



# Stages and Transitions in the Experience of Caring

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**CARERS look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.**

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# Stages and Transitions in the Experience of Caring

**CES Report No. 1 is about how carers access and experience the support and services they need to undertake their caring role and to maintain their own health and wellbeing at different stages of caring.**

It includes evidence about the kind of support carers who are in paid work need, and looks at how carers can be helped to care and to have a life outside caring too. The report examines new evidence, collected in 2006-7 (from the CES survey of 1,909 carers and in-depth face-to-face interviews with 134 carers), about the different services and support carers need at different points in their experience of caring, and how this is affected by who they care for and what their care needs are.



# Executive Summary

This report, *Stages and Transitions in Caring*, is one of a series relating to the **Carers, Employment and Services** (CES) study conducted in 2006-7 at the University of Leeds, commissioned by Carers UK, lead partner in the Action for Carers and Employment partnership. The findings reported are based on 1,909 responses to a national survey targeting carers of working age, and 134 face-to-face interviews with carers aged 25-64 living in ten selected localities in England, Wales and Scotland. The report, which also outlines the focus of the other reports available in the CES Series, explores carers' situation in: the early stages of becoming a carer (the first two years); when caring has become a longer-term commitment (2 years or longer); and as caring at home comes to an end.

*Stages and Transitions in Caring* is one of a series of publications arising from the CES study, and should be read in conjunction with the other reports. The CES study was commissioned to strengthen the evidence base available to inform future public policy and service development. It builds on previous research, also commissioned through the Action for Carers and Employment partnership, and published separately, which looked mainly at what can be done within the workplace to support carers in combining work and care.

## *New carers in the CES study:*

- 214 'new' carers responded to the survey.
- Some gradually became carers; others had caring suddenly thrust upon them.
- Two thirds of the 'new' carers were caring for 20 or more hours per week.
- Almost 60% of 'new' carers aged 16-64 were in paid employment.
- Two thirds were caring for someone who was living with them.
- Most were carers of an older person (65+) or of an adult aged 25-64.
- 41% were supporting someone who was not receiving any services at all.
- 28% were struggling financially because of low/reduced income, the costs of caring, or weaknesses in service provision.
- 42% said the person they cared for had not had their needs assessed.

### *Key issues for new carers:*

- A key problem was a lack of information; and inadequate responsiveness and accessibility on the part of service providers. Many carers felt confused, frustrated and unsupported:
  - 41% did not know what services were available locally.
  - 40% felt restricted in using services because they were not sufficiently flexible or sensitive to their specific needs.
  - Early information was needed about benefits, assessment, services, respite and breaks, and rights and options at work, but had often not been given, or was not easily found.
  - Many recounted problems in communicating with health and social care services. These had caused some carers great distress and frustration.
  - The difficulties of their caring situation were greatly eased when carers felt well-informed, adequately supported and that their own needs were being taken into account.
- Problems in combining work and care were also common:
  - How they would manage their new caring role alongside paid employment was a considerable source of worry – most did not want to give up work.
  - 46% of full-time employees, and 62% of part-time employees, felt they did not have adequate services to enable them to work.
  - Only just over half (56%) felt their employer was carer-friendly and supportive.
  - When managers and colleagues had been supportive and flexible about their new situation, carers were appreciative and full of praise.
- Resistance to using services among those needing care:
  - 42% of 'new' carers said the person they cared for did not want to use services.
  - While some wanted a loved one to provide the care they needed, some did not want to use services which they considered unsuitable, inflexible or expensive.

### *'Longer-term' carers in the CES study:*

- 1,675 'longer-term' carers responded to the survey.
- 76% were living with the person they cared for.
- 84% of 'longer-term' carers were caring for 20 or more hours per week.
- Less than half of 'longer-term' carers aged 16-64 were in paid employment: 45% of those caring for 1-19 hours per week; but only 21% of those with the heaviest caring roles.
- For over a third of the 'heavy end' carers, caring was their full-time role.
- Caring responsibilities varied: 29% cared for a sick or disabled child (under 20 years old), and 12% were looking after an older child; 24% supported a spouse or partner, and 13% were caring for a parent or parent-in-law.
- 30% of those caring for 20+ hours per week were supporting someone who was not receiving any services.
- 33% said the person they cared for had not had their needs assessed.
- 34% reported that were struggling to make ends meet.
- 27% said their health was 'not good'.

