-only group, reported leaving paid work completely or having reduced their hours as a direct result of caring. However, in some cases, cause and effect were not always as direct as this might seem; some were already caring while in paid work, and then left paid work when the condition of the person they were supporting declined and they made a successful claim for middle or higher-level DLA.

A handful of carers had left good jobs, through redundancy or their caring responsibilities. However, the majority of those who had ever been in paid work had been in low paid jobs that required little in the way of post-16 training or education.

The largest group of carers interviewed hoped to be able to take paid work at some time, but could not see how that would be possible in the near future. The most important issue for them was finding any paid work that could fit around their caring responsibilities, both in relation to the actual hours worked and in relation to the need to be flexible. This was a particular issue for those with school-aged children, but also applied to others. Others were concerned about how they might re-engage with the labour market when their skills were out of date or, in the case of skilled manual workers, their certification or licences had lapsed and were expensive to update.

Finally, a group of carers (just under a quarter of the total sample) said that they would not return to paid work while the person they cared for was alive. All saw their role as keeping the person they supported at home and cared for, for as long as was feasibly possible. Any return to paid work would have jeopardised this. These carers were involved in providing high levels of support for family members with substantial and usually complex needs.

Alternatives to the current Carer's Allowance system

The research explored a number of potential options for change in relation to CA. These were rolling CA up into some other source of income; providing a single lump sum to carers and then nothing else; and providing a smaller lump sum and then a lower regular amount of CA. We also asked carers whether services for the person they supported or for themselves would be a better option than receiving CA. Finally, we asked how they would redesign the benefits system to support carers.

There was no common message from carers about rolling CA into some other source of income. The role of CA as a source of income independent from other household members, including the person the carer was supporting, was vitally important to some carers, while those in the CA-only group supporting someone in a different household could not see how a rolled-up payment could work for them.

The one-off lump-sum option gained support from very few carers and these tended to be people who felt that they had the skills to invest the money, if it were a large enough sum, to generate income.

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The idea of a one-off lump sum followed by smaller regular payments was slightly more popular. Just over a third of carers could see some potential in the idea but said that this would depend on the details of the scheme and, in particular, whether the size of the regular payment would meet ongoing needs.

The question about services for the person being supported raised similar issues to those outlined earlier, when carers were asked about things that might be of more use to them than CA. While rather more carers were positive about services for themselves, this was about the need for support in addition to CA, not instead of it.

The research showed that a quarter of carers did not want to see any change, thinking that the current CA system was largely all right as it was or could not think of ways to improve it. Among the rest, there were many ideas, fitting into four broad categories.

The first category related to changing the current CA system so that the payment was more closely aligned to the level of carers' involvement or the additional expenditure that they regularly incurred. Stopping the deduction of CA from other sources of income was also raised, with people pointing out that either one was a carer, carrying out a valuable job that had an impact on one's expenditure and life chances, or one was not. Others mentioned the low level of the earnings cut-off and the disincentive that this created for people who might be able to undertake part-time work.

The second category of changes that carers would like to see related to administrative issues and the claiming process. They wanted to see a more integrated system that dealt routinely with linked claims for disability-related and caring-related benefits and that provided the right sort of information to allow people to get their claim 'right' the first time.

The third category related to carers' finances. Suggestions included: offering carers fuel discounts rather than cold weather payments; a transport allowance rather than bus passes (which most disabled people could not actually use, therefore carers also incurred transport costs in using cars and taxis when accompanying the disabled person); and ID cards for carers so that they could get discounts on food in hospitals, where many of them spent much time.

The final category of suggestions was about the ways in which carers are perceived and treated. Carers referred repeatedly to the symbolic value of CA, especially for those who sensed increasingly negative attitudes towards people who relied on the State for income and support. They felt that it would help if there was more emphasis on CA as something to which carers were entitled because they were doing an essential job. The role of employers in supporting carers was also included here: encouragement to employers to adapt their employment practices was a start, but what was needed to turn it into reality was enforcement.

Implications for policy

Most carers interviewed felt the symbolic value of CA is important; seeing that they were valued within the benefits system was very important to them.

For most carers interviewed, there was no obvious point at which employment policy could intervene to sustain or encourage labour market engagement.

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One small change that might encourage, if not more paid work then better paid work, would be revision of the CA earnings cut-off. As it stands at the time of writing, it allows carers to work for just under 16 hours a week at the national minimum wage. While few would be able to contemplate working for more hours than this, it was clear that some with higher hourly wages could earn more than at present and that this would be welcome in households with restricted budgets.

The earnings cut-off also presents carers with a 'cliff-edge'; if they earn a pound over the limit then they lose the whole of their entitlement to CA. Some type of sliding scale of withdrawal of CA, in line with increased earnings, therefore, might also encourage greater amounts of paid work or better paid work.

The findings show that another potentially beneficial change would be the integration of advice across the disability and carer benefits system. Co-ordination of advice would make carers lives easier and prevent situations where it was months or years before they realised that they were entitled to claim CA.

The co-ordination of advice could also usefully extend to advice about social care support. A more radical restructuring of benefits and support for carers might see a 'single door' approach that meant that the totality of carers' needs were dealt with in one place, and were reviewed on a regular basis.

This research was based on qualitative interviews with a relatively small group of carers; moreover, the sample was constructed in such a way that overall results cannot be extrapolated to CA recipients as a whole. Nonetheless, our findings about the extra costs that carers bear, and the difficulties of maintaining labour market engagement (see above) are barely different from those described by McLaughlin and by Glendinning in the early 1990s (see Chapter 1).

1 Introduction

This report presents the findings of a qualitative research project commissioned by the Department for Work and Pensions (DWP) to investigate the impact on people's lives of receiving Carer's Allowance (CA). The research was carried out by the Social Policy Research Unit (SPRU) at the University of York. The report is based on in-depth interviews held with 44 carers who claim CA or who have an underlying entitlement to it.

CA is a benefit paid to people who have forgone the opportunity to engage in full-time paid work because they care for a severely disabled person. To be eligible for CA, the person being cared for must receive Attendance Allowance (AA), Disability Living Allowance (DLA) at the highest or middle rate – (to be replaced by the Personal Independence Payment at either rate of the daily living component in due course), Constant Attendance Allowance (CAA) or Armed Forces Independence Payment (AFIP). Invalid Care Allowance (ICA) was introduced for working-age carers supporting relatives (but excluding married women) in 1976 and subsequently extended to married women in 1986. Both developments were achieved after long-fought campaigns by the carers' movement. It was renamed Carer's Allowance in 2003.

CA is relatively simple in its main eligibility criteria: the carer must spend 35 or more hours a week caring for someone who receives the relevant disability-related benefits; have weekly earnings of £102¹ or less, after allowable expenses; not be in full-time education; and be 16 years of age or over.

Entitlement to CA also brings with it automatic Class 1 National Insurance credits (unless a female carer has retained her right to pay the married woman's reduced-rate contribution), thus allowing carers, whose responsibilities have a major impact on their ability to undertake paid employment, to build up rights to a State Pension or State Second Pension. For those who are able to return to paid employment, the credits may also confer future entitlement to Employment and Support Allowance (ESA) and other contributory benefits.

However, CA has a complicated relationship with a range of other benefits that the carer may or may not claim. CA is felt to act as an impediment to engagement with the labour market for younger carers (Arksey *et al.*, 2005), and is often not claimed until many years after the carer has technically become eligible, if at all. Further, while carers receiving State Pension generally cannot also receive CA, because of overlapping benefit rules, if their pension is less than £61.35² per week (the current CA payment) they are entitled to a CA 'top-up' to that amount. In addition, where a State Pension of more than £61.35 is received and the carer meets the eligibility criteria for CA, this 'underlying entitlement' might enable the carer to qualify for the additional amount for carers in Pension Credit (PC).

The Government, as part of the 2012 welfare reforms, has announced that CA will remain as an independent benefit, but that this will be reviewed in the context of how Universal Credit (UC) operates. This study was commissioned to provide information to support this process of evaluation.

¹ From May 2013, the CA earnings limit was raised to £102 per week. At the time the research was conducted, this limit was £100 per week.

² The CA benefit amount for 2014/15 was raised to £61.35. At the time the research was conducted, this amount was £59.75 per week.

Household finances of Carer's Allowance recipients

In this chapter, we begin with a brief review of what is already known about carers' financial circumstances and the role that CA plays in their personal and household finances. This is followed by a summary of the main research questions we addressed and the methods we used to do so. We briefly describe the characteristics of the people we interviewed and then outline the structure of the rest of the report.

1.1 Previous research on carers' financial circumstances and Carer's Allowance

As part of this research we were asked to summarise the existing evidence on carer's finances. There is a considerable body of research evidence on some aspects of carers' financial situations, living standards and use of CA, but relatively little on other aspects. For example, research since the late 1980s has consistently documented the impact of caring on carers' incomes and labour market participation. On the other hand, there remain challenges in understanding how the incomes, expenditure patterns and overall living standards of individual carers are affected by patterns of household financial management, flows of resources and financial commitments within and between different types of care-giving households. There is also little evidence on the incomes and living standards of older carers – a group increasing in prevalence – or on the impact of extending CA entitlements to those over pension age.

A number of interacting factors affect carers' disposable incomes and living standards, in both the immediate and longer term. These are: their opportunities to undertake paid work; the role played by services in substituting for informal care so that carers are able to maintain contact with the labour market; the incidence of extra expenses and other care-related demands on their household budgets; and the role of social security benefits (particularly CA) in mitigating the impact of reduced incomes and/or extra costs.

1.1.1 Carers' incomes

There is extensive, long-standing and entirely consistent evidence that all carers are at substantial risk of having lower than average personal and household incomes. Analysis of the 1985 General Household Survey found the average net personal income of carers was lower than that of non-carers; this was particularly true for male carers (Evandrou and Winter, 1993). McLaughlin (1991) found that, even after taking into account actual and potential receipt of (then) Invalid Care Allowance, carers' mean personal incomes of £65 a week were on average £10 lower than those of non-carers. Carers also had lower than average household incomes, compared with the general population; their per capita household incomes ranged from £38 to £51 a week per person less than the general population. Analyses of the 1990/1 General Household Survey also showed that the mean net incomes of all carers were much lower than those of non-carers; there were particularly marked differences among men and among those caring for someone in the same household, with the latter much more likely to be in poverty than non-carers (Evandrou, 1995).

Detailed analysis of carers' household income using large data sets and comparing carers with similar non-carers, has not been undertaken for some years. However, analysis to inform the House of Commons Work and Pension Committee's (2008) report on carers showed that carers involved for 20 or more hours a week are more likely to be in poverty than the general population, and those caring for 35–50 hours even more so. Analyses of the

2009/10 Carers in Households survey showed that 19 per cent of carers lived in households with incomes below £10,400; and 46 per cent of those caring for more than 20 hours a week lived in households with incomes under £15,600 (GfK, 2010: http://www.esds.ac.uk/doc/6768/mrdoc/pdf/6768_survey_of_carers_in_households_2009_10_england.pdf).

The lower incomes of carers compared to their (currently) non-caregiver counterparts have important temporal dimensions. Analyses of the 1988 Retirement Survey of people aged 55 to 69 found that the household incomes of people who had cared for ten or more years were considerably lower than those who had cared for shorter periods (Hancock and Jarvis, 1994). A period of care giving can also affect income levels after it has ended. McLaughlin's (1993) survey of carers found that former carers' household incomes were, at around £53 a week, some £40 lower than the average per capita disposable income. Hancock and Jarvis (1994) also found former carers aged 55 to 69 had lower incomes than non-carers.

The lower incomes of carers and their households is the result of two broad factors: the adverse impact of care giving on employment and earnings; and the failure of social security benefit incomes to provide sufficient compensation for this, and for any additional expenditure they may incur (McLaughlin, 1991).

1.1.2 The impact of care giving on paid work and earnings

One of the main reasons for the lower incomes of carers, compared to their non-caregiver counterparts, is the difficulty many carers experience in combining paid work with care giving. Again, these difficulties have been documented extensively and consistently over time. The 1985 General Household and Disability Surveys (McLaughlin, 1991) both found lower rates of employment among carers, compared with the general population. This effect was apparent among those providing 20 hours-plus care a week and became more marked as levels of care giving increased. However, recent research by Pickard *et al.* (2012) has identified a much lower threshold at which caring affects paid work, with carers aged 50 and over at risk of not being in paid employment when providing as little as ten hours a week of care. All other things being equal, caring for someone in the same household reduces labour market participation by 15 per cent. Caring for 20 hours or more a week reduces labour market participation by up to 26 per cent (Heitmuller, 2007), regardless of where the caring takes place. Of course, some carers take on caring responsibilities when they are not in paid employment, making it difficult to tease out cause and effect in the relationship between caring and impact on employment. However, analysis of data from the British Household Panel Survey shows that co-resident carers experience a large impact on employment as a result of being carers.

Care giving can adversely affect paid work in a number of ways. These include giving up work entirely; switching from full-time to part-time work; reducing hours of part-time work; changing jobs or working patterns; and lowering work performance, including productivity (Arksey *et al.*, 2005). Specific responses appear to reflect the characteristics and circumstances of particular sub-groups of carers. For example, co-resident carers are more likely to leave paid work than those caring for someone in a separate household; women are more likely than men to report ever having given up work to care for a sick, disabled or elderly relative; older women are more likely than younger women to leave work altogether; female carers are more likely than male carers to switch from full-time to part-time work; and the likelihood of withdrawing from the labour market appears to increase with the duration of care-giving (see Arksey *et al.*, 2005 for a summary of relevant research).

1.1.3 The impact of services on employment

Good social services for a disabled or older person – personal and domestic help, day care or sitting services – can, in principle, help carers to remain in paid work and thus reduce the impact of care giving on paid work and earnings (Heitmueller, 2007). The 2004 Carers (Equal Opportunities) Act recognises this by requiring local authorities to take into account whether a carer works or wishes to work when assessing her/his needs. However, only small minorities of working carers report having had a carer's assessment or using social services. There are two main reasons for this.

First, only disabled or older people with critical or substantial levels of support needs are currently eligible for adult social care support in England, and after discounting any needs that are met through help from a carer. This reduces the numbers of older or disabled people receiving any formal social services. Secondly, very few working carers are offered assessments of their own needs, including employment-related support needs (Pickard *et al.*, 2012). There is also no evidence of a link between the number of hours worked by carers and the receipt of social services support (Arksey *et al.*, 2005).

