Department for Work and Pensions

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Employment support for carers

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A report of research carried out by the School of Social Policy, Sociology and Social Research and the Centre for Health Service Studies (University of Kent) and the University of Edinburgh Business School on behalf of the Department for Work and Pensions
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Summary

This report presents the findings of a qualitative research study, commissioned by the Department for Work and Pensions (DWP) in April 2008, to examine and understand what employment support is needed for carers in order for them to take up and remain in work. Many carers who are not currently working would like to do so and the DWP is keen to understand the support they require to achieve this.

The background to the project is the DWP’s aim to promote work as the best form of welfare for people of working age by ensuring that work is seen as the best way out of poverty, while protecting the position of those in greatest need. This summary provides an overview of the research findings and the policy implications of the study.

Background and aims

It is estimated that around six million adults in Britain are providing unpaid care to a sick, disabled or elderly person, and that three out of five people will be carers at some point in their lives. The challenges of combining paid work and informal care are substantial and affect the type of work that can be done, the hours of work, and the likelihood of gaining or remaining in employment. Caring, particularly intensive long-term caring, has been identified as a primary cause of decisions to reduce working hours and/or to give up work altogether (Milne et al., 2001). This is especially pronounced for women and for those offering intensive care (Palmer et al., 2008). Many carers who are not currently in work, wish to return to work and for those obliged to work reduced hours, a number would like to give up work to care (Arksey et al., 2005).

There is increasing policy emphasis and employment-related interest in promoting and facilitating employment amongst carers. A number of recent policy initiatives – such as the 2004 Carers’ (Equal Opportunities) Act, the Work and Families Act 2006, and domestic legislation on parental leave, flexible working and the organisation of working time – aim to encourage employers, carers and agencies which support carers to facilitate the continuation of employment amongst carers and/or a return to it.
In 2007, the Government launched its ‘New Deal for Carers’ in England and Wales, which was underpinned by a set of Task Force Reports one of which specifically related to employment (Department of Health (DH), 2007). In 2008, the Government published its new ten-year vision for carers – its Carers Strategy – entitled ‘Carers at the Heart of 21st Century Families and Communities’ (Her Majesty’s (HM) Government 2008). The strategy is underpinned by £255 million to implement some immediate steps, alongside longer-term plans. A wide range of commitments are set out, including: the provision of information and advice; respite provision; a review of carers’ benefits; improved support from the NHS; and support to help carers better combine work and care.

In light of the policy background and research evidence, the aims of the research were to examine what employment support is needed for carers or those who have recently ended a spell of caring in order for them to take up or remain in work. It was designed to find out how caring responsibilities affect people’s decisions about employment, to assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market. The research supports the DWP’s aim to develop its strategy for carers and decide how and by whom any support should be provided.

The principal objectives of the research are to examine what employment supports are needed for carers currently in work or those who are currently caring or have recently ended a spell of caring and want to return to paid employment. Specifically:

1 To investigate how caring responsibilities affect people’s decisions about employment.

2 To begin to fill the evidence gap on the role and effectiveness of existing services for carers.

3 To assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market.

4 To provide evidence to enable the DWP to develop its strategy for carers.

In total, 55 people in two regions were interviewed. The sample included men and women, across a range of ages, different working statuses and caring responsibilities. The semi-structured interviews collected factual and biographical data as well as more qualitative data relating to carers’ support needs and their experiences of different agencies and support providers, such as Jobcentre Plus, social services, carers centres and employers.

How do caring responsibilities affect people’s decisions about employment?

Caring places restrictions on the amount and type of paid work that carers can undertake: it may limit the hours they are available for work, how far from home
they are prepared to travel and it impacts upon job mobility and career planning. Many of the carers interviewed for this research stressed the importance of work for financial, social and personal satisfaction reasons but in practice combining working and caring was far from easy. In particular, the intermittent and unpredictable requirements of their caring role caused difficulties in working and work-related plans. Many respondents talked about the balancing and juggling that went on to stay at work, the stress this caused and the guilt they often felt both towards their employers and co-workers and the cared for person. An overarching theme was either a self-reliance or reliance on family and friends in order to be able to work.

For those not currently working the desire to work remained in principle but when explored practically they expected or encountered considerable problems: finding suitable work in terms of flexible hours; feeling that no employer would take them on because of their caring responsibilities; and concern about the impact on the wellbeing of the cared for person and their own health.

One of the key elements that facilitated the ability to work and care was work-related flexibility; this took a number of different forms: part-time work, flexitime, shift working or term-time working, and locational flexibility (e.g. working from home). However, this formal flexibility was not necessarily sufficient, it often needed to be reinforced by ‘informal’ flexibility, namely the willingness of line managers or co-workers to accommodate shift changes or early or late arrivals according to the fluctuating and sometimes unpredictable demands of caring.

The past and current employment experience of our respondents revealed that very few employers had a formal policy of offering flexible working. ‘Passive’ employer support was more common, whereby it was up to the carer to ask for support and/or flexible working arrangements.

The role and effectiveness of sources of support for carers

Carers obtained support from a wide range of formal and informal sources: the NHS, social services, voluntary organisations, family and friends as well as the DWP. With the exception of the DWP most other sources of support for carers did not conceptualise their role as supporting or enabling carers to work. For most carers contact with the NHS or social services focused on the needs of the cared for rather than their own circumstances; very few of those interviewed had had a social services assessment of their needs as a carer. There was a general sense of the fragmented nature of the support system available for carers and a strong desire for a single port of call for advice and help. The voluntary sector was highly valued by many of the carers who were interviewed because it came nearest to being not only a ‘one-stop shop’ for help but also because carers’ support groups were trusted sources of information, advice and support.

A few respondents reported that employers demonstrated an active approach to supporting employees who were carers. It was more typical though for there to
be no specific policies for carers and little awareness of what the needs of a carer might be. It was up to the carer to ask for help if it was needed and many carers felt it was their individual responsibility to manage the balance between work and caring and hence, made few demands on their employers.

As with other research into employment rights, respondents in our sample were very often unaware of their rights under the law (to request flexible working or to have time off for emergencies). Some had a general awareness of their legal entitlement but either it did not apply to them (e.g. not enough service to qualify) or they did not want to disrupt their employer and/or workplace. In general our respondents tended to view their caring responsibilities as private and were concerned not to effect a burden on employers or colleagues.

The role of the DWP and Jobcentre Plus in supporting carers to remain in, or return to, the labour market

There were varying degrees of experience of DWP and Jobcentre Plus amongst the respondents, ranging from people who had had no contact to those who had experience of job search activities and/or benefit advice. There was a widespread feeling, either through direct experience or hearsay that the Jobcentre Plus environment was unwelcoming and this was linked to the sense that carers were not really understood; that there were no specialists or experts on caring in the Jobcentre Plus offices. The issue of expertise is now being addressed with specialist training for Jobcentre Plus advisers who deal with carers.

Many respondents felt that in relation to job search Jobcentre Plus did not have the right kinds of jobs to meet their needs, either because:

- they did not have part-time or flexible jobs suitable to accommodate care-related demands; or
- they were only offered access to jobs that did not reflect their level of experience or previous job status.

There is now a system for flagging flexible jobs on the Jobcentre Plus system, which should help identify the flexible opportunities available. There has also been agreement to fund replacement care to enable carers to undertake relevant training.

Many carers who were interviewed complained about the complexity and inflexibility of benefit rules and wondered whether anyone really understood the system. This finding contributed to the widely noted view that there should be just one place that carers can go for advice on benefits and employment opportunities and that the advice needs to be provided by people who genuinely understand the situations carers are facing.
Conclusions and policy implications of the research findings

It is a safe assumption, given current demographic trends and developments in medical care, that the demand for informal care will increase in the coming decades and that the challenge of how to effectively support carers to continue working and/or facilitate their return to work will become increasingly important. Removing the barriers to employment for carers requires action on a number of different fronts and by a range of stakeholders. The DWP – as the main governmental policy agent in the field – most particularly through Jobcentre Plus and Pension Disability and Carers Service (PDCS), can play a number of roles in developing appropriate policies and procedures for their delivery. Employers will also have a pivotal role in providing and sustaining employment for carers. The NHS and social services, although primarily concerned with the needs of the cared for person, also have a role in supporting carers who wish to stay in, or return to, paid work. Lastly, the voluntary sector, which already does much to support carers on a day-to-day basis, may also be able to play an enhanced role in supporting working carers.

In all cases, the situation and needs of carers needs greater visibility and recognition. As has now been recognised there is a need for specific expertise on carers within Jobcentre Plus and an enhanced ability to locate flexible working opportunities and match carers to those opportunities. With respect to welfare benefits for carers (which are currently under review by Government) there is a need for greater clarity over benefit rules and entitlements and the interaction of different benefits.

It is important that employers become more aware of carers and their needs, creating a network of sympathetic or care-friendly employers, both nationally and locally, may be one way of raising the visibility of carers as employees. Legislative rights for carers to request flexible working arrangements are insufficient by themselves as many people are not aware of their rights or if they are may not wish to invoke them for fear of a negative reaction from their employer.

At present, and not unreasonably, professionals in the NHS and social services are primarily focused on the needs of the cared for person and do not necessarily see their role as supporting the carer to remain in or go back to work. However, there clearly are roles for GPs in being alert to the health issues that carers, combining work and caring, may be experiencing and providing good advice and or referral to occupational health services. Social services need to be more aware of carers’ rights to an assessment of their needs and this should be routinely offered and periodically revisited at every opportunity, e.g. when a visit to the cared for person is arranged.

The voluntary sector is currently a well respected and trusted source of help, advice and support for carers. The barriers to involvement with Jobcentre Plus over employment support that many of our respondents expressed might be overcome by locating employment advice and support with third sector organisations that already command the respect and trust of carers.
1 Introduction

It is estimated that around six million adults in Britain are providing unpaid care to a sick, disabled or elderly person. About a third of carers are co-resident carers, while the remaining two-thirds are caring for someone in another household. Women are more likely than men to care for a sick, disabled or elderly person: 18 per cent of women and 14 per cent of men were carers, the difference mainly being accounted for by the fact that more women care for someone in another household.

Among those spending at least 20 hours per week caring, seven out of ten were below State Pension age (SPA) and the likelihood of becoming a carer increases with age, peaking in the 45 to 64 year age group (see also Her Majesty’s (HM) Government, 2008: 34). One in 20 adults in Britain are spending more than 20 hours per week caring and half of those caring for this duration said that they themselves had a long-standing illness and a third said it limited their activities. Caring can be either long-term in duration, with three out of ten carers providing care for at least ten years or short-term. 2.2 million people enter or exit a caring role each year (Carers UK, 2006). This means that the total number of people who experience caring at some stage in their lives is very much larger than the snapshot figures recorded in the Census. Three out of five people will be carers at some point.

1.1 Caring and employment

Just less than one in eight (13 per cent) adults aged between 16 and 64 in full-time employment were caring for a sick, disabled or elderly person. However, the incidence of caring is highest of all among the economically inactive, just over one in five (21 per cent) of whom were spending time caring for someone. Only about a half of carers spending the most time (between 20 and 49 hours) caring per week were in employment in 2001. The challenges of combining paid work

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1 The background provided here, and all the figures quoted, are taken from Arksey, H., Kemp, P., Glendinning, C., Kotchetkova, I. and Tozer, R. (2005). Carers’ aspirations and decisions around work and retirement. DWP Research Report No. 290.
and informal care seems to particularly affect those undertaking substantial hours of caring per week.

Women carers were much less likely than men to be in full-time employment and much more likely to be in part-time employment. Co-resident carers were less likely to be in paid employment than either those caring for someone in another household or those who do not have caring responsibilities. Among women, caring for someone in another household was associated with a lower rate of full-time employment and a higher rate of part-time employment than non-carers.

The experience of being in work is much valued by many carers and many carers report that they enjoy work. Work can provide positive benefits in addition to the income it brings and having a job is associated with measurable psychological health benefits.

Most carers’ feel that they have little choice in becoming a carer and evidence suggests that most carers did not want to leave work altogether; instead they wanted to achieve a reasonable balance between caring and paid employment. However, research suggests that most employers have given little or no consideration to the difficulties carers face in trying to combine substantial caring with paid employment. Inflexible working hours and the absence of ‘care-friendly’ employment policies have been found to be a major barrier to managing work and caring.

1.2 Research aims of the study

The aims of the research were to examine what employment support is needed for carers or those who have recently ended a spell of caring in order for them to take up or remain in work. It was designed to find out how caring responsibilities affect people’s decisions about employment, to assess how Department for Work and Pensions (DWP) and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market. The research supports the DWP’s aim to develop its strategy for carers and decide how, and by whom, support should be provided.

The principal objectives of the research are to examine what employment supports are needed for carers currently in work or those who are currently caring or have recently ended a spell of caring and want to return to paid employment. Specifically to:

- investigate how caring responsibilities affect people’s decisions about employment;
- begin to fill the evidence gap on the role and effectiveness of existing services for carers;
- assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market;
- provide evidence to enable the DWP to develop its strategy for carers.
This research is intended to complement and build upon the research carried out in the report *Carers’ aspirations and decisions around work and retirement* (DWP Research Report No. 290). An evidence gap on the role and effectiveness of existing services for carers was identified within the report which this research sought to address.

### 1.3 Methodology

The research started with a brief literature review to set the study in context, followed by semi-structured qualitative interviews with some 55 people. The topic guide for the interviews was developed on the basis of the literature review and research specification; it was piloted before going into the field. The interviews were used to collect both factual and biographical data, about topics such as marital status, work history, employment status, health and caring responsibilities, income and wealth, benefit receipt, household composition and also more qualitative data relating to their support needs and their experiences of different agencies and support providers, such as Jobcentre Plus, social services, carers centres and employers. The interviews were semi-structured and lasted, on average, between one and a half and two hours.

At the beginning of the interview respondents were asked to complete a timeline grid outlining the key events in their working and caring lives. This was important for capturing the history and nature of the individual’s caring responsibilities and the interaction of caring with paid employment. See Appendix A for a copy of the topic guide for the interviews and the timeline grid.

### 1.4 Recruitment of respondents

The study was interested in those who are currently working and those who would like to get back to paid employment. The aim was to recruit both women and men in the 25-60 age range, whilst acknowledging that women predominate in caring roles. To reflect the range of caring roles that individuals experience it was also desirable to get a mixture of resident and non-resident carers. Existing evidence from previous research suggests that public sector employers may be better able to provide flexible employment arrangements than the private sector (Loretto and White, 2006). Size of employing organisation is similarly an important factor in employment opportunities; large companies may have greater potential to redeploy an individual or offer flexible hours, whereas a smaller organisation might be more tightly geared in staffing terms and have less room for manoeuvre. Conversely, some small organisations may be keen to retain an individual’s skills and experience and thus, be willing to work around the employee’s need for flexibility. In addition, self-employment may also afford opportunities for greater flexibility in location of work and distribution of working time across the week. It was desirable, therefore, to get a spread of respondents across different employment situations.
For those carers who are not currently working there are two distinct groups which the research wished to cover: the first is those who are currently not working but would like to if suitably flexible work could be found and second, those who have recently finished caring for someone and are looking to re-enter the labour market.

The target number for recruitment was 70 respondents from two regions:
• 28 interviews in Scotland;
• 42 interviews in England.

The main focus for interviews in Scotland was in and around Edinburgh, covering both well off and less affluent areas, urban and rural locations. In England, the main focus was east and coastal Kent which includes a number of poorer towns, with higher than national average rates of unemployment.

In the absence of access to the DWP’s Carer’s Allowance Database and Jobcentre Plus’ internal records due to embargoes on data transfer, the recruitment of respondents for interviews was achieved through a mixture of methods. The following recruitment routes were used:
• carers’ information and nursing support groups;
• local employers;
• care homes;
• adult training centres;
• local newspapers and free local newspapers;
• participant referrals.

In practice it proved difficult to recruit the target number. Explanations for this may include firstly, that carers do not always define themselves as such, rather seeing their caring as being implied in the role of a husband, mother or daughter. Secondly, caring is a very emotive role and a willingness to participate in a study may be tempered by an unwillingness to share information with a stranger. Thirdly, carers are typically stretched for time, facing conflicting priorities and for these reasons may be difficult to reach; a number of potential respondents expressed initial willingness to take part in the study but a suitable time for an interview could not be achieved. In addition to the general difficulty of contacting carers it was more difficult to recruit men to the study, this is not untypical of qualitative research projects.

1.5 The sample

Of the 55 respondents recruited to the study, 36 came from Kent and 19 from Edinburgh. There were more females than males. There was a good age spread of respondents with over 50s (31) and under 50s (24) in the sample, however, the real differences are in the gender breakdowns within these age groups. For the
under 50s, it was extremely difficult to source males (2), and females (22) were more predominant. This was possibly due to the fact that most of the under 50 females were caring for children. For the over 50s there was a more even mix of gender with 20 females and 11 males participating.

Table 1.1  Gender and age composition of the respondents

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Under 50</td>
<td>22</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Over 50</td>
<td>20</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>42</td>
<td>13</td>
</tr>
</tbody>
</table>

For many of the males it was presented during recruitment that there was a wish to participate so that others might be helped who were in a similar situation to them. For the women many commented at the end of the interviews that it had been very helpful to get their story out – the process had been cathartic. This could subtly suggest why we have more females participating than males; that the females were more willing to open up regarding this very personal part of their lives as opposed to the men who may not be so willing to do so.

Considering work status, the breakdown of the sample was spread across the three target groups: working, not working and ceased caring as follows:

Table 1.2  Work status by age and gender

<table>
<thead>
<tr>
<th>Work status by age</th>
<th>Gender</th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring and working</td>
<td>Women</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Men</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Caring and not working</td>
<td>Women</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Men</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Ceased caring and working</td>
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</tr>
<tr>
<td></td>
<td>Men</td>
<td>2</td>
<td>4</td>
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</tbody>
</table>
The numbers for ceased caring participants is comparatively low; there are several reasons why this may have happened to the sample. Initially, the definition of ceased carers was seen to be those who had ceased caring due to the cared for becoming well, dying or moving in to a home. In some cases these clear distinctions held true, and for those who had lost their cared for it is possible that they would be difficult to reach due to grief, however, we had several participants who were in the early stages of bereavement. For the most part the definition of ceased caring had to be relaxed as most ceased carers were continuing to care for their loved ones when they moved in to a care facility.

When assessing the work status by age, there is one significant point, that all the ceased caring males were not working and over 50. This has been attributed to the fact that many of them were assessing their retirement options, either because they had been able to secure pensions or saving through work at an earlier stage of their life and had been left assets when their cared for died, or due to the fact they felt it unlikely they would be seriously considered by employers for employment at their age. In regards to gender differences there are just as many females over 50 as there were under 50 in work; however, many of the over 50s had been able to maintain existing or similar work to what they had been doing prior to their caring episode. The problem for both men and women and all age groups was when they ‘fell out’ of work at some point in the caring episode or if the caring started before they were able to establish their career or prospects for a career.

For those who were working, the participants were either working for public organisations (10), medium/large private organisations (8), small private organisations (3), or were in self-employment (10). Males predominated in the self-employed category.

In regards to the caring environment, the majority of participants were co-resident with the cared for (34) and for the rest bar one, the cared for person was not resident (14). One respondent indicated that they were semi-resident, in that it was a regular occurrence that he would spend the night in the house of the cared for person but he retained his own home. This was not an unusual transition stage for parental care, where the carer shifts from being extra residents to co-resident in a similar way to this respondent. A key factor in extending the extra resident status was either the carer or the cared for person wishing to maintain their independence for as long as possible before acknowledging the need for more intensive co-resident care. There was also a transition almost in the other direction for those who had ceased actively caring when their relative was admitted to a residential care home. In this context although carers often continue to visit and attend to their relative’s needs, they are effectively extra resident. In relationship to hours spent caring, it was most likely that those providing 50+ hours of care were caring on a co- or semi-resident basis.

With respect to who was being cared for, 20 were looking after one or both parents, 17 were looking after their spouse and 13 were caring for special needs
children. There were five who were caring for others such as a neighbour, friend or grandparent. Except for one, all the carers for children were females. For the most part-care for a parent or parents was provided by a daughter; if it was the son it seemed to be a choice of last resort either due to the other siblings being unwilling or there was no one else to provide care.

Whilst our sample is not, and was never intended to be, statistically representative of working carers, it does reflect the key dimensions – outlined previously – of the broader population from which they are drawn. The gender and age profile nationally is mirrored on our sample. Further, we have a mixture of those who work full- and part-time, work in a range of employment situations, and tend towards the intensive end of the caring continuum (either now or in the future). The sample also provides a balance of self-employed and employed carers and a range of different caring contexts with a higher number caring for disabled spouses or parent(s)/in law as is the case nationally.

1.6 Data collection

Interviews usually took place at the respondent’s home. The process of filling out the timeline and the answering of the questionnaire schedule was recorded and transcribed for qualitative data analysis. Short answers to questions in section 1 of the schedule and further notes were recorded by hand by the interviewer. Before the start of the interview respondents were given a financial gift to thank them for taking part (£25 per individual respondent).

One potential concern within the data collection process was the use of four different interviewers. To ensure consistency as far as possible, all interviewers were trained by the lead researcher, with several follow up sessions to discuss process and findings. The semi-structured schedule contained detailed directions and prompts towards particular lines of questioning to further facilitate such reliability and the vetting of transcripts of the initial interviews was used to verify this was indeed the case.

1.7 Ethics

The study received approval by the University of Kent Ethics Committee. Every effort was made to ensure respondents were consenting to taking part in a fully informed manner. The form and content of the interviews were explained to them on multiple occasions.

Due to the personal nature of some of the questions, there were times when upsetting issues were raised. It was underlined to the respondents that they were free to pause or cease the interview at any stage. All interviewers were experienced in handling sensitive topics in such situations and were briefed beforehand. Respondents were also given a printed sheet detailing a number of agencies, which they could approach for further information on a range of topics.
Anonymity and data protection were also a prime concerns and ensured by the transcriptions being coded and the identity of the respondents being kept separately in locked office space. All electronic data was stored on a secure, password protected computer system.

1.8 Interpretation and analysis of data

All the interviews were transcribed and analysed using QSR NVivo 7, a qualitative analysis software programme. NVivo provides a set of tools which aid management and analysis of qualitative data such as interviews (Bazeley, 2007). Firstly, each interview was analysed for a set of respondent descriptive attributes, i.e. age, gender, employment status, location, household income, etc. Next, the interviews were coded for references or answers to direct questions that respondents were asked, for example what experiences they had of Jobcentre Plus. Thirdly, the interviews were coded interpretively for references to factors affecting continued working or ability to return to work and respondents’ experience of the support and help they received from informal and formal sources. Quotations from the interviews are employed in the report in two ways: primarily direct quotations are used in a representative manner to illustrate a commonly expressed point of view of a number of respondents; less frequently, quotations are used to demonstrate an unusual or particular experience of an individual respondent. All the names of respondents quoted are fictitious.

1.9 Report structure

Chapter 2 provides a summary of the existing literature on the employment support needs of carers and the currently prevailing policy context. Chapter 3 provides an overview of the roles that carers play and the impact that caring has on their wider social life, health and finance. This chapter is important for locating the respondents in their caring context, which for many of them is the starting point for thinking about remaining in, or seeking, work. Chapter 4 reports directly on how their caring responsibilities affected the respondents’ decisions about employment. Chapter 5 gives an account of the role of employers, the experiences of the respondents in managing work and caring and the importance of flexibility. Chapter 6 looks at the role and effectiveness of non-employment based sources of support for carers namely: family and friends, the National Health Service (NHS), social services and voluntary agencies. Chapter 7 presents the evidence on respondents’ experience of, and attitude towards, the services of the DWP and in particular of Jobcentre Plus. Chapter 8 offers details of a number of ‘caring case histories’; these provide concrete examples of the pressures and conflicting priorities faced by carers in reconciling paid employment and caring duties. Finally, Chapter 9 concludes by drawing the research findings together and considering the policy implications of the study.
2 Policy context and literature review

In this chapter we set the research in its policy and literature context by first reviewing the main policies designed to support carers in employment. Secondly, we provide a brief review of existing research on the factors affecting the labour market aspirations and participation of carers.

2.1 Policy context

There is increasing policy emphasis and employment-related interest in promoting and facilitating employment amongst carers (Yeandle et al., 2007a; Her Majesty’s (HM) Government, 2008: Chapter 4). Current estimates suggest that over three million carers combine work and caring. Caring, particularly intensive long-term caring, has been identified as a primary cause of decisions to reduce working hours and/or to give up work altogether (Milne et al., 2001). This is especially pronounced for women and for those offering intensive care (Palmer et al., 2008). Many carers who are not currently in work, wish to return to work and for those obliged to work reduced hours, a number would like to give up work to care (Arksey et al., 2005).

2.1.1 Recent legislation

A number of recent policy initiatives aim to encourage employers, carers and agencies which support carers to facilitate the continuation of employment amongst carers and/or a return to it. The 2004 Carers (Equal Opportunities) Act built on earlier legislation by aiming to give carers more choice and opportunity to lead a fulfilling life. In particular, it places a duty on local authorities to consider whether or not a carer wishes to take part in paid work, education, training or leisure activities when they are carrying out a carer’s assessment. The Work and Families Act 2006 specifically introduced the right of working carers to request flexible hours from their employer; this came into effect in April 2007.
Carers, like other groups of employees, can benefit from the 1999 Employment Relations Act which gave all employees the right to (unpaid) time off to deal with family emergencies. This measure allows carers, parents and others with dependants to take a ‘reasonable’ number of days off to deal with the immediate situation and to make any necessary longer term arrangements. The 2002 Employment Act gave employed carers of disabled children under the age of 18 the right to request flexible working arrangements such as changing start and finish times, compressed working hours, part-time working and working from home after six months in post. This right was extended to certain groups of carers for adults under the Work and Families Act 2006. All three measures cover England, Scotland and Wales.

It is additionally notable that working carers also stand to gain from successive European Directives on parental leave and the organisation of working time that have been put in place and translated into policy and legislation in the UK. Key initiatives include: the Employment Relations Act 1999 which entitles employees to take a ‘reasonable amount of unpaid (unpaid) time off work’ to deal with emergencies or unexpected situations involving a dependent relative. More recently, the flexible working regulations, included in the Employment Act 2002, give parents of children under six, or 18 if the child is disabled, the right to request flexible working. As of 6 April 2009, the right to request flexible working was extended to cover those with parental responsibility for children aged 16 and under.

2.1.2 New Deal for Carers

In 2007, the Government launched its ‘New Deal for Carers’ in England and Wales, which was underpinned by a set of Task Force Reports one of which specifically related to employment (Department of Health (DH), 2007). The package of measures introduced included a revision of the 1999 National Strategy for Carers, the provision of respite care cover in emergencies, the setting up of a national helpline and an ‘expert carers programme’ (now renamed ‘Caring with Confidence’). In 2008, the Government published its new ten-year vision for carers – its Carers Strategy – entitled Carers at the Heart of 21st Century Families and Communities (HM Government 2008). The strategy is underpinned by £255 million to implement some immediate steps, alongside longer-term plans. A wide range of commitments are set out, including: the provision of information and advice; respite provision; a review of carers’ benefits; improved support from the NHS; and support to help carers better combine work and care.

In relation to working carers the strategy acknowledges that more than three million people currently combine paid employment with caring; it also recognises the need to support carers to get into, or return to, work (HM Government, 2008). The Government will try to ensure that all carers who want to work will be able to and commits an additional £38 million of additional funding to provide:

- a Care Partnership Manager in every Jobcentre Plus district;
- training improvements for Jobcentre Plus advisers;
• funding replacement ‘care for carers’ receiving approved training;

• Department for Work and Pensions (DWP) and Jobcentre Plus will investigate feasibility of providing ‘return to work support’; this may be through third sector organisations;

• encouraging more flexible learning opportunities to be made available.

The strategy also states that employers have a responsibility to recognise staff who are carers and is investing in:

• an awareness raising campaign to ensure that carers and employers are aware of flexible working rights;

• plans for the Government to work with the business sector to produce a ‘good practice guide’ for all employers on benefits of employing carers;

• a review of the definition of the term ‘carer’ in flexible working regulations.\(^2\)

The new strategy applies in full to England; commitments on income and employment are UK-wide. Scotland and Wales have also developed ‘Carers’ Strategies’ and committed additional funding to support carers’ services; in Scotland this is part of local authorities’ General Annual Expenditure allocation, while in Wales the Carers’ Grant Scheme/Mental Health Carers’ Grant have both been introduced (Yeandle and Buckner, 2007).

A number of welfare benefits are also available to carers the main one being Carer’s Allowance (CA). Carers may be entitled to CA if they provide at least 35 hours of care a week for someone who is in receipt ofAttendance Allowance (AA) or Disability Living Allowance (DLA) care component at the middle or highest rate. Policy on carers cuts across a number of Government departments. Although this and associated research has been commissioned by the DWP, the findings are also relevant to the DH and the Department for Business, Enterprise and Regulatory reform (BERR), now called the department of Business, Innovation and Skills (BIS). Policy on social care support to carers is the responsibility of the DH and policies on flexible working are the responsibility of the BIS. The DWP has a core commitment to creating a chance to work for all; a key part of this is ensuring carers have every opportunity to remain in work and return to work once a period of caring has ended (HM Government, 2008; Yeandle et al., 2006). The DWP, through the Jobcentre Plus Offices and the Pension, Disability and Carers Service (PDCS) is directly responsible for two forms of support to carers: the provision of employment support and advice and the payment of benefits. PDCS is the combined delivery arm for pensions, disability and carer’s benefits and came into being on 1 April 2008, it is an executive agency of the DWP. The Disability and Carers Service is part of PDCS and delivers the following financial support: DLA, AA, CA and Vaccine Damage Payments (PDCS, 2008).

\(^2\) The right to request flexible working applies only where the person being cared for is a spouse, partner, civil partner or specified relatives of the carer or where the person cared for lives at the same address as the carer.
2.2 Literature review

2.2.1 Working carers

Caring has significant implications for employment, particularly for those under retirement age (Milne and Williams, 2003). According to the 2001 Census, about half of the six million UK carers combine work with caring. Of these over two million carers work full-time and one million work part-time; nearly 500,000 of those in full-time work contribute at least 20 hours of care per week. In 2001, just less than one in eight (13 per cent) of adults aged between 16 and 64 years in full-time employment were caring for a sick or disabled person.

There is a clear relationship between employment profiles and intensity of caring; far more carers who provide low levels of care are employed. Conversely, only about half of carers spending the most time – over 20 hours per week – caring were in employment in 2001 (Palmer et al., 2008; Yeandle et al., 2007). Among those caring for 50 or more hours per week, only three out of ten were in paid employment. The 2001 Census indicates that the incidence of caring is highest amongst the economically inactive, just over one in five (21 per cent) of whom are spending time caring for someone. Currently, around one in five carers give up work to care and many more reduce their hours or pass up promotion opportunities (Yeandle et al., 2007a).

Table 2.1 Economic activity by provision of care among people aged 16-74

<table>
<thead>
<tr>
<th></th>
<th>Does not provide care</th>
<th>1-19 hours</th>
<th>Provides care 20-49 hours</th>
<th>50+ hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Economically active</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Employee or self-employed</td>
<td>62</td>
<td>65</td>
<td>48</td>
<td>29</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Student</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Economically inactive</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Retired</td>
<td>13</td>
<td>16</td>
<td>17</td>
<td>26</td>
</tr>
<tr>
<td>Looking after home/family</td>
<td>6</td>
<td>7</td>
<td>18</td>
<td>27</td>
</tr>
<tr>
<td>Permanently sick/disabled</td>
<td>5</td>
<td>4</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>4</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: Arksey et al., 2005 from Census 2001 data.
Women carers are much less likely to be in full-time employment than men and much more likely to be working part-time (Milne and Williams, 2003). Further, co-resident carers were less likely to be in paid employment than either those caring for someone in another household (extra resident) or those who do not have caring responsibilities. Amongst women, caring for someone on an extra resident basis was associated with a lower rate of full-time employment and a higher rate of part-time employment than non carers (Phillips et al., 2002; Nolan et al., 1996). Being able to retire early with a full occupational pension or favourable retirement deal can be a significant incentive to leave work in order to undertake caring duties, particularly for men (Arksey et al., 2005).

The vast majority (90 per cent) of working carers are aged 30 years or over although it is important to note that a significant proportion are aged over 50. Being a carer has been identified as a key contributory factor in lowering the labour market activity rates of those aged 50 years and over (Loretto et al., 2007). For women carers in employment, five per cent are aged 16-24 years, 57 per cent are 25-49 years, 33 per cent are 50-59 years and four per cent are 60-64 years. Comparable figures for men are: five per cent, 53 per cent, 34 per cent and seven per cent (Arksey et al., 2005).

2.2.2 Combining work and family caring

Combining paid work and care causes considerable stress and can result in carers giving up work; whilst being employed does not affect whether or not carers start caring those who do start are more likely to reduce employment hours or stop working altogether (Milne and Williams, 2003). In a recent survey of working carers almost half of those working part-time had reduced their hours from full-time exclusively to accommodate care related responsibilities (Yeandle et al., 2007). Evidence suggests that those who are obliged to give up work to provide care do not wish to leave employment altogether. Instead most wish to achieve a reasonable balance between work and caring. However, research suggests that most employers give little or no consideration to the difficulties facing carers in trying to juggle caring with paid employment (Phillips et al., 2002). A recent study revealed that under two-thirds of working carers – and only about a half of those working in the private sector – regard their employer as ‘carer-friendly’ (Yeandle et al., 2007). It is co-resident carers providing 20 or more hours of care per week who face the biggest obstacles.

As might be expected, of the total number of working age carers identified in the 2001 Census, only two-thirds are in paid employment; around 1.5 million carers were not in employment who could have been. A recent representative survey suggests that more than two-thirds of carers outside employment consider that their caring responsibilities were the cause of them leaving work (Yeandle et al., 2006). For those seeking work, finding a sufficiently flexible job, concerns about ‘substitute’ support services for the cared for person, refusal by the person they care for to accept help from services and loss of confidence have all been
identified as ‘barriers’. The cost of replacement care, lack of tax incentives, and an inflexible benefits system are also factors and, for some carers, these can mean they are financially worse off by working than by remaining a full-time carer.