### *Key issues for 'longer-term' carers:*

- Financial and employment implications of caring
  - 'Heavy end' carers are the most likely to live with the person they care for, and to be struggling financially, and are also the least likely to be in full-time paid work.
  - Many of those with 'heavy' caring roles were supporting a disabled child or a partner, and many were in the 35-49 age group.
  - Impacts on their own health, financial situation and ability to work are major issues for 'longer-term' carers.
- Issues in arrangements and dealings with service providers
  - 'Longer-term' carers often reported reaching 'crisis point'; many had felt poorly supported by service providers in this situation.
  - Over the years, many carers felt they had become 'experts' in their caring situation, but they did not always feel this was recognised by the agencies they dealt with.
  - 'Longer-term' carers often reported that services are not flexible or sensitive enough to their specific needs, especially in combining work and care.
  - Many reported that those they care for do not want to use the services available; they often found this placed them under considerable pressure.

### *When caring ends:*

The issues confronting carers in three types of situation when caring at home comes to an end are briefly discussed:

- When the cared for person moves to independent living (when care often continues in a different form, and when carers often want support in returning to work and in managing their changed caring role).
- When the cared for person moves into residential care (sometimes when suitable services cannot be found to support the carer).
- When preparations for the future (when the carer will not be available) need to be made. Some carers felt they needed better and much more flexible support in making these plans.

### **Policy Implications:**

The detailed policy implications of the evidence presented in the report, and a full set of recommendations, are presented in CES Report 6 *Carers, Employment and Services: time for a new social contract?* There we stress the need for radical new thinking, and significant policy change, to enable carers to integrate their caring roles with their everyday lives, without compromising their health, finances, jobs or careers.





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# Introduction

The reports in the CES Report Series are about how carers of working age access and experience the support and services they need to undertake their (unpaid) caring role and to maintain an independent life and their own health at different stages of caring. Carers provide regular, unpaid, support or assistance to someone who needs their help because they are ill, disabled or frail. Many carers support a relative, such as an elderly parent, a sick or disabled partner, or a disabled child. But carers are not always related to those they care for, and we have therefore taken carers' own definition of themselves as our starting point. We emphasise that in using the term 'carer' we are not referring to parents who are caring for a dependent child, unless that child also has an illness or disability<sup>1</sup>, and that we are not referring to 'care workers' who are paid to provide care in the home. The reports include evidence about the kind of support available to and needed by carers of working age, especially those who are in paid work or who would like to combine paid work with their unpaid care responsibility. It thus considers how carers can be helped to care and to have 'a life outside caring' too, with particular reference to a life which involves continuing in paid work or with a career.

The main focus of the CES reports is on the detailed findings of the *Carers, Employment and Services* (CES) research project, commissioned by Carers UK from a team of researchers at the University of Leeds as part of the *Action for Carers*

*and Employment (ACE2)* partnership, and funded by the European Social Fund under the *EU EQUAL Community Initiative Programme*. The study was carried out in 2006-7. The CES project collected data from a completely new questionnaire survey of carers in England, Scotland and Wales, obtaining 1,909 responses from carers, accessed through a wide range of employers, through carers' and other voluntary organisations, via agencies responsible for the provision of social care, and using other means<sup>2</sup>. The study also included follow-up personal interviews with a sub-sample of 134 carers who had completed the CES questionnaire. Each of these interviewees lived in one of 10 localities<sup>3</sup> selected for detailed investigation. In these localities, we also collected detailed information about the provision of services - both those services specifically designed to support carers, and those used by the people they care for - and interviewed local stakeholders with specialist knowledge and expertise.

This report, on *'Stages and Transitions in the Experience of Caring'*, is one of a series of publications arising from the CES study. The full range of study findings is reported in the complete series, listed below. In addition, a set of short, specialised reports relating to Scotland, Wales and the six English localities studied will be available from late 2007 to assist local agencies involved in providing support for carers in their policy development and planning.