Services that could help carers to remain in paid work include childcare for disabled children (particularly after school and in the holidays), longer day centre hours and practical help with domestic chores. However, carers report problems with the timing, reliability and quality of social services and associated transport (Arksey *et al.*, 2005; Arksey and Glendinning, 2007). Changes in eligibility for services when care recipients move from children's to adult services or from working-age to older people's services are also problematic for carers who depend on services in order to remain in employment. Other carers refuse, or stop receiving, services if means-tested charges for services become too high (Arksey *et al.*, 2005).

1.1.4 The extra costs of care-giving

Although there is a considerable body of evidence on the extra expenditure that many carers experience, there is debate about whether this spending primarily reflects the disability-related costs of the person receiving care. Thus the most common sources of extra spending by carers in McLaughlin's (1991) survey, whether for older people or disabled children, were heating and laundry, transport, equipment and appliances and prescriptions. Glendinning's (1992) in-depth study also found carers spending extra on heating, food, laundry, clothing, bedding, household cleaning and repairs. All these arose primarily because of the disabled person's poor mobility, special dietary needs, incontinence, or behaviour difficulties.

Other sources of extra spending are much more difficult to categorise solely as disability-related costs. Glendinning (1992) found carers frequently incurred one-off 'capital' costs. These included moving to a bigger house; home alterations (whether or not involving special adaptations) to accommodate a disabled person or make it easier to care for him/her; and buying additional heating appliances, larger cars and consumer durables such as washing machines, driers and freezers. Where an older person or younger generation carer had moved specifically to create a new care-giving household, these items were often needed simply because of the additional household member(s). However, they also saved carers time and effort, and could have benefits for the living standards of the wider household.

A third common source of extra expenses is more clearly identifiable as care-related. These include: spending more on shopping for household food and personal clothing because of having less time to shop around for bargains or make items from scratch; damage to carers' own clothes because of the incontinence or behaviour problems of

the disabled person; extra use of cars to save travel time and the length of time the care recipient is left alone; and extra use of telephones to make appointments with services or keep in touch with wider family.

Some carers who are unable to obtain reliable, appropriate statutory social services for the disabled person find themselves incurring high substitute care costs to enable them to continue working (Glendinning, 1992). It is possible to offset some costs of substitute care while claiming CA, up to the value of half the carer's earnings after other deductions. By definition, only someone with a net weekly income of £200 or less could remain eligible for CA (i.e. have net earnings of under £100 after care costs) and buy care. £100 (the maximum offset under this rule) would buy a maximum of 6.67 hours a week of home care at current average costs of £15 per hour.

These additional costs are accommodated in a number of ways. Some are offset by financial contributions from the disabled or older person, particularly if they share the same household. However, the incomes of the latter may not be high enough to cover all the extra spending involved (McLaughlin, 1991). Moreover, these extra expenses need to be understood in the context of carers' lower than average weekly incomes. Thus, carers also report drawing on savings, cutting back on other routine expenditure, using credit or simply deferring spending and doing without badly needed items like furnishings, carpets and warm winter coats (McLaughlin, 1991; Glendinning, 1992). Both the latter studies identified a cluster of carers with household incomes consisting entirely of social security benefits, who are living in fuel poverty and with unmet needs for basic clothing and household items.

1.1.5 Carer's Allowance and its impact

For some carers, CA offers at least a partial solution to the dual challenges of meeting extra costs from reduced incomes. However, the eligibility criteria for CA mean that many carers providing very substantial levels of care and/or facing high extra costs cannot receive the benefit; others who are eligible delay claiming for a variety of reasons.

First, eligibility criteria preclude receipt of CA by those with more than minimal employment or earnings, including those with very substantially reduced incomes or who incur high substitute care costs in order to be able to keep working (Glendinning, 1992). Carers with opportunities for relatively highly paid part-time and/or occasional work such as supply teaching are also precluded from claiming (Arksey *et al.*, 2005). Carers aware of 'overlapping benefit' rules are also unlikely to apply for CA (Arksey *et al.*, 2005).

Additionally, both McLaughlin (1991) and Glendinning (1992) identified considerable under-claiming of (then) ICA, partly because the person being cared for was not receiving AA and partly because carers themselves were not aware of ICA. Arksey *et al.* (2005) also found significant non-take up or delayed claims for CA among potentially eligible carers.

Arksey *et al.* (2005) reported that both carers and social services staff working with carers considered the level of CA was far too low. However, McLaughlin (1991) found the (then) ICA had high symbolic value, as recognition for the 'work' of caring and as a source of independent income to counteract the fact that many carers would otherwise be wholly financially dependent on others.

Household finances of Carer's Allowance recipients

The limited evidence on the use of (then) ICA indicates it was generally used for ordinary household spending (McLaughlin, 1991; Glendinning, 1992). This is not surprising, given the lower than average incomes of carers and their households and the extra costs outlined above. McLaughlin concluded that use of ICA reflected broader household circumstances, with the lowest income households using it for essential domestic expenditure while those in the highest income groups had slightly more flexibility to put it towards extra disability and care-related costs. Even so, within these latter groups ICA was still mostly spent on food, heating, household equipment and consumer durables.

1.1.6 Variations between carers

Some groups of carers are at particularly high risk of having very low and/or insecure incomes and/or high extra costs. This reflects a complex interaction of personal and household factors including:

- the carer's age (and related employment history);
- the carer's gender (for example, women are consistently reported as being more likely than men to be able to access part-time employment opportunities that can be combined with care-giving);
- the relationship between the carer and person receiving care, and their respective economic statuses (for example, whether the latter is a disabled child, partner or older generation relative);
- the overall composition of the carer's household, in particular whether the household contains a(nother) wage earner and whether the person receiving care lives in the same household as the carer.

Moreover, in households with more than one member, the carer's financial situation will be further affected by wider patterns of household financial management that have been negotiated between those with and without independent incomes (Glendinning, 1992).

In combination, these factors can have a multiplicative effect on carers' financial circumstances. McLaughlin (1991) identified a minority of carers who were experiencing severe financial difficulties. These carers were in households without any wage earner and where the total household income came from benefits³. Carers who were comparatively better off were those living in households with a full-time earner, although of course they still experienced additional disability and/or care-related costs. Glendinning (1992) similarly identified a very vulnerable group of carers – unmarried or divorced adults living alone with the person they were caring for, where both depended wholly on social security benefits. Excluding the disabled person's disability benefits, the majority of these households were living below a notional poverty line; few had any savings and most were regularly drawing on whatever savings they had. Indeed, once the disabled person's disability benefits and/or any savings were taken into account, some carers reported they were partially financially dependent on the former. For adult children who were now financially dependent on a frail older parent, this was a major source of anxiety.

³ At that time, those receiving Income Support were worse off than those where the carer and/or a non-disabled spouse was receiving insurance benefits.

1.2 Research aims and objectives

The overall aims of the research reported here were to explore:

- carers' key budgeting issues, how important CA is in their overall household budget, and how CA is used;
- carers' aspirations and closeness to the labour market and how they can be better supported to return to work;
- key coping strategies used by carers and the wider (financial) support networks they depend on;
- the potential impacts of possible CA reforms.

Our research questions therefore focused clearly on CA's relationship to household finances and budgeting, employment, labour market engagement and, where relevant, full-time education. The questions were:

- How is CA viewed in terms of the household budget and does this vary by type of household?
- How do recipients use CA? What would they have to stop doing if they did not receive it or it was reduced in value? What impact would non-receipt or a reduced level of benefit have on the level of care provided?
- How does use of CA vary depending on other variables: sources and level of income, who is being cared for or supported and where, gender, caring intensity and duration?
- What led to the decision to claim CA and how long was this after caring began?
- Has receipt of CA had different types of impact at different times in the caring career?
- What impact has caring had on labour market participation and/or full time education? What role has CA played in that impact?
- How do carers currently see their relationship to the labour market and/or full-time education and what would help them re-establish, maintain or grow their participation?

DWP was also interested in the question of possible 'upfront' financial support when people begin their caring role and the trade-offs carers might be prepared to make between this and a lower weekly amount of CA. Knowing what we do about caring histories and trajectories, we were not sure that it would be possible to ask this question of any but a tiny minority of carers. Even those few who become potential carers 'overnight' (for example, after the birth of a severely disabled child, or after substantial trauma of a member of their household or family) are highly unlikely to become 'carers' at that instant or recognise themselves as such. The point at which they make a first claim for CA is thus unlikely to be the point at which carers are experiencing the most strain on their household finances and/or their paid employment.

1.3 Research design and methods, including sample structure

We carried out qualitative interviews with 44 carers in three regions of England. The carers were selected purposively from a sample provided by DWP, with the aim of representing roughly equal numbers of people across the following categories:

- in receipt of CA-only, CA and Income Support (IS), or were entitled to the Additional Amount for Carers (AAC) within PC;
- had been claiming CA or Carer’s Premium (CP) for under a year, between one and nine years, or for ten years or more;
- female and male carers.

Table 1.1 shows the characteristics of those we interviewed.

Table 1.1 Characteristics of the study group

	Length of claim						Total
	< 1 year		1 -9 years		10 or more years		
	Female	Male	Female	Male	Female	Male	
CA-only	3	3	2	6	2	3	19
CA and IS	3	3	4	2	2	1	15
CP with PC	3	0	2	2	2	1	10
Total	9	6	8	10	6	5	44

There was a range of household types and ages across the group although, as would be expected, those in the PC group tended to be older on average than the other groups. Further details about the characteristics of those interviewed are at **Appendix A**.

While the nature and the sensitivity of the topics to be explored required in-depth interviews with carers, we offered the choice of a telephone or face-to-face interview, believing that this would lead to the best chance of a high response rate, given the demands on carers’ time. The majority of interviews were carried out via the telephone.

We used a semi-structured topic guide for the interviews, designed to address the research questions fully, but sensitively, and this is at **Appendix B**.

1.4 Structure of the report

In **Chapter 2**, we explore the carers’ personal and household circumstances; their health, that of the person they supported, and that of any other household members; and their caring responsibilities. This sets the scene for **Chapter 3** where we report what carers told us about their household finances, the financial costs of caring and the role that CA played in those. We also track the routes that they took into claiming CA. In **Chapter 4**, we move onto examining carers’ engagement with the paid labour market by exploring their history of paid work and how that relates to their caring history and their CA claim. **Chapter 5** presents carers’ views about how CA currently works and about a variety of other possible options for supporting carers. Finally, in **Chapter 6**, we present some conclusions and discuss implications for policy and research.

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We have not drawn heavily on direct quotations from carers in this report but, where we have used their words, this is to illuminate a finding or perspective. In some places we have also used thumbnail sketches of carers' circumstances, usually to underline the complexity of their lives and/or decision making around caring and employment. These are presented in italics and can be skipped without missing any main issues. We have drawn on the words of 22 carers in direct quotations of more than a few words and the experiences of 20 carers in the thumbnail sketches. In total, these represent 30 of the 44 people interviewed. We have removed or changed details about individuals when this might compromise anonymity.

We use the phrase, 'CA-Link person' in places to signal that this is the person whose own disability benefit claim was linked to the carers' eligibility for CA.

2 Carers and their circumstances

Further details about the carers and their circumstances are in Appendix A. In this section, we summarise some of these characteristics to give a flavour of the carers' lives and to explore differences between the sub-groups. These differences are substantial in places, and this has influenced our decision in some later parts of the report to present interview material separately for the three groups.

2.1 Who were carers supporting?

There were differences between the groups in their relationship to the person they were supporting. Similar proportions of the Carer's Allowance/Income Support (CA/IS) group (4/15) and of the CA-only group (5/19) were caring for one of their own dependent children. Only one carer in the Pension Credit (PC) group was helping a child under the age of 18, and this was a grandchild. Those in the CA/IS group were also most likely to be caring for an adult child (3).

Caring for a spouse or partner was most common in the CA-only group (10/19), followed by the PC group (six, plus one person caring for a former partner). Caring for a parent or parent-in-law was relatively unusual (only five across the whole group), but most common in the CA/IS group (3). This was also where the single example of someone caring for a grandparent was found.

2.2 Age

The majority of carers in the CA/IS group were aged between 41 and 50; in the CA-only group between 51 and 60 and, as might be expected, in the PC group between 61 and 70. There was only one carer in the whole sample under the age of 26 and another two aged between 26 and 35. Three carers, all in the PC group, were aged over 70.

2.3 Household composition

Households in the CA/IS group were most likely to be single parents (6/15), those in the CA group were most likely to be couples with or without dependent children (10/19), and those in the PC group were most likely to be couples without dependent children (6/10). There were eight households across the sample that we have defined as 'complex'; these included one where a woman was carer for her husband's adult brother, who lived with them, as well as having three children; several three-generational households; and three 'missing generation' households where grandparents were looking after grandchildren, in the actual or virtual absence of the children's parents. There were also five households consisting of an adult child and one parent.

2.4 Housing

The majority of respondents (29) lived in rented accommodation – flats, houses and bungalows – although this was most common in the CA/IS group (12/14). The CA-only and PC groups were much more likely to be in owner-occupied housing, whether owned outright or with a mortgage.

2.5 Health condition or impairments of the CA link person

The largest group of CA link people (21/44) had physical or sensory impairments or health conditions, followed by those with both physical and mental health problems (7) or mental health problems alone (6). Physical/sensory problems were most prevalent in the PC group (8/10). Mental health problems alone, learning disabilities or autism spectrum conditions and Attention Deficit Hyperactivity Disorder (ADHD) were most prevalent in the CA/IS group (7/15). Carers in the CA-only group were most likely to be caring for someone who had a mental health problem or learning disability alongside physical and/or sensory problems. Even among those with 'only' physical impairments, these were usually multiple and, in some cases, very complex. These included four children and an adult with rare, multi-system conditions. Four people had dementia on top of substantial physical impairments and two of these had died very recently.

2.6 Carers' own health

Fewer than half (16) of carers reported their own health as good and with no problems. We judged that six were themselves in very poor health with multiple problems. Examples included a carer who shared a rare, multi-system condition with the CA link person, and two carers who had recently received treatment for cancer and had multiple, other physical health problems. Those we judged to be in poor health included carers with high blood pressure, spinal damage, mental health problems, and degenerative joint conditions. Another ten carers reported themselves to be generally 'OK', but reported a single issue such as a weak bladder, intermittent problems with joints or back, feeling stressed, or asthma. More than half of the CA/IS (9/15) and the PC (6/10) groups had health that we judged to be very poor or poor. By contrast, only three of the 19 carers in the CA-only group reported health problems as significant as this.

2.7 The health of other household members

Almost half the households (24) contained only a carer or the carer and the CA link person. Of the remainder, 11 respondents reported that the health of everyone else in the household was fine. Across the other nine households, there was a total of seven household members with mental health problems and/or learning disabilities, four with physical health problems, and one with both physical problems and a learning disability. There seemed to be clustering of mental health problems in some households and one where, although the middle child was the CA link person, there were significant physical problems with the other children too. This information, coupled with that about the CA link person and the carer gave a strong impression of disability and ill health clustered in households, particularly in the CA/IS group, but also in the CA-only group.