The experience of being in work is much valued by carers. It can provide positive benefits in addition to the income it brings, and having a job is associated with a range of measurable psychological health and social benefits (Arksey, 2002). Working can enable carers to avoid social isolation, can provide a break from caring, facilitate social contact, offer a purposeful activity and provide an identity outwith that of ‘being a carer’ (Becker, 2000; Seddon et al., 2004). Being in work – whether full- or part-time – has even been found to reduce the amount of stress carers experience (Hirst, 2003). Being out of the labour market, even for a short time, can result in ‘opportunity penalties’ the loss of vocational skills, a reduction in self-esteem, confidence and purpose.

Research suggests that particular barriers to carers staying in work include: restricted access to flexible working, limitations to the flexible arrangements themselves, reluctance to disclose caring responsibilities, variable responses from line managers and inflexible support services (Carers UK, 2004). The issues that research identifies as keeping carers in employment include: workplace support such as awareness of carers policies and flexibility in accommodating home-based working; flexible working such as flexible start and finish times and part-time working; a supportive work culture, and formal policies being in place (Pickard, 2004). There is also a developing evidence base supporting the ‘business case’ for employing carers. Arguments include increased motivation and productivity, reduced absenteeism and sickness, and enhanced levels of retention; this may be particularly relevant to older workers who tend to be those who have the highest level of skill and who are most likely to have care-related responsibilities (DH, 2008). Making it easier for carers to balance work and family life should also reduce premature retirement, which is important in the context of the need to sustain an ageing workforce in an ageing society (Confederation of British Industry, 2007; Loretto et al., 2007).

### 2.2.3 Financial implications of caring

Reducing working hours – even over the short-term – or giving up work altogether has significant implications for earnings and subsequent pension entitlements. This is particularly pronounced in contexts where the caring episode lasts for many years; it is also a more prominent issue for women (Carers UK, 2007). Research indicates that carers providing substantial amounts of care face much financial hardship; research conducted in 2007 found that a third of carers were in debt and one in ten could not afford their rent or mortgage (Buckner and Yeandle, 2007).

In 1996, nearly three-quarters (73 per cent) of carers canvassed by Carers UK reported that their earnings had been affected by caring (Carers Costs, 1996), a figure mirrored in more recent work which evidenced 72 per cent of carers as
'worse off' as a result of taking on a caring role (Carers UK, 2007). These findings are echoed in work by Yeandle et al. (2006) who found that compared with working carers, carers who had given up work to care were ‘struggling financially’. Most carers who leave paid employment to care are providing intensive care; a significant number are parents caring for a sick or disabled child. A reduced income not only means it is more difficult to make ends meet, it increases the risk of social exclusion for carers and cared for. It also means the carer is less able to save for their retirement or their own future care needs.

Since 2001, the Government has introduced a number of measures to help improve financial support for carers with a particular focus on those at risk of greatest hardship (HM Government, 2008). Some 229,000 carers in receipt of Income Support (IS) are now better off because they also receive a carer premium (£29.50 a week). To help carers who want to work part-time the earnings limit in CA has increased every year since 2001 and it now stands at £95 per week net. One of the longer-term aims of the Carers Strategy is to review the structure of benefits available to carers in the context of wider benefit reform and the fundamental review of the care and support system (HM Government, 2007).

Carers of working age in the UK have been estimated to save the economy £58.2 billion a year. When all carers across the whole of the UK are taken into account, the total saving to the economy is £87 billion (Buckner and Yeandle, 2005).

2.2.4 Support for working carers

Evidence strongly suggests that long-term carers appreciate support, and actively benefit from assistance from family, friends and services. Specifically, carers want: time off from caring; reliable support from services; information and advice and recognition of their caring role. Those services that improve carer well-being are respite care, day care and sitting services. A number of specialist services are also helpful for carers of people with dementia; this includes the Admiral Nursing Service, specialist respite care and memory clinics (Milne et al., 2001; Milne and Hatzidimitriadou, 2002).

Recent research by Yeandle et al. (2007) shows that amongst working carers:

- 40 per cent of those caring full-time said they would rather be in paid work but needed better support and services for the cared for person to achieve this;
- the majority said they needed at least one type of formal service which they were not currently receiving;
- one-third of carers in full- or part-time work were struggling financially;
- very few were getting breaks, and less than a quarter had access to respite care services;
- only a quarter of carers felt they had adequate support from formal services to enable them to combine work and care;
• between 40 per cent and 50 per cent reported a lack of flexibility and sensitivity in the delivery of services which undermined willingness to expand working hours;

• a third of carers felt that they lacked information about what was available from services in their area. These findings underscore the pivotal importance of care services for supporting working carers. Their absence – as noted previously – also hampers carers returning to work; recent evidence suggest that over 40 per cent of those caring full-time and not in work say that they cannot return to work because of limited availability of support services (Yeandle et al., 2006).

On a more positive note, the same group of studies found that more than half of the working carers surveyed reported their employers as ‘carer-friendly’. The fact that 93 per cent of requests for ‘flexible working’ – which carers have had the right to ask for since April 2007 – had been granted, either in full or with an agreed compromise, is particularly noteworthy.

In terms of a coherent approach, very few local authorities have begun the process of mainstreaming their support for working carers across the full range of local agencies in health, social care, employment, and education. A recent survey of ten localities reveals that the number of ‘Carers Assessments’ conducted among carers of working age is very small with even fewer local authorities proactively asking carers about their desire to work, or about the services they need to combine work and care (Yeandle et al., 2007a). The lack of a comprehensive ‘needs assessment’ leading to suitable, responsive services has been identified as a key factor in undermining the continuance or return to employment of working age carers (Commission for Social Care Inspection, 2008).

2.2.5 Carers aspirations and decisions around work and retirement

Arksey et al.’s recent report (2005) – Carers aspirations and decisions around work and retirement – conceptualised ‘support’ for working carers as falling into six categories:

• Jobcentre Plus;

• social services departments;

• financial support;

• workplace policies and procedure;

• carers centres;

• inter-agency collaboration.

With regard to Jobcentre Plus, the research team found that only a few carers had taken part in a Work Focused Interview (WFI) with a Jobcentre Plus personal adviser. The interviews did not tend to influence carers’ decisions about obtaining paid work as long as their current caring situation prevailed. However, carers
appreciated the advice, information and better-off-in-work calculations. Carers felt more critical of advisers’ lack of knowledge about caring and the impact of caring on carers’ ability to work. This deficit is, at least in part, a consequence of the very limited number of WfIs personal advisers conduct with carers compared with other customer groups. This hampered their capacity to build up a knowledge base of care-related challenges and issues, not helped by a focus on help that could be offered if the carer’s care demands change.

In relation to social services the report identified that although some carers were very positive about the support they received, others are more critical. Further, there seems to be little evidence of a link between the number of hours carers provide care and the level of support offered. Generally, social services support was not essential to the ability of carers to undertake paid work partly because it did not easily accommodate work hours or patterns – for example, day centre hours are rarely long enough to allow for a full working day. This is evidenced in other work (e.g. Phillips et al., 2002). Services that carers reported would make it easier for them to combine work and care included: longer day centre hours, childcare and after school clubs for disabled children and practical help with domestic responsibilities for older care recipients.

In terms of financial support CA is the main welfare benefit for carers. Both carers and professionals regarded the value of the benefit as too small and certainly insufficient to be a ‘substitute’ for paid work. Carers commonly agreed that the earnings threshold was low and, therefore, restrictive. There was evidence that the benefit might not act as an incentive to work, and that it could act as a barrier to working more hours. CA was not flexible enough for some carers, for example, paid work could jeopardise receipt of the benefit because of the rules regarding spreading earnings over a reasonable time period. The ceiling on earnings meant that carers who were working were unable to offer employers flexibility by occasionally working additional hours (Carers UK, 2007). This has been reported in other work and contributes to the impoverished financial status of many, particularly long-term carers. One of the key aims of the Carers Strategy is to ensure a minimum level of income for carers who are unable to work (HM Government, 2008). The National Insurance (NI) carer’s credit, due to be introduced in 2010, is anticipated to help militate against carer poverty. As 70 per cent of all caring is done by women, they are likely to particularly benefit from this initiative (Yeandle et al., 2007b).

Arksey et al.’s report (2005) also evidenced that employed carers benefited from both formal and informal workplace policies and practices. For many, these were essential to their ability to combine work and care. Flexible start and finish times, together with the ability to take time off in emergencies or for planned hospital or doctor’s appointments were particularly important. So too were sympathetic line managers and colleagues as has been demonstrated more widely with regard to family-friendly policies in general (Yeandle et al., 2002). Health and social care professionals – who were interviewed alongside carers as part of Arksey et al.’s
study – believed that employment opportunities did exist for carers who wanted to combine work and care but such jobs were typically low paid, unskilled and possibly part-time and/or seasonal. Currently, the right to request flexible working is underutilised by carers; this is due to a combination of lack of awareness of its existence coupled with reluctance on the part of employers to provide flexible opportunities (Yeandle et al., 2007). The narrow scope of the definition of who is deemed to be ‘a carer’ is also an issue; as noted previously this is due to be reviewed under the auspices of the Carers Strategy (HM Government, 2008).

Evidence from this research on the role of carers’ organisations and agencies supports wider evidence that, for those working carers who access assistance, the help received is much appreciated and valued (Milne et al., 2001). They provide information and advice, a ‘listening ear’, counselling, advocacy, referral to social services and access to short breaks. Opening hours were a challenge for those carers working full-time.

The research evidenced interagency collaboration between Jobcentre Plus, social services departments and carers’ organisations as limited. The team suggested this reflects knowledge gaps about which agencies should and do support carers and what services they offer. Jobcentre Plus staff were the most isolated professional group; advisers knew little about what carers centres and social services provide. Wider work suggest that interagency collaboration is undermined by geographical variation, the liminal status of carers as part ‘client’ and part ‘citizen’, the complexity of differential ‘support systems’ and the lack of coherent attention paid to working carers as a group by any single agency.

A recent report by the National Audit office (NAO), which investigated the DWP’s role in supporting carers to care, confirmed a number of the findings of the Arksey et al. report, concluding that:

‘The Department’s [DWP] help to carers who wish to support themselves through combining paid work with their caring responsibilities is not sufficiently effective for carers.’

(NAO, 2009:7)

2.3 Summary

In recent years the work-life balance agenda has made huge strides, embedding the idea that all sections of the population should have access to work and a life outside work. This understanding of the crucial role that work plays should apply to those with caring responsibilities as much as to anyone else, yet until recently carers have not been recognised as having any specific rights at work and many continue to lack the support they need to combine working and caring.
As the population ages and the need for family support of frail elders increases there is a pressing need to extend support for working carers, reduce barriers to continue, or return to, work and ensure the full inclusion of carers in social and economic life. The challenge of how to effectively support carers to continue working and facilitate their return to work is considerable. Although some recent work has begun to explore support for working carers, in-depth understanding of what effective support is and how different types of services may provide a single integrated ‘package’ is little understood. The economic case for maintaining carers in the workforce will become stronger as the number of carers grows.
In this chapter we report on the roles and tasks carers perform and the impact of being a carer on their lives and health. There is a relatively well developed evidence base that charts carers’ roles and the effect of caring on them, particularly for those providing intensive care and care for people with dementia. The impact of caring on the lives of working carers is only now becoming clear and is an issue that is foregrounded in recent policy changes and in plans to support carers in, or seeking, employment. This chapter adds to this evidence base.

Caring, especially over the longer-term and intensively, has been widely reported as encompassing a range of instrumental activities such as bathing and washing, alongside responsibilities such as supervising the cared for person and ensuring they take their medication. In addition to these tasks carers also tend to perform a whole set of practical less ‘hands on’ activities such as shopping, cleaning and household management. For most carers they begin supporting the cared for person in relatively low key ways such as doing their shopping or taking them to hospital appointments, but gradually over time care activities become more intensive, time consuming and intimate. This reflects the fact that most causes of long-term ill-health are deteriorating conditions such as dementia or arthritis. Less often carers become carers overnight in circumstances, for example, where the cared for person has a stroke or car accident. Parent carers are in a different category again, most have been carers from the beginning of the disabled child’s life. It is important to recognise that caring is embedded in a long-term relationship that has a personal and individual history and biography.

Hours of care provided tend to be associated with type and level of care. Those carers who provide intensive types of care tend to provide care for longer hours per week than those who provide shopping; the latter category is often referred to as ‘tending’. In the middle is a category referred to in research as ‘moderate care’; this tends to include activities such as helping the cared for person out of bed or to get downstairs but not personal care. Intensive care is associated with 50 or more hours of care per week, moderate care with 20-49 hours and tending
with less than 20 hours. Those providing intensive care tend to be supporting a disabled child, a partner or for more than one person; carers of parents with dementia may also fall into this category of caring. The cared for person being co-resident is also a key feature.

Table 3.1 illustrates the number of carers who were in different caring contexts: 20 carers were looking after one or both parents, 17 were looking after their spouse and 13 were caring for children with disabilities or special needs. Five carers were supporting ‘others’ including, a neighbour, friend and grandparent. Except for one, all the carers of children were mothers. The majority of carers of parents were daughters although there were also some sons.

**Table 3.1 Who is cared for by relationship and gender**

<table>
<thead>
<tr>
<th>Cared for</th>
<th>Gender</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
<td>Total</td>
<td></td>
</tr>
<tr>
<td>Parent(s)</td>
<td>15</td>
<td>5</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>11</td>
<td>6</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Child(ren)</td>
<td>12</td>
<td>1</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>13</td>
<td>55</td>
<td></td>
</tr>
</tbody>
</table>

3.1 Caring tasks

As can be seen from Table 3.2 most carers (34) were co-resident, i.e. they shared the household with the cared for person; 15 were extra resident, i.e. they did not share the household. One respondent was ‘semi-resident’ in that he regularly spent the night in the house of his elderly relative although he retained his own home. In terms of hours of caring, as can be seen from Table 3.3, those caring for 50 or more hours per week tended to be co-resident. Conversely, those caring for fewer hours tended to be extra-resident. This was consistent with national trends.

In our sample, most carers (38) were providing over 50 hours per week of care; in other words they tended to provide intensive care. Eleven carers provided moderate levels of care between 20-49 hours per week and six provided tending or lower levels of care for between 1-19 hours per week. Interestingly, hours spent caring was not an indicator of whether the carer was working or not. There were as many working carers caring for 50 or more hours per week as non-working.
Table 3.2  Residency by hours caring

<table>
<thead>
<tr>
<th>Residency</th>
<th>1 to 19</th>
<th>20 to 49</th>
<th>50 +</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resident</td>
<td>0</td>
<td>5</td>
<td>29</td>
<td>34</td>
</tr>
<tr>
<td>Semi-resident</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Not-resident</td>
<td>6</td>
<td>6</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>N/A</td>
<td>0</td>
<td>0</td>
<td>5*</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>6</td>
<td>11</td>
<td>38</td>
<td>55</td>
</tr>
</tbody>
</table>

* Ceased caring – hours spent caring prior to change.

Table 3.3  Work status by hours caring

<table>
<thead>
<tr>
<th>Work status</th>
<th>1 to 19</th>
<th>20 to 49</th>
<th>50 +</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring and working</td>
<td>3</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>Caring and not working</td>
<td>1</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Ceased caring and working*</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Ceased caring and not working*</td>
<td>1</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>6</td>
<td>11</td>
<td>38</td>
</tr>
</tbody>
</table>

* Ceased caring – hours spent caring prior to change.

3.1.1  Low-level caring or tending

In terms of tasks, carers reported doing a wide range. At the lower, tending, end of the continuum a number of carers did laundry, helped with finances, took the cared for person out, kept them company, and generally made sure they were alright:

‘Yes definitely, I helped him with paperwork and financial stuff. Also laundry, there’s an awful lot of it. If he doesn’t feel he can drive, which is quite often, then obviously I have to do the driving.’

(10KFNR, female, under 50, caring, not working)

‘Helping with paperwork, financial matters – well I did all of that. That was the other thing she stopped being able to do – she used to be actually very good with finances and looking after her bank account and all those things. Completely went to pot that did so I stopped in.’

(16KMNN, male, over 50, ceased caring, not working)
Also carers often took the cared for person to medical appointments or to day services:

‘If she goes to hospital I have to be there in order to give medical history and things like that.’

(26KFWR, female, under 50, caring, working)

‘I used to drop him off at [name-special head injuries service] the other side of Ashford and then go to work and then pick him up…I then leave work a bit early and pick him up.’

(14KFWR, female, over 50, ceased caring, not working)

3.1.2 Moderate caring

Many carers were also providing help with moving and handling the cared for person:

‘If he can’t get out of the bath and sometimes he needs help getting up and downstairs and in and out of bed.’

(10KFN, female, under 50, caring, not working)

‘Physical help, yes. She can’t manage stairs or walking except with a zimmer but I do help her stand up out of a chair, I put her into another chair, I help her in and out of bed, all that stuff.’

(32EFWN, female, over 50, caring, working)

Housework was regularly mentioned by carers, often as an additional job which, although they may do some of the chores anyway were part of the overarching caring role:

‘Cooking, cleaning and washing, laundry and ironing…all of those lovely jobs…I don’t always do the meal but I now [always] pack it away and put it all in the dishwasher and stuff like that.’

(15KMWR, male, over 50, caring, working)

‘There’s an awful lot of washing that goes on that I have to do in the morning [after she’s got up]…it can be full of faeces which is not very pleasant.’

(21KMWR, male, over 50, caring, working)

3.1.3 Intensive caring

For most of the carers providing 50 or more hours of care per week, they were providing personal care of some kind:
‘I go in every night and I shave him, clean his teeth, do his nails...sometime I feed him. He’s doubly incontinent...he has to be moved with hoists, he’s not even weight bearing. [Also] I cream him as he gets this funny condition, do his nails, give him drinks, give him his drugs. Just generally look after him, fuss around him really.’

(14KFWR, female, over 50, ceased caring, working)

‘I do personal care for him because he’s incontinent at night and he needs help to do...Put pads on, changing the bed at night if it’s wet. I have to give injections every day to him.’

(19KFNR, female, under 50, caring, working)

Some carers were required to do more evening and night-related activities which may involve regular overnight stays:

‘I stay overnight sometimes...I spend evening and nights at my mother’s and days at my flat which has sort of become my office for work. So long as there is something for her to eat in the day she’s ok and I like to be there at night in case there’s a health issue.’

(1KMWS, male, over 50, caring, working)

Monitoring medications and doing quasi nursing care tasks was another role commonly reported by intensive carers:

‘He [son with severe epilepsy] requires medication morning and night...we need to measure it out, keep it safe and make sure he takes it. Also we have to make sure if he goes anywhere to play or to a friend’s house that the people are aware of the disability, of the consequences of what could happen and he has emergency medication with him and people are clear about what to do if he has a seizure.’

(2EFWR, female, under 50, caring, working)

‘Also there’s the medical things now that I take care of, there’s the tube feeding and everything that goes with that. I do physio as well.’

(36EFWR, female, over 50, caring, not working)

Most intensive carers did a wide range of care tasks. This carer summarised well what he does for his very dependent mother:

‘Helping with financial matters – well I did all of that...other practical help, preparing meals, I did those, shopping, laundry, housework, gardening, all of that. Keeping her company, reading to her. Taking her out...walks, drives...taking her to visit relatives. Medication – she was really getting in a muddle with that...I do it all apart from personal care.’

(16KMNN, male, over 50, ceased caring, not working)
3.1.4 Challenging behaviour

Managing difficult behaviour was another facet of caring, particularly for carers of people with dementia:

‘He used to unscrew everything…the drain for the washing machine, he unscrewed the poles that kept it in place.’

(14KFWR, female, over 50, ceased caring, working)

‘I woke up and I could hear this beeping and I got up and looked outside. It was then I realised we had no power…and I got a torch and I was looking around and he’d weed all over the floor by the bathroom but not only on the floor, he’d weed down the wall and there was a socket and he’d fused all the lights!’

(34KFWN, female, over 50, ceased caring, working)

Cared for people with memory and concentration problems posed a particular challenge for carers in terms of supervision and help:

‘Memory, that’s going now. His short term memory is going and ability to concentrate is now…He can’t concentrate at all now. Learn or understand. Crossing the road is hopeless, he needs help.’

(18KFNR, female, over 50, caring, not working)

‘Like when my daughter got married, she’d [elderly mum in law] be in every half hour asking me what was happening tomorrow and I’ld have to go over it again and again and again, what she was going to do, what her part was, when she was coming home, the meal.’

(21KMWR, male, over 50, caring, working)

3.1.5 Other care-related activities

Another – under-recognised – care activity is related to emotional well-being. Many carers recognised that the cared for person appreciated, or even needed, the impetus to look after themselves that a regular visit from a carer afforded:

‘A visit from me gives her an emotional lift…I think people deteriorate very quickly if they feel they aren’t being visited because suddenly it become less important for them to do things, like cooking…You can see the mental, emotional deterioration amongst elderly people when they are not visited.’

(1KMWS, male, over 50, caring, working)
‘One of worst points was mum feeling dead guilty about my sister [being sectioned] and part of my role was to keep her buoyed up so that she didn’t get too depressed herself...providing emotional support, just sitting there while she cried and trying to reassure her that she was a good person...just trying to keep her spirits up basically.’

(37EFNN, female, under 50, ceased caring, not working)

A linked activity was helping the cared for person to retain some level of independence:

‘I’ll give him [dad with dementia] a list of things to get, I’ll tape the list to the dashboard...because he’s got to have his autonomy, his independence and he’s got his pride as well.’

(26KFWR, female, under 50, caring, working)

It was common for the demands of caring to increase over time; a carer often began by providing relatively low level types of support and ended up providing personal care:

‘Personal care, washing, dressing, feeding and using the toilet. Plus filling in forms, financial matters, all of that. Having said that bearing in mind that if we went back to the beginning of ten years I would have done hardly any of that for her...She was perfectly capable of all that. All of the practical help I done, preparing meals, shopping, laundry, housekeeping, eventually I did all of those. It was progressive...And keeping an eye on her all the time.’

(12KMNN, male, over 50, ceased caring, not working)

The cared for person not being prepared to use a social care service or an aid was an additional stress for some carers:

‘He won’t go to the old age place, you know, because he doesn’t want to go where all the people are old! It makes me laugh really. So that’s another thing. If I could just have a day a week free it would be lovely for me.’

(25KFWR, female, over 50, caring, working)

‘She has a hearing aid but refuses to wear it...She refuses to go into a home where at least her incontinence pads would be changed very regularly and all of that...she sends the district nurses away.’

(32EFWN, female, over 50, caring, working)

3.2 Carers’ roles

Whilst a review of the tasks carers performed for their relatives paints a distinctive and detailed picture of what carers actually do – the physical and emotional labour associated with giving care – the roles they perform go beyond the performance of tasks. In this short sub-section we offer an overview of carers’ roles above and beyond care-related tasks per se.
3.2.1 Feeling and being responsible for the cared for person

This carer encapsulated well the all-encompassing nature of her role as a carer; in particular the interlocking of physical labour with emotional labour and the performance of a wide range of tasks:

‘He can’t go upstairs so he sleeps downstairs in the chair. Feeding he can do. Shower I have to do. When he’s bad then I have to shave him and do everything. I do all the financial side. I do all the meals, shopping, housework, gardening, taking him to the doctors, hospital. I also keep him company. I do all the medication. He likes to go out in the car so I do that sometimes. And I keep an eye on him when he’s bad to make sure he doesn’t do anything…well he did have a turn once at turning the cooker on…well I changed it from gas but nevertheless. So I have to keep an eye out. I keep the doors locked if he starts to wander. But we’re pretty good. He tends to wander up to the neighbours. And I got him a calendar so he can sort the days, it helps him to know what day it is and what he’s done….’

(24KFWR, female, over 50, caring, working)

3.2.2 Interpreter

One of the greatest challenges faced by carers of people with dementia was the issue of communication. This posed problems for the carer but also for staff working in services; they sometimes had to rely on the carer to interpret what the user was saying:

‘…with dementia, the…understanding and the use of language kind of disappears so your communication is by other means. If you’re a principal carer and you are attuned to that…there’s other ways of communicating. But in a hospital the staff are asked…are trying to ask the patient every time what they want. Do you want me to do this? Do you want me to do that? Because dementia patients they can’t answer…they can’t properly communicate and that is a problem…and the only person who can be the interpreter and translator is the carer and so you have to kind of be there.’

(12KMNN, male, over 50, ceased caring, not working)

3.2.3 Monitoring self-care

Many carers need to ensure that the cared for person takes a degree of responsibility for themselves and there is often considerable tension in trying to empower the cared for whilst keeping them safe and healthy. As a mother of a boy with severe autism commented:

‘He needs his routine, first thing in the morning, last thing at night. He needs chivvying about hair washing…so I have to remind him to use the loo…and change his clothes because his attitude is “I’ve got clothes on haven’t I?” It’s only recently he’s realised what clothes to wear with regards to the weather…so yes some things have got easier in the fact he can dress himself but he still needs someone around to make sure things are safe and ok.’

(20KFNR, female, under 50, caring, not working)
For carers who looked after people with dementia the need to monitor the well being and safety of their relative tended to increase over time:

‘There was a point when I could go out for an hour, reliably and she’d be fine. Leave her in the chair with a cup of tea and say “I’ll be back in an hour, don’t move”. “Yes OK, darling television’s on, don’t worry, I’ll phone you if I need you”. That worked for quite a while. Even for two hours I could do that. Afterwards, later on, you couldn’t leave her for five minutes, she just didn’t remember that she’d had that conversation. I’d go out the door and within five minutes she was anxious about something and… get herself in a right muddle.’

(16KMNN, male, over 50, ceased caring, not working)

‘I have prepared big signs for my dad just to remind him, after his stroke he forgets. Big signs to tell him to turn off the gas cooker, the gas fire…he’s left that on a few times.’

(33EFWN, female, under 50, caring, working)

Safety was also an issue for disabled adults and children with learning disabilities:

‘You do have to keep an eye on her… well we haven’t left her with anything she can leave on that’s dangerous. There’s no gas or anything in there.’

(21KMWR, male, over 50, caring, working)

‘Roger can’t go out very far on his own, because he can’t cross roads. He’s got no judgement of speeds, distance and if he thinks it’s clear then in his mind it’s clear, you know, he won’t think to look both ways.’

(20KFNR, female, under 50, caring, not working)

These demands on carers meant that they often felt that the demands on them were constant:

‘There is a sense that we are always on call you know.’

(21KMWR, male, over 50, caring, working)

‘I never know if I’m going to get a phone call on top of going over normally… sometimes I’ve had phone calls in London and I’ve had to cancel everything and come down… or whatever and sort it out… I mean they went for a walk in the woods together [older disabled couple] and fell down a bank. They came off the footpath and decided to cut across somewhere else and of course they fell. So I get a phone call in London so I had to drop everything and go down and sort things out.’

(26KFWR, female, under 50, caring, working)
3.2.4 Arranging, monitoring and supplementing services

Another role that has been identified in research is that of monitoring the quality of services and needing to act as an advocate for the cared for person.

‘I've had to put myself out for her in the first place… I got my foot in the door at the Foreland [disabled children’s service] when no other child from Canterbury has got in there! … I had some help but you just can’t just sit there and wait for somebody to sort your child out. You’ve got to get out there.’

(14KFWR, female, over 50, ceased caring, working – referring to daughter not husband here)

‘She [mother] was sidelined a lot of the time, just sidelined but I would never have allowed her to be sidelined. I stood up and said “oi, this is my mum and you know you’re not giving her the right treatment”. So I managed to secure for her a level of treatment from the health service that it doesn’t normally give but had to do that by bashing away, by hammering on doors.’

(31KMNN, male, over 50, ceased caring, not working)

In addition to battling for particular services, many carers then feel the need to keep making sure that the services are adequate. One son, for example, noted that he kept an eye on the care provided to his mother in the care home and continued to provide some care himself:

‘So now mum’s in the home… they’re responsible for her 24/7 but I’m never satisfied with the care they give her… I don’t think I can ever be satisfied with the care that other people provide. So I like to top it up basically. I go there once a day, at mealtimes to help encourage her to eat… I take food in that she likes.’

(16KMNN, male, over 50, ceased caring, not working)

Another carer commented:

‘I had to use a lot of skills. It’s a bit like being a manager of the Rolling Stones a lot of the time. I am responsible for my mother. I’m trying to steer her through a maze of arbitrary decisions to make about her and ill informed decisions in some respects to get the best for her.’

(31KMNN, male, over 50, ceased caring, not working)

3.2.5 Caring for more than one person

It is not uncommon for carers to be looking after more than one person, this may be both parents or more than one elderly relative and a spouse or they may be part of the sandwich generation caring for children as well as elderly relatives:
‘When I had my son...and I was looking after my mother who was sort of dying really. She died in 2001...my father died in '94. That was awful because I was trying to cope with looking after my mother, I was the main carer for her and looking after the baby and my husband being a right whatsit and I had the two girls still at home too. When you look back, you know, you think to yourself “how the hell did you ever cope with that”?‘

(14KFWR, female, over 50, ceased caring, working)

One mother of a severely autistic boy was also caring for her mother in law:

‘At one stage I was helping to care for my mother in law who was living across the road and has Alzheimer’s...and then when she went into the home I went up there at least once, twice, sometimes three times a week....’

(20KFNR, female, under 50, caring, not working)

A number of respondents in the research were serial carers in that they had experienced a number of periods of caring for different people across their life course.

3.3 The impact of being a carer

Caring for a relative, particularly intensively over the long-term, is widely evidenced as stressful and demanding. Common health-related consequences include: depression, musculo-skeletal problems – due to lifting and handling – and chronic exhaustion. Less dramatically, carers, as compared to non-carers, tend to experience tiredness and sleep deprivation, isolation, reduced quality of life and social opportunities and, most relevantly to this study, constrained ability to work. Certainly, those carers doing over 20 hours of caring a week – intensive or ‘heavy end’ carers – are the most likely to be struggling financially and the least likely to be in paid work (Yeandle et al., 2007a). The impact of intensive caring on carers’ health, financial situation and ability to work are major issues for the longer-term.

3.3.1 Being and becoming a carer

The majority of carers in our study had been ‘doing caring’ for a long time; some had been carers for between ten and 20 years. Caring became a responsibility for some carers quite quickly and for others it developed over time. One daughter described how her mother deteriorated:

“Well the situation was, she went very quick. She went from being fully supportive and fully looking after herself, apart from me buying her shopping once a week and seeing her twice a week, just to say hello – normal – to be hallucinating, seeing things, not being able to look after herself in a period of six weeks!”

(5KMWR, male, over 50, caring, working)
For carers of people with dementia in particular they often described their becoming a carer as gradual:

‘Changes are well gradual…and you find you’re taking on more and more of the function of caring…it’s been coming on for years, for ten years or so I’d say I was more conscious of the caring role. But what happens for older people is the deterioration in their health limits them more and more. So in a way caring is about increasing the amount of work you have to do…rather than switching from being a non-carer to suddenly being a carer.’

(1KMWS, male, over 50, caring, working)

Some carers considered that caring was simply a vocation:

‘I think you are naturally assumed as a carer or you’re not in life…you are either that type of person or you’re not.’

(42KFNS, female, under 50, caring, not working)

Others felt that the role had been ‘thrust upon them’:

‘Carers find themselves in the caring role. They don’t actually volunteer or apply for that role, they are appointed to it. But they don’t get any training. They are innocents abroad.’

(12KMNN, male, over 50, ceased caring, not working)

And others that it was simply a ‘natural’ extension of family relationships:

‘I think it’s a natural instinct. I think maybe because I’m the daughter I see things and I do them and I don’t see myself as a carer, I just see myself as a daughter that’s doing…the roles are reversed.’

(3EFWN, female, under 50, caring, working)

Of course, in order to identify when you ‘become’ a carer the person doing the caring has to be prepared to define themselves as a carer in the first place. This is one of the issues that act as a barrier to support being offered to carers. In our study a number of carers certainly felt this way. One daughter, for example, said:

‘I don’t view myself as a carer as such. It wasn’t until I started reading through about your project that it is a title I have. It’s always just been something I’ve had to do. They’re my parents, I have to look after them. I wouldn’t ever think, “my goodness I have rights”.’

(33EFWN, female, under 50, caring, working)
Other carers had been helped to view themselves as carers:

‘They [Age Concern] advised me, “before you fill in the form [needs assessment] just stop and think that what you are doing is caring…and the whole thing is taking over your life in a way that you haven’t properly understood”. So you stand back and look at it as if you were standing on the other side of the room…rather than being part of it. That was sound advice! As I went through the form I realised I might have said “I’m doing no caring at all” and in truth I was doing a lot…it also prepared me better for the way my role developed…and [stopped me] getting resentful.’

(10KFNR, female, under 50, caring, not working)

How the carer views themselves is likely to impact directly on the services and support they seek.

### 3.3.2 Social impact

Isolation is identified widely in research on long-term caring and was reinforced by a number of carers in our study. Feeling and being socially isolated for any period of time may subsequently impact upon someone’s confidence and ability to get back into work. This may be felt more acutely by men who are less used to periods outside the labour market than many women who may have not worked for periods when their children were young.

‘...you tend to lose a lot of friends when you’re a carer and you feel very isolated and unless you’ve got like good neighbours or other relatives you can become a bit of a recluse which is what I am becoming. And I can’t really see any other way…to help that type of problem to be honest.’

(48KMNN, male, over 50, ceased caring, not working)

‘There was me, there was my immediate family who I saw because they lived in the house with us and that was it…I had very little dealings with the world at large. The only place I got to when I was with my mum at the eye hospital or went down the chemists to get her pharmaceuticals. Isolation has been the most characteristic thing that I’ve suffered. Isolation. It’s like I’ve been locked away in jail for six years and tortured, mentally tortured…it is a bit like Terry Waite.’

(31KMNN, male, over 50, ceased caring, not working)

Another common feature of intensive caring is carers feeling trapped and/or restricted in what they are able to do. The needs of the cared for person can severely constrain the carer’s capacity to go out:

‘She’s at that age...she’s 13, when she just doesn’t want to be seen out in a wheelchair. But this just limits what you can do, you just don’t go too far from home ‘cos her walking capacity is so limited.’

(23KFWR, female, under 50, caring, working)
‘You couldn’t leave them. I couldn’t leave my mum and dad. The only time I can go out is if someone’s there or if I’m just going down to the local shops…But you couldn’t go away for an hour or two hours at a time.’