### **No. 1 Stages and Transitions in the Experience of Caring**

*Becoming a carer: the impact of caring in the first two years, as experienced by carers of working age; the longer term impact of caring on carers' lives when a caring role is sustained over two or more years; carers' views and perspectives as they deal with the different ways in which caring can come to an end.*

### **No. 2 Managing Caring and Employment**

*Carers who are combining unpaid care with paid work: how they manage and cope and the difficulties which sometimes arise; why some carers have left employment to care, and what this means for them and their families; the perspectives and experiences of carers who want to work but do not have a paid job.*

### **No. 3 Diversity in Caring: towards equality for carers**

*The many different characteristics of Britain's 4 million carers of working age: carers in Britain's ethnic minority communities; caring and its challenges for carers in rural and urban contexts; caring in different financial circumstances, and the problems faced by those who are 'caring in poverty'; carers and how caring affects their health; caring in its various personal contexts - the relationships between carers and those they support, and the different conditions and needs of those they care for.*

### **No. 4 Carers and Services in their local context**

*Recent developments affecting local service provision for sick and disabled people and their carers; differences in the arrangements made in Scotland, Wales and England under devolved government; carers in 10 local contexts – differences between carers, and in the demand for care support at the local level; local arrangements for supporting working carers; the resources allocated to supporting carers; examples of best practice and innovation in supporting carers.*

### **No. 5 Action for Carers & Employment: Impact of the ACE partnership 2002-7**

*The objectives, design and outcomes of the ACE projects; the role of research in supporting the ACE strategic aims, and summary of the findings of the Carers, Employment and Services (CES) study; the work undertaken by the ACE partners in England,*

*Scotland and Wales, and their main achievements; the role of transnational activities in ACE, and their significance for future policy-making at European level.*

### **No. 6 Carers, Employment and Services: time for a new social contract? Report summary and recommendations**

*Main findings from the CES study about carers in England, Scotland and Wales; description of the CES study methodology; implications of the findings for the future public policy agenda on working carers; the rationale for developing better support for working carers at local and national levels; key challenges and how they can be tackled; recommendations about policy and practice for service providers, employers, central/local government and the voluntary sector.*

The reports in the CES series contextualise the findings of the CES study in the evidence available from the 2001 Census (which asked a question about unpaid care in 2001 for the first time<sup>4</sup>), and from other official sources. In this report, we focus on 'stages and transitions in carers' lives', paying particular attention to three stages in their experience of 'being a carer':

- the initial, 'new' carer phase, defined here as the first two years of regularly providing unpaid care;
- the 'longer term' carer phase, with 'longer term' defined as a period of caring which lasts for two years or more (in many cases involving care which lasts for a decade or longer); and
- the 'end of caring' phase, which arises when caring at home ends. Caring may end in a variety of very different circumstances – for example when a cared for person dies, moves into residential care, or becomes able to live independently, or when the end of care must be planned for, because the carer knows he or she will not be able to continue to provide support, often through personal ill-health or with the approach of old age.

# 1. Becoming a Carer – the first 2 years

This section presents statistical evidence from the CES survey, highlighting the situation of carers who had been caring for a period shorter than two years, contrasting their situation and circumstances with those of carers for whom caring responsibilities had become a well-established part of their lives: the group we call ‘longer-term’ carers (discussed in more detail below). The findings are illustrated with material from our interviews with carers, and explore some of the issues raised by them in describing their personal experiences of ‘becoming a carer’.

## New carers in the CES study

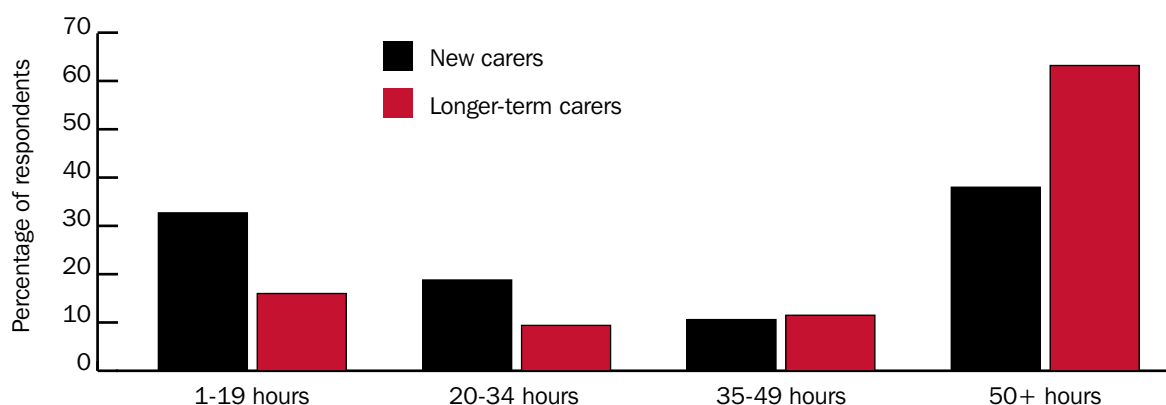
There were 214 carers (among the overall total of 1,909 respondents) in the CES Survey who had been caring for less than two years<sup>5</sup>. This group, referred

to here as ‘new’ carers, included 169 women and 39 men<sup>6</sup>, and among them there were 20 carers from non-White ethnic groups. Only 31 (14% of the ‘new’ carers, and just 1.6% of our whole sample) had been caring for a period of less than 6 months – so most had, by the time they were interviewed, begun to ‘settle’ into their new caring roles.