2.8 Caring responsibilities

All but six carers were supporting someone who lived in the same household. In four cases where the person being helped lived elsewhere, carers had taken over the caring role from another family carer (a parent or grandparent), when this person had died, or had become too old or ill to continue in the main caring role.

More than half of the carers reported that caring created unpredictable demands on them, but this was more likely for the CA-only and PC carers than for the CA/IS carers. Examples included the sudden development of sleeping problems, health emergencies, unpredictable behaviours and falls.

However, it was clear that 'predictability' did not necessarily mean 'manageability'. As one carer reported, caring was 'predictable in its exhaustiveness'.

Further, predictability meant different things for different carers. For example, carers looking after children with an autistic spectrum condition (ASC) reported having to keep their environment 'predictable', because the children found unanticipated change difficult. However, given that the world is subject to unanticipated change this meant that the child's day-to-day reactions to life could be highly unpredictable. Those supporting adults with mental health problems reported related issues; taking responsibility for all domestic tasks in the household made part of their lives highly 'predictable', but not knowing whether the person they were supporting was going to have a 'bad day' or week or month kept them 'walking on eggshells'.

The sample as a whole had much in common with any group of substantially involved carers, in that they reported heavy involvement in providing personal care to the person they were supporting – washing and showering, dealing with toileting, and dressing. Some carers were looking after people with significant clinical needs and reported tube feeding, carrying out chest drainage, supporting dialysis treatment and managing medication regimens.

Many also reported additional domestic loads associated specifically with caring. This latter could include additional laundry and house cleaning because the person being cared for was often sick, incontinent or dribbled a lot; 'super' cleaning when caring for a person with ASC or obsessive traits or with a weakened immune system; and doing all domestic work for people supported in another household.

Our existing knowledge about caring also points to the less 'physical' aspects of caring but which are nonetheless demanding, and we found this in our sample too. Those caring for people with predominantly physical needs reported having to maintain almost constant vigilance to prevent harm or distress to the person being cared for, for example, being alert during the night for people who had breathing problems or who suffered from reflux; listening out for and responding to toileting needs; and managing pain, disturbed sleep and falls. However, those caring for people with learning disabilities or mental health problems, where physical care needs might not be so prominent, also reported the need to be vigilant. People with severe learning disabilities might not recognise potentially dangerous situations, either in the house or out and about, and had to be supervised almost continuously; both they and people with severe mental health problems might need repeated prompting to carry out personal care tasks; and several carers reported the need to provide support to keep the person they were helping 'occupied' or motivated to interact with others.

2.9 Other caring responsibilities

We asked carers whether they had any other current caring responsibilities and whether they had had any in the past. This information can be important in terms of understanding an individual's history of a CA claim.

Just under a third of the sample as a whole (14) reported having other caring responsibilities, over and above caring for their (other) own children. There was little difference between the sub-groups although, as might be expected, the somewhat younger sub-groups (CA/IS and CA alone) also mentioned caring for their dependent children (other than a disabled child who was the CA link person).

Patterns of previous caring responsibility varied slightly between the sub-groups, with 6/10 of the PC group reporting that they had cared for someone else in the past. Three carers in this group reported complex, past and current histories of multiple caring roles for family members with severe and enduring mental health problems. It was also in this group that there were the most CA claimants with formal responsibility for the care of their grandchildren, because of the grandchildren's own mental health problems, or because of their parents' mental health problems and/or absence in prison.

In the CA/IS and CA-only groups, other current or past responsibilities were largely for elderly parents or parents-in-law but, again, there were two carers who had formal responsibility for grandchildren because of their parents' mental health problems.

2.10 Help from other people

Sharing responsibility with someone else can be a lifeline for heavily involved carers and we asked if our respondents could call on anyone else to help with caring. There were interesting differences here between the sub-groups. While relatively high proportions of the CA/IS (10/15) and PC (7/10) groups reported that someone else was involved in helping out, this was the case for only ten of the 19 in the CA-only group. Further, the CA-only group was the only one that reported any significant level of professional support received.

When we looked in detail at the type and level of support received from informal sources, it seemed that the CA/IS group were more likely to report significant rather than 'now and again' levels of support. In some cases, this was linked to family structure – for example, the grandparents of severely disabled children providing regular childcare and an important source of emotional support for single parents. Other arrangements were in place where formal support was not forthcoming or was unacceptable. Examples included the person who cared for a godchild from Friday evening until Monday morning to provide the equivalent of respite care, or the young woman who provided all care during the week for her grandfather who had dementia, and then went back to her own home when her aunt took over at the weekend.

By contrast, carers in the other two groups largely reported that they could call on support if they were in difficult circumstances or that others helped out 'now and again'. In all groups, however, there were examples of very heavily involved carers who reported that they had no one who could share responsibility with them.

3 Household finance and the role of Carer's Allowance

3.1 Sources of household income

We asked all respondents about the different sources of household income they had. One of the most surprising findings from this, perhaps, is the almost identical sources of income that the Carer's Allowance/Income Support (CA/IS) and the CA-only sub-groups reported.

Only six of the carers in the CA-only group had access to any source of income other than social security benefits:

- two had partners who were full-time or part-time wage earners (earning £28,000 gross pa and £1,200 net per month, respectively) and who contributed to the household income;
- three were in part-time work themselves (one where the husband was also in full-time work) and earning less than the CA limit of £100 a week;
- one carer referred to his own private pension and another said that his wife received a retirement pension and Pension Credit (PC) and that he received a 'war' pension.

For one CA-only carer their sole source of personal income (other than CA) was rental income on two houses, the majority of which went to cover the mortgages on the properties; her adult son received Disability Living Allowance (DLA) and Employment and Support Allowance (ESA). Another in this sub-group lived in a three-generational household where her father paid the mortgage, she met all other household expenses out of benefits, and her husband contributed nothing to the household from his wages. For the rest, household income in the CA-only group largely consisted of the same mix of DLA, CA, tax credits, Child Benefit (CB), and Council Tax Benefit (CTB) as in the CA/IS sub-group. The only differences between the two were the presence of ESA, tax credits and both State and private pensions in the CA-only group. Five also mentioned the receipt of Pension Credit in the household.

The PC group had a very different profile of income sources, the most important of which was, of course, the State Pension. Five carers also mentioned small or very small private or 'works' pensions. Most also mentioned Housing Benefit (HB) or CTB and some linked a reduction in Council Tax specifically to CA entitlement. The two carers in this group who were supporting grandchildren also mentioned CB and Child Tax Credits (CTCs).

Only one carer in the whole sample referred to receipt of a Direct Payment for the person being supported.

3.2 Getting by or struggling?

We explored with respondents how they felt they were managing financially and whether they had anything left at the end of the week or month that they could put by. The majority of the CA/IS and CA-only groups (11/15 and 11/19) said that they had nothing left over and that they were unable to put money by, even to cover potential emergencies. When people did have a little money left over, they put it by to cover future bills or as a buffer against an emergency. By contrast, more of the PC group (7/10) said that they had a little money left

Household finances of Carer's Allowance recipients

over, but anything that was put by was earmarked for replacement of household equipment when it 'went wrong' or for equipment to support caring (for example, an electric bed). Only two households in the whole sample – one in the PC group and one in the CA-only group – reported being able to save for extras such as holidays away from home.

Six carers specifically referred to having used up savings at some point in the past, usually related to having lost paid work or experiencing a reduced income due to their own ill health or that of the person being supported, or to meeting caring-related expenses. One of these carers was what Beresford and Oldman (2002) identified some years ago as a 'serial adapter', spending resources adapting their home to meet the current needs of the disabled family member, only to find after time that the deterioration in their condition necessitates further adaptations or a house move:

The carer had spent savings of £6,000, accumulated while he was self-employed, on moving into another house and getting it 'the way we wanted it', including adapting the bathroom for his son. He had thought that the house would meet the family's needs for the future, but with the son's rapid deterioration, this was no longer the case. They were now on a waiting list for an adapted bungalow and would thereby lose their investment in the house.

(CA/IS)

Other examples of using up savings included grandparents suddenly taking on responsibility for grandchildren and having to 'kit them out' with clothes and bedrooms and people having to make emergency repairs to cars or household equipment.

We did not initially ask questions about household debts, but some people mentioned this spontaneously; as a result, later interviews did probe for this. Overall, 14 carers mentioned significant debts and another had a budgeting loan, most of whom reported significant financial problems.

For example, one CA/IS carer was servicing Provident loans, taken out to finance Christmas presents for her children, to the tune of £60 a week, and was paying for electricity and gas on 'budgeting cards', which meant that she would be paying well above the standard price for her fuel. Another in this group had rent arrears and had just gone back onto pre-payment electricity and gas meters, which again would involve paying above average for fuel:

A CA-only carer reported that his house was in the process of being repossessed; both he and his partner (the CA link person who had a severe and enduring mental health problem) had given up work to look after the carer's grandchildren. They had been unable to keep up the mortgage repayments and although the partner had just returned to part-time work, they had not been able to prevent the repossession. He reported that he and his partner sometimes went without food so that the children could eat.

Other carers reported paying off Council Tax arrears, overdrafts, and credit card debts, borrowing in order to replace essential household equipment such as washing machines, mattresses and bedding, and borrowing from friends or relatives and then finding it difficult to repay them.

Overall, it seemed that the complexity of carers' households and the patterns of ill health and disability within them influenced whether or not people were 'getting by' or struggling. Those who had taken on 'extra mouths', in the shape of grandchildren, reported struggling until CB and Special Guardianship arrangements had been sorted out. Even those 'managing', mostly did so by dint of very careful budgeting and scrimping; recent increases in food and fuel prices were causing worry for even the most careful household budgeters.

3.3 Routes into claiming Carer's Allowance

We asked carers how they had come to claim CA for the person they were currently supporting. The strongest message that came from this was the role of other people in validating the person's role as a carer, and thereby prompting the process that led to a claim, or indeed pointing out to carers that they actually were carers.

Professionals played a large role here (mentioned by a quarter of carers across the sub-groups), and particularly during the very early childhood of disabled children, and at diagnosis for other groups. For example, the CA/IS group mother of a child born with a rare genetic condition reported a conversation with a nursing sister when she left hospital with her baby. The sister told her that she needed to fill in some forms *'because you won't be going back to work ... not if there's nobody else to look after her'*. Similarly, a woman in the CP group who was caring for her father (as well as her grandchildren) said that she thought it had been a hospital doctor who had advised her to claim.

In other cases, social workers or allied health professionals involved with the disabled or ill person, 'brought forms' or advised the carer to claim CA, often preceded by advice to claim disability benefits for the person being supported. A male carer in the CA-only sub-group said that he had found out about CA-only after an 'incident' with his father's social worker, after which a new social worker gave him a CA claim pack; but this was at least a year after he had been caring full time. Four carers also mentioned the role of advice agencies and a carers' organisation as sources of information about and prompts to make a CA claim.

Family members, friends, and in two cases casual acquaintances, were also important in validating some carers' identity (mentioned by eight carers), highlighting to them just how much they were doing to support the person being helped and/or providing knowledge about other people in similar circumstances who received CA. These informal prompts seemed most important in the CA/IS and CA-only groups.

Some carers had been technically entitled to CA for a while before they had received these informal prompts. A CA-only mother of a disabled child, for example, reported that although she was receiving higher rate DLA for her disabled child, she did not make a claim for CA until advised to do so by a friend of her mother's, who also had a disabled child. Similarly, a CA-only man who was caring for his elderly mother (the CA link person), and his son who had an autistic spectrum condition (ASC), said that he did not claim CA until 12 to 18 months after becoming a full-time carer, finding out about CA through 'a chance encounter'.

Jobcentre Plus workers or other parts of the benefits system had played a part in seven carers making a CA claim. In four of these cases, interviews about the unemployed carers' apparent inability to apply for a sufficient number of jobs or attend work preparation courses had finally led to a discussion of their caring roles. This eventual recognition of their responsibilities was a relief for these carers; as a male CA/IS carer looking after his disabled wife and his elderly mother said, 'It stops them wittering on every five minutes for you to go and look for a job, because you've got a full-time job'.

A single parent in the CA/IS group who had been providing substantial support to her grandparents (her grandfather had dementia and had died a few weeks before our interview) reported the challenges she had experienced when her son turned five and she moved onto Jobseeker's Allowance (JSA) and had to attend courses and 'sign on':

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'... if I was at my nana's that day, I'd take my son to school then I'd have to get a bus to the Jobcentre and then I'd have to get a bus, 'cos I don't drive, I'd have to get a bus back to wherever the course was and then from the course to back home [grandparents' house], and then I'd have to go back to the school ... it was just constantly back and forward, and I couldn't, I couldn't afford it either.'

The relief about not having to search for a job at the same time as caring was tempered for one male carer by his sense that the family had 'elected' him to be the carer when his father had developed heart problems. He was a single parent with a young child, and he was trying to look after both the child and his mother, who had a variety of physical health problems. He reported that the Jobcentre had suggested that he make a claim for CA. Someone had 'come out' to advise his mother about benefits and also seems to have suggested that he should claim CA. While he welcomed being freed from the continuous search for paid work, there was a strong sense of ambivalence in his account. Alone among the carers we interviewed, we felt that some other form of intervention might have been, in the longer run, a more cost-effective approach to the caring situation than encouraging this man to leave the labour market.

Five people in the PC group simply reported that they had 'stopped work' in order to care, and made a claim at that point, sometimes prompted by Jobcentre Plus workers (or their equivalent in past years).

There was a small number of 'CA aware' carers or families/households. In these, there was experience of claiming CA because of previous caring experiences in the family or household (two carers); or because the carer had made an earlier, unsuccessful claim, or was aware that there had to be an entitlement to middle or higher level DLA, and had (re) applied when the condition of the person being helped deteriorated (five carers). In two other cases, the cared-for person had encouraged the claim, based on their knowledge of the benefits system.

As is clear from the above, some carers experienced a complicated journey towards their CA claim.

The most striking example of a complicated journey was the single parent father of a young adult who has a rare, progressive condition that is likely to lead to his death within a few years. He was now using a wheelchair, and beginning to experience mental health problems also associated with the condition. The father had been heavily involved in caring for over two years but his focus had been supporting his son to make a claim for DLA. He had made three claims before being successful, and the father recounted how his son's medical team had accompanied him to the final attempt, to support his claim. Once finally awarded higher-level DLA, the father was able to claim CA. He felt that he had been struggling for two years – *'robbing Peter to pay Paul'* - and that while the CA claim in itself did not increase the household income by much (because of claiming IS) between them the two benefits could have made a large difference to their lives (CA/IS).