(41EFNR, female, over 50, caring, not working)

In a similar vein, one carer described her lack of ability to do what she wants as constraining:

‘He won’t go to the old age place [day care]…If I could just have a day a week free…I could play my music, just do whatever I want to do without thinking “oh I’d better not…better keep that down, he’s not going to like that.” So I just feel quite constrained….’

(25KFWR, female, over 50, caring, working)

One mother described the complete lack of personal space as very restricting:

‘I have to take him [son] everywhere because he can’t go anywhere on his own. I do everything. He can’t go out on his own ever, he can’t be allowed near fires, he needs continual supervision. I can’t leave him.’

(7EFNR, female, over 50, caring, not working)

At a more profound level a number of carers reported caring as constraining their life choices and as potentially oppressive. One wife considered that her husband’s illness had trapped her in her marriage and another that she moulded her life around the need to provide care:

‘If it hadn’t been for [person’s] illness…his Alzheimers. I wouldn’t still be here.’

(4KFWR, female, over 50, caring, working)

‘I am constantly modifying what I am doing in order to be compatible with what her needs are.’

(12KMNN, male, over 50, ceased caring, not working)

‘To spend your life, you know, wiping somebody else’s bottom so you don’t have the freedom to have your life…it’s a very oppressive thing to be.’

(21KMWR, male, over 50, caring, working)

The many hours of time that caring consumes is a related issue and one that many carers commented upon; for those caring 24/7 it can be likened to shift work:

‘I probably spend at least 50 hours on caring for him. I’ve been sitting here counting the hours.’

(19KFNFR, female, under 50, caring, working)
'I was basically there from eight in the morning until nine at night and very rarely had any time away.'
(37EFNN, female, under 50, ceased caring, not working)

Our boys have problems during the night, so [husband] does the night shift while I do the day shift. So we work like a timetable.’
(43EFWR, female, under 50, caring, not working)

### 3.3.3 Impact on health

There is a substantial literature on the impact of carers’ health especially in intensive and dementia care contexts. In terms of physical health consequences, lifting and handling the cared for person and managing accidents, poses particular problems:

‘It’s very difficult to get training for carers on medical things, lifting, etc. This is one of the things that often crops up. Henceforth, people hurt their backs. They should be offered the same training as formal carers.’
(36EFWR, female, over 50, caring, not working)

Tiredness and sleep deprivation were widely noted by carers in our study, as the following quotes testify:

‘During the night…I would sleep with my door open, I’d sleep with one ear open.’
(16KMNN, male, over 50, ceased caring, not working)

‘The doctor insisted I took a second week off because she said I was completely exhausted [with caring] as well as having the infection and she said she even considered putting me in hospital so I must have been really ill and tired.’
(39EFWR, female, over 50, caring, working)

For some carers it was the sleep deprivation that prompted them to seek help from services:

‘Anyway I was doing all this stuff and then going to work, working full-time and I ended up…I mean I know the symptoms of sleep deprivation and I thought…“oh this isn’t going to continue…we need services to do this stuff instead of me”. So that’s what I do, I wait until things are just impossible for me to continue with and then I say, “right I can’t do anymore, someone has to provide some help for me”.’
(32EFWN, female, over 50, caring, working)

Research evidence about the impact of caring on mental well-being is particularly robust. In our study these carers discussed the effect caring had on both their emotional and mental health:
‘Your mental faculties certainly diminish as a carer…One of the side effects of caring is psychological…If the carer develops mental symptoms then they have to be taken care of.’

(48KMNN, male, over 50, ceased caring, not working)

‘In terms of the resources…of strength from in here I think that looking after someone with dementia is…about as draining a thing as you can do. I’ve never experienced anything like it in my life; nothing in terms of its impact on you. And yet I did have strong resolve but the difficulty emotionally and psychologically that it puts on you…’

(31KMNN, male, over 50, ceased caring, not working)

One carer spoke for a number of carers when she described the tension between duty to care and resentment about the weight of responsibility. This appeared to be a particular feature of relationships that were of poor quality before caring began:

‘People who have children have chosen that path…accept that they need to look after them. Whereas I never asked for this. I mean my mother when I was a young teenager she was away. She abandoned me and left me looking after the rest of them and didn’t have an ounce of maternal instinct in her and yet here I am doing everything for her!’

(32EFWN, female, over 50, caring, working)

The negative emotional impact of being a carer may fall more heavily on men than women as illustrated by the following example:

‘I think actually what happened with [name], my husband, having to look after somebody all that time, it’s ruined his confidence and he doesn’t now feel he can go out and get a job because he’s got no value. As a male carer, especially when [name] was younger, there weren’t places to go…men didn’t go to places with children. So he kept very much to the house on his own, he learnt not to socialise. And I think looking back now, I’d say “did we make the right decision?” Should it be that you work part-time and give you some sense of value because I think carers lose value.’

(45EFWR, female, over 50, caring, working)

On the other hand caring did give some people a role and an identity:

‘When our disabled son was six years old he was a handful, so I decided that I wasn’t going to work. He [husband] wanted me to work but it was part of the agreement that I wouldn’t work…I was quite determined that…I was going to look after [name], that was going to be my work.’

(7EFNR, female, over 50, caring, not working)

A minority of carers also identified ‘being abused’ which had a profound impact on their health and well-being:
‘The toilet was the trouble I had with him, he wouldn’t sit on the toilet so I used to have to shove him on the toilet, then he’d shove me! That used to get a bit hair raising!’

(14KFWR, female, over 50, ceased caring, working)

‘Just around Christmas time [name] started getting particularly horrible and he would…well one night…well it happened more than once, he started well, for want of a better word for it, wanting sex in the middle of the night which I wasn’t the slightest bit interested in as you can imagine so he decides to push me out of bed and accuse me of having sex with other men and things like that and…So I had to lock myself in the other bedroom and…he was hammering on the door and it was…awful.’

(4KFWR, female, over 50, caring, working)

### 3.3.4 Working and caring

Exploring the impact of caring on carers’ ability to sustain employment was a key theme of the research overall and is covered in greater detail in Chapter 4. Here we can point to the fact that a number of carers noted the challenges of managing care tasks alongside trying to do paid work:

‘I’m not getting very much help myself. Because what happens is the medication that is in the infusion is prescribed by the doctor. It doesn’t include the infusion line, the plastic line with the needle and also the sharps bucket. …had to go and collect a special sharps bin from Altrincham which is 14 miles away…and I do really have to go to work and not spend my day driving all over the countryside.’

(15KMWR, male, over 50, caring, working)

### 3.3.5 Financial impact

The negative financial effects of caring are often considerable. As is clear from earlier in this chapter a number of carers had given up their jobs or reduced their hours to accommodate the demands of caring with the commensurate loss of income. Spending more money on laundry bills due to incontinence and travel costs associated with additional hospital appointments was also relevant.

‘I’ve had very responsible jobs but I’m no longer able to go out to do a job because of uncle falling over…you have to be a bit imaginative and think how you can get a source of income.’

(25KFWR, female, over 50, caring, working)
3.4 Summary

Caring, particularly intensive and dementia caring, has a profound impact on the lives and health of carers. It is often a role that relatives take on unknowingly and gradually and for many it involves a complex mixture of time consuming tasks and roles which demand a great deal of physical and emotional labour. Long-term caring leaves many carers exhausted, isolated and in poor health. Working carers are required to balance their caring demands with those related to their employment. Some achieve this balance by reducing their hours, shifting their pattern of work or, less commonly, getting regular support from family or services (this is discussed in detail in Chapter 6). Other carers are obliged to give up working altogether. Most carers want to continue working where possible and ideally wish to provide effective care to their relative whilst maintaining employment.
4 How caring responsibilities affect people’s decisions about employment

4.1 Introduction

The aim of this chapter is to profile the experiences of working recounted by the respondents across the study, and to explore in detail their reasons for working or not working and the difficulties they face in combining caring and working. The findings are presented by working status. Where relevant, attention will be drawn to factors such as gender or age of respondent or the nature of their caring situation and how these factors affect decisions about, and attitudes towards, work.
4.2 Nature of employment

Table 4.1 Overview of working and caring status of respondents, by age and gender

<table>
<thead>
<tr>
<th>Work status by age</th>
<th>Gender</th>
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<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
<td></td>
</tr>
<tr>
<td>Caring and working</td>
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</tr>
<tr>
<td>Under 50</td>
<td>6</td>
<td>1</td>
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<tr>
<td>Over 50</td>
<td>7</td>
<td>2</td>
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<tr>
<td>Ceased caring and working</td>
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<tr>
<td>Under 50</td>
<td>1</td>
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<tr>
<td>Over 50</td>
<td>4</td>
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<td>Ceased caring and not working</td>
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<td>Under 50</td>
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<tr>
<td>Over 50</td>
<td>2</td>
<td>4</td>
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</tbody>
</table>

Table 4.2 Employer type

<table>
<thead>
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<th>Gender</th>
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<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
<td>Total</td>
</tr>
<tr>
<td>Self-employed</td>
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<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Public</td>
<td>9</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Medium or large private</td>
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<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Small private</td>
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<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Not working</td>
<td>17</td>
<td>7</td>
<td>24</td>
</tr>
</tbody>
</table>

Table 4.3 Working status, by hours spent caring

<table>
<thead>
<tr>
<th>Work status</th>
<th>Hours spent caring per week</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>1 to 19</td>
</tr>
<tr>
<td>Caring and working</td>
<td>3</td>
</tr>
<tr>
<td>Caring and not working</td>
<td>1</td>
</tr>
<tr>
<td>Ceased caring and working*</td>
<td>1</td>
</tr>
<tr>
<td>Ceased caring and not working*</td>
<td>1</td>
</tr>
</tbody>
</table>

* Ceased caring – hours spent caring prior to change.
It should again be emphasised that this was a qualitative study and so we cannot make statistical claims based on the breakdown of figures contained in these tables. They are included primarily to indicate the coverage of the sample in terms of working status and circumstances of work.

With this caveat in mind, there are, nonetheless, some significant observations that arise from the tables. First, the number of hours spent caring appeared to have little effect on whether or not the respondent also worked. Further interrogation of the interviews revealed that work status and patterns more often reflected traditional patterns of gender segregation than any particular aspect of caring, such as time or who the cared for person was. Thus the women in the sample who worked were more likely than the men to work part-time.

A second observation was the predominance of self-employment. This was seen across both men and women and was viewed as a way of offering flexible work. The nature, role and importance of flexibility is explored fully in Chapter 5. A couple of carers had ‘second jobs’ in a self-employed capacity.

‘I have a full-time teaching job and then I come home in the evenings and I tutor piano and music basically. And that’s sort of during term-time obviously. And that’s to earn the extra money that really we kind of need now, now that [name of spouse] can’t work and so that I feel that I need to keep that going so that’s…I’ve been doing that…Well it’s built up quite a lot, hasn’t it, since you got ill and we’ve taken on quite a few more pupils. So I do extra…extra work.’

(51KMWR, male, under 50, caring, working)

Many of the women who were working or had worked in the past were in ‘caring’ jobs, such as nursing, personal care, cleaning, health care assistant, special needs teacher.

One respondent, a man based in Scotland, had been able to take advantage of Scottish policy which funds a personal assistant. He became his mother’s personal assistant and his caring became his work.

‘So although I actually gave up a full-time job to look after mum, and that was in January 2007, I was actually paid as mum’s personal assistant. So really actually mum’s gone into the nursing home three, four weeks ago, so my actual paid employment finished at that stage because it was in order to keep mum living at home.’

(46EMNN, female, under 50, ceased caring, not working)

4.3 Role of employment

4.3.1 Interviewees who were caring, working

The predominant reason given for working was related to financial reward. Some respondents expressed this as an essential need ‘to pay the bills’, but for others
it was to improve quality of life ‘to do some things around the home’ or to earn money for other ‘treats’.

A frequent theme for those aged over 50 was concern not only about current income but that they also needed to consider the impact on their pensions – in some cases they were continuing to work mainly to compensate for an under-performing pension.

Another common reason for working, and one that was most often mentioned by resident carers was working to escape from demands and stress associated with the caring situation. The desire to escape prevailed even when respondents found no job satisfaction through their work.

‘I don’t actually want to work. I used to enjoy working and I don’t think I do…I don’t enjoy work. Whether that’s because I’ve not found what I want to do. I work probably to get out of the house and go…get away, not I don’t think about what’s going on at home and just a bit of income really.’

(19KFNR, female, under 50, caring, working – works in care home)

One individual who looked after her husband who was disabled from a stroke and also suffered from Alzheimer’s had been advised by her doctor of the psychological benefits of working. Several carers spoke about feeling appreciated in their work, and receiving thanks, both of which were absent in the caring situation.

Frequently, more than one reason for working was given. The example below illustrates the position of an older individual who has had to reassess her financial and personal situation since becoming a carer for her husband.

‘I suppose firstly, it’s financial. And certainly I have just reached the point where shortly I will be getting my old age State Pension, but that’s the only pension I’ll receive, so if we were just to live on pensions and State benefits life wouldn’t be all that terrifically rosy. So the financial side of it is still important. But also I feel I’ve had…a big change has happened since I’ve kind of become a carer because previously I was probably only working for financial reasons and I was maybe looking forward to…I’d always hoped maybe we could retire to France or something like that and…which I mean I love France, I feel more at home there than I do here, so I’d always hoped that maybe something like that would happen. But because of the change in the situation now, I’m partly continuing to work also because although it’s hard physically, it gives me a break from being a carer, because when I’m at work I have to concentrate on other things and I don’t really have time to worry about what’s happening at home. And so I suppose that, in the last year or two, has become a secondary reason for working.’

(39EFWR, female, over 50, caring, working)

Another commonly mentioned theme was that of providing structure to daily life and a purpose to life more generally.
'Well I think it’s very important for people that are in employment as carers to maintain it. I missed the social interaction of other people very badly. I felt like a fish out of water. Suddenly you’re stranded and your life completely changes. You know, I’m quite a resourceful person and I have a lot of interests if I was able to pursue them, but you know… I always have this thing oh I’ve got that, you know, to do, but I think it must be dreadful if you are, you know, in your 30s or 40s and you are forced to give up a job that you’ve enjoyed to solely care for someone. You know, you’ve given up your life basically.’

(25KFWR, female, over 50, caring, working)

‘I just can’t envisage that my working life could be cut short. It’s not just that financially I will need to work as long as possible, because I’ve never had a big income or that, but I just need to be working. I lose the structure and lose the purpose in life and everything if I stopped working. So even the times when I haven’t been formally employed I’ve been doing voluntary work and stuff. So if I did have to give up working here or something like that, or working in the career that I have, I would do voluntary work. I would do anything rather than nothing.’

(32EFWN, female, over 50, caring, working)

Others articulated in the strongest terms that they were ‘not one of these people that can take benefits’ (40EFWR, female, under 50, caring, working).

4.3.2 Respondents who had ceased caring and were working

Those respondents who were working and who had ceased caring gave much the same reasons for working, the only difference was that they tended to emphasise how much they valued support from colleagues and the social aspects of the workplace.

‘I used to walk in in the morning, I could laugh about it in the morning. You know I’d walk in and someone would say “what was he like when you got home” or perhaps there’d been travel in the afternoon, “did you find him?” and I’d say “oh yes, I found him up the road here”, or that kind of thing.’

(14KFWR, female, over 50, ceased caring, working)

4.3.3 Respondents who were caring and not working

The over-riding issue expressed by this group in relation to work was loss: loss of mental stimulus; loss of financial independence; loss of identity; and even loss of ‘prestige’/esteem.

For a couple of women, giving up work had made them feel guilty and, as this quote illustrates, they even feel they needed the cared for person’s approval for their decision.
‘Before when I’d given up work I felt incredibly, incredibly guilty.’

Why?

‘Because, I suppose it was my husband’s attitude, whereas it was very much…I don’t know. I think it was partly my attitude, because I’ve always been very independent. Also, [name] was very, although he’s very understanding, an odd remark like “oh you’re spending my money again”, whereas it’s not his money, we share everything, you know. We’ve got a joint bank account and everything. Although it probably wasn’t an intentional thing…Whereas this time when I gave up work, it was very much…because I rang him up at work and I explained what the doctor had said and he said “right that’s it”. He, that day, phoned up straight away for the Carers…because I was earning too much at that time to have Carer’s Allowance. He phoned up straight away and got the Carer’s Allowance forms sent here and it was sort of like, it was like he gave me permission to be at home.’

(20KFNR, female, under 50, caring, not working)

Although a minority of respondents in this category were happy not to be working, a more common concern was they now felt they were no longer contributing to society in a wider sense.

‘It gives you a sense of yourself, you know, confidence, that you’re contributing to society, you know, with your taxes, etc. There’s this sort of thing about not working – it doesn’t sit well with me…’

(36EFWR, female, over 50, caring, not working)

4.3.4 Respondents who had ceased caring and were not working

This group reported many of the same aspects of work as those who were not working but still caring. In particular, individuals who had ceased caring commented that they missed the social interaction and stimulus associated with work:

‘Both working with other people and also being part of what I call the working world.’

(12KMNN, male, over 50, ceased caring, not working)

Another male in this group mentioned that they missed the sense of dignity they had gained through their work.

4.4 Carers who were working: combining caring and employment

4.4.1 Key characteristics and themes

Despite the importance of work to their lives, analysis of respondents’ accounts of combining work and care revealed an often difficult balancing act.
Several respondents said that the needs of the cared for person meant that work had to fit around caring. This was seen in relation to the often intermittent and unpredictable requirements of their caring role, or as this example below illustrates, where the cared for person’s needs meant that the entire responsibilities of caring fell to the respondent.

‘She wouldn’t want someone else in and I think at this point in her illness, as well, you have to be pretty stable and not kind of bring different things in to the mix, because that could disrupt her.’

(11EFWN, female, under 50, caring, working – referring to her mother who has Alzheimer’s)

‘My parents would always be my priority really; quite simply.’

(3EFWN, female, under 50, caring, working)

A key finding was that respondents took the responsibility for combining work and caring on themselves. They felt it was up to them to adapt to the work – and not the other way round. Several accounts highlighted the feeling that they did not expect much (anything) from employers (employer support is explored in detail in Chapter 5).

‘I’ve managed to keep everything going and I try not to let what’s happening to me at home infringe on work because, well for two reasons. One is I’m working in a tough, competitive environment, they can’t afford to carry dead wood, you know. I need to be able to do my job properly. I can’t expect them to, you know, carry me, so that means… I mean luckily I’m good at it, so you know I can do my job OK. But the other thing is I need to keep the worst of what’s happening out of work so that I don’t even think about it because then I don’t get upset at work. So that’s why I never discuss anything that’s bad at work, because I don’t want to get upset.’

(32EFWN, female, over 50, caring, working)

There was a strong perception, often based on experience, that employers would view their caring responsibilities as an unwelcome intrusion.

‘Employers don’t like it. They’re not really interested in what’s going on in your personal life. They don’t care. You’re there to do a job of work and that’s… So you can’t blame them, they’re paying your money.’

(24KFWR, female, over 50, caring, working)

The result of bearing responsibility, and often hiding their true circumstances from employers was stress, often accompanied by feelings of guilt.

‘I hated having to pretend to be a different person and it was really, a tough time.’

(39EFWR, female, over 50, caring, working)
'At [name of previous employer] I really felt like my dirty laundry was getting hung up for everyone to see...I always felt so guilty, I always felt like there was a burden upon me and I was like “I’m so, so sorry that this has happened”.'

(33EFWN, female, under 50, caring, working)

This led to respondents feeling indebted to employers in that they were just grateful that someone would employ them.

An overarching theme was either a self-reliance or reliance on family and friends in order to be able to work. This was seen in relation to being able to work in the first place, where we heard frequent references about only being able to work because of the support received from others, most often family members. In many cases, this has obvious implications for the overall quality of life: For example, ‘Rachel’ cares for her son who has severe epilepsy. Her husband starts work at 5am, finishing at lunchtime to allow her to work until the early evening. They both report frequent disturbed nights because of the nature of their son’s disability (for further elaboration see the case study at Section 8.2).

Other respondents felt very strongly that it was up to them to create their own employment possibilities. The quote below is from a woman who is operating a bed and breakfast business from her own house so that she could care for her uncle and still work.

‘Well you have to be a bit imaginative and think of how you can have a source of income...I’ve had to give up my career really and I’m doing bed and breakfast that I really don’t particularly enjoy but it’s a necessity, you know.’

(24KFWR, female, over 50, caring, working)

Another common theme to emerge from the interviews was an anticipation of work ending. It was quite clear that even where respondents enjoyed their jobs and valued them for providing a life outside of caring, if it came to a choice between caring and work, they’d give up work.

‘When you look at it, it’s quite good and it works out quite well. But there could be a time when it doesn’t work out so well, you know, in which case the work would have to come to an end in some way, shape or form.’

(15KMWR, male, over 50, caring, working)

For those who did not enjoy their work, they would stick at what they did for the sake of the cared for person. Some interviews indicated a concern that if the carer was unhappy or suffering from stress, this would have a negative impact on the cared for person. Others voiced their ‘commitment’ to work in terms of their commitment to their cared for person. For example, the woman mentioned above who was running a bed and breakfast business fervently wished to honour her commitment to her mum to look after her uncle.
4.4.2 Restrictions on work

It was clearly apparent that respondents felt that their caring responsibilities restricted their working opportunities in several key ways.

Respondents maintained that caring limited the time they could spend at work (and away from the cared for person). We received several mentions from people who wanted to work for longer than their caring circumstances would allow. Caring was also seen as limiting the patterns of work, with part-time and other forms of flexible working, such as being able to work from home, valued highly. Flexible working is explored further in Chapter 5.

A further restriction related to the type of work that can be done – certain work environments were seen as incompatible with caring responsibilities.

‘Retailing is a dire situation to have telephone calls at work.’

(39EFWR, female, over 50 caring and working)

Several respondents commented that they could not undertake a job that involves travel.

Caring was also seen to restrict career planning and job mobility:

‘It is that but even though I can stay in work and I can do those hours I’ve lost out on promotion prospects a hell of a lot because most of the girls who qualified with me are Sisters and that now but I can’t maintain the work record and it costs...You just cannot get a permanent job because your priority at the end of the day has to be the family and as soon as you take that stance you’re penalised for it.’

(52KFWR, female, under 50, caring, working)

‘It restricts the...the sort of the career opportunities that you’re going to go for because as you become more and more of a carer then obviously there are certain things that you just won’t even consider you won’t go for them because you realise that right from the start that they’re...they’re out. So in a way you kind of frame your career increasingly, including the caring aspect in it. How will the caring fit in amongst it?’

(1KMWS, male, over 50, caring, working)

As the following quote shows a fear of having to explain their caring circumstances to new employers prevented respondents from exploring other job opportunities.

‘So it puts you off thinking about other jobs.’

‘It does. Yeah. It does because then you’ve got to explain everything, that you’re a carer, you know, home has to come first in a way and...I don’t know how employers would be. Would they not employ me if I needed to take time off with a week’s notice or something?’

(19KFNR, female, under 50, caring, working)
However, further comments from people in these situations revealed that they would rule themselves out of job possibilities without even speaking to employers.

Aligned to this was a fear that if they had to give up work because caring responsibilities increased, they would not be able to get back into employment.

4.5 Carers who were not working

4.5.1 Key characteristics and themes

Only a minority said they would like to work and definite plans were rare.

‘…if a position came up.…’

(55EMNN, male, over 50, caring, not working)

Not surprisingly the main barrier to work centred around their caring role and commitments. Most often, respondents were worried that they could not commit to regular hours because of their caring responsibilities – especially as these could be unpredictable in nature.

‘I would love to be able to work. Currently I don’t think it’s possible, because what I have to do at home has to take priority and because of how my husband is, he still needs, at the moment, he’s still getting used to the idea. Consequently he does use me a bit as an emotional crutch and, you know… I can’t really see me being able to say “right I’m going to work”. Go into work and then getting a phone call that says “actually can you come home because I’ve got problems here” as in, if he’s in pain or whatever, which he quite often is. Or if he has a tremor and collapses, which has happened before. I can’t really commit to a job at this precise moment in time when, you know, he could quite easily knock himself on the head and knock himself out, which has happened.’

(10KFNR, female, under 50, caring, not working)

‘You know, if I’ve got to work on a Monday morning, for example, and mum’s got an appointment with the consultant at the hospital and those kind of appointments are very hard to shift. And some employers, you know, are brilliant, they are flexible but obviously you can understand from their point of view maybe they can’t be flexible so I’m aware that when I go back to work there may…there may well be issues.’

(6KFNR, female, over 50, caring, not working)
This respondent added that she would be prepared to lie to get into a job:

‘For example I wouldn’t say I’m the only person who can look after my mum. You know, I would tell a white lie and say it’s not an issue, you know, in order to get the job and then…and then once I’ve got the job then I can cope with any problems that arise. At the moment I just want to get a foot in the door and get back to work.’

(6KFNR, female, over 50, caring, not working)

However, she was also concerned that she would face double discrimination in trying to re-enter the job market – being discriminated against on account of her age as well as because she was a carer.

‘…on the last few CVs I’ve sent out I’ve just started not putting my date of birth on there because, you know….’

(6KFNR, female, over 50, caring, not working)

Others felt that the cared for person would not want them to work, or in the case of disabled children, would not understand them working.

‘Well when I did go into work, and the reason I had to leave was because I actually was so stressed out juggling both at the time, I pulled my muscle. So my doctor actually gave me a sick…I was really ill, but I still was in work. I didn’t want to really leave my work because I was really enjoying it and because of the tension of…I mean your carer’s role does not stop. All the responsibility I have at the office, that does not come into the house, but my children don’t understand, they don’t have sense of feelings, they don’t understand how a person feels. They’ve got to be what they are at that time.’

(43EFWR, female, under 50, caring, not working)

Very often the decision whether to work or not was taken as a couple – either husband or wife would give up work to become the principal carer. Financial circumstances and decisions featured prominently here as did emotional and physical stress.

Some alternatives to regular employment were mentioned. For example, one respondent mentioned that she made some money by providing accommodation for overseas students in the summer.

4.5.2 Reasons for leaving work

The barriers to working discussed above were frequently based on negative experiences which had caused the respondents to leave work in the first place. We received several accounts of unsympathetic employers who had not made it easy for the carer to take time off or who asked them to work extra hours without realising the stress this might cause. For a few individuals, it was the travel associated with their work which became unsustainable.
Some cited financial reasons for leaving working. One carer described how her job in a fashion retailer at £5 per hour left her no better off than having been in receipt of benefits.

‘No. But it was just…Like by the time I’d paid it I had to have a uniform, I had to wear…I think it was all black. I didn’t have anything so I had to buy all that. …it’s just ridiculous and Housing Benefit of course that all gets stopped until they re-do it all and everything and I was just working for nothing. Even the Housing Benefit people agreed with me and the jobcentre. It was working for nothing so….’

(17KFNR, female, over 50, caring, not working)

Because of these reasons, for several, trying to combine work and care simply became too stressful. For some, most often women, the trigger to leave work came in the form of successive caring episodes. Another common exit pathway from work was through illness – respondents took long-term sick leave and then eventually left their job, often more or less completely unnoticed by employers or managers.

‘When I found out…or we found out that she had cancer I become depressed quite honestly and I went to see the doctor and she signed me off for four to six weeks with what she put on the sick note as mental incapacity. It was depression or whatever you like to call it, you know. And subsequently that went when I…other things came along and I resigned from that post. I was Centre Leader for YMCA Training in Margate and that was one way of coping with it and because of their attitudes also so…towards my caring. And thank God that cleared up after that so…It was to do with employer/employee relationships and their attitudes to my caring duties and things like that so….’

(27KFNS, female, over 50, caring, not working)

For several of our respondents aged over 50, it was clear that early retirement had provided a convenient route out of work.

‘I’d been for several interviews because I was off work because of the stress with my mum and my dad and things, so I was off kind of long-term sick. And I went in for several interviews with my manager and they very kindly were trying to work round it, you know, trying to reduce my hours and things like that, but at that stage I realised that it wasn’t going to be possible because I would have had to get someone in, obviously the times that I wasn’t there, because my mum at that stage really wasn’t capable of doing any sort of cooking or shopping or things like that. So I spoke to my manager and I said “I really don’t want to take on the situation, so I’d much rather just go for the early retirement”, which I did.’

(41EFNR, female, over 50, caring, not working)
4.6 Summary

This chapter has provided an overview of respondents’ attitudes towards, and experiences of, work. The focus has been on the difficulties in combining work and care. The overarching finding is that respondents who worked found combining work and care difficult. In the main, they took the responsibility for trying to juggle their responsibilities upon themselves, preferring not to involve employers, perhaps because they had received less than sympathetic treatment in the past. The following chapter explores issues surrounding support in the workplace in more detail.
5 The role of employers

5.1 Introduction
As was seen in Chapter 4, many respondents who were working did so on a so-called flexible basis, i.e. working on some other basis than a full-time, nine to five standard employment contract. This chapter explores the nature of patterns and incidences of flexible working in more detail. A key focus is on the utility of flexible working in helping the respondent to combine work and caring. The second part of the chapter examines the support received from employers, managers and colleagues in the workplace.

5.2 Flexible working
Many of our respondents worked ‘flexibly’. The most common forms of flexible working were part-time working and self-employment. Working from home (which frequently overlapped with self-employment) was also prevalent.

5.2.1 Importance of flexible working
Several respondents emphasised the importance of working part-time to allow them to combine working and caring.

‘Eileen’ was an example of a carer who had reduced her hours from full-time to 24 hours per week (six hours a day for four days). She was keen to emphasise that her decision was facilitated by both the nature of her work (on an IT project team) and by the supportive culture she worked in. Support received is examined further in Section 5.3.

Flexibility was often valued above career and financial priorities, as the following case illustrates:

‘Jacqui’ was caring for her mother who was in the early stages of dementia. Jacqui’s mother lived in a rural part of Scotland, and Jacqui had recently moved to be closer to her. This move entailed a change of job. Jacqui had previously been a lawyer working in a city. She had worked hard to achieve her career goal, and her employer had wanted to retain her.
‘They offered me, part-time, they offered for me trebling my salary, but the job itself was pretty stressful, but it was also pretty fixed. You could never get away with… well it was in [name of city] as well and at that point I was having to be able to go in a lot more often and it would take me the hour and a half to get through to [name of place where her mother lived], so three hours a day was not at all….’

(11EFWN, female, under 50, caring, working)

Her current job in no way used her skills or training and there was no career progression, but it afforded her the flexibility she needed. She was working the equivalent of three days per week for a charitable organisation. Crucially for her, she could work from home and vary her hours on a day-to-day basis if needed.

As this case shows, being able to vary one’s hours can be as important if not more important than reducing the number of hours via part-time work. Several respondents emphasised that working flexibly was not simply a case of fixing up a certain pattern of hours, as their needs changed as caring responsibilities changed (most commonly in response to the deteriorating health of the cared for person) or because of successive caring responsibilities.

5.2.2 Self-employment

Self-employment covered a wide range of occupations: our sample included a self-employed consultant, a journalist, several in the building trade, a bed and breakfast owner, a picture framer and a locum optometrist, among others.

It was clear that for most of these respondents the key advantage of self-employment was that it offered them more control over their pattern of working. However, despite this, it was not viewed as an easy option, as the case of ‘Geoff’ (47KMWR) clearly illustrates.

‘I am self-employed. I price work to customers and go and do work so if things like hospital appointments turn up then I don’t go to work and if she doesn’t feel right I don’t go to work. So it’s very, very flexible.’

(47KMWR, male, over 50, caring, working)

However, Geoff also noted that this flexibility came at a price. Firstly, that attending hospital appointments limited the amount of work he could take on and thus, the income he could earn. He was also very aware of the responsibility of being his own boss.

‘But then there is… With being self-employed you’ve got to find the work, you’ve got to price it, you’ve got to do invoices, you’ve got to do everything. So in some respects it would probably be easier if you were working for someone. But then when you can’t go to work it’s not so easy to be working for someone and so on balance I would say being self-employed is the only thing I could do… really the only way to go.’

(47KMWR, male, over 50, caring, working)
The resulting stress that Geoff hinted at was portrayed more explicitly by others, notably ‘Charles’ (12KMNN) who had been a general manager of a property development company in Australia and then moved to Britain to become head of a regional office. His account highlights the stress involved in trying to combine running his own business with caring for his mother. The situation got so bad that he stopped working.

‘You know, if we wanted to take a normal work situation, what was my role? My role was the boss, or more like the business owner really, so I could organise, and sometimes from the phone, not even being on site, I could organise the trades as necessary, set things up in advance. One really needs to be there ideally, but what I could do was the carer would come here at 8 o’clock in the morning to get mum up and give her a shower and breakfast, I’d be out the door as she arrived, I’d go and spend an hour on site, get, hopefully the day’s or the morning’s work organised and come back. And so they’d be off…you know, of course it definitely isn’t the most efficient way of doing it.’

(12KMNN, male, over 50, ceased caring, not working)

‘Yes, like, again, I’d have some teenagers, like my girlfriend’s daughter would come and sit in with mum for an evening, let’s say. She’d do it for a bit of pocket money and I’d take that opportunity to go down to the job site, see what had happened earlier in the day, make my materials list or my, you know, next day’s to do list, snag list. Whatever I could do I could do in the evening whilst the babysitter was here and then organise it on the phone or the next morning in that first hour. So, from that point of view, it was very flexible. But I think probably by now you realise it could have been quite stressful!’

(12KMNN, male, over 50, ceased caring, not working)

Another variant of self-employment was freelancing.

‘Caring is about having to fit in with events as they happen. You can work around a lot of things but you still need flexibility from the point of view of work which is why for me freelancing from home is ultimately the…the best option because it gives me freedom to make my own arrangements within the…the times that the work has to be done over a period of time but the…my clients aren’t concerned about which days I work as long as the work is done within the deadline. But when you work in an office that’s different, you have to fit in with…with their arrangements because you can’t sort of suddenly turn up and say “hi, I’m working today”, you know, and they’ll accept it. You have to say “well next week it’s going to be Monday, Tuesday, Wednesday”. But mostly they will want you to say “it’s going to be Monday, Tuesday and Wednesday” or whatever every single week.’