Despite having acquired their caring role relatively recently, two thirds of these ‘new’ carers already had what we refer to here as ‘significant’ (20-49 hours per week) or ‘heavy’ (50+ hours per week)<sup>7</sup> caring responsibilities – thus the large majority reported that their caring role occupied 20 or more hours each week (Figure 1.1). Nevertheless, most (nearly 60%) said that as well as caring, they were also in

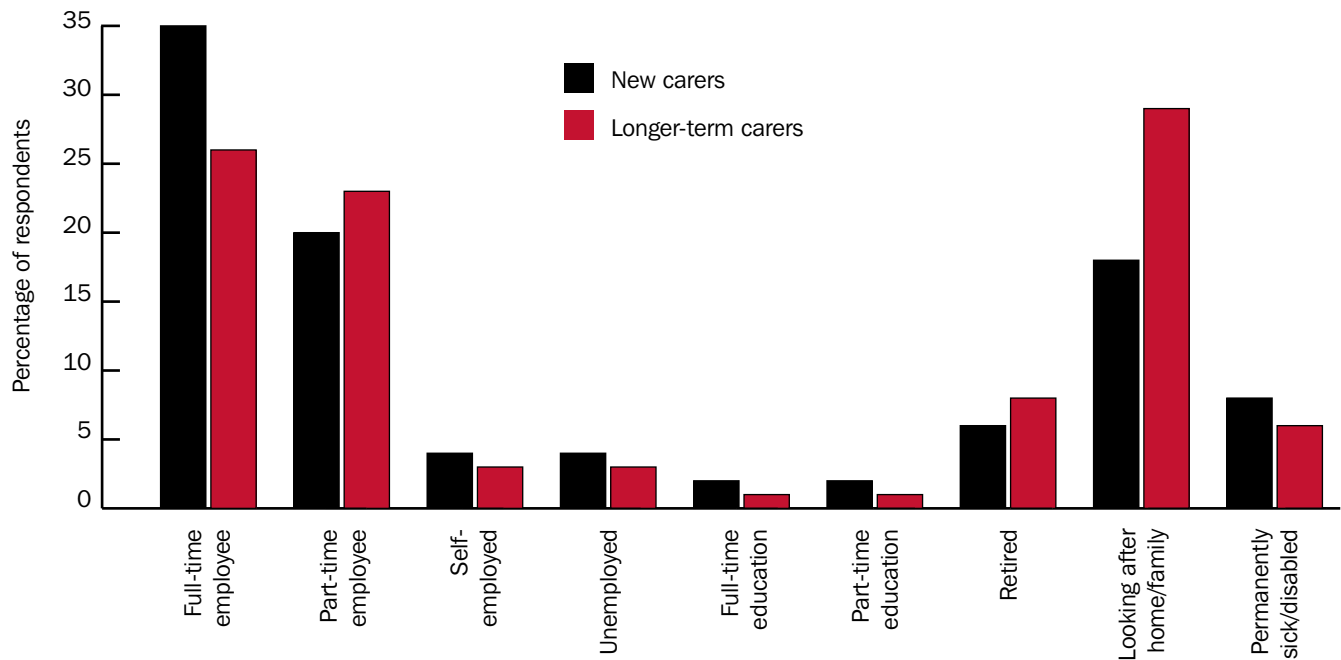
**Figure 1.1 ‘New’ and ‘longer-term’ carers by weekly hours of care provided**