3.4 The costs of caring

We asked carers to talk to us about the types of expenditure they incurred because of being carers. As in so much of the earlier literature, most carers found it almost impossible to portion out what was spent because of the impairments or condition of the person they were supporting and what was spent on 'caring', per se. As might be expected, this was particularly the case in households where carer and supported person lived together and even more so in households where all sources of income went into a 'single pot'. As a result, it is difficult to tease out which costs 'should' be covered by DLA and which by CA.

CA-only carers were slightly more likely to report buying specialist aids or equipment or having paid for housing adaptations themselves. Beyond this, there were few differences in the types of additional expenditure reported by the three sub-groups of carers.

The extra costs reported most often across all groups (35 carers) were related to transport – having to run a car or having to rely on taxis to get the CA link person from place to place and also to help the carer be a carer, for example, where they lived in a different household from the person they were supporting. While the need for a car or taxis was predominantly to do with mobility issues, there were also those who reported that behavioural or mental health issues meant that the CA link person could not use public transport. Some carers felt that they were running a bigger car than they would otherwise, to enable wheelchairs or mobility scooters to be carried. Use of taxis was often reported in relation to hospital visits or care appointments of some sort; round trips costing £20 or £30 were not unusual.

Fuel costs were a large part of many carers' accounts (19), usually because the person they supported was at home all day, was relatively immobile and/or their condition meant that they needed to be kept warm at all times. Having to do large amounts of laundry also had an impact on fuel bills; incontinence, dribbling, reflux and feeding difficulties all increased the number of times clothes and bedding were washed. A few households were running medical equipment such as oxygen masks, nebulisers and feeding pumps, sometimes almost continuously.

The problems that created extra laundry also led to higher levels of replacement of clothes, bedding, mattresses and upholstery. Further, a small group reported having to replace these and other sorts of domestic items more frequently because of behavioural problems or simply because the CA link person's impairments made them more likely to drop or break things.

Extra spending on food was also reported often. Some carers had to buy special foodstuffs related to the CA link person's condition (for example, liquid food for food pumps, diabetic specialist foods). Others had to buy more or better quality 'ordinary' foods because the person they supported had difficulty maintaining a healthy weight or because their feeding problems meant only certain types of foods were tolerated. Others just felt that the CA link person needed better quality food to keep them as healthy as was possible, given their condition.

A small group of older carers, in both the CA-only and PC groups, who were themselves becoming increasingly frail, reported spending more money on food because they bought ready meals or did their grocery shopping online to reduce the burden on themselves. This older group of carers was also more likely to report having to spend money on hairdressing or chiropody services because neither they nor the CA link person was any longer able to wash their hair or cut their toenails.

A wide range of other expenditure was reported less frequently. This included paying for substitute carers and respite care; buying specialist clothing or shoes; buying or hiring aids and equipment; buying things or services (for example, TV subscriptions, broadband connections) to provide the person being supported and sometimes the carer with 'something to do'; and extra spending on cleaning or personal hygiene products.

Across the whole sample, there were only two examples reported of expenditure that was specifically 'for' the carer; in one case transport to a carers' support group and in the other a weekly Tai Chi class to provide a break and relaxation.

We asked carers whether anyone else helped them with the expenses they incurred in supporting the CA link person. Some reported support from the NHS, local authorities or Motability that they were, in any case, entitled to receive. Only five reported receiving financial support (or support in kind that saved the carer having to spend themselves) from anyone else. This was most usually help from the carers' parents or siblings and included things such as buying groceries, providing a disabled grandchild with pocket money, loaning the carer the use of a car, or small contributions towards petrol money.

3.5 The role of Carer's Allowance

For most respondents, questions about the role of CA in meeting additional caring costs were meaningless; all their household income was put into a single 'pot' and all household expenditure, for whatever purpose, came out of that pot. Only nine carers referred to CA as being 'for' those types of expenditure.

When we asked for their views about whom CA was 'for', we found a range of views that suggested that carers thought differently about CA, even though the majority actually used it for general household expenditure.

First, we found a small group of carers (5) who believed that CA was 'for' the CA link person and another two who said it was for both the CA link person and themselves. One of these had cared for her grandfather and spent five days a week in her grandparents' house providing a high level of care. Despite this, she said that she saw CA as belonging to her grandparents and had initially found it difficult to use the money to support her own caring expenses, such as the substantial 'bus fares she incurred running between their house, her house, shops and pharmacies, and her son's school.

Another 19 were clear that CA was for them, as carers – although none actually used the money exclusively or at all for expenditure for themselves. They recognised that CA was in some small sense a 'compensation' for caring or a 'wage', but also felt that the money was not 'for' them:

'I don't feel any money belongs to me because I've got me children.'

(CA/IS)

'I know it's supposed to be mine [but it 'belongs' to household].'

(CA/IS)

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Men were more likely than women to identify CA as being a recompense for caring activity or to see it as a wage for caring. For example, one CA-only carer saw CA as belonging to him, as a payment for caring, albeit 'slave labour'. Another male CA-only carer also saw CA as belonging to him, as wages for caring, but wages that did not reflect the '24/7' care he provided. Similarly, in the PC group, male carers saw CA as belonging to them as 'a small reward' for acknowledgement of their caring role. By and large, female carers did not think of CA in the same way, unless they were younger and had more recent experience of the labour market. For example, the CA/IS mother of a disabled child said that she saw CA as a wage of sorts, because it would be impossible for her to take even part-time paid work given the demands on her time. However, in reality, CA was 'a [financial] necessity rather than compensation' for not being able to do paid work.

The remainder of carers, across the groups, did not see CA as separate from any other source of household income or belonging to them rather than to the household as a whole; it was just something that made a (small) difference to their overall budget and the household as a whole.

As already referred to above, most carers reported that CA went into the household 'pot', although the ways in which this was actually done varied considerably, often following the way in which the carer thought about CA. So, for example, a CA/IS carer said that CA was incorporated in general household spending and was 'swallowed up in food and bills', going on to comment that as it was *'just seen as a wage [for caring] ... you wouldn't separate your wage anyway, would you?'* By contrast, even when CA was seen as part of the household pot, it was sometimes earmarked for particular types of expenditure, often via direct debits. Thus, a CA/IS carer reported that his CA went into his bank to cover a number of direct debits including telephone/internet, fuel, water, and life insurance. A CA-only carer had the allowance paid into his bank account and used it for food shopping, while his wife's ESA and DLA went into her account and was used to cover direct debits and other household expenditure. As these examples suggest, household structure could also influence the apparent separateness – whether real or conceptual – of CA and its use.

3.6 Frequency of payment

The majority of carers (30) received CA on a weekly basis; ten received it monthly and the remainder were unsure of the frequency or said that they received it fortnightly. CA can be paid either weekly, monthly or quarterly so it is possible that those who said they received it fortnightly were confusing it with IS or some other benefit paid at this frequency. The two carers who were unsure about the frequency of payments were adult carers of parents in the same household, where their mothers (the CA link person) were still in control of household finances. CA/IS carers were most likely to report weekly payment; those in the CA-only and the PC groups were more likely to report monthly payment but, even here, weekly payment was more common.

A minority of carers remembered being given a choice over the frequency of payment (19) and most of these (14) had opted for weekly payment.

We also asked carers about how the CA payment frequency fitted in with their household budgeting or other income sources. Fit to their budgeting strategies was the main issue for most. Well over half of the whole sample said that weekly payment fitted with their weekly budgeting strategies and, for some of these, this frequency meant that they were able to fill gaps in income flow when other sources were monthly or fortnightly. Being sure that the CA

was 'there' when other income had been fully committed was very important to some of the hardest pressed carers. For example, one carer said that knowing the CA was 'going to be there every Friday' was psychologically important – whatever else happened it was good to know that there was money to buy food for the coming week.

Most of those on monthly payments also felt that this fitted best with their budgeting strategies.

A couple of carers on weekly payments referred to difficulties of budgeting monthly or felt that CA paid monthly would be a 'temptation' to buy lumpy purchases such as shoes when, in fact, it was needed for regular payments. Two other carers said that they would like to change frequency – one in each direction. For example, one recent CA claimant said that she had chosen the weekly frequency to see 'how things went', but now felt that monthly payment would suit her budgeting patterns better.

3.7 What would the impact of not receiving CA be?

We explored with carers what they would stop doing if there were no CA, and the responses here did vary a little between sub-groups.

As one might expect, the CA-only group seemed to find the prospect of not having CA the most alarming, because they were the ones for whom it made the greatest real difference to income. Five in this sub-group, including one for whom CA was her only independent source of income, said that they really did not know how they would manage without CA. Six referred to cutting back on food, four to cutting back on fuel and two to reducing transport costs, which for one carer would involve doing less caring for his parents, because he would not be able to get to their house as easily. Two said that they would have to stop caring altogether and find work.

Only two in the CA-only group could **not** identify any potential impact of the potential loss of CA, beyond some reduction in optional expenditure. In both cases, the households contained an unmarried couple, with no children or other household members, where the carer was a man in middle age caring for an older female partner who was old enough to be claiming PC.

For the PC group, loss of CA would mostly have an impact on their entitlement to other benefits. Even here, however, carers spoke of having to reduce expenditure on food, fuel and transport:

One PC carer said categorically that her household would break up if she did not receive CA. She was in a complex household that contained herself, her teenaged grandchild [the CA link person] and an older lodger whom she was also supporting. Her grandchild, who had mental health problems and possible learning difficulties, had recently been reassessed and higher rate DLA had been stopped. This made a difference of over £300 per month to the household income. In addition, she had recently been told that she would have to start paying £20 a month towards her council tax, presumably reflecting the loss of the grandchild's DLA entitlement. The carer had health problems of her own, for which she received the lower level mobility component. She also said that she was 'not a very good reader', which made it difficult for her to understand why she was now paying some council tax. It was not clear what benefits, if any, her grandchild was now receiving; presumably, as still at school, none.

(PC)

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The CA/IS group were already in straightened circumstances, and the extra small amount per week that CA entitlement represented for them was important. As one carer pointed out, although it was not a large amount of money 'when you're budgeting it's actually a lot of money'. This group of carers all said that they would have to give up or reduce some aspects of household expenditure, but mentioned a wider range of things than the other two sub-groups – lumpy purchases such as children's shoes, food, petrol or giving up the car altogether, children's clothing, activities for children, and internet connections. Two carers said that they would have to return to paid work if CA was not paid, but these responses seemed to signal a belief that if they were no longer receiving CA then the benefits system would no longer see them as carers. We return to the symbolic value of CA later.

3.8 What difference does CA make?

We asked carers what they liked about receiving CA, what difference it had made to them, and whether anything else might be more helpful to them than CA.

3.8.1 What do carers like about CA?

The views of the CA/IS group about what they liked about CA were different from those of carers in the CA-only and PC groups. For the latter, CA's role as a form of income was predominant in their accounts. For the CA/IS carers, however, recognition of their role and the appreciation of this that CA seemed to confer were the most commonly reported benefits:

'... it's an appreciation of the person who is doing the caring, who's had to change their life, lifestyle to fit in around becoming that carer.'

Recognition for some carers also brought with it a reduction of stigma that might otherwise come with receipt of IS:

'It's so easy to be typecast [as] the sort of person that's on the Jeremy Kyle show and I'm not ... I have a hard job as a carer, it's not an easy task.'

(CA/IS)

[People think] 'Oh well, if you're claiming benefits you've never worked, you've never done anything, rather than actually, we understand that families' lives change and sometimes you are hit from behind with a hammer and it knocks your life apart, and actually we need to support you while you get to this new stage. And I think that Carer's Allowance, to a certain extent, recognises that you're doing something.'

(CA/IS)

As we saw earlier, this reduction in stigma was related, in several carers' accounts, to the relief they had experienced when the pressure to search for paid work was removed. For example, one carer said that he didn't 'like' CA, as such, but that claiming it was the lesser evil, keeping 'benefits off your back' and saving him from having to sign on and look for jobs that he could not do because he had a disabled child to care for. Similarly, the mother of a disabled child spoke of the relief she experienced in no longer having to sit in the Jobcentre and be told, 'Well, you're obviously not looking for a job hard enough' (CA/IS).

Some carers also spoke specifically of how claiming CA 'allowed' them to be carers and to provide the support that they wanted to provide to the family members they loved. A man who was caring for his mother said that CA gave him the freedom to care. While CA was, in

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some sense, a 'payment for what you do', he argued that if people had sufficient financial resources without recourse to CA then they would 'do it out of love'. Similarly, the man caring for his son who had a degenerative condition said that claiming CA had given him the freedom to be at home and do everything he could for his son in what was likely to be only a few remaining years of life.

These types of accounts of the value of CA were much less evident in the other two sub-groups. Here, the main value of CA was its role supporting income. Carers spoke of CA making it easier to manage financially, providing extra income with which to pay bills, and helping them to 'get by':

'I'd say £58.95 a week, that's the difference!'

(CA-only)

'... it's sort of a bit of a lifeline.'

(PC)

Only two carers across the CA-only and PC sub-groups spoke about the importance of CA as recognition for what they did, or about its role in reducing stigma. The underlying rationale, however, seemed similar to that of people in the CA/IS group:

'It's just being paid to say "Thank you" ... but you don't get much which just upsets me.'

(CA-only)

'To me CA is basically like a badge, if you like, you can say to people I'm a carer for my wife, you know, I'm not on the dole.'

(PC)

These two groups, and particularly those in the CA-only group, were more likely than the CA/IS group to like CA because they saw it as a payment for caring or as a form of compensation. Carers who thought of CA as a payment often also compared it to how much it would cost to care for the CA link person elsewhere. For example, a man who had given up work to care for his wife felt that 'the Government' were saving a lot of money by relying on him to care:

'Sometimes I think the carers are the mugs of the Health Service and we can't do much about it 'cos we care too much for the people [we're looking after].'

(CA-only)

A carer in the PC group, similarly, contrasted the level of the Additional Amount for Carers (AAC) she received with the £700 per week she had to pay when her husband went into respite care.

Overall, male carers were more likely to see CA as payment for caring, but some female carers also saw it in this way. For example, a female carer in the PC group said that she had initially seen CA as a payment for caring, because she had given up work to care for her husband. Now, however, she saw it more as a form of IS.

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There was one carer, in the CA-only group, for whom CA was her only independent source of income in a complex household where her husband appeared to make no contribution to joint expenditure. She spoke about the sense of security that this gave her, knowing that the CA was there whenever she needed it (CA-only).