(1KMWS, male, over 50, caring, working)
There was a division between those (most often men) who had always been self-employed and those who became self-employed in order to combine work and caring. The former group was typified by 15KMWR (male, over 50, caring, working) a builder who declared that self-employment is ‘in the blood’, or by 26KFWR – a self-employed picture-framer who reckoned that similar skills and ‘strength of character’ were needed to care for relatives as were needed to be self-employed. In contrast, there were a few individuals who were concerned that self-employment did not constitute a ‘proper job’ (26KFWR, female, under 50, caring, working).

### 5.2.3 Working from home

While many of our self-employed respondents worked from home, other (employed) respondents were able to introduce flexibility into their work by doing some of it at home, often in their own time.

‘Yeah. They’re quite good. Yeah. If there’s extra work to do I can do it at home and I can bring stuff home if I need to…they’ve been…there’s a lot of flexibility and support there really.’

(30KFWR, female, under 50, caring, working)

Having some flexibility in taking work home was viewed as essential by some even when there was already some other form of flexible working in place. The following respondent was on a 50 per cent job-share contract but very much valued being able to work from home.

‘A very flexible department who are willing for me to sort of work from home if necessary, carry hours over so I can work from home if necessary. I’m fortunate enough to have a job that allows this. A lot of my work is sort of computer-based, dealing a lot with sort of excel document spreadsheets and so it is work that I can do at home. So they’re very understanding and know that there are times when I have to leave early because I’ve got appointments and they’re very helpful and very flexible and without that it would be virtually impossible for me to work.’

(8KFWR, female, under 50, ceased caring, working)

Another advantage of working from home was to accommodate the health problems reported by many of the carers.

### 5.2.4 Time off

One respondent (38EFWN, female, under 50, caring, working) spoke of her employers five day per year ‘special request for leave of absence’ which helped her along with her line manager’s generally supportive approach. However, this was an exception: much more common was the situation whereby respondents used holidays to take both planned and unplanned time off.

A frequent way of introducing flexibility into employment was to use holidays to accommodate caring requirements.
'I suppose it can be flexible. Because I've got regular clients I go to it's sometimes…it's difficult…Well I have to take holiday…If I need to take time off if my husband needs to go to hospital I have to take holiday or…you know, and sometimes they’re a bit off if I ask for time off.’

(14KFWR, female, over 50, ceased caring, working)

Being able to take unpaid leave was not seen as particularly helpful.

‘In the past they’ve been…well I’ve had various different employers in schools so some have sort of said “well, you know, you can have this week off but you will be unpaid”. Some have said that and…But then the pressure’s there to go back really soon because we can’t pay the mortgage, we can’t…you know, if you can’t eat you can’t care for someone either so it’s…you know.’

(51KMWR, male, under 50, caring, working)

5.2.5 Term-time working

This was a form of flexible working favoured by respondents with children. Although it freed up the school holidays, it was also seen to limit flexibility in other key respects, as the case of ‘Rachel’ below demonstrates.

‘Basically my hours are set, there’s not really any flexibility in them. Because I only work term time – semester time – I don’t have holidays. I basically don’t have any sort of time-off-in-lieu type way that I can move things.’

(2EFWR, female, under 50, caring, working)

It was quite clear that any flexibility in Rachel’s case was achieved through detailed co-ordination with her husband to ensure their son was cared for.

‘For example if my son had a seizure and was in hospital, the way that I try to approach it is if it happens in the morning, then I go to hospital with him, my husband goes straight from work to the hospital and then I go to work, because, although obviously I would rather be with my son, equally it creates a lot of problems for my colleagues. It means other people have to cover, you know, it just creates a whole mammoth sort of thing and I kind of feel, I know people say “you should be with your son”, at the end of the day it just messes everybody else up. It totally screws the schedules, so as long as one of us is with him, you know, that’s pretty much how we’ve done it. Because certainly as well, with my husband’s work, initially when my son developed epilepsy, his work just said “fine, just go” but obviously now because it could be a regular thing, you know, he essentially, no matter how rubbish it makes him feel, if our son’s in hospital he has to work because there’s only so much kind of time off and sort of sympathy an employer can give you and you just have to face it.’

(2EFWR, female, under 50, caring, working)

It was clear that this form of flexibility severely affected her work-life balance. She worked Sundays – the only day her husband has off, so the only time they have
to be together as a family is Saturday afternoons. She admitted that occasionally she had swapped shifts with her colleague who works on Saturdays, but made it apparent that she did not expect her employer to do anything.

‘I suppose informally, the person who works Saturdays and I have occasionally swapped, you know, he’s worked a Sunday for me and I’ve had a weekend off or vice versa and we’ve kind of done that and it’s probably not a very formal arrangement, and it’s been good that we’ve been able to do that at times, that’s helped. It’s difficult to see how they could be more supportive really, it’s just the nature of the job and the kind of out-of-hours element of it that makes it hard to support it.’

(2EFWR, female, under 50, caring, working)

Rachel’s case also illustrates the point that respondents frequently took the burden of combining work and care personally and generally expected little from their employers. This theme is explored further in Section 5.3.

5.2.6 Agency work

Our sample contained a couple of respondents, both working in caring jobs, who belonged to an agency or ‘bank’ of staff which enabled them to control when they worked.

‘Claire’ was an agency nurse.

‘Yes. But I don’t have a contract as such because I’m a bank worker, so I don’t have a contract, I only work when they need me, or when I’m able to work.

So, there are advantages in not having an employment contract?

Yes. And I quite like not having a contract, so that when the summer comes I can just say “I’m not available”.

(13EFWR, female, under 50, caring, working)

Another advantage for Claire was that she could work a certain number of hours per year in order to comply with requirements of her profession. However, she was also aware of the limitations of working on this basis: because she was not an employee she had no rights to request flexible working.

5.2.7 Informal flexibility

Although flexible work was most often mentioned in terms of hours of work or place of work, there were other, less formal aspects of flexibility which often made a real difference to the respondent’s experience of work. As seen in Chapter 4, very often a key caring requirement was being contactable at work. But there was a strong perception, often based on experience, that employers saw this as an unwelcome intrusion.
Employers don’t like it. They’re not really interested in what’s going on in your personal life. They don’t care. You’re there to do a job of work and that’s…So you can’t blame them, they’re paying your money.’

(24KFWR, female, over 50, caring, working)

‘Charlotte’ had moved from a large bank to a small consultancy company. Her case clearly shows the value of being contactable at work. Her account clearly contrasted her current and previous experiences.

‘Yes, I was heavily involved with my parents and there was problems with me being unable to come into work for several days, which they weren’t happy about. Which being a big corporation, the silly things, like my [current] boss lets me have my mobile phone on my desk so that I can always be contacted, whereas [name of previous employer] just wouldn’t allow that.’

(33EFWN, female, under 50, caring, working)

‘I couldn’t have the mobile and I felt that the management structure was not sympathetic of my situation at all. I got told a few times that I was exactly the same as everybody else in the office who had children to care for, when of course it’s completely different. So my dad had some strokes when I was there, they were not helpful about giving me time off. And I think that really stressed me out and that’s when I had such a sore stomach and, in hindsight, I think that that was perhaps brought on, or made more severe, with stress. Perhaps. I mean it was easy for me to just get a doctor’s note and stay off and then I could be with my parents, because I just wasn’t offered any, I mean no support at all. My parents weren’t allowed to phone in the office or, see what I mean? I was sitting all day thinking something might have happened and I don’t know, and there was no system in place where…I mean right now, if something were to happen to any one of my parents, I could text my boss at any time, through the night, and I wouldn’t have to worry about it.’

(33EFWN, female, under 50, caring, working)

Charlotte’s story was echoed by others and illustrates the short-sightedness of employers who discourage contact at work. Previously, her focus on work had been disrupted because she would worry about her parents. Now, with that worry removed, she could get on with her work and consequently be a better employee.

Another advantage of being allowed some flexibility in the use of the phone at work was to allow for outward communication.

‘Well basically if there’s phone calls to be made I do a lot from my work, you know. My work are quite understanding, you know, and I can maybe type up things, letters, and make phone calls and when I finish work my husband will take me round after work and I’ll gather her washing or whatever.’

(38EFWN, female, under 50, caring, working)
5.3 Support from employers

5.3.1 Official policy on employing carers

The past and current employment experience of our respondents revealed that very few employers had a formal policy of offering flexible working. The clearest example of a central approach to flexible working came from a large retailer.

‘When you get an application from Asda, you’ve actually got a time grid on the front of the application form that you can specify which hours are actually OK for you working.’

(40EFWR, female, under 50, caring, working)

The more common scenario was that illustrated by Claire (13EFWR, female, under 50, caring, working) or Rachel (2EFWR, female, under 50, caring, working) in Section 5.2, whereby their employers (nursing agency and university respectively) made no special allowances for being a carer – it was simply the nature of the job that meant there was some flexibility in combining working and caring.

5.3.2 Employer support

As was seen in Section 5.2, despite a lack of overall official policy some respondents did receive support from their employers to work flexibility. This support manifested itself in a number of ways, including making adjustments:

‘When I was doing FPC qualification it was technically we have to go away to Birmingham for three weeks, continuous weeks, and I had actually said to them that’s there no way that I could do that and what they eventually did was they actually got a trainer to come to Edinburgh and train me one-to-one. They actually sent somebody here for three weeks instead to train me one-to-one.’

(45EFWR, female, over 50, caring, working)

Other employers offered support by holding a job open during a particularly difficult time for a carer:

‘I mean they were fantastic because they actually said to me “oh do you want to do it and do you want to continue doing it?” And I said “oh yeah”. And it’s just a matter of when [name of son] is ill they know I won’t be there and I just phone up and they say “right that’s fine” and we’ll just find somebody which sometimes can be a nightmare but at other times…I mean that’s a nightmare for them but they are very good with me and they’ve been fantastic to hold my job open for me. So...Because there’s not a lot of people that would do that I don’t think, especially when it’s so unsure about what’s going on with me.’

(29KFNR, female, under 50, caring, not working)
This support was most often seen in relation to long-serving employees.

‘Yes, they’ve always been good. They were good when [name of daughter] was ill, because as I say I’ve been there for about 30 years, 30-odd. More than that, but I was part-time the other time, it didn’t count or something. But, no, when [ ] was very ill and they thought she wouldn’t live they gave me, they paid me kind of a little bit of money which kept me going, which was very helpful, so they’ve been good to me, I’ve tried to repay it.’

(14KFWR, female, over 50, ceased caring, working)

The experiences shared by the respondents revealed that although a few employers were active in identifying when a carer was struggling and would help them come to some suitable arrangement, a more passive approach where it was up to the carer to approach the employer was much more common. The quotes below illustrate examples of active and passive approaches to employer support.

Active management

‘But what was happening now is I changed my work time a bit and I spent…I had a longer lunch break. I started a bit earlier and finished a bit later but that meant I could come up here. So [name of wife] instead of being all day to herself she was now…had two sections because up until this time she was still mobile and could get around and…out and about to the shops and that but then that was becoming more difficult for me. No, it was at this time here, sorry, that I started to actually…2004 I started to work four days a week and that was for two and a bit years. And then at this stage I needed to come down to three days a week but in fact things had got to the stage…because that had gone on a little bit longer than I expected. By the time I needed to come down to three days a week [name of wife] really needed me there all of the time so I actually worked from home for those three days a week and we’d already decided who was going to take over from me and he just came into that role a little bit more precipitously than he thought he might do but obviously I was on the end of the phone and we’d talk and…So that changeover was a little bit difficult. And then I stopped more or less when I’d expected I would have done, which was February of ‘07 when my normal retirement age would have been now, October 2008.

OK. OK, well that’s excellent. So it sounds like it was quite a collaborative effort.

It was.’

(12KMNN, male, over 50, ceased caring, not working)
Passive approach

‘I had a team leader at the time and I went to her and said, “you know, it’s just becoming…” No, I’d had to approach them before that because I think I was doing the nursing care and still the consultant that wanted my mother being brought into the clinic twice a week and it was only running in the mornings and I was going to have to be coming in and going out. I needed to get some sort of authorisation for that. So I had brought it up and the team leader that I had then, she was someone who was very difficult to get to know as a person, I didn’t know what to expect from her, but she was actually very, very sympathetic. And that was about three months before I asked for part-time work, because I realised I couldn’t continue, I couldn’t do enough caring to meet my mother’s needs at the time. We had tried to talk my mother into getting the home-helps and the various council support which she refused. So I thought, well, it’s me that has to do it. So then I went and said I’d like to work part-time and here’s a working pattern I’ve worked out, what do you think about it?’

(32EFWN, female, over 50, caring, working)

Other employees received very hostile treatment in aiming to combine work and caring, as a return to Rachel’s case shows:

‘No. I didn’t want to go back full-time. It was looking like I was going to have to go back full-time. I’d applied to work flexibly and it was turned down, and basically there was just no degree of flexibility whatsoever. I was told basically full-time at the exact times or nothing. But obviously I had to go back to pay back my maternity money, which at that point was just not an option. So that was extremely stressful, and really difficult, and then I managed, practically the week before I was due to go back to work full-time to get a part-time position with another department and basically they just kind of let me go without giving any notice, so that….’

(2EFWR, female, under 50, caring, working)

In some cases, such as that illustrated below, this lack of sympathy and support led to the respondent leaving employment.

‘Yes. Dad passed away the end of December, I was on my Christmas holidays of course, Christmas, New Year. I had to decide what we were going to do. My work gave me three days compassionate leave and that was it. Just three days. Which I felt a bit… I mean the rules that they did, but when I thought about it, I couldn’t remember the last time I’d had a day off sick. I mean the whole of 2006 I hadn’t had a day, I know for a fact. 2005, I think maybe one or two odd days, you know. So I went to my doctor anyway and he really signed me off for two weeks. He said “I can’t give you any more, but I can certainly sign you off for two weeks, I wouldn’t worry about that”.

The role of employers
Well he just put ‘stress related to death in family’ and that was it. And it gave me a bit of time to think what we were going to do in terms of looking after mum. So I put my notice in at the end of the time, thinking I’d like to see my employer and handed my four weeks’ notice. And actually they were quite good in the end, they didn’t bother making me work any of that time. They said “that’s fine”, you know, they understand, etc. So that was that.’

(46EMNN, male, under 50, ceased caring, not working)

### 5.3.3 Line managers

A supportive line manager was often key in the experience of combining care and employment. In many cases, despite no official policy to support carers, line managers were very supportive of individual cases. For example, despite having no official policy of flexible hours, 38EFWN reported how her line manager was able to assist.

‘I mean if I have to, my line manager’s not too bad by the fact that I’ll maybe cut my lunch hour short the next day or whatever, to make up sort of. We’ve had to attend meetings as well maybe, concerning mum’s care, and I will get, you know, I’ll put that in, but they tend to put it in blocks of half days, you know. So I try and maybe just make up the time.’

(38EFWN, female, under 50, caring, working)

Another carer spoke of how her boss supported her attending her local carers’ association.

‘I suppose even coming for these meetings for Vocal, for five weeks, I wanted to come to these training sessions and obviously they were during the working day and I was just told by my boss “take the time. If you want to find out what you need to know, I don’t have a problem with that, take your time and just go”. I told them enough time in advance what I wanted to do and it was very much like “just do it”. So they are supportive in that way, they will give me time for like attending Vocal things.’

(45EFWR, female, over 50, caring, working)

And another account showed how informal support from the line manager continued, despite a set-back in official policy.

‘When the discussion was going from part-time to full-time they were fully aware of the situation and with the flexi-time system they said yes, take what flexibility you need and they would try to find ways to help. So very supportive. Then of course just before Christmas we had this thing come out of the blue banning all flexi-time. So there are times when I have to take time off. I keep my own time record. My supervisor hasn’t asked me for it, but she can see it any time she wants to, and my conscience tries to…I try to make up the time as and when I can. So it is a flexi-time situation, but it definitely took a dent when we had that universal email coming round.’

(9KFWN, female, over 50, ceased caring, working)
However, having a sympathetic line manager was not viewed as a suitable substitute for an overall policy in that differing practice across areas of an organisation could cause problems.

‘Well you have to ask and it’s all at the director’s discretion. That’s the problem with the University. It’s not “here’s a policy” and everyone has to follow it. They have policies and then they say “ah but we’ll just let all these little autonomous autocrats determine everything for themselves” and there are all sorts of things going on here and it’s different all over the place.’

(32EFWN, female, over 50, caring, working)

The case of ‘Alan’, a teacher highlights what can happen when a sympathetic line manager is replaced by one who is less supportive. As Alan’s wife explains a lack of consistency of approach was seen to be very unhelpful:

‘Obviously with his job recently changing, his head [teacher] recently changing, and it’s a shame that it seems to me that she’s not aware of the policies about flexible working for carers or that carers should be afforded this like emergency time to care for someone who is in crisis because she doesn’t appear…well her actions don’t support that she understands any of those policies and so I guess it would be nice to think that there was some kind of programme that was making employers aware of that. And we’re working in the public sector so especially, you know, even in that sector which is more controllable probably than the private sector in some ways but not even happening there. So it seems very person dependent is our experience. We’ve had two good heads and two bad ones, for this purpose, you know.’

(Wife of 51KMWR, male, under 50, caring, working)

Another issue arose when an individual boss might be supportive but then need to be backed up by the employer, or by their representative – Human Resources (HR) in this case.

‘Yes I took a week off recently because [name of son] had had an operation and I had to do that at fairly short notice because I wasn’t aware that I was going to have to take a week or so off work without him going back to nursery or what have you. But the department had absolutely no problem with that. Had to persuade HR that they had no problem with that, but the department were fine! …I mean there’s things like you’re supposed to give two or three weeks for a period of parental leave and then in small print “unless the department agree otherwise” and HR were saying “well we’ve not had our three weeks notice” and the department’s saying “no, it’s fine”.

(8KFWR, female, under 50, ceased caring, working)

In line with Alan’s account, this respondent very clearly articulated the value of having an overall policy that was shared by individual managers.
'I think in order to stay employed I do need to have an employer that will understand and will appreciate the sorts of external pressures I have as well as the internal deadlines as well.'

(8KFWR, female, under 50, ceased caring, working)

5.3.4 Support from colleagues

Several respondents spoke very warmly about the positive support they received from their colleagues. This support was emotional:

‘They’re great. They can be very, very supportive. They’re always there to listen.’

(40EFWR, female, under 50, caring, working)

‘I suppose there’s the emotional support in terms of if I’ve had a bad day or bad morning, there’s always people I can have a moan to, let off a bit of steam with. So I suppose they may not realise it but they do actually give me a degree of emotional support as well.’

(8KFWR, female, under 50, ceased caring, working)

And instrumental:

‘My colleagues were as flexible as it was humanly possible to be and yes they were very understanding. ...I was specifically told when I was being interviewed and I was trying to ask a question like could my three days a week be bunched into four days a week in term times and then could I have weeks off when my son’s home? And they said “don’t ask that question, we’ll organise that informally”.’

(50KFWR, female, over 50, ceased caring, working)

However, set against this were frequent mentions of lack of support and understanding from colleagues.

‘You just get little comments like that, you know. Sometimes I do know in advance of hospital appointments and things like that and I do give them notice but, you know, anything could come up out of the blue just....’

(19KFWR, female, under 50, caring, working)

Another, older respondent spoke about how she had been marginalised by her younger colleagues for ‘always’ talking about her mum.

Given this sort of reaction, it is unsurprising that several respondents chose not to tell their work colleagues about their caring responsibilities.
‘So you seem to have very supportive management?

Very supportive.

And what about colleagues?

Yes, I would say they’re supportive. I mean they don’t know of my situation.‘

(33EFWN, female, under 50, caring, working)

‘To be honest, I don’t really talk an awful lot to my colleagues about…I mean they do know that my son has epilepsy, they do know that. They don’t know so much that I have depression because I’d prefer…I think sometimes people view you quite differently and label you. I don’t really say too much about that. And on a Sunday I’m a lone worker, so I have nobody to talk to and that didn’t bother me when I worked Saturdays and Sundays on my own, but more recently I’ve found that quite isolating and didn’t really enjoy it as much.’

(2EFWR, female, under 50, caring, working)

This latter quote is another from Rachel (see Section 5.2.5), and emphasises the socially isolated position she was in at work. This lack of colleague support and isolation extended to her line manager who was in a different location and, therefore, only contactable by phone or email.

This relates to a more general point, that telling colleagues that they were a carer was a big event for many of our respondents. This reflects the point raised in Chapter 4 about carers viewing their caring responsibilities as private and trying not to effect a burden on employers or colleagues.

‘Yes. But I don’t really discuss it at work at all. I did tell, well not quite the owner, but the semi-owner of the business, at the beginning of the year that [name of husband] had also been diagnosed with Alzheimer’s, because I thought I should tell her that there were problems. And she was actually very nice about it. But I said that I really didn’t want it to affect, it wouldn’t affect my work, and I was just telling her to keep her informed. And I wasn’t upset when I was telling her, it was rational, calm, and I said that, you know, I would do my job as usual, but I thought she ought to know. So they do know, but I don’t talk about it at work. I mean I might occasionally make a joke, you know, and I do now say more than I did a year ago. A year ago I wouldn’t have said anything at all. But I’ve realised now that I have to, I can’t pretend everything’s alright anymore, which is what I used to do. So now I will maybe say to the girls, I’ll tell the girls for instance that [ ] doesn’t go to the supermarket any more and that I’m now getting a home delivery from Marks and Spencer’s to make my life easier because I’ve got a lot to do. So I will say things like that, which 12 months ago I probably wouldn’t have said.’

(39EFWR, female, over 50, caring, working)
However, keeping caring private and hidden is not necessarily a good strategy. As has already been shown in Chapter 4, this was stressful for the respondent. The following quotes show a rare example where the cared for person – the respondent's son – was visible. The fact that colleagues knew her son meant that colleagues were more supportive.

‘What about colleagues? What sort of support do you get from them? Is there any difficulty there?'

No. Probably as the manager they don’t question what I do! And I must admit they’re very, you know, “[name of son] comes first” as well because they’ve all met [ ].’

Oh, in what circumstance?

Probably because my husband’s brought him in to meet me after work on a Saturday so they’ve all met. They’ve all met him and a lot of my staff have been there five years so they know all about him, not know him, but they know who he is.’

(45EFWR, female, over 50, caring, working)

5.3.5 Culture of the organisation

Several respondents spoke about working within a supportive culture, where colleagues and managers alike were sympathetic and helpful. For example, Eileen (see Section 5.2.1) worked in a department which generally supported part-time working whatever the needs for this.

‘No, there’s lots of people part-time. There was even one guy who’s still there, he works half time now, 50 per cent, and it’s really because he wants to spend, he’s got two young children – he’s a couple of years older than me and he’s got these very young children – and he just wants to spend more time with them….’

(32EFWN, female, over 50, caring, working)

‘Jill’, also highlighted the support she received from her school and wondered if their sympathetic approach might arise from the nature of the job.

‘Yeah, and they’re also very good if there’s illness and…if there’s a problem, a hospital appointment for him or anything like that they’re very good and supportive for that sort of thing.’

(30KFWR, female, under 50, caring, working)

‘Well I know some other parents have said…you know, who work in a normal nine to five job and they’ve had issues coming to appointments for their children, you know, and so…I don’t know if that’s because of working in a school or something…you know, that they are more understanding of what I have to go to, you know?’

(30KFWR, female, under 50, caring, working)
5.3.6 Employer trust

A recurring theme was respondents feeling that employers did not trust them. ‘Charlotte’ (see Section 5.2.7) had previously worked for a large bank and spoke about the difficulty of taking time off to care for her parents and the lack of trust from her managers and colleagues.

‘But I got asked a few times, like “well if you can prove to us, because you could just be doing anything, couldn’t you?” You know what I mean? It was so mis-trusting and they just didn’t believe for a second that I was doing what I said I did….’

(33EFWN, female, under 50, caring, working)

She had since moved to a much smaller organisation who were much more trusting and accommodating. She contrasted her current and previous situations.

‘I mean right now, if something were to happen to any one of my parents, I could text my boss at any time, through the night, and I wouldn’t have to worry about it. Whereas with [name of previous employer], if I had to take a day off then I would have to phone at 9 and then I had to phone back at 10 and explain to them whether I’d be in and there was an awful lot of rules which got in the way of my responsibilities.’

(33EFWN, female, under 50, caring, working)

5.3.7 Limits to support

Even the most supportive situation was seen to have its limits – in several cases this manifested itself through an ignorance and lack of understanding of the nature of caring responsibilities and the difficulties in being a working carer. For example, although Eileen’s employers were clearly supportive of part-time working, it became apparent that they did not fully understand the requirements that caring might involve and the needs for other forms of flexibility. For Eileen, the problems came when she tried to take emergency time off to look after her mother.

‘You know, the nurse just phoned me at work and I had to go. But it was an emergency, it was completely unplanned and this director says to me “oh the policy we operate for family leave is that it is to cover for emergencies” and OK he accepts I had one, “but obviously I hope you don’t have more on this particular event. Are you through the period where unexpected issues are going to happen?”.’

(32EFWN, female, over 50, caring, working)
‘Well one of these things, like family leave. It’s a problem in itself because it is OK just for emergencies but you apply for it, or you request it in retrospect. You have an emergency, they phone you up “we’ve got an ambulance coming”, you get out there, you get over to where she is and you deal with it then. And the next day you come back to the office maybe and then you say “could I please have family leave for yesterday?” What if they say no? Why should I not…I threatened with my own manager, I said, “look, next time I’m just going to phone in sick”. It’s a bit difficult when you’re sitting there at your desk and you get the phone call from the nurse and it can’t be “oh I’m feeling unwell!”.’

(32EFWN, female, over 50, caring, working)

Another respondent spoke of how employer sympathy was very much second-place to the needs of the business.

‘I’d say it was management. They were more worried about having the centre run effectively and efficiently with a body in there than worrying about me worrying about my caring. And as I remember I phoned them up…I went from work with my wife for her diagnosis and I came back home…well to the job…the place I was working and I was upset rightly and I just phoned them up and I said “I need to have time off because I’ve just found out my wife’s got cancer”. And I had a deputy there but they were more worried about making sure that they had somebody over her in authority than just letting me go off. They said “you can’t just go off home now” and that, you know? It was a bit heated and a bit upsetting and things like that. But from then down on their attitude to me was…It just became more distant. They said they understood but there was always these management issues behind it that they had somebody over her in authority and delivering the contract and that sort of thing so…Yeah.’

(35KMNR, male, over 50, caring, not working)

5.3.8 Disempowered employees

As with other research into employment rights, respondents in our sample were very often unaware of their rights under the law (to request flexible working or to have time off for emergencies). Some had a general awareness of their legal entitlement but either it did not apply to them (e.g. not enough service to qualify) or they did not want to disrupt their employer and/or workplace.

‘That was what was suggested to me by my counsellor at Vocal today. She said “what about having an extra half day off a week if they would let you do that?” And my reply to that was, “well for a start I wouldn’t even dream of asking them at the moment because we’ve got a lot going on and we’re short-staffed and there’s a lot of pressure, so it wouldn’t be the right time to ask”.’

(38EFWN, female, under 50, caring, working)
Even where employers were supportive (as in the case of Charlotte), respondents frequently felt uncomfortable in asking for more.

‘I’m at the bottom of the ladder, you know, I’m an assistant consultant, I’m struggling to get…you know, I’m struggling to get up the ladder and I don’t know how comfortable I’d be asking for anything more than what’s already given to me. Despite the fact that I may or may not be entitled to whatever. I still, I would feel that it would hold my personal development back.’

(33EFWN, female, under 50, caring, working)

### 5.3.9 Need for a range of sources of support

It was very clear from a number of accounts that employment support for carers was much broader than employers’, managers’ or colleagues’ support. ‘Ash’ (43EFWR, female, under 50, caring, not working) had previously been employed as an information advocacy worker, helping other carers who looked after children with special needs. She enjoyed her work, felt experienced and useful and was supported by colleagues.

“In our [name of place] office there were four of us and then there was the manageress and there was an information worker. And they were very good because everybody was a carer except for the two of them.’

(43EFWR, female, under 50, caring, not working)

However, the sheer weight of caring for two children with special needs with only a minimum of other support highlights the fact that employment support for carers needs to be examined from a range of support sources. This is the subject of Chapter 6.

### 5.4 Summary

This chapter has provided a detailed examination of the ways in which employers, managers and colleagues supported carers in the workplace. A patchy picture emerged, one with some positive aspects, but a key finding is that carers are not particularly visible to employers. There was, at times, a lack of understanding or appreciation of the particular requirements and difficulties of combining care and employment. And the predominant approach was ad hoc rather than strategic or informed.
6 The role and effectiveness of informal and formal sources of support for carers

In this chapter we report more generally on the role and effectiveness of both formal services and family and friends in supporting carers, and those they care for, to be able to work or seek employment. Inevitably, and as is consistent with wider research, carers’ perspectives on the role of support reflected the multifaceted nature of being a carer and the interlocking needs of carer and cared for. The chapter is made up of three sections: one focusing on formal support, one on informal support, and one on overarching issues. Whilst the emphasis in this chapter is not on employment directly, the broader context of support, or lack of it, is significant for carer’s ability to remain in, or go back to, work.

6.1 Support from formal agencies

As was made clear in Chapter 2, over the last decade there has been increasing emphasis on enhancing the role of statutory and voluntary sector agencies in supporting family carers. A particular policy driver is the need to support carers to continue to, or seek, employment opportunities. There is now widespread recognition that in order for carers to be able to work services for their disabled relative need to be accessible, robust and reliable. The predominant formal agencies involved with disabled people and their carers are the NHS, social services departments and the voluntary sector. Evidence in this section is, thus, presented around these three providers and reflects both the effectiveness of services for cared for relatives and carers themselves.
6.1.1 The NHS

Mixed views emerged about support from the NHS. Overall there was much less said about the NHS than social services; this reflected the fact that most disabled people and their carers need ongoing support, which is primarily the responsibility of the local authority, as well as the fact that helping carers is traditionally viewed as a social care function rather than that of health.

For some, primary care and most notably the GP, was a source of constancy and support:

‘Mum’s doctors, her GP especially, has been wonderful.’

(41EFNR, female, over 50, caring, not working)

For others the GP has provided access to, and a link with, a range of services:

‘My GP, she’s very good. And I see a counsellor at the practice as well. And there’s an Admiral Nurse that I’m going to be seeing and Ann the CPN comes around quite frequently and always goes with us when we go to see Dr Smith who is the psychiatrist.’

(4KFWR, female, over 50, caring, working)

As is clear from the last quote, nurses also have a significant role to play. A minority of cared for people received input from nurses; some were specialists in the particular health condition. Although appreciated, carers felt that they were in short supply and tended to focus on specific health care tasks rather than on providing support to either themselves or their relative:

‘Well the specialist nurse rings me now and then…but she doesn’t really visit, only if I really need help with Richard’s medicines, then she’ll come along.’

(26KFWR, female, under 50, caring, working)

‘The Parkinson nurse…she doesn’t actually pay visits, only if you ring her for some reason. She’s spread from Ashford to Thanet to London…..’

(15KMWR, male, over 50, caring, working)

‘He had a Community Nurse who comes in at the moment one day a week to site his infusion and they ring up most evenings to check whether he can take it out by himself because the [home] carers aren’t allowed to touch it officially.’

(50KFWN, female, over 50, ceased caring, working)

In contrast a number of carers with relatives with dementia got specialist input from an Admiral Nurse; these are specially trained nurses whose role it is to provide practical advice and support to dementia carers. In addition to home-based, one-to-one input they often run local carers groups. They tended to be highly appreciated:
‘We also have an Admiral Nurse…she is brilliant.’

(18KFN, female, over 50, caring, not working)

‘…My carers group, that’s run by Admiral Nurses. And that’s been very good, very useful indeed.’

(12KMNN, male, over 50, ceased caring, not working)

Discharge of their relative from hospital appeared to challenge the NHS in terms of providing a package of support and medical advice:

‘When Jasmine [disabled daughter] came out of hospital I realised I needed a commode and stuff like that for her at home and nobody had sort of said to me where to get it…they sent us back to Dover from a London hospital with nothing and you’re on your own with this child and this big bag of medicine. And she can’t walk and she can’t move…and you know she’s 13 but she’s 11 and a half stone so I was lifting her and picking her up and virtually carrying her around.’

(23KFWR, female, under 50, caring, working)

A number of carers also commented on waiting lists for primary care-based services such as counselling:

‘I did apply for a counselling service but the waiting list was six months…and by the time my name came to the top of everything that I’d wanted to speak about at the time has changed so much was just “what’s the point”’.

(37EFNN, female, under 50, ceased caring, not working)

6.1.2 Social services and social care

Broadly, the social care sector is made up of local authority social services departments and private social care providers such as home carers who may be purchased directly by users or carers or commissioned by social services. Both disabled people and carers are eligible for ‘assessments of need’ by their local social services departments, to care plans and packages of service provision. Accessing this depends on the level and type of ‘eligibility criteria’ which tend to be set at a relatively high level i.e. a person has to have a serious level of disability before they are eligible to receive support.

Evidence relating to social care falls primarily into three key areas: respite care; social work and assessment of need; and paying for care.

**Respite care**

Respite care refers to alternative care that provides ‘respite’ or a break for carers. It most often takes the form of a period in a care home for the disabled relative or a sitting service whereby a paid or voluntary carer comes into the home whilst the carer goes out. Greater availability of reliable respite care, particularly in an...
emergency, is one of the key provisions outlined in the Carers Strategy\(^3\) mentioned in Chapter 1. Research evidence suggests that respite care tends to be highly valued by carers; it performs a pivotal role in helping carers to live a life ‘outside of caring’ and, for some, to rest.

Respondents in our study viewed respite as providing an opportunity to manage domestic activities, pursue interests or simply have a break from caring:

> ‘Respite care…it was really a sitting service and I had carers in for two occasions during the week for about 2.5 hours. This allowed me just to take some time to go out and do things such as going to the dentist and the other session allows me to play in an amateur orchestra every Monday evening.’

(12KMNN, male, over 50, ceased caring, not working)

> ‘…and I got to a point when I was just so low and I thought I’ve just got to do something about this. And I phoned my husband and said “I’ve blanked out three weeks in October”, I said “I’m phoning social services and I’m going to see if I can get respite care”, which I’ve done. He’s going to go for three weeks to Sampson Court and they are lovely there and I have booked to go to Italy. Because we’ve not had a holiday since I can’t remember….’