Source: CES Survey, University of Leeds 2007



**Figure 1.2 'New' and 'longer-term' carers by economic activity: carers aged 16-64 only**

Source: CES Survey, University of Leeds 2007



**Table 1.1 'New' and 'longer-term' carers by aspects of their care circumstances**

Source: CES Survey, University of Leeds 2007

Circumstances of carers	New carers (%)	Longer-term carers (%)
<i>Relationship to/condition of person cared for:</i>		
The carer's parent/parent in law	44	24
The carer's adult son or daughter	3	17
Someone with a long-term illness, recovering from illness or terminally ill	43	30
Someone living with the carer	66	76
<i>The person cared for is aged</i>		
0-19	9	29
20-24	1	6
25-64	36	40
65-84	43	22
85+	13	14
<i>Situation with regard to formal services</i>		
Needs of cared for person have been assessed	58	67
Needs of carer have been assessed	17	30
Cared for person is NOT receiving any services	41	30
<i>Carer's financial circumstances</i>		
Struggling to make ends meet	28	34
Managing on money coming in	44	40
Reasonably comfortable	29	27

some form of paid employment (Figure 1.2). Only a minority (38%) of 'new' carers, were - as yet - in the extremely 'heavy' caring situation of providing 50 or more hours of unpaid care each week. This compares, in the CES study, with the much higher proportion (63%) of carers in these 'heavy' caring roles found among those who were 'longer-term' carers.

The 'new' carers in the CES study were slightly younger than other carers (14% were under 35 years old, compared with just 7% of 'longer-term' carers), and only 48% were aged over 50 (compared with 56%). When contrasted with 'longer-term' carers (a larger group), the 'new' carers were much *more* likely to care for a parent or for someone with a long-term illness, recovering from illness or terminally ill, and they were *less* likely to care for a child, for an adult son/daughter, or for someone living with them (Table 1.1). In fact, 43% of all 'new' carers in the CES survey were supporting someone aged 65-84, compared with just 22% of the 'longer-term' carers. These figures reflect the fact that 'longer-term' caring often involves caring for someone under 65 with a condition or disability which lasts for many years (such as MS, a learning disability, etc.), or for a disabled child who may require parental care beyond childhood and into adult life.

### **Key issues for 'new' carers**

For many carers, the first few months and years of caring are ones in which their lives change very significantly. For some, caring roles emerge over time; for example when an older relative gradually becomes frail, or when someone with a progressive condition begins to need support. For others, caring may come on suddenly and unexpectedly, perhaps when a relative or friend has a stroke, accident or unexpected diagnosis. All carers find that the first weeks and months of caring bring particular challenges. In the CES study, carers told us about the specific issues they faced at this time, in identifying sources of help and advice and in making adjustments to everyday life at home and at work. Although some secured formal support and assessment of the cared for person's needs quite quickly, a large group of 'new' carers (41%) were coping – or 'having to manage' - *without* any support at all from formal services. Often, the person they cared for had not had their needs

assessed (42%), even though in most cases (86%) caring had been going on for at least 6 months. In the following paragraphs, we discuss some of the main issues raised by our findings as they relate to 'new' carers. These include lack of information, responsiveness and accessibility on the part of service providers, and problems in combining work and care. Some of those we interviewed had also experienced resistance to using services among those they cared for, sometimes because that person preferred the unpaid and familiar help of a family member or neighbour to assistance from a professional, paid worker or 'stranger coming to the house', but also because the available services were considered unsuitable, costly, or simply not within reach. During this relatively early phase of caring, only very few 'new' carers (17%) had had their own situation reviewed through a Carer's Assessment process. Box 1 gives brief details of three relatively 'new' carers, highlighting some of the difficulties and frustrations they face in managing their new caring responsibilities alongside paid work and other aspects of family life.

### **'New' carers' access to services**

Reflecting their rather different caring roles and relationships, as well as their shorter experience of caring and their smaller concentration in the heaviest caring roles, 'new' carers in the CES study were less likely than 'longer-term' carers to be supporting someone using certain kinds of services (Table 1.2). Fewer 'new' carers reported having the use of respite, sitting and carers' services. By contrast, they were slightly *more* likely than 'longer-term' carers to be caring for someone receiving nursing and domiciliary care services – perhaps not surprising, as many 'new' carers support a partner who is ill, or an elderly parent who has become frail or disabled.

When asked about whether certain factors limited the use of services in their own personal/ family situation, 'new' carers were clearly hampered by their relative lack of access to information, and were considerably more likely than 'longer-term' carers to say that they 'did not know' to the range of questions we asked on this topic (for example, 40% of new carers, compared with 26% of 'longer-term' carers, answered 'don't know' to our question about whether there were suitable services in their area). In addition, 41% of

### **Box 1.1 Three ‘new’ carers and how caring is affecting their lives**

**JANE:** Jane works full-time, lives with her husband, and has no children. She is in the 35-49 age group. Recently she has started to care for her mother, who lives nearby in sheltered housing and has been diagnosed with terminal cancer. She estimates that, at the moment, caring for her mother occupies up to 20 hours each week. Jane feels under great strain, as she has to divide her time between care, her job, and her husband. She has been struggling to get adequate services to support her mother, and to enable her to continue working. Although her place of employment has a carer-friendly policy, she has also had problems with an unsympathetic line manager, after taking 6 months off when her mother was first diagnosed with her illness. Jane is adamant that her mother will not be taken into residential care before she dies, and she is determined to care for her until her final days, despite all the difficulties she is encountering.