3.8.2 What difference does receiving CA make to carers and households?

The main difference that carers in all groups referred to was the additional income that it provided for their household. Although all sub-groups referred to this difference, this was most likely in the CA-only and PC groups. The CA/IS group were more likely than other carers to talk about CA giving them the choice to be carers (4), that CA made them feel appreciated (2), that it reduced stigma (1), and that it allowed them not to have to search for work (3).

Only carers in the CA-only and PC groups referred specifically to CA allowing them to meet the costs of being a carer; in all three cases this referred to covering the costs of fuel or taxis that enabled them to care.

Two of the CA-only group mentioned the value of CA in giving them an income of their own and, thereby, a degree of independence from other household members.

3.8.3 Does the impact of CA change over time?

Few people were able to provide an answer to our question about whether the impact of receiving CA had changed over time. The majority in all three sub-groups talked about how initial receipt of CA had reduced financial pressures on them or had given them peace of mind. For some, the latter was related directly to not having to look for a job. Beyond this, only a few were able to point to any actual change in the impact of CA over time. A couple of carers pointed out that children grow and become more expensive, so CA did not stretch as far as it used to. A few carers who were now receiving PC felt that CA was less important to them than it had been, which is not surprising given the relatively hidden nature of CA for most in this group.

3.8.4 Would something else be better than CA?

We also explored with carers whether something else would make more difference to them than receiving CA. This was a difficult question for most to deal with; given the tight financial circumstances many were in, this is perhaps not surprising. Money was the main issue and few could see anything else that would help:

A CA-only carer said that while it would be 'handy' to have someone to clean and to sit with his mother while he went to the shops, 'the main thing is to have enough money to settle bills and not end up in debt'. A job would mean that he could earn money, but he would have to earn enough to pay someone else to care for his mother. He, like others, could not see an obvious way out of this 'chicken and egg situation'.

This area of questioning also caused the most bemusement or ruefulness: as many pointed out, services would be unable to replace what they did for the CA link person. People referred to the continuous nature of what they did or, by contrast, its episodic and reactive nature, neither of which fitted with either the resources that local authorities had available or the timetables of conventional services:

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'Social services can only do so much ... they can't provide twenty-four seven care anyway'.

(CA-only)

Even when the CA link person was receiving a substantial package of care, this did not mean that the carer was free to do other things. One carer's husband had services coming in to support him, but these cost her more than she received in CA. Despite this input, the alternative to her continuing to care for him for the rest of the time would have been residential or nursing home care, and she did not want that.

In some cases where people were supporting a CA link person with mental health problems, carers were simply sceptical about the availability or responsiveness of any services in their locality, usually based on hard experience.

Carers also mentioned the quality of the services that might replace at least some of their input. Carers of disabled children worried that respite services, for example, would not understand their child as well as they did or that the child might feel rejected or 'different' if going away from home. In any case, periodic respite would not free up a carer to take paid work. A man recounted how his father had been receiving services to manage his personal care and to change his catheter. This was costing £100 a week. The son had had to 'step in' because the paid carers had time only to clean his father up and leave him a cup of tea and some toast, when what his father actually needed was someone to cut up his food and encourage him to eat and drink (CA-only).

The quality of alternative care was also related to what the person being supported was prepared to accept. Many carers reported that the CA link person was reluctant to accept 'outside help' or to have 'total strangers' looking after them. As a PC group carer pointed out, the problem of getting services in was that both the carer and the person being helped had to agree to this. While he **could** access services for his wife and get respite for himself through his local Carers' Centre, she would not have anybody in the house apart from him to look after her (PC).

A sense of duty, or simply love, also pervaded some carers' accounts of why substitute care services would not be helpful. For example, a man in the CA/IS group caring for his mother who was dying summarised what many others also articulated. Services might allow him to work, but would not give him peace of mind:

'I'd rather be the person who's doing it primarily, rather than somebody coming in and me going to work every day ...'

(CA/IS)

Similarly, the detailed knowledge that carers had of the needs of the person being supported allowed them to provide the person they loved with the best possible care:

'I know [son's] needs and I know ... his mood swings. I know his ways, I'd rather me deal with it than let somebody else have to come in and deal with it'.

(CA/IS)

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While acknowledging that it would be difficult to replace with services what they did as carers, several respondents did suggest things that would make their lives a little better. A more proactive approach to providing information, carer training, adult company via a group of some sort, and domestic help were all mentioned.

Only two carers mentioned employment as a better option than CA. We reported above the 'chicken and egg' situation that one of these identified. The other, the mother of a young disabled adult, said categorically that she would prefer to be employed than receive CA, but that this would also require someone to come into the home to care for her son while she was out. However, she also pointed out that if her son had a support worker he, too, might be able to have some sort of paid work, which would help both his self-esteem and the household income (CA-only).

4 Carers and employment

We spent a considerable part of the interview exploring carers' current or most recent paid employment status and how this was related to their caring responsibilities and their Carer's Allowance (CA) claim. We talked to them about their job-related education and training, and how this was linked to their employment history. Finally, we discussed what their current aspirations were in relation to paid work.

4.1 Recent and current employment

4.1.1 Carers who had never been in paid work

Three carers – all women – had never had paid work, in all cases because they had married soon after leaving school and started families. The third woman was now a widow, caring for her adult son and was keen to find paid work:

The carer had started to train as a teaching assistant while her husband was alive, but she reported that 'then everything just sort of collapsed' when he died. She had subsequently learned other skills to help in her search for work. Her son had recently received the 'all clear', after six years of treatment for a life-threatening illness, and she felt this freed her to take up work. However, his other impairments meant that he would still need support and any work she did would have to continue to fit in with his needs.

(CA-only)

This seemed to be the only carer among those not currently in paid work who was 'near' to re-entering the labour market; she had applied for jobs and had registered for supply work as a teaching assistant, but had not yet been successful.

4.1.2 Carers currently in paid work

As we saw in Chapter 3, only three carers in whole sample were currently in paid work of any type; all were in the CA-only group and, as would be expected, were in part-time jobs. One woman caring for her disabled child was working as a teaching assistant; a man caring for his disabled son worked for 16 hours a week in a shop; and a man caring for his disabled wife had a part-time job helping people with 'a bit of shopping and just looking after them and that' (CA-only). In all these cases, caring and CA played a role in their decisions about employment and seemed to hold them from more, or more rewarding, work:

The woman caring for her disabled child said clearly that her career had been held back because of the need to care for her child and that she had always had to put her aspirations on 'the back burner'. Her husband was in full-time work. She would have liked to train as a teacher, but had neither the time nor the money to go to university; she felt strongly that she had to put her family first. This carer had also deliberately reduced the hours she worked as a teaching assistant, when the pay rate had increased, so that she could retain CA.

(CA-only)

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The man caring for his disabled son had been in a skilled manual job but was made redundant in 2008. He looked for other work but with little success. He and his partner had then decided that it would make sense for them to switch roles, with him becoming the main carer for their son (and other children) and her returning to her studies at university. His part-time work was possible because his employer was 'very understanding' and allowed him to work around his caring: 'I can pretty much drop everything if I need to'.

(CA-only)

The man caring for his disabled wife had run his own business, but he ran it down when his wife became ill and then gave it up completely to look after her. After six years, he took a part-time delivery job when his wife had a good care package put in place; however, this had to stop when a wage rise took his earnings above the £100 CA threshold; subsequently he took up the part-time caring job that he had when we interviewed him. He said that he kept this job because it allowed him to retain his WTC [Working Tax Credit] but was also clear that he would like to work more but did not do so because he would be no better off. He pointed out that earning £1 over the £100 earnings limit would mean losing £58 in CA and could not understand why the 'system' did not operate on a sliding scale – deducting the amount earned over the threshold, rather than losing the full CA payment. This carer was fully expecting to return to work when his wife died.

(CA-only)

4.1.3 Carers not currently in paid work for (initial) reasons not related to caring

The majority of carers across the three sub-groups (26 in total) were not in paid work because of factors other than caring, although, as we shall see below, caring probably played a role in relation to subsequent engagement in the labour market. Thus, people who had moved out of the labour market for one reason and then acquired caring responsibilities found it difficult to re-engage.

Even though (initial) disengagement from the labour market for reasons other than caring was the largest category overall, the pattern varied across the sub-groups. All but three of the Carer's Allowance/Income Support (CA/IS) group were out of the labour market for reasons other than caring; the CA group was evenly divided between those whose paid work had been affected by caring and those where some other factor was the main driver; and just under half of the PC group had not been in the labour market for a reason not related to caring.

Marriage, family and childbirth

The main reason for not being in the labour market across all three sub-groups was marriage, family and childbirth (11 carers) and this group was exclusively female. Most of the women had been working before the birth of their first or only child, but had not had paid work since. Others had a pattern of low-paid, part-time work that they fitted in around childcare that had subsequently become impossible when they took on caring responsibilities.

As might be expected, given their older average age, the PC group contained the women who had been out of the labour market the longest – over 30 years in two cases.

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By contrast, the CA/IS group contained younger women who had stopped work to care for a disabled child or another relative:

One woman had been working full time during a difficult pregnancy that involved several hospital stays. When her daughter was born with very complex needs she was effectively told by hospital staff that she would have to care 'full-time' and would not be able to return to work. Soon after, her husband left her and she became a single parent by default.

(CA/IS)

Another mother had worked full-time up to a month before the birth of her son. The business that employed her closed down just before she was due to go on maternity leave so there was nowhere for her to return to and she became a full-time mother. When her son was around three her grandfather started to need intensive care, and she stepped in to support her grandmother five days a week. He had recently died and she was hopeful of being able to return to work although she had not yet heard from the Jobcentre about an appointment to discuss her options.

(CA/IS)

The CA-only group also contained women who had given up paid work when they had children, but subsequently became carers. For example, a woman caring for her husband who had severe and enduring mental health problems had been in a senior position in a profession before marrying and having a family. She had been out of the labour market for several years before her husband's ill health. Her daughters were now in their early teens, but she did not see herself likely to be able to return to paid work at any time in the near future. She estimated that her husband's needs took up around 60 per cent of her day. Another woman in this group had stopped working when her youngest child was born; this child was subsequently diagnosed with autistic spectrum condition (ASC) at the age of two and the mother had not been able to work since.

Redundancy and job loss

Another group whose disengagement from the labour market was not initially related to caring was those who had been made redundant or had otherwise lost a job and had subsequently taken on a substantial caring role. This pattern was more prevalent in the CA/IS and CA-only sub-groups, but one Pension Credit (PC) carer had also experienced this:

A son caring for his elderly mother in the same household had been made redundant from a full-time job and, despite taking NVQs [National Vocational Qualifications] and other training on his own initiative, had not been able to secure paid work again. His mother was then diagnosed with a life-threatening illness and he decided to 'become a full-time carer'; he had been caring for her in other ways for around six years before this, so the new responsibilities were an extension of the old ones. It was not until five years after losing his last job that he made the claim for CA.

(CA/IS)

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A woman was caring for her adult child who had severe and enduring mental health problems and also had formal responsibility for her grandchild. She had been in full-time work, earning a reasonable salary, but had been made redundant just before her husband was diagnosed with a terminal illness; he died very quickly and, for obvious reasons, she did not seek paid work during the few months he survived. She had expected to seek paid work again after his death, but her adult child almost immediately had a recurrence of mental health problems and continued to be unwell. This carer wanted to return to paid work, but there were serious questions about whether her adult child would ever be well enough to take over care of the child again.

(CA/IS)

Similar patterns were evident in the CA group, but only among male carers who had lost paid work at some point before the CA link person needed care. The only PC carer with this experience had been made redundant at the age of 59, some 13 years before we interviewed him. While his wife was already beginning to need some care at that stage, he continued to apply for jobs, but with no success. He subsequently made a claim for CA and devoted himself full time to her care.

Carers' own ill health

Four carers, three of them in the CA/IS group and one in the PC group, had left the labour market because of their own ill health. In two CA/IS cases, female carers had already been providing care before their health problems meant that they had to leave paid work. The two other carers who had stopped work because of their own health were both men. One had been in his early 40s in a skilled manual trade when he had an accident that caused significant physical problems. His wife then had an accident that meant that he had to care for her. The other man had to take long-term sick leave and then retirement because of a physical problem in his mid-50s. Not long after, his wife had a major illness that left her with significant impairments.

4.1.4 Carers not currently in paid work for reasons related to caring

Sixteen carers, most (10) in the CA-only group, reported having left paid work completely, or having reduced their hours of work, because of their caring responsibilities. However, cause and effect were not always as clear as this suggests. In most cases, the carer was already involved in providing care when the decision to leave the labour market was made – a decision that was sometimes related to the CA link person's continued decline and successful claim for higher level DLA:

A male carer had been a manager. When his wife was awarded DLA [Disability Living Allowance] he gave up his job to be her carer; she was 'in and out of hospital' at the time and he felt that he needed to bring some 'stability and control' into the situation. He was now 60 and although would have liked to return to work, felt that this would have a very negative effect on his wife who would then not survive long.

(CA-only)

A male carer gave up work to care for his mother, with whom he shared a household, because his work took him away from home for long days. He was concerned that his mother might fall while he was away and he could not afford the £9 an hour that substitute care would cost : 'When you try and find out the costs of putting a carer in to look after her while you're at work, it actually works out more than your salary'. His mother made a successful claim for Attendance Allowance and he left work and claimed CA. Thirteen years later he was still caring; he was now 55 and his mother 87.

(CA-only)

Only one carer who said that they had given up work to care had, in any sense, become a carer 'over-night'; he left work ('retired' as he described it, although he was only 45 at the time) when his father, who had been his mother's carer, died. His mother, a wheelchair user, lived in a separate household and he was with her for between seven and nine hours a day, six days a week (CA-only).

4.1.5 Complex routes into caring and out of paid work

Finally in this section of the chapter, we deal with a small number of carers (4) who had such complicated histories that it was impossible to identify a single main contributory factor in their disengagement from the labour market. In three of these cases, there was a complex mix of child-care responsibilities (usually following the breakdown of a partnership), caring responsibilities for a disabled or ill family member, and problems obtaining or sustaining paid work that, all coming together, simply made the 'CA route' the best thing to do, both for them as carers and all the others involved in their web of obligation.

The fourth person in this group was rather different. He was now 47 and had never been in full-time work for any sustained period. He reported being on 'government schemes' after leaving school, involving low-grade manual work and he had no qualifications or training. His most recent work had been a part-time job with a charity, but this was on a casual basis only; when the charity closed the shop there was no further work. His mother had severe physical problems and needed constant care. While he said that he would like to work, he did not see it as possible currently, given his mother's needs. He was also anxious about what would happen when his mother was 'gone' (CA/IS).