(25KFWR, female, over 50, caring, working)

Some carers needed trained paid or voluntary carers to provide a sitting service:

> ‘The other thing we do get is four hours a fortnight respite care. It’s kind of like a sitting service. The lady comes, she’s trained to deal with epilepsy and she comes in and gives Alan his medicine and plays with him and then puts him to bed and is there whilst he’s sleeping.’

(2EFWR, female, under 50, caring, working)

It was striking how little carers received in terms of respite care and how difficult it could be to access it:

> ‘She [daughter] went in for two weeks respite. Well maybe it was naïve, I guess I thought originally that we would maybe get respite every weekend or something like that. The social worker came round and said you’re entitled to four to six weeks of respite a year and it has to be in blocks of a week minimum at a time.’

(46EMNN, female, under 50, ceased caring, not working)

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‘I only get respite because Greg went into crisis. Greg was ill and just went totally, like, mad…getting up in the middle of the night and eating…loaves of bread and six yoghurts and I couldn’t cope any more.’

(19KFNR, female, under 50, caring, working)

Also, if cuts were made to respite provision how difficult that can be for carers, as these parents of two autistic children attested:

‘I waited five years for the Action Group…and we could have up to five weeks, the boys would be off to a summer play scheme, meeting other children, making friends. That gave us a bit of a break to recharge our batteries and be ready for them. …and now because of the funding issue they’ve cut down to two weeks. So we actually now get seven weeks of summer holidays with the children but two weeks of respite. So it’s not really enough.’

(44EMWR, male, under 50, caring, not working)

The role of respite care in facilitating employment was less clear although a small number of carers did comment on its value in this respect:

‘Well the support of the carers [sitting service]…gave me the freedom to get on with my work without the worry of coming home and funding mum in some terrible mess.’

(16KFWR, male, over 50, ceased caring, not working)

‘Yes I have a carer comes in and does nights whilst I work.’

(24KFWR, female, over 50, caring, working)

For most working carers though, however useful respite care is, it was not directly beneficial in helping a carer to work. Before it could be considered useful for working carers there would need to be much more investment in respite provision and it would also need to be far more accessible and flexible:

‘The most respite care I’ve had is four weeks. I have to book respite a year ahead if I want to get it in Edinburgh, so within the realms of being able to work if I needed emergency respite.…’

(36EFWR, female, over 50, caring, not working)

Paying for care

Unlike NHS provision, which is free at the point of delivery, care provided or commissioned by social services can be charged for. In addition a minority of carers opt to pay privately for care services, most usually home care or a sitting service.

Charges are paid only by those whose income is above a certain threshold; most only pay for a part of their care package:
‘She pays for part of it [care package]…she was assessed financially, she has two pensions which makes her above some sort of limit so she pays.’

(21KMWR, male, over 50, caring, working)

‘…the only thing we pay for is respite. They paid for the bulk of it [social work services] which was over £500 and I think the family had to pay £70.’

(46EMNN, female, under 50, ceased caring, not working)

‘The only thing we currently pay for is if somebody’s…a sitting service, people babysit for James so we would have to pay for baby-sitting or, for example, during the school holidays to look after him during the day so I can go to work.’

(8KFWR, female, under 50, ceased caring, working)

Some social services departments provide vouchers for carers to use to buy in their own care, whilst others use direct payments or welfare benefits to help with service costs:

‘We get respite vouchers to be used at the Lothian Autistic Society that produce a list of carers that have worked with children with autism. We’ve got a carer called Ben who takes them [two autistic sons] every fortnight because that’s all I can pay him…the vouchers [cover] the number of hours he’s working with the children, extras we have to pay for…around about £10-£20 depending on what activities they’re up to.’

(43EFWR, female, under 50, caring, not working)

‘I paid for most of it [sitting service] out of my own pocket. I managed to spread the direct payments out to cover some of it and I made up the rest myself.’

(16KMNN, male, over 50, ceased caring, not working)

‘For the Independent Living Fund [ILF] you are financially assessed and you contribute towards the home care and we contribute towards the respite care. The money from the ILF is to pay for a personal carer to come in.’

(36EFWR, female, over 50, caring, not working)

The potential to use direct payments to fund care to help carers to work was noted by a few respondents. One parent, for example, wanted to use them to extend her working day:
‘I’m wanting to investigate direct payments and things like that. Because it would be easier for me if I didn’t absolutely have to work school hours, because it makes my day very condensed. Literally I’m dropping James off at school, run into work, do as much as I can before I have to turn around and come back and pick up James. Direct payments could be used to pay for one to one support after school, I can then work longer hours and take proper breaks.’

(8KFWR, female, under 50, ceased caring, working)

Some carers paid privately for care services. Although this is expensive it tends to offer choice and flexibility and the carer, and user, can build up a relationship of trust with agency staff:

‘So I went to this agency and I got regular carers from there now and they’re very good. They’re not trained nurses but they’re compassionate and have an understanding of the old. They know how to change them and make sure there are no bed sores…So it works but it’s expensive.’

(26KFWR, female, under 50, caring, working)

‘I’ve found people privately…via somebody else who was in a very, very similar situation but a few years ahead of me. So these people are working not only for my mother, they’re also working for this other chap. I’m getting the people that I think suit mum. Continuity of whose coming in. …I know who’s coming in and I’ve built up a relationship with them. It costs a lot though, the people they came to me from told me they’d spent over £50,000! It’s really scary.’

(9KFWN, female, over 50, ceased caring, working)

Social work and assessments of need

In law only carers that provide, or intend to provide ‘regular and substantial levels of care’ for someone for whom the local authority may provide community care services are eligible for an assessment of need (Carers UK, 2001). Although it was clear from the interviews that carers were not always sure whether they had had a formal needs assessment or not, surprisingly few carers appeared to have asked for, or received, an assessment. As most would qualify for one, this is a concern. Higher numbers of carers had regular dealings with social workers or care managers whose role was primarily to assess the needs of, and provide services for, the cared for person.

Assessments were felt by carers to be primarily focused on practical support for the user and that after the assessment and care planning period regular input from a social worker ceased. If needs changed this required a new referral:

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‘Right at the very beginning I said that all the things they were offering like meals on wheels or cleaning or washing I could do myself. I didn’t need anybody to come in and pay somebody for what I could do...so [they said] “we’ll leave it with you, just get in touch if things change”. That was the only assessment.’

(48KMNN, male, over 50, ceased caring, not working)

‘That’s one of the problems with social work, it’s not ongoing…there’s no ongoing check to see if you are ok. Once they’ve finished with you they close the case down.... And then when you start again you’ve got to go through all the rigmarole again.’

(48KMNN, male, over 50, ceased caring, not working)

‘I have no social worker or care manager ‘cos he [the user] does not need personal care and the case has been closed down so I’ve got no one to fight my corner.’

(19KFNR, female, under 50, caring, working)

Some carers had tried hard to get access to a carer’s assessment or a care manager:

‘I’ve been trying and trying to get one [an assessment]. My cousin lives in Liverpool and she is a social worker and she says I’m entitled to a carer’s assessment…I sent e-mails and I had the head of the area of social services for this area and he said I am not entitled to it because what am I doing when my child is at school? …I have respite then. That’s what he said to me. I have got the letter somewhere, it’s absolutely disgusting. And my cousin in Liverpool is going off on one but she can’t really intervene but they won’t give me one. They say it’s for people that are looking after elderly people, not for somebody that’s at school.’

(16KFWR, male, over 50, ceased caring, not working)

‘I tried but there are too many people wanting a social worker…I did ask for one but was turned down.’

(23KFWR, female, under 50, caring, working)

Others had high praise for their care manager:

‘My care manager is fantastic!’

(14KFWR, female, over 50, ceased caring, working)

Where assessments had been done, or were about to be done, they acted as a trigger for services for the cared for person:
‘…they did a proper assessment of her mentally, all the rest of it and it was through that that she now has a carer that comes every morning which is great.’

(21KMWR, male, over 50, caring, working)

‘It was our disability social worker…we managed to get her after five years…once we did get a social worker we had a Section 23 done [assessments of children in need] and then we got respite care and other services.’

(43EFWR, female, under 50, caring, not working)

‘…I am in the process of getting in touch with the epilepsy support charity social worker for a needs assessment. I want to make sure the transition arrangements between the nursery and the school are in place and the school staff are aware of my son’s needs….’

(21KMWR, male, over 50, caring, working)

There were one or two examples of social workers employing ‘creative accounting’ to facilitate the carer working whilst also ensuring that the cared for person was appropriately supported:

‘Once she [SW] could see that I was determined to carry on working, she then came up with an idea and said “well there is Carer’s Allowance but its not a lot of money. But there is another idea”. She obviously went back and discussed it with her colleagues and she said “Well what we could do is employ you as your mum’s personal assistant using the Independent Living Allowance…it enables your mum to stay at home, which is what you want and she wants, then we could set this up”. It was complicated ‘cos my brother had to employ me on my mum’s behalf. It got very convoluted but we did it!’

(46EMNN, female, under 50, ceased caring, not working)

Being au fait with the system and knowing who to contact was also regarded as an advantage:

‘…a friend of mine is an ex-teacher whose wife has got dementia and he gets a lot of help because, you know, he phones up the right people, you know, he gets respite, he gets day care, he wants it so he follows through.’

(48KMNN, male, over 50, caring, not working)

6.1.3 Voluntary sector

The voluntary sector was universally highly regarded by carers. It tends to be an anchor; it provides much needed advice and information (including financial and benefits), a guide through the care system, and it also directly provides services for carers such as support groups and emotional and personal support. As there were a range of people in different caring situations supporting people with widely different caring needs, this was particularly notable.
Acting as an advocate and adviser was identified by a large number of carers as a key role of voluntary agencies:

‘Sheila’s been great, she attended meetings with us, she’s taken up a role to give us extra back up and advice on everything we need. The problems we’ve been having with mum’s care…she’s been a godsend. [She also has] a case worker from Perennial, the Gardeners Benevolence Society, through dad…whose been very, very good as well. Lots of advice and financial advice. Sheila’s our guardian angel really.’

(38EFWN, female, under 50, caring, working)

Also they were often reliable sources of information:

‘The Vocal meetings were looking at what happens after they leave school, what the entitlements were, the benefits…looking at the care plans written by social services once they were actually going to be independent, what happens with employment. It looked at writing trusts and the wills and how we actually make sure that he’s safeguarded in the future.’

(45EFWR, female, over 50, caring, working)

Voluntary agencies routinely hold carers’ meetings or run support groups which are highly valued by carers and which often led to the development of friendships:

‘Myself I got involved with Vocal, the carers organisation. They were a great help in terms of, you know, they run evening things and good clubs and you get together with other carers and chat things over and that was…and that was a support to me personally.’

(46EMNN, female, under 50, ceased caring, not working)

‘[Name of town] Parent Support Forum is made up of a large majority of parents like me who have got children with special needs or who are trying to work and look after them and are juggling things. So when we have a meeting we make sure we have like a half hour networking slot where we can just talk or moan or whatever we want to do.’

(23KFWR, female, under 50, caring, working)

‘We kind of built up a support network from that [the epilepsy support group], several of the mums have got quite friendly and you know, we chat to each other in between times and not just at the meetings…about issues that surround epilepsy and our children and their differing needs.’

(2EFWR, female, under 50, caring, working)

Some groups are run for the carer and the cared for, particularly in the dementia field.
‘We go together to the Young Onset Dementia Project which we go to once a fortnight…there’s five couples that go, one partner has dementia. And we do activities, go for walks…we all cook lunch together and we eat lunch together and we do gardening and things like that. And we’ve made friends there…even been on a short holiday with the a couple from there.’

(4KFWR, female, over 50, caring, working)

Another issue relates to specialist knowledge; most of the voluntary sector agencies have expertise in conditions, e.g. dementia, autism, or in caring per se. Some of the more specialised voluntary agencies provide training on how to support the cared for person effectively:

‘I’d done some Alzheimer’s training…that’s helped…it’s useful in terms if content but I think actually it was just as useful in terms of talking to other people with similar problems and learning the ‘tricks of the trade’.

(16KFWR, male, over 50, ceased caring, not working)

‘In the past we attended intermittently, my husband and I, a group for parents of children who have epilepsy, organised by the local epilepsy support organisation. And I attended some parenting classes on how to deal with behaviour that could arise from children who had seizures…which was good as it gave you tools and tips, how to deal with situations when you are totally frazzled, and try and get a wee bit more control…and a wee bit more understanding about what its like to actually experience a seizure. It was useful….’

(2EFWR, female, under 50, caring, working)

Support for the cared for person is also provided via the voluntary sector which carers appreciated and trusted:

‘She gets help from Penumbra which helps people with mental health problems…do workshops on increasing confidence…she thinks she’d like to do counselling for young people who’ve had similar problems.’

(36EFWR, female, over 50, caring, not working)

‘The local Autistic Society produces a list of carers that have worked with children with autism in the play scheme. And so we’ve got a carer called Bill who takes the children every fortnight…the children like him and they get a chance to go out.’

(43EFWR, female, under 50, caring, not working)
‘Vol Care [local voluntary sector agency] provides a girl who comes one day a month to keep mum company; she also did come for a week when I went away with my daughter. I also had one lady come from Crossroads who came every Monday to relieve me…also much earlier on in the piece when mum wasn’t so bad I had arranged for a CSV volunteer to be here. …So I’ve had good coverage….’

(16KFWR, male, over 50, ceased caring, not working)

‘The Royal National Institute for the Blind has been extremely helpful. Before she went into hospital they were the prime source of setting up the care package for our aunt.’

(55EMNN, male, over 50, caring, working)

There are four particular characteristics of voluntary sector organisations which mark it apart from the statutory sector: the local nature of the service; its familiarity and reliability; its accessibility; and its constancy – it is there for the longer term. Carers trusted voluntary sector staff, they built up a relationship with them over time and came to rely on them. For this reason alone carers felt they were understood; the term ‘always there when you need them’ appeared regularly in the interview data:

‘[name of town] District Social Care Group, they’re really good. They’re really, really good…they’re there when you need someone on the end of the line. You can ring them anytime.’

(26KFWR, female, under 50, caring, working)

‘If you were to ask me which of all things that were available had the biggest beneficial influence, I’d say it was carers’ support and in particular Tessa actually. She’s brilliant…It’s local and psychologically, I know she is just a phone call away…I can pop in for a coffee and have a shoulder to cry on…human contact, empathy, sympathy, support.’

(16KFWR, male, over 50, ceased caring, not working)

Voluntary sector provision is not for everyone though. For some carers the expectation that you will ‘join in’ is uncomfortable, for others sharing the challenges of being a carer simply serves to reinforce how difficult their current situation is or may become:

‘…and I went for a while to the local Alzheimer’s Society…All of those were joint meetings, carers and cared for. I didn’t eventually find those worked out too well for us. They were heavy on biggish social events which has never been our kind of thing.’

(12KMNN, male, over 50, ceased caring, not working)
‘The Parkinson’s Society has groups. But we don’t really want to go there and sit amongst people and you think “I might be like that one day”. It’s depressing in itself isn’t it?’

(14KFWR, female, over 50, ceased caring, working)

One mother of a disabled child pointed out that as most support groups are populated by women, men tend to feel rather excluded:

‘I go to the carers support group…there aren’t many dads there so he [dad] feels uncomfortable when all the ladies talk about their own issues. He feels left out.’

(43EFWR, female, under 50, caring, not working)

Another feature of the voluntary sector is that they are regarded by carers as treating them as experts on the needs of the cared for person which is in sharp contrast to their perceived treatment by statutory agencies:

‘…the system didn’t help me at all, they saw me as not the person at the centre of attention, my mum was the centre of attention, I was irrelevant. You know, I was an impediment, everybody wanted to get me out of the way so that they could deal with my mum and no one had any interest in asking me about what I thought or anything about it. But I was the one doing the…I was the one in the driving seat but no-one gave me any credibility for it until the Alzheimer’s Society who try to plan care for both of us.’

(31KMNN, male, over 50, caring, not working)

6.1.4 Support from family and friends

Evidence suggests considerable variety in the level and type of support offered to carers by family and friends. The majority of relatives and friends provide practical support, relieve the carer so they can go out to work, or help out in emergencies.

For those who received regular support it was much appreciated and pivotal in enabling the carer to work and/or have any kind of life outside caring:

‘My daughter does a lot actually…she is my mainstay. She and her husband, they do a lot for me.’

(41EFNR, female, over 50, caring, not working)

‘If my father wasn’t around I wouldn’t be able to work, you know.’

(19KFNR, female, under 50, caring, working)
‘Her sister and my daughter also…a mix…they allow me to work…if I didn’t have that I couldn’t have worked for the last two or three years. That’s what you need to work, you’ve got to have that back up from family and friends. Also when mum was really ill my brother came over from France with his wife and helped out.’

(5KMWR, male, over 50, caring, working)

‘His mum and dad help with him [husband]. His father takes him out. When I go to work he will take him out and take him to the resource centre once a week.’

(19KFNR, female, under 50, caring, working)

Some carers had a network of relatives and/or friends who provided quite a lot of support:

‘I am the main carer but my husband really takes his fair share…and my parents were a great support. They’d take him out places and sit with the girls whilst I had things to do with [name]. Babysit to let my husband and I out…my sister lives nearby and she’s very helpful.’

(13EFWR, female, under 50, caring, working)

‘I do get support…like when my mum had pooed everywhere all over the carpet and the wall and she was sitting in it…and I’d have to clean it up. My wife would crawl around on her hands and knees and clean it up. Sometimes my daughters also did. So the whole family was involved to a greater or lesser extent.’

(31KMNN, male, over 50, caring, not working)

Others had a more informal arrangement with friends of neighbours who would help out at short notice or in an emergency:

‘Yes we’re lucky in that I don’t have close family nearby but when they are available they’re pretty good with my children. If there is a hospital appointment people will collect my kids from school…and give them their tea.’

(10KFNR, female, under 50, caring, not working)

‘…everyone in the street is aware of Mark’s illness [diabetes and epilepsy] Topsy [the dog] saved [name] life twice – for some reason she can sense it…she brought him round a couple of times.’

(40EFWR, female, under 50, caring, working)

Some carers got no support from family or friends at all and were isolated in their caring role:
'We have family who’ve sort of run away from us...we’ve never been invited to a wedding at all, my brother’s wedding because it’s too much for them...they don’t advertise that we’ve got children with a disability. In Asian families it’s a taboo thing. ...So they kind of sideline us so we are isolated.'

(43EFWR, female, under 50, caring, not working)

‘...you tend to lose a lot of friends when you’re a carer and you feel very isolated and unless you’ve got, like, good neighbours or other relatives you can become a bit of a recluse which is what I am becoming. And I can’t really see any other way...to help that type of problem to be honest.’

(48KMNN, male, over 50, ceased caring, not working)

Others had a more difficult relationship with their relatives:

‘Unfortunately my sister’s basically accused my husband and I because of financial matters. She considers herself to be the one who should be dealing with things. But I’ve always dealt with mum’s financial matters and she’s basically accused us of taking money and had us investigated. Which is now in the hands of the public guardians.’

(38EFWN, female, under 50, caring, working)

‘My ex-husband doesn’t live far away and he does come although I can’t leave them alone together, he just winds [name] up and gets him really upset so I can’t leave them alone together for long.’

(17KFNR, female, over 50, caring, not working)

6.2 Cross cutting issues

In addition the issues that relate specifically to particular agencies or types of support a number of cross-cutting themes emerged.

6.2.1 Support, information and advice located in one place

Many carers identified the fragmented nature of the ‘support system’ and the fact that they have to go to a number of different agencies to get information on the range of services and advice they may need. This includes specific services for themselves and the cared for person, information on benefits, the role of the voluntary sector and ‘who does what’. What carers wanted was one place they can go to get clear advice on all of these issues:

‘One thing I feel, particularly in the dementia field, there are lots of organisations out there but they’re not very well integrated together and finding out what you need, what is available and whether it would suit you is a big task for a carer and there’s not an easy way through. Getting it all from one place would be great.’

(12KMNN, male, over 50, ceased caring, not working)
One carer suggested that Admiral Nurses could perhaps take this role on as their remit is exclusively to support the carer or that it could be located with one person who worked for the local authority:

‘We have an Admiral Nurse now…she’s there to help carers so part of [her job] might be to pull together all the different services and benefits under her umbrella. Or if there was a designated person on the council…social services or local authority for carers that found out about what you could have and not have across all departments.’

(48KMNN, male, over 50, ceased caring, not working)

A number of carers also identified a role for an agency to help carers get work and engage with normal activities after the end of a period of caring:

‘I wonder if there was another department that could organise the return to society after caring ends. You become institutionalised doing caring. You need someone to help you, lead the way back, give somebody like myself an inkling of what’s out there socially and work wise, you know what clubs there are and what jobs.’

(48KMNN, male, over 50, ceased caring, not working)

6.2.2 Variable support from services and limited integration

There was evidently considerable variability in what kinds and levels of support carers get across, and even within, the two sample areas. This appeared to be a combination of where you live, different criteria for accessing social care services, how informed you are, how hard you or your advocate are prepared to ‘fight for services’ and what condition the cared for person suffers from, i.e. whether you have an autistic child or a parent with dementia.

Eligibility criteria for social care services appeared to be set at a very high level:

‘I’ve had no support from anywhere and I’ve been onto Social Services. He’s disabled but even though I get the highest rate of Caring Allowance he’s not disabled enough for them to put him on the disability team.’

(17KFNR, female, over 50, caring, not working)

Although integration is a key aim of recent health and social care policy, it is evident from data already reviewed, that this is difficult to achieve. Part of the explanation may lie in continual service reorganisation:

‘Another part of it is to provide a more integrated service…the health and social care. And certainly they do try. But it’s just impossible as it was. It’s basically because Edinburgh’s reorganising, restructuring itself over and over again…it’s chaotic.’

(32EFWN, female, over 50, caring, working)
A minority of carers did say that their package of care was integrated:

‘They’ve [SSD] given me a lot of help with all the aids…I can’t fault social services and the team of physios and I know if I have a problem I can phone them and they will help me with it. They were very good in…with the mobility, getting him up, showing him how to manage stairs and helping me, you know, to show me what to do, get him out of the bath and all of that….’

(25KFWR, female, over 50, caring, working)

‘We’ve now got a social worker for [name]…they [home care] go in to do her breakfast Tuesday to Friday and somebody puts her to bed. We do all her meals. She’s never been in respite…but for the past three months she’s gone to hospital on a Monday to the Templar Day Unit.…’

(40EFWR, female, under 50, caring, working)

A few packages were even set up quickly and in a way that allowed the carer to work:

‘With his vascular dementia it deteriorated very quickly, it goes in steps. I was amazed at how quickly they set up a care package because within a week of him being diagnosed I had them round here…carers coming in every night. It felt a bit invasive although it relieved me…they said take the time off, go for a walk or whatever you want. They’d also come in when I was working… also Crossroads and a day centre.’

(34KFWN, female, over 50, ceased caring, working)

6.3 Summary

Although it is clear from this chapter that there are a number of specific ways in which services impact on work-related considerations, there is a wider sense in which formal support is simply out of step with the lives and concerns of working carers. At present, there are two ways in which services do, or do not, help carers to work: via services for the cared for person, and carers’ support services. The former tend to act as a substitute for the carer to release them from caring whereas the latter tends to provide emotional and sometimes practical support for the carer. Care packages are rarely set up with any reference to the carer’s need to work; the primary focus is the cared for person and their need for support rather than the caring dyad being treated as one ‘case’ and services being developed to ensure the maintenance of both their lives, including employment. The voluntary sector appears to be more accessible, flexible, to treat carers in an holistic way and offer an ongoing service; it is widely trusted and relied upon by working carers. A higher level of integration between services, earlier intervention to plan for future care needs, and acknowledgement that part of the role of health and social care is to help ensure that the carer can continue to work would go some way to meeting carers’ needs more effectively.
The role of the DWP and Jobcentre Plus in supporting carers to remain in, or return to, the labour market

In this chapter we consider respondents’ knowledge and experience of the Department for Work and Pensions (DWP). Through its two executive agencies Jobcentre Plus and the Pension, Disability and Carers Service (PDCS), the DWP is responsible for two forms of support to carers: the provision of employment advice and support, and the payment of benefits. With respect to employment advice and support there is no dedicated welfare-to-work programme for carers as there has been for other client groups, for example the over 50s, disabled people or lone parents under the New Deal programmes. Carers are not required by law to be available for work or to attend Jobcentre Plus as a condition of receiving Carer’s Allowance (CA). The PDCS, which delivers CA, was created in April 2008: it combines the Pension Service and the Disability and Carers Service. Many of our respondents will have first claimed the relevant benefits prior to the formation of the PDCS and in any case the new combined agency in its own words: ‘will be largely invisible to our customers as we continue to operate with both our Pension Service and Disability and Carers Service brands’ (PDCS, 2008: 2). A few respondents mentioned The Pension Service but no-one directly referred to the PDCS or its predecessor the Disability and Carers Service. The discussion here concentrates on respondents’ experience of employment advice and the payment of benefits.

The respondents fell into three broad groups: those with recent knowledge and experience; those with experience in the distant past and those with little or no contact and little knowledge of the DWP and its executive agencies. The first
group are the most useful barometer of attitudes towards current Jobcentre Plus practice, whilst those with historic experience are most likely describing systems and policies which no longer exist. Nevertheless, such experiences from the past serve to condition people’s attitudes to future possible contact with Jobcentre Plus and the DWP more widely and are interesting from this point of view. The third group despite little direct involvement with DWP are, nevertheless, worthy of note as they suggest views or perceived wisdom that may be prevalent in the general population from which future carers will be recruited. The review of evidence will consider respondents’ experiences and attitudes in three sections: general views about the location and nature of Jobcentre Plus offices which have an impact on any of the services which Jobcentre Plus is providing; the specific provision of employment advice and support; and thirdly, the payment of benefits.

### 7.1 Jobcentre Plus offices

A number of respondents made reference to the fact that there had been closures of Jobcentre Plus offices so that the nearest Jobcentre Plus office was now some way away:

‘Particularly when you think about the jobcentre’s actually being closed down, so we’d have to go to [name of town]. So we’d have to travel to find out.’

(20KFNR, female, under 50, caring, not working)

Although perhaps a relatively minor point, it was interesting that a number of people referred to the distance they would have to travel and this may be of particular significance for carers who potentially have to arrange for alternative care for the cared for person whilst they visit Jobcentre Plus. It may also be a disincentive in terms of cost if the individual had to use public transport to access the nearest Jobcentre Plus office.

A significant proportion of those with recent experience of Jobcentre Plus made comments about the environment or atmosphere in the Jobcentre Plus office. The rollout of new style Jobcentre Plus offices was only completed last year so it is likely that some of the respondents here are referring to their experiences prior to the changes. Although jobcentres do not actually have security guards (they have customer care officers who operate as a co-ordinated team with Jobcentre Plus staff in the management of jobcentre public areas) the reference to the presence of security guards was common:

‘But the general sort of ambience of the place is…is just…is just not conducive to being made to feel welcome. First of all there’s like security guards on the door.’

(48KMNN, male, over 50, ceased caring, not working)

Jobcentres also provide services for people who cannot work because of sickness or disability and people wanting to change jobs as well as out of work jobseekers. Jobcentre Plus staff are equipped to serve people with a variety of circumstances
and needs. Nevertheless, a number of respondents also mentioned the other clients and the sense that they themselves were different as carers:

‘I’ve been in once and that was enough…They’re not people like me.’
(42KFNS, female, under 50, caring, not working)

Comments of the latter sort in part referred to a sense that as a carer you were in a different position to the unemployed and this needed to be recognised (see further comments below).

There were also a number of observations about the impersonal nature of the experience at Jobcentre Plus, feeling like a number and only being given a short amount of time:

‘I’ve always been treated with a great deal of respect and…and the people have tried to put themselves in my position. But the fact is they have to have a number on their form.’
(25KFWR, female, over 50, caring, working)

‘They didn’t seem to volunteer any information. I got the impression it was just you were there for your allotted time and when you’re gone it’s the next one, you know?’
(48KMNN, male, over 50, ceased caring, not working)

Other respondents commented upon the open plan nature of the space and the lack of privacy in discussing personal matters.

These concerns about the degree to which Jobcentre Plus offices are welcoming places may not be peculiar to carers but they may amplified by carers’ sense that they are not understood or shouldn’t be treated like other Jobcentre Plus clients:

‘I don’t know, I don’t think they did enough to try and help you. Well certainly they didn’t with me. I might as well have been invisible.’
(49KNFS, female, over 50, ceased caring, not working)

‘Another experience, you know, when I was sitting there with the young chap, he’s going through his process and his system and asking questions, much as you have to do. But he said to me “when did you take up caring?” I said “2003”. And he goes “well you’ve been out of work a long time”. And I thought “didn’t I not just say I was a carer?” You know, they equate that always as unemployment, not being economically active, you know, as being unemployed, you know? So that’s something else that they should look at also, not just see “oh you haven’t worked since then until now, therefore, you’ve been unemployed”. And I mentioned I was a carer but they had no sense of what that involved.’
(35KMNR, male, over 50, caring, not working)
7.2 Provision of employment advice and support

There were mixed responses from those respondents who had recent experience of Jobcentre Plus. Some felt positive: that people at Jobcentre Plus had been helpful but even amongst this group there was a sense that the help available was limited. A number of respondents felt that their circumstances were understood by those they saw at Jobcentre Plus:

‘Actually I must say very nice. I have the same woman…I know other people I’ve heard other things but I can only say in [name of town] they’ve only ever been very polite and very nice to me and made it quite clear they’re not forcing me to get a job because of my situation, you know, but yet they’d like you to, obviously they would.’

(17KFNR, female, over 50, caring, not working)

This sense of surprise that Jobcentre Plus was welcoming or helpful is noteworthy as it suggests that there is a common view amongst those without prior experience of Jobcentre Plus that it may not have much to offer them as carers. This may be unfair to the service but, nevertheless, it is something that needs to be countered if people are to be encouraged to use its offices. Negative views of recent experience with Jobcentre Plus revolved around a number of different elements; some to do with location and environment, as detailed above, others concerned the expertise or services available at Jobcentre Plus. It is worth considering these separately.

7.2.1 Expertise about carers

A point made by a number of the respondents was the need for someone in Jobcentre Plus with specific expertise on carers. This took a number of different dimensions, from issues of identity as a carer, to the need for practical understanding of the challenges that carers face.

‘Because I asked whether or not they had somebody, an adviser to deal with people who have been out of work as carers for some time and needed help to get back into the work situation and they said they don’t have people to do that specifically, just general, you know, search facilities and advisers… Have somebody specifically trained to help carers get back into the swing of things, either full-time or part-time, either into voluntary work….’

(35KMNR, male, over 50, caring, not working)

It is worth noting that Jobcentre Plus is working towards fulfilling the commitment in the Government’s Carer’s Strategy to introduce specialist training for advisers.

7.2.2 The type of work being offered

A number of respondents felt that Jobcentre Plus did not understand or offer the kind of flexible jobs that carers need:
‘And very rarely in jobcentres will you find part-time work or temporary work. Obviously it’s going to be the 30 hours a week stuff.’

(10KNFR, female, under 50, caring, not working)

Assumptions like these may deter carers from even approaching Jobcentre Plus. There was a suggestion that this might apply to jobs under 16 hours or voluntary activities as well. For Jobcentre Plus a part-time job under 16 hours a week or voluntary activity does not count as ‘a job outcome’ and hence, does not meet the targets that Personal Advisers are working towards. If it is effectively seen as a failure to get someone into a job under 16 hours a week this may act as a significant barrier in providing employment support to carers, especially for those carers who are trying to keep a toehold in the labour market whilst caring, in readiness for a fuller return to work in the future. It is worth noting that one of the roles of the new Care Partnership Manager, appointed in each district, will be to work with personal advisers to help improve their understanding of the needs of, and opportunities available to people with caring responsibilities. This will include promoting part-time paid employment as a realistic job goal.

Other respondents, those with recent and those without recent experience of Jobcentre Plus felt that it mainly only offered lower level jobs that were not relevant to them:

‘I’m used to being a manager and I also find that the staff, generally speaking, haven’t got a clue about anything beyond their own level of employment. So unless I want to go to Jobcentre Plus and be employed as a civil servant in some, whatever grade they are, it’s pretty hopeless. So if you’ve got anybody who’s got any degree, I think, of…especially what I would call “life experience”, which you can’t expect these young people to have, I think they undervalue you. I would expect, my anticipation is, that they would undervalue my skills and experience and I’m sure I’d be offered some work, but I’m equally sure that it wouldn’t be work that I’d be…’

(16KMNN, male, over 50, ceased caring, not working)

The following respondent had two experiences of Jobcentre Plus a recent encounter over benefits and a past experience of employment advice, which coloured his impression of what Jobcentre Plus today might be able to offer him now as someone who had ceased caring:

‘The seeking advice [on benefits] was OK and the unemployment was a bit negative, you know, a bit…you know, “how old are you? Oh you’re 50 plus, oh well, you know, we might have trouble finding a job for you, it’s going to be low paid manual type of work” which was depressing so…But that’s not their fault. I mean that’s the economy.’

(48KMNN, male, over 50, ceased caring, not working)

The issue of qualifications or experience could also run the other way when someone was willing to take less-skilled work:
'I was too well qualified for anything they had! Not that they had anything to offer in [name of town] anyway. And, quite frankly, if I go back there, I'm going to have to not tell them what I can do, because like I said to you, I'm quite happy to shelf-fill in Asda if I have to, you know, in terms of like three or four hours a night. But the last time I went for an interview there they said “well we would want you for an office job and there are no office jobs going”.'

(10KFNR, female, under 50, caring, not working)

7.2.3 Forward looking support

The group with the least experience of Jobcentre Plus was, as might be expected those who were currently in employment; when asked if they would think of using Jobcentre Plus for job search or finding out about training opportunities, many of these said no. A minority had practically no knowledge of what Jobcentre Plus had to offer, others made the assumption that if they were looking for a job they would use their own resources or networks:

‘Well I would look at the…Well I’ve got the internet so I would…there used to be a jobcentre here but they’ve closed. I know it’s in [name of town] now.’

(28KFWR, female, under 50, caring, self-employed)

For a lot of these working carers Jobcentre Plus was simply not on their radar as may be true for many of the general working population without caring responsibilities. The self-employed respondents in particular were likely to refer to using their own contacts to get further work.