**MARGARET:** Margaret is in her early 60s, works part-time, and lives with her husband. Her mother, who has severe arthritis, has recently come to live in their home, and requires a lot of help, especially with mobility. Margaret estimates that this support now takes between 20 and 49 hours of her time each week. Margaret’s husband has retired, and although largely supportive, he is slightly resentful that he and Margaret are unable to enjoy their own ‘old age’. He nevertheless drives his mother-in-law to a day care centre 20 miles from their home, so that Margaret can continue to hold down her job. Margaret now feels very restricted at work, limited in the number of hours she can work and unable to apply for promotion. She is pleased that her job allows for a degree of flexibility, as this is essential for her in continuing to provide care for her mother, but she really wishes the day care centre was open earlier in the mornings and later in the evenings, so that her time could be freer.

**CAROL:** Carol, aged 35-49, works full-time, and lives with both her 9-year old daughter and her mother who now suffers from dementia. As her mother’s condition has worsened, Carol has taken on almost all of her care; this currently occupies at least 50 hours of her time each week. Her mother attends a day care centre, but struggles to use community transport, and is unhappy about doing so, because she suffers delusions about strangers. Carol has found it very difficult to access adequate services, and feels that although staff members are individually friendly, they are nonetheless poor at working as a team, and only really respond to crises. Fortunately, Carol works for an understanding employer. She feels she has been offered sufficient time away from work to deal with her mother’s care. She holds strong views about the services available, and is convinced that services in general would benefit from better organisation at the institutional level.

‘new’ carers (compared with 36% of ‘longer-term’ carers) specifically said that use of services in their own particular circumstances was limited by the fact that they ‘did not know what is available locally’.

Among those who were able to give an opinion (i.e. excluding all who replied ‘don’t know’), significant numbers of ‘new’ carers reported that, in their own particular care situation, use of services was limited by specific factors (Table 1.3). These included the unwillingness of the person they cared for to use services (42%), and their own perception that the services available were neither flexible enough

(40%) nor sufficiently sensitive (40%) to meet their particular needs, as well as their limited access to information. Generally, however (and as we discuss in the next part of this report), it was ‘longer-term’ carers whose use of services was most limited by negative perceptions or experiences of the services available (Table 1.3).

Testimonies from our interviews about how caring began, and about the support carers received in the first months and years after caring started, show how hard it is for carers when they have to struggle to access information and support, and just what a



**Table 1.2 'New' and 'longer-term' carers by use of services**

Source: CES Survey, University of Leeds 2007

	New carers (%)	Longer-term carers (%)
<i>Services used by a <b>higher</b> proportion of 'new' than of 'longer-term' carers</i>		
Domiciliary care/home care	27	24
Specialist, nursing or palliative care	13	11
<i>Services used by a <b>lower</b> proportion of 'new' than of 'longer-term' carers</i>		
Day Care	15	22
Community Mental Health	12	14
Respite Care	15	23
Sitting Services	8	10
Residential Care	4	5
Community Transport	6	11
Carer's Services	6	10
Other services	7	11

**Table 1.3 'New' and 'longer-term' carers by the factors limiting use of services**

Source: CES Survey, University of Leeds 2007

	New carers (%)	Longer-term carers (%)
<i>Carers saying their use of services is limited because:</i>		
The person I care for does not want to use services	42	44
I/they don't know what services are available locally	41	36
Services are not sensitive enough to my/their personal needs	40	44
Services are not flexible enough	40	47
Services are too expensive	26	34
I/they don't like the way services are organised	25	31
Services are not reliable enough	24	31
There are no suitable services in the local area	20	39
I/they don't like the people who deliver services	12	16

difference it makes to their lives when services meet their needs. Below we present some of these 'real life' experiences in carers' own words about what happened to them in their first months and years as a carer<sup>8</sup>.