4.2 Carers' education and training

We asked CA/IS and CA-only carers about their most recent job and its relationship to their education and training. The majority reported no or relatively low levels of post-16 education or training ('City and Guilds' certificates in health and social care; and NVQs at level 2 or 3). Five men reported manual trade qualifications and training, one woman had a Higher National Diploma (HND) and another was a qualified nurse. Three men had been in senior positions in their workplace without necessarily having obtained formal qualifications. Beyond this, the remainder reported having trained 'on the job'. There was no obvious difference between the two groups in the level of post-16 education or training reported by carers.

As we have seen throughout this chapter, some carers had left good jobs, either through redundancy or because of the need to care. The majority, however, had been in relatively low paid work that required little in the way of post-16 training or education. Despite this, as we have also seen above, some were keen to return to education to improve their chances of obtaining work if and when they could manage their caring and a job. Three were also now looking at returning to work, as their caring had ended or had reduced in intensity.

4.3 Aspirations and intentions in relation to paid work

As will be clear from much that we have reported earlier, many carers were in a position where full-time work would be impossible without significant packages of support being put in place for the CA link person. In the current funding and assessment environment in local authorities (see Chapter 1), taking on full-time work would realistically have meant admission to long-term care for the CA link person. Even in the two instances where substantial packages were in place, the carers' continued involvement was crucial to the CA link person's being able to continue to live at home.

We explored these issues further with carers in this separate part of the interview, asking direct questions about their current plans and ambitions for paid work and also how they saw this playing out in the future. This was a sensitive part of the interview because, for many carers, it meant thinking about their lives if the CA link person died or entered long-term care.

The majority of carers who were not already beyond State Pension age spoke of hopes of returning to work, although there was also a group within the CA-only group where this was not the case.

4.3.1 Carers hoping to return to paid work soon

Among those who spoke of a return to work, there were only four for whom this was a hope for the immediate future. The group with the highest level of hopes of a rapid return were those whose children were about to start school, where some additional health problem for the CA link person had recently been resolved, or where the CA link person had recently died.

Two carers that we interviewed were receiving the CA extension after the death of the person that they had cared for and both were keen to return to paid work:

A female carer had worked full time before the birth of her son and taking on caring responsibilities, and had thought hard about the refresher and new skills courses she would need to do to start practising her trade again. The cost of one of the courses she wanted to do was an issue and she felt that she might have to forgo this and go straight into a refresher course. She was aware that the Jobcentre could give her advice about this, although they had already indicated that she would not be able to get support for the course she was most keen to do. Despite this enthusiasm, her continuing role as a single parent of a five year old son meant that she was likely to be looking for work that would fit with the school day.

(CA/IS)

A male carer had been made redundant after a long career in a skilled manual trade, at the point when his father had started to need very substantial care. He felt that, had he not been available to care at that point, his father would have had no option but to enter long-term care as his mother was too frail to care for him. His father had now died and the carer was actively looking for work. However, he felt that his age and the loss of skills in the months he had been caring, might make it difficult to return to his previous work. His 'operating ticket' for his line of work had also expired and he would have to pay for a new certificate in order to return to this type of job. He had been applying for less skilled jobs but had not yet been successful. He also said that he would prefer to work nights because that would allow him to take care of his mother.

(CA-only)

We described the female carer whose son had just been given the 'all clear' after cancer treatment and her job seeking earlier in this chapter. The final carer who seemed close to re-entering the labour market was a single mother who was attending work focused interviews every six months. Her youngest child (not the CA link person) was starting nursery later in the year and she expected this would make her freer to take part-time paid work. She had already done some 'health and social care' courses so she was hoping to find work as a support worker or something similar. However, she pointed out how important it was that any employer would have to be understanding about the sometimes unpredictable demands that caring for her son sometimes created.

4.3.2 Carers who would not return to work while the person they cared for was still alive

Ten carers said categorically that they had no intention or hopes of returning to paid work while the person they cared for was still alive. All these carers saw their role as keeping the CA link person at home and well-supported for as long as was feasibly possible. Any return to paid work for them would jeopardise this.

As might be expected, these carers were involved in high levels of caring activity for family members with substantial and usually complex needs. Examples included adults with rare genetic conditions that affected many systems of the body, children with (severe) learning disabilities and additional physical problems, adults with severe and enduring mental health problems (in one case exacerbated by significant physical problems), and adults with complex physical and life-threatening conditions.

Also important in some of these carers' accounts of why they did not wish to take paid work currently were issues of love, duty and obligation. Phrases such as 'the family comes first', 'he's my son and he's my responsibility', and 'it's my job' ran through their explanations. Most looked to a time when the person they were supporting died or the level of care needed just became 'too much' for them to provide and acknowledged that, at that point, they might have to look for paid work.

4.3.3 Carers' own health issues

We saw in Chapter 2 that several carers had significant health problems of their own, and earlier in this chapter that these problems had sometimes precipitated a move out of the labour market. These carers also felt that these issues would hamper any attempt to return to paid work. Five pointed out that the longer they were caring, the older they were getting and that, in the current economic climate, people in their 50s who had not worked for some years were not likely to find paid work easily. However, a few did hope that they might be able to re-engage at some stage, particularly if their own condition improved with time. However, as with the carers we discuss in the next section, they pointed out that they might have to retrain and, if still caring, find work that would 'fit' their other responsibilities.

4.3.4 Hopes for paid work in the longer term

By far the largest group among the carers not currently in any type of paid work were those who said that they would like to work, but could not see how that would be possible in the near future.

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A few parents of young disabled children, predominantly mothers, looked to a time when the children were settled in school and work that fitted around school hours might be possible. At the other end of the school-age range, however, one mother was worrying about what her son would do when he left school and she was a full-time carer again.

The most important consideration for carers in this position was that the hours or days of any job would have to 'fit' their caring responsibilities. This was a particular issue for those with school-age children, as might be expected, but also applied to others. For example, a man caring for his wife who had a severe and enduring mental health problem, as well as physical problems that might necessitate the use of a wheelchair in the near future, felt that if he could renew his 'certificates' and find a job for three or four hours a day, that would 'work round' his wife's needs.

Fit to caring responsibilities for some was more about flexibility; the demands of the caring role were often unpredictable for these carers. If the CA link person had behavioural problems, for example, and 'kicked off' while away from home, schools or day services called carers in to deal with it. Another sort of unpredictability came when the condition of the CA link person meant that they experienced episodes of acute health need:

A mother caring for a daughter with a rare genetic condition said, 'For three weeks [she] might be having an absolute crisis and you can't do anything'. Finding a job that was flexible enough, and an employer who was understanding enough to accommodate that degree of unpredictability seemed unlikely to her; she had fully expected that she might have returned to work 'by now' (her daughter was at school) but was not hopeful. Some days, she said, 'it's bleak' because it was difficult to see her daughter ever being able to live independently.

(CA/IS)

Other carers' concerns were more to do with how they would re-engage with the labour market when their skills were out of date or the certification or licenses that allowed them to do certain types of skilled manual work had lapsed. Both retraining and re-certification had substantial cost implications which they were unsure how they would meet. For example, one male carer, who was currently working part time, said that it would cost £2,000 to update his registration and licenses if he were to return to his original occupation.

Finances played a much smaller part in carers' accounts of any future return to paid work than might have been expected. Three specifically referred to the need to ensure that any return did not leave the household any worse off financially. Another, in the CA-only group, said that he knew that he would be worse off if he earned more from his part-time work (though there was no likelihood of a return to full-time work given his wife's condition) because the minute he earned over £100 he would lose £58 of CA. He fully expected and wanted to 'throw' himself into work when his wife died, even though he was already 60 years of age (CA-only).

5 Alternatives to the current Carer's Allowance system

In the final part of the interviews with carers we explored with them a range of alternatives to the current Carer's Allowance (CA) system suggested by the Department for Work and Pensions (DWP). There were: rolling CA up into some other source of income; providing a single lump sum to carers and then nothing else; and providing a smaller lump sum and then a lower regular amount of CA. We then asked carers whether services for the CA link person or for themselves would be a better option than receiving CA. Finally, we asked them how they would redesign the benefits system to support carers.

5.1 Rolling up CA into some other source of income

All of the Pension Credit (PC) carers pointed out that they already received CA rolled up into another source of income and/or received higher rates of other benefits because of their underlying entitlement. However, three of the ten in this sub-group, all men, said that they would like to see CA unrolled from other income. Doing this would make it much clearer that they were, indeed, carers, giving them a status and showing that they were appreciated for the role they carried out. One also said that he found the system so complex that unrolling CA would enable him to understand how much exactly he was receiving for caring for his wife.

In the Carer's Allowance/Income Support (CA/IS) and CA-only sub-groups, opinions were divided about this option. Five of the CA/IS group and one of the CA-only group said that it would be all right to receive CA as part of something else, as long as the overall amount received was no less than currently and that there was still some distinct recognition for them as carers. Four CA/IS carers and most (12) of the CA-only group felt that it would make no difference one way or the other what CA was called, or how it was paid, as long as the total amount remained the same. However, some of these carers pointed out that as weekly payments suited the way they ran their household budgets, tying CA into the fortnightly IS pattern, for example, would make budgeting more difficult for them.

There was a small, but important, group for whom rolling up CA would not be acceptable. These carers, like those in the PC group with similar views, wanted CA kept totally separate from other benefits, so that it could be seen for what it was (and would much rather that it was not deducted from those other benefits):

It's the one thing that sets you apart from being just at home. No, I think ... keep it separate. At least ... it's a remuneration for work that you are doing.

(CA/IS)

Others were just more comfortable seeing CA as a separate part of their income. For a few this was related to dynamics in the caring dyad or wider household; if it were rolled up into DLA, for example, the carer would be forced into a dependent position, having to 'ask' the CA link person for their money or use that person's bank card to get money out of the bank. For the CA-only carer whose husband made no contribution to household expenditure,

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rolling up CA into her daughter's DLA would mean that she would have no independent source of income at all. CA-only carers supporting someone living in a separate household were also anxious about how rolling up CA would work for them if it were rolled up into the CA-link person's income.

5.2 Paying CA as a 'one-off' lump sum with no further payments

Almost no carer felt that paying CA as a one-off lump sum with no further payments was a better option to the current CA system – all but five of the whole sample were negative about this idea.

There were several common themes in carers' views and across the sub-groups. First, there was simple bemusement about how this could possibly work, given the very different lengths of time for which people were carers; questions were raised about how the size of the lump sum would be calculated given the difficulty of predicting how long caring might last, the variability of the financial impact of caring over time, and whether carers would be expected to pay back some of the lump sum if the CA link person died 'too soon':

'... situations change, people get worse, like Mum, and then a lump sum wouldn't be enough'.

(CA/IS)

A carer in the PC group, with his tongue firmly in his cheek, pointed out that a lump sum might advantage older carers such as himself 'because we haven't got long to go, so let's have a bit of money and spend it!'

Most were negative about the idea of a one-off lump sum because of the difficulty of budgeting. On the one hand, a lump sum might well be useful for meeting items of large expenditure related to caring, but then how would one meet the ongoing costs of caring? On the other hand, not knowing how long the lump sum had to last would make it difficult to know how much one should draw down each week or month.

Some carers felt that in their straightened circumstances, having access to a lump sum would simply be a temptation. This was not to say that they would spend it on things unrelated to caring, but that it would be easier to spend it on items related to caring:

'... would I save it [to eke it out] or would I find something else that I felt it was necessary to spend the money on?'

(PC)

It was interesting that many people initially thought that what we meant by 'a lump sum and no further payments' was an annual lump sum and no payments for the rest of the year. For them, this was the only sensible way in which a lump sum could possibly address the needs of a carer and they could see some advantages in it. It would allow people to pay annual sums such as car tax or insurance, or would allow the replacement of domestic equipment that, as we saw in Chapter 3, in some caring situations wears out more quickly than usual.

The few carers who did think the one-off lump sum might be a good idea pointed to their high level of budgeting skills, but wondered how others with fewer skills might manage. Some also pointed out that the sum would have to be sufficiently large to produce a regular income when invested. Another talked about buying a house suitable for herself and her disabled children's needs.

A carer who was not keen on the lump sum idea queried how it would work alongside the savings limit for IS.

5.3 A one-off lump sum followed by smaller regular payments

This option was slightly more popular than the previous one; 17 carers could see some potential in the idea but said that it would 'depend' on the details.

Again, there was a lot of initial misunderstanding about what the lump-sum element might entail, with many carers thinking that the suggestion was for an annual lump-sum and smaller regular payments. Similar benefits to this were rehearsed as above – mainly the usefulness of meeting annual lumpy expenses related to transport costs and the home.

The few carers who immediately understood the idea could see that someone who needed to set up their home to meet the needs of a disabled person or where households were merging to accommodate caring might find a one-off lump sum useful. However, the size of the lower weekly amount and whether it would be sufficient to meet ongoing needs was a concern.

For the majority, however, this idea was as unattractive as the 'one-off' lump sum, mainly because of the difficulties it would cause with their current budgeting patterns and the concomitant reduction in regular income. The temptation that a lump sum might present was also raised again.

5.4 Services for the CA link person

The question about whether services for the CA link person would be a better way of dealing with the needs of carers raised similar issues to those outlined when we asked about things that carers might find more useful than CA (see Chapter 3).

First, there was the group of carers who simply saw it as their duty to the CA link person to care for them; no amount of offers of services would change their views about that. The views of the CA link person also played a part here. Secondly, there were those who said, of course, services would help, but who was going to fund a care package sufficiently large to make their input as carers redundant? Even in the few cases where care packages were in place, the carer's input was still needed to enable the CA link person to remain living at home. Fourthly, there was the issue of the quality of services; this was particularly the case where the CA link person had a rare condition or required a highly structured environment. In many cases, these issues were inter-related:

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A man caring for his wife who had severe and enduring mental health problems said that the acceptability of services to the person being supported was crucial and felt that this was more of an 'issue' for people with mental health rather than physical problems. Services, he believed, could never replace what a partner or husband can do for the loved one; they could not provide the same 'quality of care'. And even if services are available, the carer is still very much a part of things – 'it won't happen unless I'm involved with it'.

(CA-only)

The older carers in the PC sub-group had similar views to those in the other sub-groups, but here people were more likely to acknowledge that they might have to accept services in the future if they themselves became frail or otherwise unable to cope any longer. One carer in this group also wondered whether older people, compared to younger disabled people, might struggle more with the notion of people coming into their homes to 'help'.

5.5 Services for the carer

The majority of carers rehearsed the same reasons for not wanting services for themselves as they had in relation to services for the person they were supporting. An interesting finding here was the carers who said that they turned to other family members for respite care.