A small number of people had experience of trying to get training or being offered training designed to get them back to work but were not necessarily impressed:

‘Well, I appreciate that they want to get people back to work, but in some situations it’s not possible to go back to work immediately, but there’s a kind of long-term prospect that, you know, “sure I can’t go back to work just now for reasons x, y, z,” but I have every intention of going back to full-time employment and I want to get as good a job as I can in the future. I mean the only courses they offered me were a CV workshop and an ‘improve your computer knowledge’ workshop. Both of which were things that I could do, you know. It wasn’t going to improve my chances of gaining employment either now or at any point in the future….’

(37EFNN, female, under 50, ceased caring, not working)

7.2.4 Work Focused Interviews

There was a policy change in 2005 under which Work Focused Interviews (WFIs) were no longer mandatory for carers receiving CA (the main benefit for those spending at least 35 hours a week caring and who are earning no more than £95 a week). Although they are still required for those on other benefits such
as Income Support (IS) or Incapacity Benefit (IB) (now Employment and Support Allowance (ESA)), which may include some people with caring responsibilities. The majority of respondents had not had, or had never heard of, WfIs; only two had a direct experience as they had to attend as a condition of benefit. Both felt that it was a hoop that they had to jump through but that they were under no pressure to find work:

‘But, basically, all they do is ask what you’re doing and then they usually say “oh that’s fine”, so it’s a joke because, well, basically because they’re not actually helping you to focus on getting back to work in any way…it didn’t really give me much hope that there was a job that I could have done. Certainly not while I was caring. So I just, I didn’t really try any more.’

(37EFNN, female, under 50, ceased caring, not working)

7.2.5 Better Off Calculation

For carers who are not currently working but may be considering returning to work Jobcentre Plus can offer a Better Off Calculation (BOC), which would assess the monetary benefit of working. The majority of respondents had not had, or had never heard of, such BOCs. Four respondents had experience of BOCs. Of these, two found that they would only be marginally better off and two found that they would be worse off. One of the latter felt slightly affronted by the whole experience as she had not gone back to work for the money:

‘But he actually did say to me, he said “you should have come to me and I could have told you. I mean financially you weren’t any better off, why did you?” and I didn’t go back because of money. I knew we weren’t financially better off by £20. It was my self-esteem I wanted to do it for.’

(43EFWR, female, under 50, caring, not working)

7.3 Benefits

Respondents received information and advice about benefits from a range of sources in addition to the DWP: social services, carers’ groups and friends and family were the most common mentioned. Many stressed the difficulty of finding out about the different benefits and the relationships between them:

‘Well when you have Carer’s Allowance, if you know you can have Carer’s Allowance, because what I do is when we have new parents contact us, I send out a pack and I put all that sort of information in there, because we didn’t know about it, we didn’t know about Disability Living Allowance or anything, nobody told us. But if you get Carer’s Allowance, wouldn’t that sort of thing, you know, could they not put a leaflet in about that?’

20KFNR, female, under 50, caring, not working)

Some had been helped to sort out their benefit situation by Jobcentre Plus, however, as many felt that the benefits were too complicated and that no-one really understood them. Some respondents expressed surprise that their experience of Jobcentre Plus was positive:
'It was fine. To my amazement actually it was fine.’

(39EFWR. female, over 50, caring, working)

Others assumed that they would not be eligible for benefits or simply had not managed to get around to sorting it out:

‘You know, it’s just one of those ironies that when you need the help the most you don’t have time to go and get it. And so I never applied for Carer’s Allowance or anything, because I’d hoped that when I saw the carers’ support group they would be able to help me out with all the forms, because they’re quite complicated and I couldn’t…You know, because I was tired, my concentration levels were not as good as they could have been perhaps and it wasn’t in the priorities, you know. The priorities were the day-to-day things, get food, get dinner cooked, get the house clean, get my mum up, try and encourage her to take a walk, make sure that she’s not spending the whole time in bed. And so it never happened.’

(37EFNN, female, under 50, ceased caring, not working)

Fifteen respondents were currently, or had recently been, in receipt of CA; some respondents had not claimed CA because of the impact on the cared-for’s benefits:

‘I can have Carer’s Allowance, but then they’d take away mum’s something or other and it worked out the same…Yes, I’d looked into it and it’s an absolute farce because I’d end up getting pretty much the same amount of money and pay tax on it, whereas if mum got the money she didn’t pay tax on it. So it was like “oh, that’s a no-brainer”. The benefit system when it comes to carers is abysmal.’

(16KMNN, male, over 50, ceased caring, not working)

The main issues that respondents raised about benefits were the general complexity of benefit rules; the value of benefits and the inflexibility of CA with regard to the earnings rule. We will consider these in turn.

7.3.1 Complexity of benefits

There was a widespread feeling that benefits were too complicated, difficult to find out about and to understand:

‘I think they need to have a bit of a more human approach to this, you know, because I’m sure if this is happening with me and I’m not an unintelligent person “I dread to think how some other people are coping with things. I think they probably don’t even bother to go there with it. I don’t think people even realise the things you can claim. I didn’t actually realise, you know, until the Deal Carers said to me oh wait a minute you should be getting the carers”.’

(25KFWR female, over 50, caring, self-employed)
Another issue of expertise emerged for those respondents who felt that they had been given poor or wrong advice and a few people mentioned a lack of consistency in advice they had been given by DWP staff.

‘But generally every time you go in there you get told something different. Even if you speak to the same person three months after you’ve spoken to them before and they tell you something different again.’

(53KFNR, female, under 50, caring, not working)

Another aspect of complexity, which acted as a disincentive to those currently not working and in receipt of benefit was the prospect of going back to work, being unable to sustain employment and then having to reconstruct the benefit package they had before:

‘I think that needs to be looked at, to be more of an incentive, a financial incentive, for people to start working. Because you get one or the other and then if things don’t go well, you have to come away from work, then you’ve got to reapply for these again and that’s quite a minefield.’

(36EFWR, female, over 50, caring, not working)

7.3.2 Value of benefits

Ten respondents had household incomes under 10K per annum and only two of these were working. A majority of respondents had incomes under 20K per annum, just under half of these were working. The majority of those with higher incomes were in employment; as demonstrated in other studies many carers are living in relative poverty because of the impact of caring on their ability to work. The value of benefits is, therefore, of considerable concern to non-working carers:

‘And Carer’s Allowance isn’t anywhere near enough. £50, they’re having a laugh aren’t they? Especially for people that look after elderly people and they’re with them all the day long.’

(17KFNR, female, over 50, caring, not working)

However, despite the monetary value of CA it is important for other reasons:

‘The people I see who come to me and say “can you help me with benefit claims?” Which is one of the things that I do because I’ve done it and tried it. They say the Carer’s Allowance, it’s hardly worth the effort of getting it and if you do almost anything to bring in some money you’ve got too much to allow them to have it. The one benefit it does have, which is not made clear to everybody, is that it gives you things like pension contributions and it puts you on a register as existing and doing something which may entitle you to other things.’

(50KFWN, female, over 50, ceased caring, working)
7.3.3 Inflexibility of benefit rules

A number of respondents commented on the conditions for CA, mainly with respect to the earnings limit rule and the problems these caused for sustaining part-time work.

‘To keep the hours down, yes. But sometimes that puts you in a difficult position because you might want to work a little bit more, but if you work a little bit more then the benefit is taken away.’

(13EFWR, female under 50, caring, working)

Another respondent pointed out that it was difficult to find work and stay within the earnings rule:

‘But my main problem is that, you know, you can only earn £95 a week because of the Carer’s Allowance so you can’t like work more than…If you’re earning say £6 an hour, for example, you can’t really work more than 15 hours. And if you look at the jobs in the paper most of them are, like, 20-odd hours for part-time work. So there are…What jobs there are there there’s very few that I can actually apply to and even the ones that maybe do fall into the category I can apply for sometimes, the advert will say “must be able to do extra hours during school holidays” or something like that but I can’t commit to extra hours, not because I don’t want to but because of this £95 ceiling. You’re not allowed to earn more than £95. £95 used to sound a reasonable amount because I know obviously you can’t earn a fantastic salary and then still claim for your Carer’s Allowance. I realise that. But, you know, £95 nowadays is nothing, you know, so….’

(6KFNR, female, over 50, caring, not working)

A mother of a disabled son made the point that because he was very difficult to leave with anyone else a term only contract would be attractive but this presented problems in terms of benefit rules:

‘It’s the council tax and the Housing Benefit. If they could get that somehow and let you work and…because I can earn it’s £90 I believe before my Carer’s Allowance takes…They’ve just put it up. But the main thing is you can’t get anything…I’ve got no family actually here so I’ve got nobody to leave him with. So unless I could be guaranteed a job at term time only and the money has got to also they told me carry through the same all through the year. If I get a job that only pays while I’m working that will muck me all up. She said you’ll just have to reapply for Housing Benefit and they’ll stop it and it will all have to go through again. It’s ridiculous. That’s what they told me at the Jobcentre. So you can see why people don’t bother.’

Some respondents in receipt of a pension felt it was unfair that they could not qualify for CA:
'I would say I think it’s wrong that I’m not allowed Carer’s Allowance because I’ve got a pension. I mean I think I should have something, if it’s only £10 a week. But apparently the Government’s saying that if I have a pension I’m not allowed.’

(24KFWR, female, over 50, caring, working)

The comments made about the benefit rules reinforced the early points about the general complexity of benefits and the difficulty of understanding them.

7.4 Summary

There was a spread of knowledge about DWP and its executive agencies amongst the respondents: some having recent contact, others having little or no knowledge of Jobcentre Plus’ role. No-one explicitly mentioned the new executive agency, PDCS. Either through direct experience or hearsay, there was a widespread feeling that the Jobcentre Plus environment was unwelcoming and this was linked to the sense that carers were not really understood. As a result, a majority of respondents had negative views primarily about what was available through Jobcentre Plus.

In relationship to employment support quite a lot of carers self-select not to use Jobcentre Plus and do not see it as a relevant source of help to them. This included a number of dimensions: that Jobcentre Plus will only offer low-skilled work; that it does not access the part-time and flexible jobs that many carers seek and that it offers nothing on top of what the individual can access through the internet or their own networks or connections.

There was also a sense from some respondents with recent experience of Jobcentre Plus that they received mixed messages, for example, being told that they won’t be much better off in work but somehow feeling that they should work; being expected to work but not offered suitable work; wanting to work but then losing a benefit. This was compounded by the rules for CA, which seemed to frustrate individuals’ willingness and ability to work part-time.

With respect to advice on benefits there was a high level of discontent over the complexity and inflexibility of benefit rules and a general wish that there was just one place that you could go for advice on this from people who understand the situation you are in.
8 Case histories

In this chapter we look at a number of individual case studies, which illustrate the wide range of respondents’ circumstances. In the rest of the report we are generally concerned to look at a particular aspect of our respondents’ experiences: for example, the nature of the caring, which they undertake or the support they receive from a specific agency or from their employer. By examining some individual case histories we are able to put the carers’ stories back together, and provide a flavour of their lives and situations – in particular the tensions they experience in reconciling work and care or in considering re-entering the labour market. The cases have been chosen as illustrations of different caring scenarios, for example, caring and not working, ceased caring and looking for work, caring and working, they do not ‘represent’ these different situations in the sense of being typical cases but they allow us to consider the real-life dilemmas which a number of our respondents faced.

8.1 Balancing work and caring, but for how much longer?

‘Chris’ is 62 and works full-time as a construction manager for a large building company. He also cares for his wife ‘Pat’ who is 59 and has front temporal dementia (a form of dementia which tends to affect relatively young adults and is aggressive). At the time of the interview Chris was on sick leave from his job, having been signed off with stress. Prior to this he had been working full-time, four days at work and one day working at home per week. His job is very flexible he can work from home and schedule the site visits he has to do around caring. He has worked for the company a long time, enjoys his job and there is considerable goodwill towards him. His company have been very supportive and the team of workers that he manages have been happy to work round the other demands on his time.

Pat needs constant attention and cannot be left alone. Chris had in place a package of care, which allowed him to continue working, his sister-in-law and daughters who live close by help to look after Pat, she went to a day centre a couple of times a week and there are close friends who can be called upon at short notice. As Chris said:
'Well what they were doing, you see, they were allowing me to work. Now without that, if I didn’t have that, I couldn’t have worked for the last two or three years.’

Pat’s condition had been worsening but the situation came to a head in the last six weeks. She had become very distressed whenever Chris left and was increasingly difficult for other family members to look after: she would cry all the time and could no longer be taken to the day centre. He decided to take time off work to see if her condition improved or if they were at a new point in the trajectory of the illness when he might need to consider giving up work. As soon as Chris was around all the time Pat’s emotional state improved. This meant that Chris was in a very difficult dilemma. He was feeling guilty about not being at work and letting his co-workers and the company down but he also felt that he couldn’t go back to work because of the effect his absences were having on Pat and the rest of the family.

Chris also had some caring responsibilities for his mother whose situation had dramatically changed in the previous three months. She was living independently and was fine, he used to do shopping for her once a week and pop in a couple of times to see her, but then she had a stroke and rapidly became unable to look after herself. The family rallied round and eventually they managed to find a residential placement for her. Although, this was working out Chris felt guilty that after his mother had cared for everyone else through her life and when she now needed care he wasn’t able to give it.

Before the recent events Chris had thought that he might gradually scale down his work, move from five to four and then to three days through to retirement. Now he simply wasn’t sure what was going to be possible, whether he would get back to work, which is what he wanted to do, or be forced to take early retirement. On the morning of the interview his GP had signed him off work for another three weeks so he was facing some difficult decisions. As to possible sources of help, he did not really see what social services could offer if the real issue was that his wife couldn’t cope with being looked after by someone other than him. His company were not putting any pressure on him but he felt a loyalty to them that meant he did not want to mess them around.

8.2 Working and caring: split shifts and split lives

‘Rachel’ is 31 and works a part-time term only contract as a library assistant for about 17 hours a week. She cares for her son who is four and has epilepsy and some brain damage from earlier seizures. He has considerable care needs and the nature of his disability means that Rachel is on alert throughout the night. Rachel herself has bouts of depression, which she thinks is possibly affected by the general pressure of caring for her son; she has sought counselling support for her depression, but she endeavours to keep her own health issues hidden from her employer.
She took the library job two years ago as it fitted better with caring for her son:

‘It took away the need for actually acquiring formal childcare. It meant that my husband and I could care for our son without actually needing nursery or child-minders or anything. So that was really the main reason why I moved.’

She had previously been working for the same organisation but in a higher graded job. Rachel and her husband have found a pattern of working that allows them to split the care for their son:

‘Basically, my husband works in the morning and finishes at lunchtime, and I work in the afternoons, therefore, he’s caring for our son while I’m at work essentially.’

However, this is at the cost of having very little time together as a family or as a couple as Rachel has to work Sundays and her husband works Saturday mornings. At the time of the interview they were getting four hours free respite care from a charity every other week, which allowed Rachel and her husband to go out for an evening.

Rachel is glad to work as the family needs the money but also it provides ‘a bit of life outside the home’, though the job is not fulfilling as it is monotonous and does not use the training and skills that Rachel has. Rachel also does voluntary work as a Brownie leader with the Girl Guides and helping to write a newsletter for the National Childbirth Trust.

Rachel has applied for better jobs within the same organisation but has not been successful; she feels there is little that her current line manager can do to improve her situation as there is little flexibility over hours. Rachel feels that if she does not make a shift then it just falls on someone else, she does have an informal arrangement with someone who works on Saturday and they swap the Sunday for the Saturday if needs be. She has not confided in colleagues and works in isolation from her manager who is located elsewhere in another building. Generally, she feels it is up to her husband and her to manage and only so much can be expected from your employer.

8.3 Working but struggling

‘Emma’ is 33, married, with a ten year old son and works part-time (eight hours a week) for a private Home Care company. She is the main carer for her husband, ‘Terry’, who is retired on ill-health grounds following surgery for a brain tumour. He has very poor short-term memory and complicated medical needs including incontinence, epilepsy and a complete lack of awareness that he has the condition.

Emma’s job involves domestic care such as shopping and cleaning for her clients, she does not provide personal care. She took up this job when she was made redundant from a retail job:
'I’m in a bit of a rut. I don’t quite know what I want to do but this just fits in…fits in with my husband, fits in with my son at school. You know, it just fits in really and I can choose the hours I work.’

Emma feels under a lot of pressure at home and suffers from tiredness, disturbed sleep, being short tempered and irritable. She gains little emotionally from her marriage and carries a heavy weight of responsibility for both Terry and their son. She was on anti-depressants for a while but stopped taking them. She does not enjoy her current job and it is not well paid:

‘I don’t actually want to work. I used to enjoy working and I don’t think I do…Whether that’s because I’ve not found what I want to do. I work probably to get out of the house and go…get away, not that I don’t think about what’s going on at home and just a bit of income really.’

Part of this stems from the attitude of her employer, which is not sympathetic to her situation. Her mother and father-in-law help look after her husband, which allows Emma to work but due to the complex nature of her husband’s health there are sometimes extra hospital visits that cannot be rescheduled:

‘My husband was going to hospital everyday for an ear problem and I booked the Friday off and it was “why was that? Why have I got to take it off?” And I couldn’t take it off unpaid, I had to use up a holiday day and that happens quite a lot if I get an appointment because I have to go to [London hospital] quite a lot…No I don’t expect to be paid for taking the time – a day off, you know, but I think, you know, just their rules is that I have to take a holiday day.’

The family are not allocated a permanent care manager from their local authority social services department despite their complex situation and changes to NHS provision may mean that Terry can no longer have access to regular respite care in hospital, a service Emma trusted and relied on. Emma was not aware of the legislation giving the right to request flexible working. When asked what would help her most she replied:

‘All I want is respite. That’s all I would want is respite really and to be able to go to work because if his father wasn’t around I wouldn’t be able to work.’

Looking ahead Emma does not know to what extent her husband’s condition might worsen and who will help her manage the needs of the family:

‘And what the future is I just don’t know.’

8.4 A life of reconciling care and work

‘Mary’ is 64, married with two grown up children. She works full-time in a car dealership, where she has been for 30 years. She cares for a severely learning disabled daughter who is in residential care during the week but comes home at weekends. She also has a husband with Creutzfeldt-Jakob disease (CJD) who
went into full-time residential care a little over a year ago. Although he is in a home, she visits him every evening and at weekends:

‘I go in every night and I shave him, clean his teeth, do his nails, you know, the sort of things that I can…it’s really to help them as much as him. He shouts at me just as he shouts at them sometimes.’

Over the years there have been periods of intense caring for both her daughter and her husband as his condition was worsening. She feels that she has been well supported by social services and always managed to find a package of private- and publicly-funded care that allowed her to carry on working. When the children were young (she also has a son) she worked part-time for a number of years. Since the age of seven her daughter has been in many different special residential schools and Mary has been a tireless advocate for her daughter, ensuring that she is getting the best placements available.

Her employer has been very accommodating, recognising the pressure she has been under at different times. Although she works a standard pattern week, in practice she is allowed a degree of flexibility:

‘Well I vary the hours as I can skip away on a Friday to pick [daughter] up, so basically, my paid hours are 9 to 5.30. I actually work probably about 8 ‘til 5.20 and then go at half past 3 on a Friday. But basically I think on my contract it probably says 9 to 5.30.’

Mary really values her work for: ‘Money. And sanity’ and gets on well with the people she works with and appreciates their interest and concern for her:

‘…but people knew, people cared and that. And they knew [husband], I mean [husband] used to work, I mean that’s how we met – he used to work for them years ago, so people there did still know him. But he had done some driving and that, you know, when he wasn’t working for them for a while, so they did know him. And, you know, this is what my friend, Angela, she couldn’t understand, she said “the trouble is, I don’t know how you cope because he doesn’t look any different”.’

Mary is not sure how much longer she will continue to work, she has thought she might stop her full-time job and work just a couple of nights in the residential home where her husband is but she has not made up her mind yet.

8.5 Self-employment as a solution to caring responsibilities

‘Sarah’ is 48, single and a self-employed private teacher for children with special needs, mostly those with emotional and behavioural problems. She has a complex range of caring responsibilities; she cares for her mother and father who are in their 80s and have health problems, a family friend of 95 who lives in the next village to her parents and various nieces and nephews who come to stay at her parents’ house. She has power of attorney for her parents and the family friend.
Her mother has cancer for the third time, her father is waiting for a heart operation and the family friend has a range of mobility and memory problems not untypical for a 95 year-old.

Sarah has her own place in London and splits her time between there and her parents’ house; her caring responsibilities have built up over the last 20 years:

‘I had to spend more time down here so yeah. And because I’m self-employed I can do that. So…Yeah, so I change my work patterns according to the needs here. At the moment I go…That’s why I do three days a week in London and four days up here because I don’t want to do full-time up here because it’s not fair on my mum. Because it’s…my dad would want it, she doesn’t, and it’s like the Queen Bee, you know, you’ve got to still have…This is her house so I have to have somewhere else which can be my house. Yeah. And you’ve got to balance it. So at the moment she is still Queen Bee so I do only four days here and three there. Yeah, because she’s…As it occurs we can change it. You see if I had a proper job…or some people call it proper, I couldn’t do that. But…yeah, it’s important for them.’

Despite the rather hectic schedule Sarah enjoys her work:

‘What does work mean to me? It’s very satisfying. I never had…Yeah, sorry, it’s very satisfying, especially working with the kids when you see them responding so it’s…I couldn’t do an office job or something like that, that would kill me. Having more things to think about doesn’t really matter if you get satisfaction out of it.’

Sarah is also a trained framer and gilder so can turn her hand to self-employment in this field if necessary and has done so in the past when she needed to live full-time at her parents for a period of time when her mother was very ill and undergoing treatment for an earlier cancer. Asked about the effects of caring on her own health:

‘Well I don’t know if I can say I feel depressed because you don’t have time to feel depressed. You know it’s sort of…I go out…It’s like at night if I…Like the other night it was an all nighter with [family friend] in the next village and I came back and I just went up and I sat up on the far end of the garden and just looked at the stars. It was a lovely night and I looked at the milky way for about ten minutes. The dog loved it and it was great, you know, and you just…you just let it go at one end and come in the other sort of.’

When asked if she had thought of giving up work she replied:

‘No. I’d go mad. I’d go mad. No, you’ve got to have…you’ve got to have…I mean the people who are caring 24 hours a day for their relatives I…I really tip my hat to them because how they do it I don’t know. It’s as though you’re trapped in a prison. If you didn’t have some…something else to think about, to run concurrently you can’t survive, you really can’t survive. You need to have it.’
8.6 Not working but would like to work

‘Jane’ is 41 and married with two children under 12. She is the main carer for her husband who has a progressive disability caused by a rare tumour in his spinal cord. Her husband was retired early on ill-health grounds from his well paid professional job. Jane is a qualified accountant and had worked for the Inland Revenue for 20 years, full-time and then with reduced hours when she had the children. She is also a fluent French speaker and used to do translation work at the Revenue. She had to give up the civil service job three years ago following a car accident in which she sustained a significant back injury. She finally had an operation, which improved her back just at the point at which her husband’s condition was diagnosed.

At the time of the interview she was registered as a full-time student; something she was doing to improve her longer-term job prospects. In the meanwhile she would love to work, not least for the money as their income has dropped considerably but also as an ‘escape from what’s going on at home’. She is willing to take almost any work and has considered supermarket till work as she said about working:

‘It’s not only the money, but you earn your place in society.’

She has been to her local Jobcentre Plus but felt that they wanted to offer her office work because of her work history but they did not having anything flexible enough. Ironically she felt that Jobcentre Plus had been more helpful to her husband:

‘I mean certainly they’ve been more helpful to my husband in that when he was filling in all his different forms and everything else, they actually said to him “when you feel up to it, come and see our disability officer and we can probably get you four hours of work, or whatever, a day to fit in with your disability”. They’ve been more proactive regarding him than they have with me and I’m well...He’s more employable!’

Jane was undertaking some work, which had originally been voluntary that of helping people complete their tax returns. She also did odd bits of French translation. These used her previous experience and skills. Given Jane’s range of competences and willingness to work it seemed likely that with some further support she would be able to find a flexible job. However, her previous experience left her sceptical about Jobcentre Plus’ ability to help her.

Jane is not eligible for Carer’s Allowance (CA) because she is a full-time student but felt that the benefits system did not really recognise the situation of people like her. She did not define herself as a carer ‘because he is my husband and I suppose it’s just become part of life for us’ but, nevertheless, because her husband wasn’t fully independent, her ability to work is circumscribed. She thought that there should be a carer’s register, which then allowed those registered to get some tax credits for the caring they do.
Jane felt that the coming together of her own health problem with that of her husband had made things much more difficult, if she had been working at the time of his diagnosis things might have been different:

‘I have to say that if I had been in work when all this was taking place they would have been very flexible. I will say that about the civil service. If I had said to them “I’m sorry, my husband is really quite sick” a) they would have given me time off when he was sick, and b) they would have said “what kind of hours can you work?” and I could have turned round to them and said “well I can only do 16 hours now” and they would have accepted that… if you’ve already got a job that you’ve proved yourself in, people are more willing to accept that your life has changed.’

8.7 Ceased caring and retraining to regain employment

‘John’ is 57 and married with two children, he spent seven years caring for his elderly mother who had dementia. She died at the age of 93 last year and he has since been struggling to get back into employment. Prior to giving up work to look after his mother, who he moved into his house so he could care for her, he ran his own consultancy, having worked as a professional in industry before that.

After his mother’s death he experienced severe depression and also had a bout of pneumonia, he felt that the experience of looking after her, especially in the later stages of her illness, had depleted his own physical and mental health. In particular, he had felt very unsupported in his role as carer and described the ‘mental torture’ of having to provide intimate personal care to her. He also felt guilty about his wife and his younger daughter feeling that he wasn’t doing a good job of looking after any of them because of the competing demands. Although he felt ‘morally bound’ to look after his mother, he knew that many of his family and friends thought that he should have put her in a home and as a result did not show him much sympathy.

‘But isolation has been the most characteristic thing I’ve suffered…I’ve been isolated like being locked away in jail for six years and tortured, mentally tortured for six years or whatever and now I’m expected to go out into the world as though it hadn’t happened and no-one gives me allowances for actually what has happened.’

He had some problems with benefits after his mother died and sought advice from Jobcentre Plus. He was advised to get his doctor to sign him off sick. With regards to getting back to work he had low self-confidence:

‘I said “look I’m 57 nearly, and I am 57 now, and I haven’t worked in the job market for x number of years. I’ve been looking after my mum and I just feel that I can’t go out – I haven’t got the wherewithal to go out and fight back to get where I am”.’

Subsequently an adviser at Jobcentre Plus suggested, given his work background, that he might consider being a classroom assistant or teaching in further education:
'She helped me a lot. And she said now there is more of a thrust now not to be ageist in the policies and the Government policy that people shouldn’t be discriminated according to age.’

John then decided to start a teacher training course at a local university and was a student at the time of the interview. He was finding it difficult to manage the course and wasn’t confident that he would complete it but he valued it:

‘It gives me intellectual exercise, social contact, a feeling of value and self-worth, a feeling that I’m contributing towards society. A feeling that I’m progressing and developing myself and moving forward and...Life’s, you know, pathways. That’s what I feel.’

8.8 Ceased caring and considering the different options

‘Fraser’ is 43, single and is currently unemployed having recently ceased full-time caring for his mother, who went into a residential home a month before the interview. He had worked for 18 years as a warehouseman and gave up work in January 2007 to help care for his mother. His mother has had long-term health issues, diagnosed as a schizophrenic and in more recent years suffering from dementia. Fraser’s father had been the main carer until his death in December 2006. This change of circumstances led Fraser and his brother to consider different care options for their mother.

‘So there was mum, my brother and my father in the house. My father passed away and my brother worked during the day time, so an issue came, you know. We knew mum needed support, couldn’t manage on her own any time really. I mean you can maybe nip to the shops for ten minutes but you couldn’t leave her any longer, you see. So we had to decide – was mum going to have to go into care? And at that stage I decided that I would look after mum during the day time, you see, while my brother was at work.’

Fraser was relatively dissatisfied with his work, his employer had only given him three days compassionate leave following his father’s death and he had been signed off by his GP for a further two weeks for ‘stress related to death in the family’. He did not explore the possibility of changing his hours of work with his employer and was not aware of legislation giving the right to request flexible working arrangements. A social worker tried to persuade Fraser not to give up work but as he had decided that this was the best solution in terms of providing care for his mother the social worker came up with another idea that he be paid as his mother’s personal assistant from her Independent Living Allowance. This funded 22 hours of his time a week; although the time he spent caring for his mother was in excess of this.

At the time of the interview Fraser’s mother had been in the care home for four weeks and he had arranged a rota with his siblings for visits, so he was going over to her twice a week. Fraser wanted to get back to work:
‘I think it gives you a sense of dignity and it gives you an interest in your life. Earns you some income, you would hope.’

He was unsure, however, as to what line of work he wanted to do. He didn’t want to go back to being a warehouseman or an office job but was wondering about whether to go into care work on the basis of his recent experience as a carer. He had been in touch with Jobcentre Plus:

‘I went to the office and told them I’m now looking for employment and they said “well your initial contact is you go through an interview over the phone, and you give your National Insurance Number and past and present employment, etc, any mortgage details and whatever”. So you’ll have a 40 minutes, roughly, interview on the phone and then what normally happens is they’ll arrange for you to come in to a local jobcentre and you’ll have a person to person interview.’

Two weeks later at the time of the interview ‘Fraser’ had not contacted Jobcentre Plus further as he was worried about being propelled into a line of work he did not want to do, he wanted a bit of time and space to adjust to the new situation and work out what he really wants to do:

‘I’m frightened I’ll get pressured into wanting to look at jobs they’ve looked at. I mean whether they’d give me some time to, you know, I’m sure once you’ve been in Jobseeker’s Allowance for six months or what, then I’m sure there’s a bit of pressure on you, but whether initially…I could hint to them that I’m not sure what I want to do…Well I’m not sure I’d want to go back to what I did for 18 years.’

8.9 Employment not really possible at the moment

‘Rani’ (34) and ‘Tariq’ (48) are married with two sons aged nine and 11. Both sons have autistic disorders and have problems with mobility, communication, concentration, sleeping, with no awareness of physical risk or danger. One son also has asthma. They need care 24 hours a day and cannot be left alone.

Originally from Pakistan, ‘Tariq’ moved to the UK in the early 1990s, and had worked in retail until two years ago. He stopped working because of the increasing needs of the children. ‘Rani’ wanted a break from caring and found a job working for a voluntary organisation as an information advocacy worker for parents of children with special needs. She had really enjoyed her work, but had left a few months before the interview as she suffered both mental and physical injuries from trying to combine work and caring.

‘…and the reason I had to leave was because I actually was so stressed out juggling both at the time, I pulled a muscle…I didn’t want to really leave my work because I was really enjoying it and because of the tension of…I mean your carer’s role does not stop. All the responsibility I have at the office, that does not come into the house, but my children don’t understand, they don’t have sense of feelings, they don’t understand how a person feels.’
As well as providing constant care for their sons at home, Rani and Tariq have to cover hospital appointments and cope with the logistical problems involved in each son attending a different specialist school. Tariq suffers health problems in part arising from lack of sleep as he looks after the boys during the night.

With support from their local carers’ association, they received an assessment of their support needs from a social work nurse. This resulted in two hours per week of respite care. They consider this inadequate, and are trying to get more help.

They have no support from friends or neighbours, and their families ‘keep their distance’. Rani explains that they are isolated from other Asian families because having sons with disabilities does not sit well within a culture of arranged marriages. While Rani derives some support from her local carers’ support group and association, Tariq feels excluded from this because he is a man and it is mainly women who attend these events.

Tariq thinks he might go back to work, but would only consider self-employment. He admits that it would be difficult to find and sustain a job that would pay as much as they currently receive in benefits. (They currently receive CA, Income Support (IS), Disability Living Allowance (DLA), Housing Benefit (HB) and Council Tax Benefit (CTB) and Child Tax Credits (CTC).) He also feels there is a lack of Government support for ‘older entrepreneurs’.

Rani had attended an interview at her local Jobcentre Plus when she gave up work. The attitude of the staff there was that they would never have recommended that she work as they could see it would not be financially beneficial to her. Her response was that she wanted to work for reasons other than money.

‘It was my self-esteem I wanted to do it for.’

They are both attending IT classes at a further education college in order to gain some computing skills. This was not on advice from Jobcentre Plus but in response to a newspaper advertisement they came across by chance. Their main motivation is to be able to help their sons with homework and learning, but also hope the skills will be useful for any future potential employment.

Despite the fact that they have each valued their time working and would like to work again in the future, their current priority is their sons’ well-being. They feel that their sons have benefited from them not working and becoming full-time carers.

8.10 Summary

This sample of individual cases illustrates both the diversity of caring experiences and the complexity of the demands that many carers face, particularly those with intensive care demands. None of the cases is ‘typical’ as there is probably no such thing as a typical caring scenario but there are a number of recurring themes that epitomise the challenges of combining work and caring. Caring is clearly hard work – whether combined with paid employment or not, a majority of our carers
experienced physical and emotional strain as a result of their roles, and a number had impaired health as a consequence of long-term caring.

The unpredictable nature of the caring situation, both now and in the longer term, is another common feature, and one that has significant implications for sustaining paid employment or getting back into it. Carers have no option but to prioritise the needs of the cared for person, which makes planning to return to work and/or maintaining a regular pattern of work difficult. The complexity of managing their care tasks alongside organising services for the cared for person, attending hospital appointments and often ‘supervising’ the overall well-being of their relative cannot be underestimated. The sense of isolation and ‘just getting on with it’ is another shared issue, although for a minority, friends and family do provide a key source of practical and emotional support. For some carers there is the need to reinvent a life after caring when they have been out of the labour market and perhaps social and public life more generally for some time. Also, for many there are the frustrations of working out benefit entitlements and operating within earnings or hours rules. Overall, however, what is absolutely striking about these case studies, and many of our other respondents, is the extraordinary resilience shown by carers in reconciling competing demands and pressures and in their determination to provide care for their relative(s) and seek or sustain paid work wherever possible.
9 Conclusions

One of the Department for Work and Pension's (DWP's) aims is to promote work as the most effective route out of poverty for those of working age whilst ensuring the protection of vulnerable groups and those in greatest need. The critical role that work plays in our society should apply to those with caring responsibilities as much as to any other group at risk of falling out of work, yet until recently carers have not been recognised as having any specific rights at work and many continue to lack the support they need to combine working and caring. Unlike other groups such as lone parents, or the young unemployed there have been no specific welfare-to-work policies targeted at supporting carers either in, or back into, employment. A number of factors come together to suggest the demand for informal care will increase. The first is the demographic fact of an ageing population: it is expected that the number of frail elders will increase and with it the demands on families to provide care. In addition Health Service policy (care in the community), advances in medicines (e.g. lower mortality rates for disabled neo-nates), advances in technology (making care at home more feasible) and disabled people's own aspirations regarding their care are all important factors in increasing the demand for informal care. In these contexts the challenge of how to effectively support carers to continue working, and/or facilitate their return to paid work, is considerable.

The aim of the research reported here was to better understand what employment support is needed for carers in order for them to be able to take up and/or remain in work. To this end carers in a range of situations were interviewed: those working and caring; those seeking to get back into employment after a period of caring and those currently not working but who would like to work now or in the future. Specifically the objectives of the research were to:

- investigate how caring responsibilities affect people's decisions about employment;
- begin to fill the evidence gap on the role and effectiveness of existing services for carers;
- assess how DWP and Jobcentre Plus can effectively help claimants with caring responsibilities to return to the labour market;
- provide evidence to enable the DWP to develop its strategy for carers.
This chapter reports the findings of the research by addressing the first three questions and concludes by drawing out the policy implications of the research data for the DWP's strategy for carers.

9.1 How caring responsibilities affect people's decisions about employment

This research, and the report, are primarily concerned with the employment aspects of carer's lives but given that caring intersects with all facets of daily life, it was very important to explore their views of their role and situation through the lens of caring. Caring responsibilities have to be met somehow; the needs of the elderly relative, the disabled child or spouse cannot be ignored so actual or prospective employment has to accommodate care-related demands unless suitable substitute care can be found. Caring, particularly intensive and dementia caring, has a profound impact on the lives and health of carers. For the majority the caring role develops gradually as the cared for person's health deteriorates but for a minority it happens overnight following a car accident or major health event. Most carers, therefore, become a carer unknowingly and gradually and for many it involves a complex mixture of time consuming tasks and roles which demand a great deal of physical and emotional labour. Long-term caring leaves many carers exhausted, isolated and in poor health.

Carers do not always define themselves as such; they may simply be the parent, or the husband or the daughter and feel that caring is an intrinsic part of their family role. This means that they may not respond to initiatives directed at 'carers' and may not appear on the 'carers radar' of agencies with an interest in, or duty towards, carers. Related to this is the finding that many carers are unhappy with being labelled 'unemployed' as they do not see themselves as belonging to this category; for men especially, the term 'unemployed' may serve to diminish the value of the hard work of caring (Arber and Ginn, 1995; Hirsch, 1996). These issues illustrate well the conceptual and practical complexity of 'being' a carer and underscore a point identified by a number of carers interviewed for this project: that they felt people did not understand their role or situation. It also helps to explain why 'carers' associations' were such trusted sources of advice, information and support because it is in this context that carers felt their needs and situation were genuinely appreciated. These overarching points are important because they provide both a context for, and influence, how and where a carer starts from in thinking about, and coping with, employment.

This research confirmed many of the findings from previous studies, such as the importance of working for carers in terms of financial benefits and personal satisfaction. Our findings also supported the main restrictions that caring imposes on working – carers were limited in the hours they could work, in how far they could travel to work, and were constrained in terms of job mobility and career planning. Beyond this confirmation, our study has provided a more in-depth
understanding of some of the key difficulties in combining working and caring, and highlights gaps in employment support provided and received.

Despite unanimous agreement of the importance of work in our study sample, it was clear that combining working and caring was far from easy. The key themes raised were balancing/juggling, stress, and guilt. Respondents who worked found themselves constantly having to balance their work requirements with the needs of their cared for person. This was viewed as a source of great stress, not least because they tended to regard the responsibility for managing the work/care balance as solely theirs; to offer care to a dependent relative was viewed as a private choice and therefore, an individual responsibility to resolve the inherent tensions. This stress was frequently compounded by guilt: people felt guilty that they could not focus entirely on the cared for person; they also felt guilty because they could not focus on their job as much as they might have liked to; and often they felt guilty for not disclosing their caring circumstances to their employers or colleagues but they worried about the stigma that might attach to them if they disclosed their caring situation.

For carers not currently working the desire to work remained in principle but when explored practically they expressed considerable anxiety about how any suitable work could be found. The view that no employer would want to take them on if they knew about their caring responsibilities was common. In addition there were concerns about the impact of going back to work on the health or happiness of the cared for person and the impact on their own health of having to juggle work and caring. This may illustrate the varied responses that different research strategies may elicit: in surveys, carers, people with health issues and lone parents may well give positive responses to the desire to get back to employment; when interviewed in depth they may retain this in principle motivation but explore in much greater detail the practical barriers to effecting a return to work.

One of the key elements of facilitating effective management of the work/care balance was work-related flexibility. The term ‘flexible working’ covers a very wide range of working practices, and is most often understood as some form of deviation from so-called ‘standard’ employment, i.e. full-time employment contract, working a standard working day and a standard working year at the employer’s place of work.

The circumstances of our respondents reflected all these dimensions of flexible working. Part-time working was common, and other forms time-based flexibility included term-time working and annual hours contracts, flexitime and shift working. A key finding here was that often these forms of flexible working did not afford a great deal of flexibility to the carer. The nature of care giving was often unpredictable, so having, for example, a fixed part-time hours contract was not especially helpful. Although term-time working provided flexibility to carers of children to cover school holidays, this came at a personal cost to the carer who in effect sacrificed any holidays they might have had.

Conclusions
Contract flexibility was seen most often through self-employment, but there were also some agency workers in our sample. Although self-employment was seen to offer a level of control, it too had its limitations; the stress experienced by the carer in being simultaneously responsible for their own business and the cared for person is a key issue. A few respondents had shifted to different types of employment, typically less demanding work in order to accommodate caring responsibilities.

These last points reflect what we have termed more ‘informal’ flexibility. In many respects this was the most valued of all forms of flexibility. Key here was being contactable at work. This gave the carer peace of mind and they felt that they could be better employees as they could focus more on their job. A vital facet of informal flexibility was employer trust which was highly prized, but more often than not, absent. Some of the carers in the study gained flexibility and trust by working for smaller organisations.

Working carers are required to balance their caring demands with those related to their employment. Some achieve this balance by reducing their hours, shifting their pattern of work or, less commonly, getting regular support from family or services discussed below. Other carers are obliged to give up working altogether.

9.2 The role and effectiveness of existing services for carers

Carers obtained support and sought help from a wide range of formal and informal sources: social services, the NHS, voluntary organisations, family and friends, and the DWP through its operating agency Jobcentre Plus. The formal services, with the exception of Jobcentre Plus, do not conceptualise their role as supporting or enabling carers to work. This section focuses upon the roles and effectiveness of existing services other than those of Jobcentre Plus, which are dealt with in Section 9.3; in addition it reviews the evidence about the role of employers in supporting carers.

9.2.1 The NHS and Social Services

For most of those interviewed the contact they had with the NHS and social services was primarily negotiating services for the cared for person. Care packages were rarely set up with any reference to the carer’s need to work; the primary focus was the cared for person and their need for support rather than services being provided to ensure the well being of both carer and cared for, including the need to be in paid employment.

Assessments of carers’ needs were rare amongst our respondents, despite the fact that many of them would have qualified for such an assessment in law; other respondents were not clear whether they had had an assessment or not, as most of their contact with social workers focused around the needs of the cared for person. What was striking was how little carers get and want. Many of our respondents only wanted a few hours of respite a week, reliable day care, or
flexible, accessible support at short notice, something agencies appear to find it very difficult to provide.

Many carers complained about the fragmented nature of the ‘support system’ available to them and the desirability of a single port of call that offers a range of carer-focused services including advice on benefits and employment/training. This problem is acknowledged by the House of Commons Work and Pensions Select Committee (HCWPC, 2008b: recommendations 7, 9, 32 and 33).

9.2.2 The voluntary sector

The voluntary sector was highly valued by many of the carers we interviewed. It appears to be accessible and, flexible and to treat carers in an holistic way; it also offers an ongoing service throughout the entire caring trajectory and is widely trusted and relied upon by working carers. A number of characteristics of the voluntary sector served to differentiate it from statutory services: the fact that it was locally based, friendly and accessible; it was seen as reliable in providing specialist advice and services and to some extent functioned as a ‘one-stop’ shop; it was constant, and there for the long-haul. In short, the majority of respondents felt understood and respected by the voluntary sector, which was not how many felt in their dealings with statutory agencies.

9.2.3 Employers

In Section 9.1 the importance of flexibility for working carers was discussed in this section we consider the extent to which our respondents were helped to achieve a balance between working and caring by their employer, including the issue of flexibility.

Despite the importance of flexible working in facilitating work and care, our respondents’ accounts revealed a very patchy picture of workplace support. They reported that some employers were wholly unsympathetic to the needs of their employees with caring responsibilities: it was this lack of sympathy that had forced some carers out of their jobs. The experience also damaged their prospects of future employment in that they were afraid they would merely receive the same hostile treatment from the next workplace.

A few respondents reported that employers demonstrated an active approach to supporting employees who were carers. This manifested itself in having an overall policy (rare) or in offering support to accommodate particular activities, e.g. training, or to support specific episodes relating to caring, such as providing time off at short notice. However, the predominant approach was a passive one. Most employers appeared not to have an explicit policy, and it was up to the carer to ask for help if required. Our respondents reported that such employers often demonstrated a complete lack of knowledge or awareness of what the needs of a carer might be. Examples included assuming the needs of a carer would be the same as the needs of a parent, or failing to understand the fluctuating and often unpredictable nature of caring.
This passive approach was also seen to contribute to the ways in which carers who were no longer working left employment. A common exit-route was via long-term sick leave, whereby the employee slipped away from employment, often completely unnoticed. For older respondents, the route of early retirement was used in a similar way.

Although some respondents praised their colleagues and line managers for providing both emotional and practical support, the more common scenario was one where employees did not tell people about their ‘guilty secret’ and tried to struggle on as best they could. This contributed to the ‘understanding gap’ highlighted above.

These findings support studies in other contexts which challenge the contention that providing employees with legislative rights – in this case to request flexible working or to take time off in emergencies – empowers them (see Dwelly and Bennion, 2003; Vickerstaff, Loretto and White, 2008). Many people are not aware of their legal rights and hence, are not in a position to invoke them. We found that many of our employed carers were, on the whole, disempowered – they were grateful to employers for giving them a job in the first place and did not want to do anything which would jeopardise their work situation. Thus, our overarching picture is one of a group of largely invisible employees, reluctant to divulge their circumstances to employers for fear of reprisal or being seen to be a weak or less committed employee. There is clearly a need to raise awareness amongst employers of carers and their needs and to enhance understanding of the role of the employer in supporting workers who hold responsibilities for caring.

9.3 The role and effectiveness of existing DWP services for carers

Currently, through its two executive agencies the Jobcentre Plus and the Pension, Disability and Carers Service (PDCS), the DWP has responsibility for two forms of support to carers: the provision of employment support and advice and the payment of benefits. With regard to employment support there is no dedicated programme for carers as there has been for other client groups, such as lone parents or the disabled. There was a wide range of experience of Jobcentre Plus services amongst respondents, varying from people with recent first hand contact to others who had had no interaction with Jobcentre Plus and knew very little about what they offered. For this latter group the Jobcentre Plus was simply not on their radar as an agency that might provide help.

For others, either through direct experience or hearsay, there was a widespread feeling that the Jobcentre Plus environment was unwelcoming and this was linked to the sense that carers were not really understood; that there were no specialists or experts on caring in the Jobcentre Plus offices. Others felt misunderstood by Jobcentre Plus, for example, being labelled as ‘unemployed’ when they felt they
were ‘working’ full-time albeit termed ‘caring’. As a result, a majority of respondents had negative views about what was available through Jobcentre Plus.

Other respondents felt that in relation to job search Jobcentre Plus did not have the right kinds of jobs to meet their needs: either because they did not have part-time or flexible jobs suitable to accommodate care-related demands or because they were only offered access to jobs that did not reflect their level of experience or previous job status. For these reasons a number of carers self-selected not to use Jobcentre Plus.

Amongst some of those with recent experience of DWP, either for job search or benefit purposes there was a feeling of receiving mixed messages; for example, that they should consider getting back to work but then discovering that they would not be much better off; wanting to work a very small number of hours but this being something that Jobcentre Plus did not really provide access to. This sense of confusion was further compounded by the rules for Carer’s Allowance (CA), which seemed to frustrate individual’s willingness and ability to work part-time.

The PDCS had only just come into existence as the respondents were interviewed and no-one mentioned the agency directly or its predecessor the Disability and Carers Service. Many respondents complained about the complexity and inflexibility of benefit rules and wondered whether anyone really understood the system. This finding contributed to the widely noted view that there should be just one place that carers can go for advice on benefits and employment opportunities and that the advice needs to be provided by people who genuinely understand the situations carers are facing.

9.4 Policy implications of the research findings

The focus of this research has been on exploring in greater depth the employment-related support needs of carers, both those currently in employment and those looking to return to work now or in the near future. The objective was to provide evidence to enable the DWP to develop its strategy for carers. Since the research began there have been a number of relevant policy developments (see HM Government, 2008:82-99; Employment Task Force, 2008) and a report by the National Audit Office (NAO) into the DWP’s support for Carers (NAO, 2009); and the reports of the Work and Pensions Select Committee (HC Work and Pensions Committee, 2008a, 2008b). In the discussion which follows on policy implications we note where our findings overlap with points made in these other documents.

Removing the barriers to employment for carers requires action on a number of different fronts and by a range of stakeholders. The DWP – as the main governmental policy agent in the field – most particularly through Jobcentre Plus and PDCS, can play a number of roles in developing appropriate policies and procedures for their delivery. Employers will also have a pivotal role in providing and sustaining employment for carers. The NHS and social services, although primarily concerned with the needs of the cared for person, also have a role in supporting
carers who wish to stay in, or return to, paid work. Lastly, the voluntary sector, who already do much to support carers on a day to day basis, may also be able to play an enhanced role in supporting working carers. For ease of consideration the policy implications of the research findings are presented around the roles of these different stakeholders.

9.4.1 DWP

Carers need greater visibility as they have very specific needs for support in relation to remaining in, or returning to, work. Currently some advisers in Jobcentre Plus do not have specific expertise on the caring or on the employment needs of carers. As a result many carers we interviewed did not have confidence in Jobcentre Plus’ ability to provide appropriate advice or help. Our findings, therefore, confirm the conclusion of others that there is a need for specialist training for Jobcentre Plus advisers who work with carers (Employment Task Force, 2008:9; HCWPC, 2008b: conclusion 4). This would also help to address the problem of consistency in advice and support that a number of respondents referred to.

Flexible patterns of working were found to be critical for those respondents who were already working or considering getting back into work. However, there was the feeling that Jobcentre Plus did not provide access to these kinds of job opportunities. Our findings therefore confirm the conclusions of other work that Jobcentre Plus needs a better system for identifying and flagging up flexible job options especially in jobs that are commensurate with the skills and experiences of those seeking work (Employment Task Force, 2008: 9; NAO, 2009:7; HM Government, 2008:93).

If measures were taken to deliver on the previous two points it might be easier for Jobcentre Plus to market itself as a source of useful help and advice to carers; unfortunately, many of those we interviewed assumed that Jobcentre Plus has nothing to offer them. There is a distinctive ‘information gap’ at present with many carers not knowing about the services that Jobcentre Plus can offer, e.g. Better Off Calculations (BOCs) and access to training, and some Jobcentre Plus staff not appreciating what carers actually do. However, before communication can be enhanced there needs to be an overall improvement in the marketing of Jobcentre Plus and PDCS so that carers feel that these are places that can provide them with relevant help and information. The role of the new Care Partnership managers in each district will be critical here.

There was limited experience amongst our respondents of advice on training to help them get back to work, but where this had been offered there had been problems with the content (too basic) or the logistics (how to attend for training and still provide care). In the latter case DWP needs to investigate further whether it is possible to fund replacement care for the period of the carer’s training and build on the commitment, which has now been made for those on approved training (see also Employment Task Force, 2008:10; HCWPC, 2008: conclusions 18 and 41).
This research suggested that there is a real need for a liaison between employers and carers: both need to understand the needs of the other, and where a match between job and skills can be accommodated, Jobcentre Plus advisers could bridge the gap to employment for carers; a number of changes would facilitate this:

- firstly, that Jobcentre Plus advisers have an understanding of the skills their clients have and how to match them to the jobs employers have available in their area;

- secondly, that Jobcentre Plus has close contact with local employers to get a sense of what is available for flexible work; and

- thirdly, that DWP and Jobcentre Plus take every opportunity to sell the benefits to employers of employing or retaining carers.

This last point is reinforced by the fact that this research suggests that providing employees with legislative rights – in this case to request flexible working or to take time off in emergencies – is not sufficient on its own to guarantee access to either. Some of our carers did not want to risk asking for ‘special consideration’ fearing that their position would be undermined. Empowering carers to make use of their rights requires a significant campaign of awareness raising amongst employers as well as recognition that carers are often loyal employees (see also HCWPC, 2008b: conclusions 49 and 50).

In terms of welfare benefits this research suggests that there is a need for greater clarity over benefit rules and entitlements and the interaction of different benefits. In addition, if carers with substantial and/or intensive caring responsibilities are to be encouraged to remain in work, consider getting back into work or simply want to keep a toe hold in the labour market, the earnings rules for entitlement to CA may need to be reviewed. Financial support for carers is currently under review by Government. (HCWPC, 2008b).

### 9.4.2 Employers

It is important that employers become more aware of carers and their needs, creating a network of sympathetic or care-friendly employers both nationally and locally may be one way of raising the visibility of carers as employees. It was not exceptional for our respondents to keep their caring a secret at work, or at least from their managers. This may be a choice, for example, in order to keep a clear line between work and caring and to preserve a space in which the carer can escape their caring role, but for most it was out of fear of the reaction they would get from their employer. Employers need to appreciate that carers who require flexibility are not malingerers and that having access to a phone or the ability to make calls at work may simply allow them to concentrate and get on with their job.

Employers need to have a good sense of which roles within their organisation could be flexible and in what ways. This would enable them to market vacancies as suitable for people with caring responsibilities. It is also important that employers manage more actively those who may be in danger of slipping out of
work because of pressures related to caring. Those on long-term sick, or with an emerging pattern of absences may be desperately trying to balance the needs of caring and working and modifications to work patterns might enable them to remain in work.

It would also be helpful if employers were more aware of benefits rules, so that some employees with caring responsibilities may not be in a position to vary their hours or take on extra shifts.

9.4.3 NHS and social services

At present, and not unreasonably, professionals in the NHS and social services are primarily focused on the needs of the cared for person and do not necessarily see their role as supporting the carer to remain in or go back to work. However, there clearly are roles for GPs in being alert to the health issues that carers combining work and caring may be experiencing and providing good advice and or referral to occupational health services. Social services need to be more aware of carers’ rights to an assessment of their needs and this should be routinely offered and periodically revisited at every opportunity, e.g. when a visit to the cared for person is arranged.

It would be helpful for all professionals involved with carers to take a more holistic view of the cared for/carer for dyad with corresponding and overlapping needs rather than as individuals to be assessed separately. It may also be that these services are the first point of formal contact in an individual’s caring history and could provide access to a range of information (HCWPC, 2008b: conclusion 7).

9.4.4 Voluntary sector

The voluntary sector is currently respected and trusted by most carers and is a vital source of information and advice as well as physical and emotional support. In many respects it comes close to the ‘one stop shop’ that many carers noted as a key service in the research. It offers the possibility of joining up the different elements of care and support that the carer has to access. The voluntary organisations that our respondents had contact with were seen both as experts and supporters; all were regarded as sympathetic. The barriers to involvement with Jobcentre Plus over employment support that many of our respondents expressed might be overcome by locating employment advice and support with third sector organisations that already command the respect and trust of carers.
Appendix A
Fieldwork instruments

Information letter - Edinburgh:

EMPLOYMENT SUPPORT FOR CARERS

The research is commissioned by the Department for Work and Pensions and is designed to understand what employment support is needed for carers in order for them to remain in or take up work. In the region of 13 per cent of adults aged between 16 and 64 in full-time employment were caring for a sick, disabled or elderly person. Many of these people (and those working part-time and caring) face pressures managing their work schedules and looking after the person they care for. The research wants to investigate the support they currently receive from their employer, family, social services or the health service and what further support they need. Many carers who are not currently working would like to do so and to combine working with caring responsibilities. The research is keen to understand the support they require to achieve this.

The research will consist of a series of interviews with carers (both current carers and those who have recently ended a spell of caring) who are not currently working but want to do so, as well as those who are working or have recently left the labour market. The interviews will cover the history and nature of the caring that the person does, their employment record and the support they currently receive in their caring role from a variety of sources.

If you are interested in taking part in this research and want to find out more, please contact the lead researcher.
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If you are interested in taking part in this research and want to find out more, please contact the lead researcher.
**Gift Receipt:**

**The Employment Support Needs of Carers**

I acknowledge the gift of £25 in recognition for participating in this research project.

I understand that this gift does not have to be declared for tax purposes, and that it will not affect any benefit entitlements.

_____________________________  ______________________________
(Name of Person – please print)  (Signature)

_____________________________  ______________________________
(Name of person making payment)  (Signature)
Cover Letter:

University of Kent

Dear...

I am a researcher at the University of Kent and I would like to invite you to take part in a research study about being a carer and wanting to do paid work, which is being undertaken on behalf of the Department for Work and Pensions. The title of this research is:

Employment Support for Carers

We are keen for you to be part of the research, but before you decide, it is important that you understand what the research is about and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you want to.

What is the research study about?

People who want to work and also have responsibility for caring for relatives or friends have particular difficulties getting work that will fit in with their caring responsibilities. We want to find out more about the views and experiences of people like you. We particularly want to get a better understanding of what you think can be done to support you to find suitable work, continue in work or return to work. We would like to find out whether there are any particular things about your caring responsibilities and general circumstances that stop you from working or make it difficult for you to work, and what could be done to overcome these difficulties.

If I want to take part, what do I have to do?

Either myself or another member of our research team will be contacting you to arrange to talk to you, either by visiting you at your home or at another place of your choice. Firstly, we’d like to talk to you about the research some more, give you the chance to ask any questions, and get you to sign a consent form. As well as the sorts of topics mentioned above, we will be asking you questions about your life, your health, and what sort of impact your caring responsibilities have had on your decisions about working and on your financial circumstances. The interview will be recorded with your permission and last about an hour and a half. This recording will be destroyed once the study is finished.
I would like to reassure you that any information collected about you will be strictly confidential, and no one will be able to identify you from your replies. If you are able to take part, you will receive a small gift of £25 in recognition of your time. This gift does not have to be declared for tax purposes, and if you are on benefits, it will not affect any of your benefit entitlements.

**Do I have to take part?**

The research is voluntary and it is entirely up to you whether or not to take part. If you decide to take part but change your mind afterwards, you are also free to do so. We will check with you when we speak to you that you are happy to take part.

If you would like some more information about the study or there is anything that is not clear, please do not hesitate to contact myself or the DWP contact.

Yours sincerely
Consent form:

Title of the Project: Employment Support for Carers

Please initial the boxes on the right, write your name in capitals and sign at the bottom of the page. Thank you.

1. I confirm that I have read and understand the information letter about the research and have had the chance to ask questions

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and this will not affect me in any way

3. I give my permission for the interview to be recorded

(Name of Person – please print) (Signature)

(Name of person taking consent) (Signature)
Working

Interview Schedule: Employment Support for Carers

ID Code:

PART A  Background information about yourself

1. What is your age? .......................  

2. Are you male □  female □  ?

3. What is your marital status?
   never married □  married □  co-habiting □  divorced □
   separated □  widowed □

4. Who lives in your household with you?
   □  spouse or partner
   □  adult son or daughter
   □  child (step/foster)
   □  parent or parent-in-law
   □  grandparent
   □  friend
   □  other (please specify) .................................
   □  no one, live alone

5. What is your ethnic group? tick one box only

   White  Black or Black British
   British  □ Caribbean  □
   Irish  □ African  □
   Any other white background □ Any other Black background □

   Mixed  Asian or Asian British
   White and Black Caribbean □ Indian  □
   White and Black African □ Pakistani  □
   White and Asian □ Bangladeshi  □
   Any other mixed background □ Any other Asian background □

   Chinese or other ethnic group
   Chinese  □
   Any other □ (please specify)
6. What is your current employment status?

**Working**

Full-time ☐ Part-time ☐
Semi-retired ☐ Permanent ☐
Fixed-term ☐ Employed ☐
Self-employed ☐

Types of fixed-term:
- Temporary employee ☐
- Temporary agency worker ☐

Working patterns:
(tick all that apply)
- Term-time ☐
- Job share ☐
- Hours vary from week to week ☐
- Compressed week ☐
- Standard daytime hours (e.g. 9-5; 8-4) ☐
- Flexitime Night/early/back shifts ☐
- Fixed Night/early/back shifts ☐
- Rota ☐
- Other ☐
- Please specify …………………..

**Not working**

Unemployed looking for work ☐
not looking ☐

If not working:
- retired ☐
- ill-health and/or disability ☐

Have you ever worked? Yes ☐ No ☐

If yes, when did you stop working? ……………

Do you undertake voluntary work? Yes ☐ No ☐

7. What is the nature of your employment/ What was your main line of work?

Job title ……………………………………………..
8a. What type of organisation are you/did you work for?

- Public organisation
- Large private business (over 250 employees)
- Medium-size private employer (between 50-249 employees)
- Small private business (less than 50 employees)
- Self-employed

8b. How many hours per week are you/did you work for most recently?

- Less than 16
- 16-29 hours
- 30 or more hours

8c. Would you describe your employment history as

- Consistent/regular employment
- Intermittent due to caring/parenting
- Never worked due to caring/parenting
- Other

Please specify………………………………………………

9. What is your main source of income?

- Employment □ Benefits □
- Pension □ Savings □
- Other (please specify……………………………………

10. We would like to get an idea of which income band your household falls within. Can you tell me approximately how much you get per year?

(Include benefits, salaries, rental income from property, income from children, pensions. Probe for disability and sickness benefits)

<table>
<thead>
<tr>
<th></th>
<th>Annual</th>
<th>Monthly</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Under £10,000</td>
<td>Under £800</td>
</tr>
<tr>
<td>B</td>
<td>£10,000 - £20,000</td>
<td>£800 - £1,600</td>
</tr>
<tr>
<td>C</td>
<td>£21,000 - £30,000</td>
<td>£1,700 - £2,500</td>
</tr>
<tr>
<td>D</td>
<td>£31,000 - £40,000</td>
<td>£2,600 - £3,300</td>
</tr>
<tr>
<td>E</td>
<td>Over £41,000</td>
<td>Over £3,300</td>
</tr>
</tbody>
</table>
11. Are you receiving any of these benefits in your household? Please mention all that apply. (nb check current potential benefits)

☐ Carer's Allowance
☐ Attendance Allowance
☐ Incapacity Benefit
☐ Disability Living Allowance
☐ Jobseeker's Allowance
☐ Income Support
☐ Pension Credit
☐ Housing Benefit/Council Tax Benefit
☐ Tax Credits
☐ Any other state benefit
   (please state………………………………………………………………………………)
☐ None of these

12a. On the whole, over the last 12 months would you say your health has on the whole been good, fairly good, or not good?

☐ Good
☐ Fairly good
☐ Not good

12b. Do you have any long-standing physical or mental impairment, illness or disability? By ‘long-standing’ I mean anything that has troubled you over a period of at least 12 months or that is likely to affect you for a period of at least 12 months?

☐ Yes
☐ No

12c. Does this/do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life? Please tick any that apply to you

☐ mobility (moving around)
☐ lifting, carrying and moving objects
☐ manual dexterity (using your hands to carry out everyday tasks)
☐ continence (bladder and bowel control)
☐ communication (speech, hearing or eyesight)
☐ memory or ability to concentrate, learn or understand
☐ recognising when you are in physical danger
☐ your physical co-ordination (eg balance)
☐ other health problem or disability
   Please specify ……………………………………………………………
☐ none of these
12d. If yes:
Does this health problem affect

☐ The kind of work that you might do?
☐ The amount of work that you might do?
☐ How long you might work for?
   If yes, how many hours can you work?....................................

12e. Do you receive care yourself?

☐ Yes
☐ No

13a. Has your own health been affected by your caring responsibilities?

☐ Yes
☐ No

13b. In what ways? Tick any that apply

☐ Feeling tired
☐ Feeling depressed
☐ Loss of appetite
☐ Disturbed sleep
☐ General feelings of stress
☐ Physical strain (e.g. back ache)
☐ Short-tempered/irritable
☐ Had to see own GP
☐ Other
☐ No, none of these

About Your Caring Responsibilities

14a. Are you still providing care?

☐ Yes
☐ No

14b. If yes, how would you describe your caring responsibilities?

☐ on-going
☐ fluctuates
☐ ad hoc
14c. Do you share the caring responsibility with other people?

☐ Yes
☐ No

14d. If yes, please give a view of the caring responsibility. Are you:

☐ the main carer and others provide some help
☐ equally responsible for providing the care
☐ helping out the main carer

15. How old is the person you care(d) for .................

16. Is/was this person male or female?

Male ☐ Female ☐

17. What is/was your relationship to this person?

I am/was looking after my
☐ spouse or partner
☐ adult son or daughter
☐ child (step/foster)
☐ parent or parent-in-law
☐ grandparent
☐ friend or neighbour
☐ other (please specify) ..................................

18a. Where does/did the person you look after live?

☐ In their own home
☐ With me in the same household
☐ In a care home/hospital
☐ In sheltered accommodation/housing with extra care
☐ other (describe)

18b. How long does it take you to get to where the person is, if he/she is not in the same household?

Hours/minutes............................................
18c. How do you get there?

☐ Walk
☐ Car
☐ Bus
☐ Train

19. What sorts of health problems does/did this person have? Please tick any that apply.

☐ mobility (moving around)
☐ lifting, carrying and moving objects
☐ manual dexterity (using your hands to carry out everyday tasks)
☐ continence (bladder and bowel control)
☐ communication (speech, hearing or eyesight)
☐ memory or ability to concentrate, learn or understand
☐ recognising when they are in physical danger
☐ physical co-ordination (eg balance)
☐ other health problem or disability

Please specify…………………………………………………………

20. When did you start caring? Approximate year…………………………

21. For about how long have you been providing/did you provide support or care to your relative/friend?

☐ Under a year
☐ 1-3 yrs
☐ 3-5 yrs
☐ 5-10 yrs
☐ More than 10 years

22. Please tick the nearest amount of time you currently spend/used to spend providing support or care in a typical week.

☐ 1-19 hours a week
☐ 20-49 hours a week
☐ 50+ hours a week
23. **What kinds of activities do you/did you regularly help them with?**

Please tick all those that apply.

- [ ] Physical help e.g. walking, getting up and down stairs, getting in and out of bed
- [ ] Personal care e.g. washing, dressing, feeding, using the toilet
- [ ] Helping with paperwork or financial matters e.g. filling in forms, dealing with bill, banking
- [ ] Other practical help e.g. preparing meals, doing his/her shopping, laundry, housework, gardening, taking to the doctor's/hospital
- [ ] Keeping him/her company e.g. visiting, sitting with, reading to
- [ ] Taking him/her out e.g. taking out for a walk or drive, taking to see friends/relatives
- [ ] Giving medicines e.g. making sure s/he takes pills, injections, changing dressings
- [ ] Keeping an eye on him/her to make sure s/he is alright/not doing anything risky e.g. leaving the gas on unlit, wandering out of doors
- [ ] Other (please state) ............................................................................

24. **Do/did these care needs**

- [ ] Fluctuate
- [ ] Remain constant
- [ ] Increase
25. Do/did you, or the person you support, receive any help from the following? Tick those that apply.

<table>
<thead>
<tr>
<th></th>
<th>Yourself</th>
<th>Cared for person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relatives</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Friends</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Neighbours</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

And what about more formal sources of help?

<table>
<thead>
<tr>
<th></th>
<th>Yourself</th>
<th>Cared for person</th>
</tr>
</thead>
<tbody>
<tr>
<td>District/community nurse</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Social worker/care manager</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Home help/care worker</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Meals on wheels</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Respite care (eg in a care home)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Sitting service</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Day centre/hospital</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Carers social or support group</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Other support from carers agency</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Other services</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>please specify..................</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

26. Do/did you pay any charges for these services (not private ones)?

- Yes  □  No  □

27. Have you ever been offered or had an assessment of your needs by a care manager/social worker? This would include a dedicated discussion of your needs as a care giver.

- Offered  □  Yes  □  No
- Had      □  Yes  □  No
PART B  Interview: Views and Experiences of Working and Support Needs

Those who are currently working

1. How are you managing to care for your relative/friend and work at the same time?

Prompts:
- What are your main reasons for working? (probe: financial/social)
- What helps you to stay in work? (probe: flexibility; economic, emotional, psychological, social factors)
- Do you think you are better off financially? If you receive Carers Allowance, please tell me about any impact this has on your financial situation.
- What sources of support do you get outside of the workplace that help you stay in work? (probe: respite care, childcare, support groups)
- Have you ever considered giving up work? If so, why? What stopped you?
- What has your working pattern been like since you took on a caring role? How has it suited you?
- How do your caring responsibilities fit with your work experiences, especially if the nature of your responsibilities change, fluctuate or are ad hoc?

2. What do you think about your current job?

Prompts:
- Do you feel you are in a job that matches your skills/qualifications?
- Does it fit with your caring role?
- What about job satisfaction?

3. Tell me about the nature of the support that you get from your workplace

Prompts:
- What are the main sources of this support?
- What has been most helpful in allowing you stay in work? (probe: sympathetic/supportive colleagues and management)
- What sorts of things could be improved?
- Are you aware of flexible working legislation?
- How does your workplace react if you have to take unplanned time off? (eg from hospital appointments to crisis with cared for person)
• What if the care needs of the cared for person are unpredictable or fluctuating – how does your workplace react?