While rather more carers were positive about services for carers than they were about services for the CA link person, this was about the need for support in addition to CA, not instead of it. A wide range of input was mentioned as potentially helpful, covering respite care or a holiday for the whole household, carer training, information services, and access to practical and emotional support.

5.6 Carers' ideas about how to redesign the benefits system to support them

Almost a quarter of carers (11) thought the current CA system was largely all right as it was and who did not want to change it or could not think of any way to improve it:

'Why fix it when it isn't broken? Why, why muck with stuff when it works?'

(CA/IS)

Among the rest, however, there was a wide range of ideas about how to change the benefits system to support them better and most carers gave more than one suggestion. Many were clearly drawing on their individual experiences as carers and gave examples. These ideas fitted into four main categories.

5.6.1 Change to current CA system

The first set of ideas was about changing the way that the current CA system was run.

One suggestion here was to make CA more closely aligned to caring responsibilities, by taking into account the amount of care being provided and/or the number of people being supported. As one carer asked, if Disability Living Allowance (DLA) could be paid at different rates to reflect level of impairment, why could CA not be as flexible?

Related to making CA more closely reflect people's involvement, carers suggested allowing the payment to reflect additional travel expenses that carers supporting someone in a different household incurred or the additional expense that hospital treatment at a distance created. Another carer wondered why it was not possible to transfer CA to someone else if the carer was temporarily unable to care. This man, caring for his disabled wife, had been in hospital and his daughter had taken over his caring role completely. He felt that she was entitled to CA for that period; she had refused to take payment from him and this made him feel more dependent on her than he liked.

Another set of issues in this category was about the relationship between CA, other benefits and savings. Carers across all three sub-groups felt strongly that the effective deduction of CA from other sources of income was difficult to understand; either one was a carer, carrying out a valuable job that had an impact on one's expenditure and life chances, or one was not. What difference did the other sources of one's income make to that?

'It should be like a premium where it's, it's there ... a reward for what you are doing ...'

(CA/IS)

Some carers pointed out that if they were not doing what they did then the state would be facing a large bill for long-term care or substantial packages of support. And, as one carer pointed out in an ironic aside, the extra £40 or so a week that she would get from this type of change would hardly free her up 'to read magazines all day' (CA/IS).

Others talked about the inadequacy of the £100 per week earnings cut off for CA entitlement and the benefits 'cliff-edge' that it created.

5.6.2 Administrative issues

A second set of issues that carers felt could be addressed were related to the administration of CA and the claiming process (both for CA itself and its relationship to related claims for DLA and IS).

Carers expressed frustration with a system that they saw both as complicated and remote.

Unnecessary complication was seen to arise from the apparent inability of the claiming process to deal with inter-related claims for DLA, CA and IS at the same time and by the same part of the system. When these different benefits were being paid, why was it not possible to ring a single contact point and deal with enquiries about all of them at the same time? One carer gave the example of having to ring five different places – for CA, DLA, IS, tax credits and Child Benefit (CB) – to inform them that he and his household had moved.

Carers also could not understand why they were not given essential information that would enable them to get their claim 'right' the first time. A telephone helpline or proactive advice and guidance when making a first contact were suggested as ways of making this easier. Someone to talk and guide them through the benefits and services to which they might be entitled when they first identified themselves as carers would be invaluable; otherwise 'you're like chasing the horse as soon as it's gone out the ... stable' (CA-only). Related to this was the view that carers should not have to rely on contact with carers' organisations to find out to what they might be entitled.

The remoteness of the CA system was also outlined when carers suggested the need for a more frequent review of their circumstances. One carer, for example, said that his claim had not been reviewed for 13 years. A more regular review system would allow both the carers' and the CA link person's changing needs to be assessed.

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A final issue raised in this category was actually about DLA claims. With a small qualitative study it is difficult to be sure about this issue, but we gained the impression that disabled young men were experiencing particular difficulties with assessment and reassessment of their DLA status, which then had an impact on the carers. We described earlier the number of times a young man with a serious degenerative condition had applied for DLA before he was successful. There were hints of similar things going on for others. The mother of the deaf young man who had only recently been given the 'all clear' from cancer treatment recounted how upset he (and she) had been when 'disability advisers' at his Jobcentre had laughed when he said that he was reliant on a vibrating alarm clock to wake up. She was not the only person to feel that the quality of interaction with the 'system' for people who were already in difficult circumstances was not all that it could be.

5.6.3 Other ideas

Most of the other ideas that carers articulated during this part of the interview were actually related to services and support and were similar to those described earlier in this chapter.

One new set of ideas that came up was about carers' finances and so we have included it here. Suggestions for reducing carers' expenditure included offering them fuel discounts rather than cold weather payments, a transport allowance rather than free bus passes (which most CA link people could not use) and carer ID cards that would enable carers and those they were supporting to get discounts on food in hospitals (where many of them spent much time) .

Finally, there were ideas only partly about CA itself, but which those who suggested them clearly felt would help carers' financial circumstances. They believed that there needed to be a change in the way that carers and caring were perceived.

We saw earlier how important the symbolic value of CA was to people currently claiming benefits, giving them a sense of 'being different' from other claimants in an atmosphere that was increasingly antagonistic towards those who were dependent on the State. Carers felt that recasting CA as an entitlement and carers as people who did an essential job could do nothing but help here.

Another carer argued the need to ensure that employers also understood that message. She knew that employers were being encouraged to be more 'carer-friendly, but also knew from her own experience that, for that actually to happen, a proactive, government-led campaign was needed. This should say that carers were valued and needed and that employers must adapt employment practices to accommodate them. She said that 'encouragement' to employers was not enough because:

'... it doesn't happen in reality and that's where the Government needs to wake up, it doesn't happen. Flexi-hours doesn't [happen]. [Carers' leave] doesn't happen. ... You go back into the workplace and you're cold shouldered. I've seen my boss do it'

(CA/IS)

6 Implications for policy

6.1 Answering the research questions

6.1.1 How is CA viewed in terms of the household budget, and does this vary by type of household?

Across all claimant sub-groups there were easily identified extra costs that came with disability and caring, although as we saw earlier, it was usually impossible to distinguish between these when the carer and Carer's Allowance (CA) link person shared a household. When the carer was in a different household, the additional cost of transport to and from the home of the CA link person was the most obviously visible cost of care.

CA was thus a vitally important part of carers' household income and supported both their everyday expenditure and the additional costs that they incurred. However, most carers put their CA into the general household 'pot' and therefore found it difficult to discuss what the CA was 'for'. The majority, across all groups, did not see CA as separate from any other source of household income or belonging to them rather than the household as a whole. It was simply something that increased their household budget by a given amount.

A small group felt that CA was for the CA link person or for themselves and the CA link person together. However, none of those who felt that CA was 'for' the carer actually spent it exclusively or even in part on anything that supported their role as a carer, per se.

Male carers and younger female carers who had relatively recent experience of the labour market were more likely to see CA as a 'wage' or recompense for their caring activities.

6.1.2 How do recipients use CA? What would they have to stop doing if they did not receive it or it was reduced in value? What impact would non-receipt or a reduced level of benefit have on the level of care provided?

Regardless of how they perceived CA, carers did use it in different ways, but there were no obvious differences between different types of carers or groups of claimants.

Even when seen as part of the household 'pot', some households earmarked CA for meeting particular sorts of outgoings, often via direct debits from the bank account into which CA was paid. Others paid all sources of income into a single account or purse, and from that all household costs were met. Another pattern observed was where one partner or household member met certain costs from their incomes, while other members met other costs.

As all this suggests, household structure and dynamics were probably as important in determining what CA was actually used for as were carers' views about what its role was.

The CA-only group of carers were the ones most anxious about the prospect of there being no, or a reduced amount of, CA. This is understandable given that they were the carers for whom CA receipt made the greatest real difference in income. One carer in this group had no other independent source of income and around a quarter said that they had no idea how they would manage without it. Others said that they would have to cut back on food, fuel or

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transport costs. For one carer supporting a parent in another household, fuel costs were the major part of his additional caring expenditure and he said that without CA he would be able to visit them less often. Two carers said that they would have no option but to give up caring and seek paid work.

Although some in the Carer's Allowance/Income Support (CA/IS) group felt that they benefited from CA by only £20⁴ or so a week, their generally straightened circumstances meant that even this amount was vital to keeping their household budget in balance. They mentioned a wider range of things that they would have to cut back on; as well as food, fuel and transport they mentioned children's shoes, clothing and activities. Two people said that they would have to seek paid work, but this seemed to signal their belief that if they were no longer receiving CA then the system would no longer see them as carers and they would have to 'sign on'.

The impact of loss of CA for the Pension Credit (PC) group was largely related to the loss of entitlement to other benefits, so it was more difficult for them to calculate the overall loss. Here, again, however, food, fuel and transport figured in their assumptions about where cuts would have to be made. One carer said that her household would break up without CA.

Given the strong sense of love, duty and obligation in many carers' accounts of why they continued to care, it seemed unlikely to us that many carers would actually 'give up' without CA. However, it was also clear that a reduction in household income would make their job even harder than it currently was, and particularly given the additional costs they bore. Many pointed to the value of what they did by referring to what a place in long-term care or even a half-way decent package of support at home would cost if they were no longer able to care.

6.1.3 How does use of CA vary depending on other variables: sources and level of income, who is being cared for or supported and where, gender, caring intensity and duration?

One of the striking things about our findings was the commonality in sources of income between the CA/IS and CA-only group. With the obvious exception of receipt of IS, the sources of income for both groups were very similar. Few of the CA-only carers or anyone else in their household was in paid work. Even in the two households where there was an adult other than the carer in paid work, in this qualitative enquiry we could observe nothing that was substantially different from the other households.

Overall, then, across the groups there was no indication that source or level of income or any of the other variables listed above had any real impact on how CA was used.

However, it was clear that what carers thought about the value of CA in their particular circumstances did vary between the groups. For the CA-only and PC groups, CA's main value was as a form of IS and they were more likely to appreciate it for its value as a recompense for caring.

⁴ Although the Carer Premium (CP) in IS is £22.20 a week, some households were beginning to feel the impact of the Benefit Cap. These were households where the CA recipient was caring for an adult child who is defined, for benefits purposes, as a separate household, and where there were other (dependent) children in the household.

By contrast, while CA/IS carers also valued the small amount that CA contributed to their household income, its symbolic value was high. This value was often articulated as something that gave them status and reduced stigma in a public atmosphere that was seen as increasingly antipathetic towards people who had to rely on social security benefits. Closely related to this was the relief that carers experienced when they no longer had to justify their job seeking behaviour and its (lack of) success. Giving them the 'freedom' to care, to look after someone they loved to the best of their ability, was to several a highly valued outcome of the CA claim.

6.1.4 What led to the decision to claim CA and how long was this after caring began?

The most interesting finding in relation to this question was the role of other people in validating the carer's role as someone who might be entitled to CA or prompting carers to think of themselves as carers. Professionals were important here, particularly during the early years of disabled children's lives or when adults were diagnosed with a condition that would necessitate care. Family members or friends also played a role, as did Jobcentre Plus or benefits staff when carers were being interviewed about their job seeking activities.

Only a few carers or other household members were 'CA aware' and they had claimed at the point when they became entitled. Other carers waited for months or, in some cases, several years before they claimed.

6.1.5 Has receipt of CA had different types of impact at different times in the caring career?

Few people were able to identify any way in which the impact of receiving CA had changed over time. Most talked about the initial relief that they had experienced when their claim was successful, though tempered for many by the subsequent realisation that it would mean a reduction in other benefits. This initial reaction included the sense of reduced financial pressures, peace of mind, and, for some, coming off the treadmill of job seeking while also trying to provide care.

The only real change anyone was able to point to was that children seemed to get more expensive as they grew, meaning that CA did not stretch as far.

6.1.6 What impact has caring had on labour market participation and/or full-time education? What role has CA played in that impact?

The main finding here is the diversity and complexity of carers' lives and their engagement in the labour market.

There were some (all women) who had never had paid work or whose engagement had been short because they had married relatively young, had families soon after and at some later stage become carers.

There was a very small number currently in part-time paid work (5) and in all cases but one, caring had played a role in their decisions about paid work and seemed to have held them from more, or more rewarding, work. In only one case, was this barrier related to receipt of CA, but not wholly determined by it.

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The mother of two disabled children had moved to a less well-paid job to bring her earnings below the £100 a week CA threshold. However, the issue that actually prevented her from following more rewarding work was the time and economic impact of taking up higher education to pursue the career she really wanted.

The majority of carers, and across all groups, were not in paid work for reasons that, initially, had nothing to do with being carers. The main reason for female carers having left the labour market, and seen across all the sub-groups, was marriage, childbirth and subsequent family responsibilities. Redundancy and job loss were most prevalent in the CA/IS group and included both men and women. This reason was also found in the CA-only group, but only with male carers. Finally, carers' own ill-health had led to their labour market disengagement, found exclusively in the CA/IS and PC groups.

Most of those who had left paid work directly because of caring were in the CA-only group, but there were also those in the CA/IS group (largely female, single parents) who had followed this pattern. In the CA/IS group, the relationship between caring and not being in paid work was largely very direct and related to the birth of a disabled child. In the CA-only and PC groups, however, the causal relationship was not always unidirectional. Many carers had already been supporting the CA link person before some event triggered the need for full-time care and/or a successful claim for higher level DLA which subsequently facilitated a claim for CA.

Only one carer who had given up paid work for care could be said to have become a carer 'overnight'.

A small group of carers, across all the groups, had experienced very complex routes into caring; multiple issues, including the need to take over child care from others, caring responsibilities for a disabled or ill family member, and problems sustaining or obtaining paid work, in combination, made a claim for CA the best thing to do to enable the needs of, sometimes quite large, groups of children and adults to be met.

There was no carer currently under the age of 26 in our sample, so we were limited in our ability to explore the relationship between caring, CA and full-time education. Further, we found no case in our sample where there had been any observable effect on carers' educational opportunities when they had been younger; none had been 'young' carers.

One mother of a disabled child did feel that her opportunities to return to education (which she had hoped to do after family formation) had been affected by becoming a carer. However, this was because services could not replace her full-time involvement in caring sufficiently to give her time to go to university and, in any case, she doubted that the household could afford for her to do so.

6.1.7 How do carers currently see their relationship to the labour market and/or full-time education and what would help them re-establish, maintain or grow their participation?

A small number of carers were relatively close to the labour market; all had recently ceased caring because the CA link person had died, or had seen a reduction in their caring responsibilities for other reasons. These carers were actively planning a return to paid work, but had yet to be successful.