• Do you get any support from elsewhere that helps you to stay in work?

4. What further support do you think you need from your employer or other sources, particularly to help you stay in work?

Prompts:

• Where would you go for advice and support?

• What sorts of things would meet your needs better? (probe: help from family and friends, sources of information, childcare, provision of formal care, respite care, financial etc).

• If you needed advice on employment issues (re; return to work/job change/FT-PT options etc) where would you go?

• Have you used the services at Jobcentre Plus to obtain work or get advice?

If yes …

o What was this for? What was your experience?
  ▪ Did they help you in to employment previously/are they currently helping you to find employment?
  ▪ What was/is the nature of the support received?
  ▪ If you are currently receiving support to find work now, do you feel encouraged to find work by JC+/do JC+ seem keen to help you? Please describe the ways they did or didn’t help.
  ▪ How effective was the support and advice? Did it meet your needs?
  ▪ Are there things you think Jobcentre Plus could do more of/less of/differently/anything in addition to what they already do?
  ▪ Would you like to receive any kind of support described or wanted from JC+ in another place or in a different way? Please describe.

o Were you offered:
  ▪ A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
  ▪ Advice and/or access to advice about training opportunities? [If yes] did this include a plan of action for you indicating training you need? Have you completed the training? If not, what was the reason? If a provision was provided to offer care services while you attended training, would this make it more likely for you to attend training?

• If you receive Jobseeker’s Allowance, as part of discussions with Jobcentre Plus advisors regarding your JSA, were your care responsibilities taken into account? If yes, how did the advisor indicate this?
If no (you haven’t used JCP)...

- Might you consider getting advice from Jobcentre Plus? If not why not? (probe – just never thought of it or are there barriers such as exposing self as ‘in need’, concerns about benefits being taken away etc, concerns about being forced to work or do they perceive JCP negatively but without personal experience)?

- Might you be interested in any of the following services:
  - A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
  - Advice and/or access to advice about training opportunities? If a provision was provided to offer care services while you attended training, would this make it more likely for you to be interested in training?

- If you get Carer’s Allowance, or other benefits related to caring, has this influenced how you feel about working?
  - Do you know about the Carer’s Allowance work rules?
  - Do you know about Working Tax Credit assistance?
  - Have you ever been asked to attend a work focused interview (WFI)?
    - If so, how did it go (probe: were you comfortable with what was asked, did you feel it was useful and appropriate to your situation, did you feel understood and that your situation was handled appropriately.)
    - Was it useful? (if yes how? If no, why not?).
    - If caring responsibilities, or other circumstances, made it difficult for you to attend the interview, did you ask for it to be deferred to a later date or any other request for accommodation?
    - You are not obliged to take the advice given at the WFI or take any job available (esp. if that job does not fit with your work history or qualifications, or with your caring responsibilities). Knowing this, are you more inclined to attend a WFI or attend one in the future?
      (Note to interviewer: If the carer is over 60 or under 18 they will NOT be asked to attend a WFI. Carers do NOT need a work-focused interview if they work at least 16 hours a week and don’t get Income Support.)

- Have you received any other help from DWP and its agencies? What was your experience of that help?

Thank you for your help.
Non-Working

Interview Schedule: Employment Support for Carers

PART A  Background information about yourself

1. What is your age? .....................

2. Are you male □ female □ ?

3. What is your marital status?
   - never married □ married □ co-habiting □ divorced □
   - separated □ widowed □

4. Who lives in your household with you?
   - spouse or partner
   - adult son or daughter
   - child (step/foster)
   - parent or parent-in-law
   - grandparent
   - friend
   - other (please specify) ...........................................
   - no one, live alone

5. What is your ethnic group? tick one box only

   **White**
   - British □
   - Irish □
   - Any other white background □

   **Mixed**
   - White and Black Caribbean □
   - White and Black African □
   - White and Asian □
   - Any other mixed background □

   **Black or Black British**
   - Caribbean □
   - African □
   - Any other Black background □

   **Asian or Asian British**
   - Indian □
   - Pakistani □
   - Bangladeshi □
   - Any other Asian background □

   **Chinese or other ethnic group**
   - Chinese □
   - Any other □ (please specify)
6. What is your current employment status?

**Working**

- Full-time ☐ Part-time ☐
- Semi-retired ☐ Permanent ☐
- Fixed-term ☐ Employed ☐
- Self-employed ☐

**Types of fixed-term:**
- Temporary employee ☐
- Temporary agency worker ☐

**Working patterns:**
- Term-time ☐
- Job share ☐
- Hours vary from week to week ☐
- Compressed week ☐
- Standard’ daytime hours (e.g. 9-5; 8-4) ☐
- Flexitime Night/early/back shifts ☐
- Fixed Night/early/back shifts ☐
- Rota ☐
- Other ☐
- Please specify ....................

**Not working**

- Unemployed looking for work ☐
- not looking ☐

- If not working:
  - retired ☐
  - ill-health and/or disability

- Have you ever worked? Yes ☐ No ☐
- If yes, when did you stop working? ............
- Do you undertake voluntary work? Yes ☐ No ☐

7. What is the nature of your employment/ What was your main line of work?

Job title ..........................................................
8a. What type of organisation are you/did you work for?

- Public organisation
- Large private business (over 250 employees)
- Medium-size private employer (between 50-249 employees)
- Small private business (less than 50 employees)
- Self-employed

8b. How many hours per week are you/did you work for most recently?

- Less than 16
- 16-29 hours
- 30 or more hours

8c. Would you describe your employment history as

- Consistent/regular employment
- Intermittent due to caring/parenting
- Never worked due to caring/parenting
- Other

Please specify………………………………………………

9. What is your main source of income?

- Employment
- Benefits
- Pension
- Savings
- Other (please specify……………………………………

10. We would like to get an idea of which income band your household falls within. Can you tell me approximately how much you get per year?

(Include benefits, salaries, rental income from property, income from children, pensions. Probe for disability and sickness benefits)

<table>
<thead>
<tr>
<th>Annual</th>
<th>Monthly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under £10,000</td>
<td>Under £800</td>
</tr>
<tr>
<td>£10,000 - £20,000</td>
<td>£800 - £1,600</td>
</tr>
<tr>
<td>£21,000 - £30,000</td>
<td>£1,700 - £2,500</td>
</tr>
<tr>
<td>£31,000 - £40,000</td>
<td>£2,600 - £3,300</td>
</tr>
<tr>
<td>Over £41,000</td>
<td>Over £3,300</td>
</tr>
</tbody>
</table>
11. Are you receiving any of these benefits in your household? Please mention all that apply. (nb check current potential benefits)

☐ Carer’s Allowance
☐ Attendance Allowance
☐ Incapacity Benefit
☐ Disability Living Allowance
☐ Jobseeker’s Allowance
☐ Income Support
☐ Pension Credit
☐ Housing Benefit/Council Tax Benefit
☐ Tax Credits
☐ Any other state benefit
   (please state…………………………………………………………)
☐ None of these

12a. On the whole, over the last 12 months would you say your health has on the whole been good, fairly good, or not good?

☐ Good
☐ Fairly good
☐ Not good

12b. Do you have any long-standing physical or mental impairment, illness or disability? By ‘long-standing’ I mean anything that has troubled you over a period of at least 12 months or that is likely to affect you for a period of at least 12 months?

☐ Yes
☐ No

12c. Does this/do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life? Please tick any that apply to you

☐ mobility (moving around)
☐ lifting, carrying and moving objects
☐ manual dexterity (using your hands to carry out everyday tasks)
☐ continence (bladder and bowel control)
☐ communication (speech, hearing or eyesight)
☐ memory or ability to concentrate, learn or understand
☐ recognising when you are in physical danger
☐ your physical co-ordination (eg balance)
☐ other health problem or disability
   Please specify ……………………………………………………………
☐ none of these
12d. If yes:
Does this health problem affect

- [ ] The kind of work that you might do?
- [ ] The amount of work that you might do?
- [ ] How long you might work for?
  If yes, how many hours can you work?.................................

12e. Do you receive care yourself?

- [ ] Yes
- [ ] No

13a. Has your own health been affected by your caring responsibilities?

- [ ] Yes
- [ ] No

13b. In what ways? Tick any that apply

- [ ] Feeling tired
- [ ] Feeling depressed
- [ ] Loss of appetite
- [ ] Disturbed sleep
- [ ] General feelings of stress
- [ ] Physical strain (e.g. back ache)
- [ ] Short-tempered/irritable
- [ ] Had to see own GP
- [ ] Other
- [ ] No, none of these

About Your Caring Responsibilities

14a. Are you still providing care?

- [ ] Yes
- [ ] No

14b. If yes, how would you describe your caring responsibilities?

- [ ] on-going
- [ ] fluctuates
- [ ] ad hoc
14c. Do you share the caring responsibility with other people?

- Yes
- No

14d. If yes, please give a view of the caring responsibility. Are you:

- the main carer and others provide some help
- equally responsible for providing the care
- helping out the main carer

15. How old is the person you care(d) for?

16. Is/was this person male or female?

- Male
- Female

17. What is/was your relationship to this person?

- I am/was looking after my
- spouse or partner
- adult son or daughter
- child (step/foster)
- parent or parent-in-law
- grandparent
- friend or neighbour
- other (please specify)

18a. Where does/did the person you look after live?

- In their own home
- With me in the same household
- In a care home/hospital
- In sheltered accommodation/housing with extra care
- other (describe)

18b. How long does it take you to get to where the person is, if he/she is not in the same household?

Hours/minutes
18c. How do you get there?

☐ Walk
☐ Car
☐ Bus
☐ Train

19. What sorts of health problems does/did this person have? Please tick any that apply.

☐ mobility (moving around)
☐ lifting, carrying and moving objects
☐ manual dexterity (using your hands to carry out everyday tasks)
☐ continence (bladder and bowel control)
☐ communication (speech, hearing or eyesight)
☐ memory or ability to concentrate, learn or understand
☐ recognising when they are in physical danger
☐ physical co-ordination (eg balance)
☐ other health problem or disability

Please specify........................................................................

20. When did you start caring? Approximate year.........................

21. For about how long have you been providing/did you provide support or care to your relative/friend?

☐ Under a year
☐ 1-3 yrs
☐ 3-5 yrs
☐ 5-10 yrs
☐ More than 10 years

22. Please tick the nearest amount of time you currently spend/used to spend providing support or care in a typical week.

☐ 1-19 hours a week
☐ 20-49 hours a week
☐ 50+ hours a week
23. **What kinds of activities do you/did you regularly help them with?**

Please tick all those that apply.

- [ ] Physical help e.g. walking, getting up and down stairs, getting in and out of bed
- [ ] Personal care e.g. washing, dressing, feeding, using the toilet
- [ ] Helping with paperwork or financial matters e.g. filling in forms, dealing with bill, banking
- [ ] Other practical help e.g. preparing meals, doing his/her shopping, laundry, housework, gardening, taking to the doctor's/hospital
- [ ] Keeping him/her company e.g. visiting, sitting with, reading to
- [ ] Taking him/her out e.g. taking out for a walk or drive, taking to see friends/relatives
- [ ] Giving medicines e.g. making sure s/he takes pills, injections, changing dressings
- [ ] Keeping an eye on him/her to make sure s/he is alright/not doing anything risky e.g. leaving the gas on unlit, wandering out of doors
- [ ] Other (please state) .................................................................

24. **Do/did these care needs**

- [ ] Fluctuate
- [ ] Remain constant
- [ ] Increase
25. Do/did you, or the person you support, receive any help from the following? Tick those that apply.

<table>
<thead>
<tr>
<th></th>
<th>Yourself</th>
<th>Cared for person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relatives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighbours</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

And what about more formal sources of help?

<table>
<thead>
<tr>
<th></th>
<th>Yourself</th>
<th>Cared for person</th>
</tr>
</thead>
<tbody>
<tr>
<td>District/community nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social worker/care manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home help/care worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meals on wheels</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respite care (eg in a care home)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day centre/hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers social or support group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other support from carers agency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>please specify............................</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

26. Do/did you pay any charges for these services (not private ones)?

☐ Yes  ☐ No

27. Have you ever been offered or had an assessment of your needs by a care manager/social worker? This would include a dedicated discussion of your needs as a care giver.

Offered  ☐ Yes  ☐ No

Had  ☐ Yes  ☐ No
PART B  Interview: Views and Experiences of Working and Support Needs

Those who are not currently working

1. How do you feel about working?

Prompts:
- Would you like to work?
  o If so, why? – what do you feel you would get out of working i.e. financially, socially etc? Do you feel you would be better off financially/socially?
  o Explore situation if retired – if you retired early was this due to caring demands? Please describe.
- Have you tried to get a job at all?
  o If yes, why? What sort of work were you looking for? What were your experiences of doing this? (probe: qualifications, confidence, job readiness, closeness to the job market, nature of caring responsibilities, potential financial disincentives)
  o If no, why is that? (probe: qualifications, confidence, job readiness, closeness to the job market, nature of caring responsibilities, potential financial disincentives)
- What sort of work do you feel you could do? (probe: types of work, number of hours, flexible working/hours, location, getting to work)
  o Do you think that type of work is available? Why do you think it is not available? (probe: why do you believe this is not the case and are they aware of flexible working legislation)
- If you needed advice on employment issues (re; return to work job change/FT-PT options etc) where would you go?
- Have you used the services at Jobcentre Plus to obtain work or get advice?
  If yes …
  o What was this for? What was your experience?
    - Did they help you in to employment previously/are they currently helping you to find employment?
    - What was/is the nature of the support received?
    - If you are currently receiving support to find work now, do you feel encouraged to find work by JC+/do JC+ seem keen to help you? Please describe the ways they did or didn’t help.
    - How effective was the support and advice? Did it meet your needs?
• Are there things you think Jobcentre Plus could do more of/less of/differently/anything in addition to what they already do?

• Would you like to receive any kind of support described or wanted from JC+ in another place or in a different way? Please describe.

  o Were you offered:

    • A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?

    • Advice and/or access to advice about training opportunities? [If yes] did this include a plan of action for you indicating training you need? Have you completed the training? If not, what was the reason? If a provision was provided to offer care services while you attended training, would this make it more likely for you to attend training?

• If you receive Job Seeker's Allowance, as part of discussions with Jobcentre Plus advisors regarding your JSA, were your care responsibilities taken into account? If yes, how did the advisor indicate this?

If no (you haven’t used JCP)...

• Might you consider getting advice from Jobcentre Plus? If not why not? (probe – just never thought of it or are there barriers such as exposing self as ‘in need’, concerns about benefits being taken away etc, concerns about being forced to work or do they perceive JCP negatively but without personal experience)?

• Might you be interested in any of the following services:

  o A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?

  o Advice and/or access to advice about training opportunities? If a provision was provided to offer care services while you attended training, would this make it more likely for you to be interested in training?

• If you get Carer’s Allowance, or other benefits related to caring, has this influenced how you feel about working?

  o Do you know about the Carer’s Allowance work rules?

  o Do you know about Working Tax Credit assistance?

  o Have you ever been asked to attend a work focused interview (WFI)?

  o If so, how did it go (probe: were you comfortable with what was asked, did you feel it was useful and appropriate to your situation, did you feel understood and that your situation was handled appropriately.)

  o Was it useful? (if yes how? If no, why not?).

  o If caring responsibilities, or other circumstances, made it difficult for you to attend the interview, did you ask for it to be deferred to a later date or any other request for accommodation?
o You are not obliged to take the advice given at the WFI or take any job available (esp. if that job does not fit with your work history or qualifications, or with your caring responsibilities). Knowing this, are you more inclined to attend a WFI or attend one in the future?

(Note to interviewer: If the carer is over 60 or under 18 they will NOT be asked to attend a WFI. Carers do NOT need a work-focused interview if they work at least 16 hours a week and don’t get Income Support.)

• Have you received any other help from DWP and its agencies? What was your experience of that help?

In relation to previous work experience...

2. How has your caring role impacted on your experiences of working?

Prompts:

- What are your previous experiences of working and caring?
  o What sort of work did you do? (probe: hours, flexibility)
  o What was your working experience like? Tell me about good and bad experiences.
  o How did your caring responsibilities fit with your work experiences, especially if the nature of your responsibilities changed, fluctuated or were ad hoc?
  o What sorts of help did you get from your workplace – colleagues, managers etc? (probe: direct support from manager or colleagues, flexible shift patterns/working hours to suit care demands)

- Why did you give up?
  o Did you have to give up work to care for someone? Please tell me about the circumstances.
  o Did the help from your employers/the workplace meet your needs? If not, why was this? Where were the gaps?
  o Did you try and negotiate different arrangements with your employer? If yes, what happened? (n.b. Are you aware of the right to request flexible working and did you pursue this option before leaving?)
  o What more could have been done to help you to stay in work by family, friends, or health and social care agencies?
3. If you were to consider getting a job, what sorts of things would help you the most?

Prompts:

- Out of choice, where would you go for help and support?

- What sorts of things would meet your needs better? (probe: help from friends and relatives, sources of information, childcare, provision of formal care, respite care, financial etc).

- What sort of practical support would you need to help you find a job? (probe: help with application forms, finding out about job vacancies, interview practice, help with confidence building/self-esteem and where you would like to go to for that support)

- Have you ever had help or advice from any person or organisations? If so, please describe what this help was and who it was from.
  - Was it useful?
  - Did it meet your needs?
  - Was there a particular reason why you went specifically to them?

- Have you ever gone back to a previous employer or colleague for help or any other reason? If so;
  - Was it useful?
  - Did it meet your needs?
  - What do you think of this idea?

Thank you for your help.
Ceased Caring

Interview Schedule: Employment Support for Carers

ID Code:

PART A Background information about yourself

1. What is your age? .........................

2. Are you  male □ female □?

3. What is your marital status?
   never married □ married □ co-habiting □ divorced □
   separated □ widowed □

4. Who lives in your household with you?
   □ spouse or partner
   □ adult son or daughter
   □ child (step/foster)
   □ parent or parent-in-law
   □ grandparent
   □ friend
   □ other (please specify) .................................
   □ no one, live alone

5. What is your ethnic group? tick one box only

   White □ Black or Black British □
   British □ Caribbean □
   Irish □ African □
   Any other white background □ Any other Black background □

   Mixed □ Asian or Asian British □
   White and Black Caribbean □ Indian □
   White and Black African □ Pakistani □
   White and Asian □ Bangladeshi □
   Any other mixed background □ Any other Asian background □

   Chinese or other ethnic group
   Chinese □
   Any other □ (please specify)
6. **What is your current employment status?**

   **Working**
   - Full-time  
   - Semi-retired  
   - Fixed-term  
   - Self-employed  
   - Part-time  
   - Permanent  
   - Employed  

   Types of fixed-term:  
   - Temporary employee  
   - Temporary agency worker  

   **Working patterns:**  
   - Term-time  
   - Job share  
   - Hours vary from week to week  
   - Compressed week  
   - Standard daytime hours (e.g. 9-5; 8-4)  
   - Flexitime Night/early/back shifts  
   - Fixed Night/early/back shifts  
   - Rota  
   - Other  
   - Please specify ………………….

   **Not working**
   - Unemployed  
   - looking for work  
   - not looking  

   If not working:  
   - retired  
   - ill-health and/or disability  

   Have you ever worked?  
   - Yes  
   - No  

   If yes, when did you stop working?  
   - ……………

   Do you undertake voluntary work?  
   - Yes  
   - No  

7. **What is the nature of your employment/ What was your main line of work?**

   Job title …………………………………………………………….
8a. What type of organisation are you/did you work for?

- Public organisation
- Large private business (over 250 employees)
- Medium-size private employer (between 50-249 employees)
- Small private business (less than 50 employees)
- Self-employed

8b. How many hours per week are you/did you work for most recently?

- Less than 16
- 16-29 hours
- 30 or more hours

8c. Would you describe your employment history as

- Consistent/regular employment
- Intermittent due to caring/parenting
- Never worked due to caring/parenting
- Other
- Please specify………………………………………………

9. What is your main source of income?

- Employment
- Benefits
- Pension
- Savings
- Other (please specify…………………………………………

10. We would like to get an idea of which income band your household falls within. Can you tell me approximately how much you get per year?

(Include benefits, salaries, rental income from property, income from children, pensions. Probe for disability and sickness benefits)

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11. Are you receiving any of these benefits in your household? Please mention all that apply. (nb check current potential benefits)

- Carer’s Allowance
- Attendance Allowance
- Incapacity Benefit
- Disability Living Allowance
- Jobseeker’s Allowance
- Income Support
- Pension Credit
- Housing Benefit/Council Tax Benefit
- Tax Credits
- Any other state benefit
  (please state…………………………………………………………)
- None of these

12a. On the whole, over the last 12 months would you say your health has on the whole been good, fairly good, or not good?

- Good
- Fairly good
- Not good

12b. Do you have any long-standing physical or mental impairment, illness or disability? By ‘long-standing’ I mean anything that has troubled you over a period of at least 12 months or that is likely to affect you for a period of at least 12 months?

- Yes
- No

12c. Does this/do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life? Please tick any that apply to you

- mobility (moving around)
- lifting, carrying and moving objects
- manual dexterity (using your hands to carry out everyday tasks)
- continence (bladder and bowel control)
- communication (speech, hearing or eyesight)
- memory or ability to concentrate, learn or understand
- recognising when you are in physical danger
- your physical co-ordination (eg balance)
- other health problem or disability
  Please specify …………………………………………………..
- none of these
12d. If yes:
Does this health problem affect

- The kind of work that you might do?
- The amount of work that you might do?
- How long you might work for?
  If yes, how many hours can you work? ...........................................

12e. Do you receive care yourself?

- Yes
- No

13a. Has your own health been affected by your caring responsibilities?

- Yes
- No

13b. In what ways? Tick any that apply

- Feeling tired
- Feeling depressed
- Loss of appetite
- Disturbed sleep
- General feelings of stress
- Physical strain (e.g. back ache)
- Short-tempered/irritable
- Had to see own GP
- Other
- No, none of these

**About Your Caring Responsibilities**

14a. Are you still providing care?

- Yes
- No

14b. If yes, how would you describe your caring responsibilities?

- on-going
- fluctuates
- ad hoc
14c. Do you share the caring responsibility with other people?

☐ Yes
☐ No

14d. If yes, please give a view of the caring responsibility. Are you:

☐ the main carer and others provide some help
☐ equally responsible for providing the care
☐ helping out the main carer…………………………………………

15. How old is the person you care(d) for ………………………

16. Is/was this person male or female?

Male ☐ Female ☐

17. What is/was your relationship to this person?

I am/was looking after my

☐ spouse or partner
☐ adult son or daughter
☐ child (step/foster)
☐ parent or parent-in-law
☐ grandparent
☐ friend or neighbour
☐ other (please specify) ……………………………

18a. Where does/did the person you look after live?

☐ In their own home
☐ With me in the same household
☐ In a care home/hospital
☐ In sheltered accommodation/housing with extra care
☐ other (describe)

18b. How long does it take you to get to where the person is, if he/she is not in the same household?

Hours/minutes………………………………………………..

Appendix – Field instruments
18c. How do you get there?

- Walk
- Car
- Bus
- Train

19. What sorts of health problems does/did this person have? Please tick any that apply.

- mobility (moving around)
- lifting, carrying and moving objects
- manual dexterity (using your hands to carry out everyday tasks)
- continence (bladder and bowel control)
- communication (speech, hearing or eyesight)
- memory or ability to concentrate, learn or understand
- recognising when they are in physical danger
- physical co-ordination (eg balance)
- other health problem or disability

Please specify……………………………………………………………………

20. When did you start caring? Approximate year…………………………

21. For about how long have you been providing/did you provide support or care to your relative/friend?

- Under a year
- 1-3 yrs
- 3-5 yrs
- 5-10 yrs
- More than 10 years

22. Please tick the nearest amount of time you currently spend/used to spend providing support or care in a typical week.

- 1-19 hours a week
- 20-49 hours a week
- 50+ hours a week
23. What kinds of activities do you/did you regularly help them with?
Please tick all those that apply.

- Physical help e.g. walking, getting up and down stairs, getting in and out of bed
- Personal care e.g. washing, dressing, feeding, using the toilet
- Helping with paperwork or financial matters e.g. filling in forms, dealing with bill, banking
- Other practical help e.g. preparing meals, doing his/her shopping, laundry, housework, gardening, taking to the doctor's/hospital
- Keeping him/her company e.g. visiting, sitting with, reading to
- Taking him/her out e.g. taking out for a walk or drive, taking to see friends/relatives
- Giving medicines e.g. making sure s/he takes pills, injections, changing dressings
- Keeping an eye on him/her to make sure s/he is alright/not doing anything risky e.g. leaving the gas on unlit, wandering out of doors
- Other (please state) .................................................................

24. Do/did these care needs

- Fluctuate
- Remain constant
- Increase
25. Do/did you, or the person you support, receive any help from the following? Tick those that apply.

<table>
<thead>
<tr>
<th></th>
<th>Yourself</th>
<th>Cared for person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relatives</td>
<td></td>
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<tr>
<td>Friends</td>
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<tr>
<td>Neighbours</td>
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</tbody>
</table>

And what about more formal sources of help?

<table>
<thead>
<tr>
<th></th>
<th>Yourself</th>
<th>Cared for person</th>
</tr>
</thead>
<tbody>
<tr>
<td>District/community nurse</td>
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<tr>
<td>Social worker/care manager</td>
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<tr>
<td>Home help/care worker</td>
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<tr>
<td>Meals on wheels</td>
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<tr>
<td>Respite care (eg in a care home)</td>
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<tr>
<td>Sitting service</td>
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<tr>
<td>Day centre/hospital</td>
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<tr>
<td>Carers social or support group</td>
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<td></td>
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<tr>
<td>Other support from carers agency</td>
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<tr>
<td>Other services</td>
<td></td>
<td></td>
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<tr>
<td>please specify....................................</td>
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</tbody>
</table>

26. Do/did you pay any charges for these services (not private ones)?

☐ Yes  ☐ No

27. Have you ever been offered or had an assessment of your needs by a care manager/social worker? This would include a dedicated discussion of your needs as a care giver.

Offered  ☐ Yes  ☐ No

Had  ☐ Yes  ☐ No
PART B Interview: Views and Experiences of Working and Support Needs

Those who are no longer caring but would like to work

1. How do you feel about working?

Prompts:

- Would you like to work?
  - If so, why? – what do you feel you would get out of working i.e. financially, socially etc? Do you feel you would be better off financially/socially?
  - Explore situation if retired – if you retired early was this due to caring demands? Please describe.

- Have you tried to get a job at all?
  - If yes, why? What sort of work were you looking for? What were your experiences of doing this? (probe: qualifications, confidence, job readiness, closeness to the job market, nature of caring responsibilities, potential financial disincentives)
  - If no, why is that? (probe: qualifications, confidence, job readiness, closeness to the job market, nature of caring responsibilities, potential financial disincentives)

- What sort of work do you feel you could do? (probe: types of work, number of hours, flexible working/hours, location, getting to work)
  - Do you think that type of work is available? Why do you think it is not available? (probe: why do you believe this is not the case and are they aware of flexible working legislation)

- If you needed advice on employment issues (re; return to work/job change/FT-PT options etc) where would you go?

- Have you used the services at Jobcentre Plus to obtain work or get advice?
  - If yes …
    - What was this for? What was your experience?
      - Did they help you in to employment previously/are they currently helping you to find employment?
      - What was/is the nature of the support received?
      - If you are currently receiving support to find work now, do you feel encouraged to find work by JC+/do JC+ seem keen to help you? Please describe the ways they did or didn’t help.
      - How effective was the support and advice? Did it meet your needs?
• Are there things you think Jobcentre Plus could do more of/less of/differently/anything in addition to what they already do?

• Would you like to receive any kind of support described or wanted from JC+ in another place or in a different way? Please describe.

  o Were you offered:
    • A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
    • Advice and/or access to advice about training opportunities? [If yes] did this include a plan of action for you indicating training you need? Have you completed the training? If not, what was the reason? If a provision was provided to offer care services while you attended training, would this make it more likely for you to attend training?

• If you receive Job Seeker’s Allowance, as part of discussions with Jobcentre Plus advisors regarding your JSA, were your care responsibilities taken into account? If yes, how did the advisor indicate this?

  If no (you haven’t used JCP)…

  • Might you consider getting advice from Jobcentre Plus? If not why not? (probe – just never thought of it or are there barriers such as exposing self as ‘in need’, concerns about benefits being taken away etc, concerns about being forced to work or do they perceive JCP negatively but without personal experience)?

  • Might you be interested in any of the following services:
    • A better-off calculation to help you make an informed choice regarding combining caring and entering or increasing hours of work?
    • Advice and/or access to advice about training opportunities? If a provision was provided to offer care services while you attended training, would this make it more likely for you to be interested in training?

• If you get Carer’s Allowance, or other benefits related to caring, has this influenced how you feel about working?

  • Do you know about the Carer’s Allowance work rules?

  • Do you know about Working Tax Credit assistance?

  • Have you ever been asked to attend a work focused interview (WFI)?

  • If so, how did it go (probe: were you comfortable with what was asked, did you feel it was useful and appropriate to your situation, did you feel understood and that your situation was handled appropriately.)

  • Was it useful? (if yes how? If no, why not?).

  • If caring responsibilities, or other circumstances, made it difficult for you to attend the interview, did you ask for it to be deferred to a later date or any other request for accommodation?
You are not obliged to take the advice given at the WFI or take any job available (esp. if that job does not fit with your work history or qualifications, or with your caring responsibilities). Knowing this, are you more inclined to attend a WFI or attend one in the future?

(Note to interviewer: If the carer is over 60 or under 18 they will NOT be asked to attend a WFI. Carers do NOT need a work-focused interview if they work at least 16 hours a week and don’t get Income Support.)

- Have you received any other help from DWP and its agencies? What was your experience of that help?

In relation to previous work experience...

2. How has your caring role impacted on your experiences of working?

Prompts:

- What are your previous experiences of working and caring?
  - What sort of work did you do? (probe: hours, flexibility)
  - What was your working experience like? Tell me about good and bad experiences.
  - How did your caring responsibilities fit with your work experiences, especially if the nature of your responsibilities changed, fluctuated or were ad hoc?
  - What sorts of help did you get from your workplace – colleagues, managers etc? (probe: direct support from manager or colleagues, flexible shift patterns/working hours to suit care demands)

- Why did you give up?
  - Did you have to give up work to care for someone? Please tell me about the circumstances.
  - Did the help from your employers/the workplace meet your needs? If not, why was this? Where were the gaps?
  - Did you try and negotiate different arrangements with your employer? If yes, what happened? (n.b. Are you aware of the right to request flexible working and did you pursue this option before leaving?)
  - What more could have been done to help you to stay in work by family, friends, or health and social care agencies?
3. If you were to consider getting a job, what sorts of things would help you the most?

Prompts:

- Out of choice, where would you go for help and support?
- What sorts of things would meet your needs better? (probe: help from friends and relatives, sources of information, childcare, provision of formal care, respite care, financial etc).
- What sort of practical support would you need to help you find a job?
(probe: help with application forms, finding out about job vacancies, interview practice, help with confidence building/self-esteem and where you would like to go to for that support)
- Have you ever had help or advice from any person or organisations? If so, please describe what this help was and who it was from.
  o Was it useful?
  o Did it meet your needs?
  o Was there a particular reason why you went specifically to them?
- Have you ever gone back to a previous employer or colleague for help or any other reason? If so;
  o Was it useful?
  o Did it meet your needs?
  o What do you think of this idea?

Thank you for your help.
ID Code: ______

Age: ___

### Timeline Grid – Key events in my life

<table>
<thead>
<tr>
<th>Age</th>
<th>Work history, type of work</th>
<th>Qualifications (NVQs/Degrees/etc.)</th>
<th>Marriage and Partnerships</th>
<th>Periods of dependent children</th>
<th>History of caring, stages, events</th>
<th>Periods where caring and working combine</th>
<th>Health events</th>
<th>Other significant life events</th>
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Appendix – Field instruments
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<tr>
<th>Age</th>
<th>Work history, type of work</th>
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<th>Other significant life events</th>
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Where to go for information and advice

**General**

**Citizens Advice Bureau**
Offers advice on a wide range of subjects from housing and health to debt and consumer issues.
**Phone** 020 7833 2181
**Website** www.adviceguide.org.uk

**Directgov**
This website offers people guidance about working patterns that would suit them by first taking them through a set of questions about their current job circumstances and their ideal working arrangements.

As well as suggesting suitable flexible working patterns it gives advice on presenting a case to an employer and outlines any rights to flexible working
**Website**: www.directgov.gov.uk

**Working Life**

**Age Positive**
Promotes the benefits of employing a mixed-age workforce, including older people.
**Email** agepositive@dwp.gsi.gov.uk
**Website** www.agepositive.gov.uk

**Jobcentre Plus**
Can help you find the right kind of job: full-time or part-time, temporary or permanent.
**Phone** 0845 6060 234 (textphone 08456 044 022)
Open weekdays 9am to 6pm, and Saturdays 9am to 1pm
**Website** www.jobcentreplus.gov.uk

**New Deal 50 plus**
A programme for people aged 50 or over who have been out of work and claiming benefits for at least six months.
**Phone** 08456 062 626 (textphone 08456 060 680)
**Website** www.jobcentreplus.gov.uk/JCP/Customers/NewDeal/index.html

**Learning opportunities and leisure**

**LearnDirect**
Provides online courses, and information about the network of learndirect centres.
**Phone** 0800 100 900
**Website** www.learndirect-advice.co.uk
UK online
Their network of centres provide access to computers, internet and email locally.
Phone 0800 77 1234
Email ukonlinecentredata@ufi.com
Website www.ukonlinecentres.com/consumer/

Money matters

The Pension Service
The Pension Service is the part of the Department for Work & Pensions that works out and pays pension entitlements.
Phone 0845 6060 265 (textphone 0845 6060 285)
Open Monday to Friday, 8am to 6pm
Website www.thepensionservice.gov.uk

Carers Issues

Carers UK
Carers UK is the voice of carers across the UK. It provides a wide range of advice and information to family carers – those who look after an ill, frail or disabled family member, friend or partner. It also campaigns to end injustice.
Phone CarersLine on 0808 808 7777
Website www.carersuk.org/

THANK YOU FOR TAKING PART
References