Many carers, however, would have been unable to contemplate any (or more) paid work without significant packages of substitute support being put in place. Most were realistic (if rueful) about the likelihood of that ever being the case. Even in the tiny number of cases where substantial packages were in place, the carers' input was still essential in enabling the CA link person to remain at home.

Another group had no intention of seeking paid work while the person they were supporting was alive. All in this group were involved in high levels of caring activity for CA link people who had complex and multiple needs, and commitments to these people because of ties of love, duty or obligation played a part in their decisions.

As we saw earlier, some carers had significant health problems of their own and they, too, felt that these issues would likely hamper any return to the labour market.

The largest group of carers not currently in paid work were those who said that they would like to have paid work again, but could not see how that would be possible in the near future. Parents of disabled children looked to a time when their children might be settled at school and they could contemplate part-time work to fit around school hours. For others, too, it would be essential to find paid work that 'fitted' caring responsibilities, and could be flexible when unanticipated needs presented themselves, if they were to re-engage in the labour market. Finally, there was a group who, even if they could find ways of substituting for their caring activity, would need to retrain for paid work, because their skills were out of date, or would need financial help to update their registration and certificates of practice.

6.2 Implications for policy

Given the diverse and complex lives that carers in our sample had, it seems clear that any single policy solution in relation to the benefits system to address their needs is unlikely to be helpful. While CA/IS carers might not see much difference if CA is rolled up into their other benefits, CA-only carers living in separate households from the person they supported could not quite understand how this might work for them. Further, for those who had no other independent income, the incorporation of CA into some other source of household income, over which they might have no control, had potentially very negative implications.

Even if CA was rolled up for those who also claimed IS, it would be important to retain its symbolic value by ensuring a separately identified stream of income. Seeing that they were valued within the benefits system, even if only to a relatively small amount in total in reality, was very important to carers in both the CA/IS and PC groups.

Few CA/IS or PC carers could understand the logic, in their circumstances, of reductions in one type of benefit when claiming another. Even if all the additional costs of disability were met through disability-related payments (which they were not), being a carer cost carers a lot more than £20 to £35 a week. They felt that they did a valuable job for the country and pointed to the very substantial extra bill the State would be facing without them.

For most carers that we interviewed, there was no obvious point at which employment policy could intervene to sustain or encourage their labour market engagement. Even those who said that they had left or reduced their paid work because of caring, had actually been carers for some time before this. The only alternative to reducing their paid work activity would have been a substantial package of substitute care for the CA link person. In the current funding and assessment climate for social care, such support packages were unlikely for all but those close to death or admission to long-term care. Two carers did report significant support packages for the CA link person, but this did not mean that they could take up (more) paid work.

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One small change that might encourage, if not more paid work than better paid work, would be a revision of the CA earnings cut-off. As it stands at the time of writing, it allows carers to work for just under 16 hours a week at the national minimum wage. While few would be able to contemplate working for more hours than this, it was clear that some could earn more for the same number of hours and that this would be welcome in households with restricted budgets.

The earnings cut-off also presents carers with a 'cliff-edge'; if they earn a pound over the limit then they lose the whole of their entitlement to CA. Some type of sliding scale of withdrawal of CA, in line with increased earnings, therefore, might also encourage small amounts of paid work or better paid work.

Another change that might benefit carers would be the integration of advice across the disability and carer benefits system. Given the administrative link between CA and disability benefits, treating the claims separately, or not providing advice about how the benefits are related seems counterintuitive. Co-ordination of advice would not only make carers lives easier, but also prevent situations where it was months or years before they realised that they were entitled to claim CA.

The co-ordination of advice could also usefully extend to advice about social care support. There was only one CA link person in the sample who had a Direct Payment and many seemed to have had only minimal, if any, contact with local authority social services. A more radical restructuring of benefits and support for carers might see a 'single door' approach that meant that the totality of carers' needs were dealt with in one place, and were reviewed on a regular basis.

All our findings and policy recommendations chime with those of the House of Commons Work and Pensions Committee report (2008) on carers.

Our work was based on qualitative interviews with a relatively small group of carers; moreover the sample was constructed in such a way that overall results cannot be extrapolated to the population of carers as a whole. Nonetheless, our findings about the extra costs that carers bear, the difficulties of maintaining labour market engagement, and the lack of support from social care services are barely different from those described by McLaughlin and by Glendinning in the early 1990s (see Chapter 1).

Appendix A

Details of carers

Table A.1 Age range of carers by CA status and sex

CA+IS	Males	42–52	Females	24–52
CA only	Males	28–60	Females	35–51
PC	Males	66–71	Females	61–76

Table A.2 Relationship of carer to CA link person

	Parent	Spouse/partner	Son/daughter	Other	
CA+IS	8	2	3	2	
CA only	6	10	3	-	
PC	-	6	1	3	
Total	14	18	7	5	44

Appendix B

Topic guide

Carers Allowance Draft Topic Guide (with briefing notes)

The aims of the interview are to:

- Provide information about the claimant's personal background and circumstances, including their current caring responsibilities.
- Explore their caring history and the links between this and their CA claim and receipt.
- Explore the links between their caring history, their engagement in paid work and their aspirations for paid work.
- Understand their perceptions about and use of CA, especially in relation to the rest of the household budget.
- Explore their views about other ways of supporting their caring activities.

Although the topic guide is laid out in sections that we believe flow well, there is no guarantee that the interview will follow this sequence. If people raise a topic covered in another section, then follow through the topics from that section. At the end of the interview, use the topic guide to check that everything in the guide has been raised and explored.

Preliminaries

Introduce self, the project and SPRU.

Remind respondent that they were selected because they receive CA or are entitled to it.

Explain that DWP gave us the names and contact details of people who receive CA or are entitled to it.

Outline aims of interview:

- Get some detail about you and your caring responsibilities.
- Talk about how and when becoming a carer led to your claim for CA.
- Talk about how being a carer has affected your paid work and what your hopes are for the future.
- Understand what role CA plays in your household finances and the sorts of things you use it for.
- Ask for your views about different ways of supporting you as a carer.

This will help DWP understand how CA is supporting carers and whether there are additional or different things that could be done to help.

Stress independence of research.

IF TELEPHONE INTERVIEW: Explain that a 'thank you' of £20 will be sent by recorded delivery after the interview

Explain about confidentiality and anonymity. If respondent is happy with this, explain about recording and likely length of discussion. **TURN ON RECORDER** – seek permission to continue.

Check signed consent form and understanding of consent and ability to withdraw.

IF TELEPHONE INTERVIEW, then **CONSENT NEEDS TO BE ON RECORDING**. Offer to send a printed copy of the consent for after the interview, for info, if participant desires.

A. Personal and household circumstances

Briefing note

We are looking here for basic information – no need to probe deeply, except to clarify household composition, if necessary.

The check about paid employment will help to guide subsequent sections of the interview as half the sample will be of pensionable age.

- 1 Family and household composition.
- 2 Age and sex of family/household members.

Quick check here about carer's paid employment and whether other household members are in paid employment.

- 3 Housing

Probe: rented, mortgaged, owned.

- 4 Own health/impairments/conditions.
- 5 Health/impairments/conditions of other family/household members.

B. Caring history and current responsibilities

- 1 Who is CA link person and where does this person live?
- 2 Health/impairment/condition of CA link person (if not already established).
- 3 Length of caring history for CA link person.
- 4 Current intensity of caring for CA link person

Probe: hours, times of week, times of day, nature of caring activities and pattern over the months.

- 5 How predictable are current care needs of CA link person?
- 6 Anyone else involved in providing (informal) care to CA link person?

If so, for more or fewer hours and what is the current pattern and intensity? – see above.

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7 What led to decision to claim CA for this linked person?

Probe: When and how?

Previous claims for other people?

8 Any other **current** caring responsibilities in addition to CA link person?

Establish other person being cared for and where they live.

9 Any caring responsibilities in the **past** for other than CA link person?

Establish timeframes of past caring in relation to caring history for CA link person.

C. Organising and managing money

Briefing note

The next and subsequent similar questions will need to be adapted, depending on household composition – single person, family, non-family household etc.

Explain to participant that we have some quite detailed questions about their household finances because the research is looking at where CA fits into overall household budgets. Remind participant that they can choose not to answer any questions which ask about things they would prefer not to share.

1 Main sources of income for carer/household/family (use checklist).

Check how much CA they are getting. Some people, for historical reasons, are still getting the child dependant addition (£8.10 per week) and/or the adult dependant addition (£34.40).

2 For everyone in household/family who is in paid work, how much is coming in to the household/family from that person's wages/salary?

3 Does carer/household/family usually have some money left over at the end of the week/month?

4 Where would carer put self/household/family now, financially?

Prompt: financial problems; struggling a bit; managing on income; financially secure; living comfortably.

5 Is carer/household/family able to put anything by these days?

Prompt: rainy day/contingency; pensions; savings; investments.

Probe: whether has or is drawing on savings and, if so, for what type of expenditure.

D. CA and how it is used in household spending

Briefing note

We know from other research that there are many different ways that households organise their finances. Examples include:

- household members combine all their income into a single 'purse' and pay for everything out of that;
- household members each take responsibility for different items of major expenditure such as rent/mortgage and utilities, but combine resources for 'everyday' spending such as food;
- household members each contribute a set amount to major items but take it in turns to buy food or other 'everyday' items.

Some households may budget on a daily basis others weekly or monthly. There are many more examples of different patterns.

We are interested **here** in how CA fits into whatever pattern each household has adopted, how much control the respondent has over CA's use, and what it is used for.

1 Is CA received weekly or monthly?

2 How does this fit with household budgeting/flow of money in household?

Check whether household budget is organised weekly or monthly or some other pattern.

3 Why carer chose to receive CA at this frequency?

4 How is CA used within household budget?

Probe: is it kept separately or pooled?

5 Who does carer see CA as 'belonging' to?

Prompt: to carer, household as a whole, CA link person.

6 Is there anything that the carer would stop doing if there was no CA?

Probe: for details and for their thoughts on if/how they may try to compensate to maintain these things (e.g. drawing on savings, 'going without' in other ways).

E. Costs of caring

Briefing note

We know from previous research that there are two different types of spending associated with caring responsibilities – that **for** the person being cared for and that which **supports the carer's** activities directly. In this section, we are trying to distinguish between these but also to understand if the respondent thinks of CA contributing to one or the other, both or neither of these types of spending.

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- 1 What things does carer pay for to help manage caring responsibilities? What source of income is used to pay for these?

Probe and differentiate between:

- a. What carer pays for that is **for** CA link person. Examples might be care services, aids and equipment, extra heating.
 - b. What carer pays for that is specifically to **support caring**. Examples might be cost of travel to unshared home, cost of running vehicle to enable cared-for person to travel, paying for utilities in shared household, extra cleaning, ready meals.
- 2 Does carer think of CA being specifically for any of these types of spending?
 - 3 Does anyone else help to pay for any of these things?

F. Employment history and links to CA claim

Briefing note

We know from other research that there is a link between caring and reduced levels of labour market engagement. However, the direction of that link is not always clear, and may differ for different carers and at different points in their lives.

In this section, we want to explore the carer's views about the relationship between their employment and caring history, and how this was linked to their decision to claim CA.

- 1 Relationship between employment history and caring history.

Was there any link between caring history and any decision to stop work?

- 2 Current (or most recent) employment status.

Probe: hours currently (or most recently) worked if in paid employment.

- 3 Relationship between current/most recent employment status and current CA claim.
- 4 Relationship between current/most recent employment status and qualifications/training/skills.
- 5 Current employment/education/training plans and ambitions.
- 6 Relationship between caring and current labour market engagement and/or full-time education or training:

Probe:

- Aspirations for doing more and when that might be.
- Feasibility of doing more.
- What would help/enable doing more?
- Would that need further training/education?
- Does receipt of CA support or hinder these aspirations?

7 Does carer see self in paid work/working in a different way at any time in the future?

This question is about whether the carer would enter or change paid work after caring stops. It is difficult to ask it in a more direct way, because the end of caring usually comes when the person being cared for dies or enters long-term care.

Check at end of this section:

If not already clear, labour market engagement of CA link person.

If not already clear, labour market engagement of (non-CA link person) spouse/ partner.

G. CA specific issues

Briefing note

CA is a compensatory payment that acknowledges the carer's reduced engagement in paid work. However, we know from earlier research that carers do not always see CA in this way. This section explores the respondent's views about CA and its impact on them and their household.

1 What does carer like about CA?

Probe: how does carer 'see' CA – income support, compensation, payment for care or what?

2 What difference does CA make to:

- carer?
- household?

3a. If receiving CA for more than 1 yr (check with carer).

Has receipt of CA had different impact at different times?

Probe: Has the way CA is used changed over time?

3b. If receiving CA for <1 year (check with carer).

What was the impact of first receiving CA?

4 Is money the main 'issue' in relation to caring or are there other things that would make more of a difference?

Prompt: how useful would the carer would find the following, compared to CA:

Services for CA link person?

Services for carer?

Employment for carer?

Employment for CA link person?

H. Potential change in CA/income levels

Explain that, as they may be aware, many parts of the benefits system are changing. There are no definite plans, at the moment, to change Carer's Allowance, but in this research the DWP have asked us to explore different ways of supporting carers, and to get your views on what might be more useful. DWP to provide 'crib sheet' on PIP etc.

- 1 Explore five different scenarios with carer. If not a single person household, for each scenario probe difference to carer and difference to household/family as a whole.
 - a. CA 'rolled up' into some other source of income that carer/family/ household receives e.g. Universal Credit; tax credit.
 - b. A lump sum.

When would a lump sum be most useful?
 - c. A lump sum but with a lower weekly amount subsequently or no further payments.
 - d. Services for the CA link person.
 - e. Services for carer.
- 2 If carer were redesigning the way that the benefits system supported carers, what would they do?

Check that all relevant topics have been covered.

Check to ensure we have all the necessary socio-demographic information. Ask about ethnicity at this stage, asking people to assign themselves to standard ONS categories. If asked, explain the importance of ensuring that we can represent a wide range of people and views.

I. End of interview

THANK AND ASK CARER IF THERE IS ANYTHING ELSE THEY WANT TO ADD OR IF THERE ARE ANY QUESTIONS.

REASSURE AGAIN ABOUT CONFIDENTIALITY AND ANONYMITY.

Turn off recorder.

Remind about recorded delivery of 'thank you' £20 and that it will include a receipt and an SAE. Ask that they sign and return it.

Appendix

Income sources checklist

Paid work

Income Support

JSA

ESA/IB

DLA

WTC

CTC

CB

HB

CTB

Pensions – state and other

Any other source of income

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