### Sudden transitions

Those whose caring role began when someone close to them suffered a sudden, transformative life event, such as an accident, stroke, or heart attack, reported

that they were under enormous pressure right from the outset, with practical, financial and emotional difficulties at home (sometimes including the need to identify precisely 'who will care' within the extended family), important issues to resolve about the compatibility of work and care, uncertainties about how employers, managers and colleagues would respond, and negotiations to be started with social, health and welfare organisations about services, funding, entitlements and official procedures.

The difficulties of this inevitably demanding time had been eased for some when they had felt well-informed, adequately supported, and that their own needs, as well as those of the person now unexpectedly requiring care, were being considered and taken into account. Although some carers later develop positive relationships with those providing services and eventually feel confident about approaching relevant agencies (see below) 'new' carers all too often reported that this early stage in their experience of caring involved feeling perplexed, confused, unsupported, frustrated and angry. The examples below illustrate a range of situations in which carers had experienced these early difficulties. Lack of information, as for this carer supporting his wife, was often the first problem:

*We expected someone to come and sit down and tell us exactly what we were entitled to, and that didn't happen. We had to find out the hard way.*

Male, 35-49 age group, full-time carer

Adjusting to a very demanding new situation was difficult too, as in this case, where the caring role began in earnest when the carer's increasingly frail mother came to live with her:

*It's like when you first have a baby, and your life changes completely: everything has to be organised. It's more difficult than we could have imagined. My husband does resent not having the freedom, and really does resent not having my attention.*

Female, 60-64 age group, in part-time employment

For some, life changed completely, almost from one moment to the next. This male carer explained how his role in looking after his wife began:

*One day I came home, and she was just sitting on the sofa, crying. And that was my introduction to depression.*

He quickly arranged for her to see their GP, who prescribed medication, but this encounter was not very satisfactory because of the GP's 'absolutely hopeless bedside manner.' Very soon this 'new' carer found himself 'taking on the household chores', while at the same time 'trying to keep up' with his job. And after just three months, he reported, his wife's 'life had disintegrated' – although previously she had been both in employment and a very active member of their local community:

*From that point onwards, my caring role has been total commitment, really - but also trying to maintain a working life.*

Male, 50-59 age group, self-employed

In a different case, another male carer explained that when his parents died, the care of his sister, a woman with learning difficulties and 'challenging behaviour', suddenly became his responsibility. He had been forced to take a break from his paid job while he tried to make suitable arrangements:

*I'm trying to arrange additional services for my sister, to enable my return to work under conditions where I can be sort of secure, knowing that she's well taken care of.*

Knowing that 'historically there have been limitations' in getting care appropriate for his sister's condition, he was rather anxious about the future. In his view:

*What is perceived as a challenge by the services tends to be pushed aside.*

At the time of his interview, some new provision had recently been agreed, but, as he pointed out, 'resources are short'. His experience – like that of many other carers in the study - was that people 'have to fight' for services, and indeed to find any really appropriate support:

*There are no services which adequately deal with challenging behaviour. That's what we're up against, essentially.*

Male, 50-59 age group, in full-time employment

Carers of disabled children often reported initial difficulty in identifying support which met their needs too. One mother had been particularly annoyed by the advice she was given in the period immediately following her child's diagnosis:

*I was told, your social worker will be really good, as long as you tell her what you want. .... If I could tell her what I want, I'd be a social worker!*

Female, 35-49 age group, in full-time employment

Another reported that, when her 23 year old son had his first psychotic episode, she 'wasn't sure what questions to ask'. At the time of the first episode her son 'didn't have a GP', and she was shocked by the response he received:

*The hospital said that they couldn't do anything - and he had to go. There was absolutely no help at all.*

Female, 35-49 age group, in full-time employment

Although eventually, through her GP, she was given some information about referral arrangements, even then she was given 'no other information'.

Sometimes the pressures in the new caring situation had their roots in a complex family situation. In some cases the new care responsibility had arisen in a context of family tension or conflict about 'the best/right thing to do'<sup>9</sup>. One of our interviewees, a woman in full-time employment, explained that her own caring role began when, following a stroke, her father was placed in residential care by her step-mother, a move she was upset by and considered very inappropriate. At that point, she felt she was the only member of her family who was willing to devote time to her father, and this made her especially determined to provide him with all the support she could. Her care of her elderly father involved daily visiting during the week, alongside her job, and at some cost to her own life at home, as she explained:

*You can only spin so many plates, and something's got to go on the back burner. For me, maybe my relationship took a back burner. I had to carry on with my college work and my job. I felt that, if I couldn't do it, out of the family, then nobody else would – and they'd just leave him there. Maybe I had stronger bonds with him than the rest of the family, I don't know. You just can't help your own personal feelings – I just felt that he needed support – to motivate him, to boost him and encourage him to use the facilities, limited though they were – and to encourage him to eat and such like.*

Female, 35-49 age group, in full-time employment

### **Gradual acquisition of caring responsibility**

The sudden change in circumstances described above was not every carer's experience, however, as one, caring for her co-resident mother, put it:

*I'm not really sure when my role as a carer began...it just kind of crept up on me, really.*

Female, 35-49 age group, in full-time employment

Another carer in the study spoke of how her role as the carer for her grandmother had gradually

emerged, resulting recently in moving in to live with her. Here it is hard to distinguish between being 'new' to caring, and having been involved over the longer term in providing family support:

*I've helped her out since my grandfather died twenty years ago, maybe at the weekends helping with her messages, painting the house, or curtains - and I've gradually done more and more. That became part-time work, and then I stayed at the weekends. Then I had to make the decision to move in full time.*

Female, 35-49 age group, full-time carer

Carers in this group were typically caring for someone in one of the following situations:

- a child or baby with a recently diagnosed disability or long-term illness, likely to have a serious impact on the child's long-term health and development, but at this stage requiring care similar to that needed by a healthy infant of similar age
- a person with an illness or disability which was only just beginning to have a major impact on their ability to live independently
- an older person who was becoming increasingly frail, either physically or mentally, but who had until recently been living in an independent situation

Those in these or similar situations sometimes found it difficult to get their caring situation acknowledged, and to secure the services and support they needed. As one mother of a young disabled child expressed it:

*I would like to have had support from birth to enable me to go back to work. I gave up work because she needed me, but when I wanted to come back to work, I was faced with: 'We don't provide childcare to let you go back to work.' But I've got as much right as anyone else to work. I can't put my child in childcare, because my child requires two people most of the time - and no childcare service is going to take her, £25 a day, for four times as much work.*

Female, 35-49 age group, in full-time employment

This carer, along with many others, raises issues about carers' rights and entitlements to live a life which is not totally dominated by their caring role –

and in particular their rights to be in paid work and to have a career. These issues are explored in CES Report No. 3, *Diversity in Caring: towards equality for carers*.

## Caring and Work

Whether the demands of becoming a carer struck suddenly or emerged gradually, working carers almost always found that the reactions of their employers, managers and colleagues became important factors shaping their early experience of caring. The full range of issues about juggling both sets of responsibilities raised in our interviews with working carers is discussed in detail in our separate publication, *Managing Caring and Employment* (Report 2 in the CES Report Series). Here we briefly summarise the most important points which were raised by 'new' carers.

Some 'new' carers needed quickly to make adjustments at work, to their working hours or to other aspects of their job. This could be a positive experience, leading some carers to feel valued and supported, and consequently more loyal and committed to work than perhaps they had been before<sup>10</sup>. Others had negative, distressing experiences, or felt unable to discuss their caring role, as their managers or colleagues had no interest in 'anything that happens outside work'. 'New' carers' experiences were mediated in important ways, both by the attitudes/support they encounter in the workplace, and by the extent to which other support is available to help them in their caring role, either from other family members or friends, or from formal services.

Our interviews make it clear that, for many 'new' carers, the question of how they are going to manage their caring role alongside their responsibilities in paid employment is a considerable worry. It was therefore rather reassuring to find that a (small) majority of the working carers in the CES survey described their current employer as broadly supportive<sup>11</sup>. (Here we should bear in mind that some carers in the study were accessed through their place of work. This may have resulted in a relatively high number of carers with positive experiences at work, as employers unsympathetic or hostile to carers were less likely to allow research

access.) Of the 104 'new' carers who were in paid employment at the time of the survey, 56% (compared with 58% of 'longer-term' working carers) referred to their employer as 'carer friendly'.

Some spoke appreciatively about the way their employers and managers had responded as their new caring role took shape:

*I had to phone my boss, and I just said 'I've got to go', and he said 'just fill me in', and was very good about it. I do work hard for him. It's give and take. That shows you the sort of boss I've got. I'm very lucky, at the moment. I don't know how it would stand if I needed a lot more time off, that's a different scenario.*

Female, 35-49 age group, in part-time employment

By contrast, other carers had experienced negative reactions from their managers when they first started to care. One woman explained that after needing six weeks away from work to support her mother, who had been given a terminal diagnosis, her manager (who had since 'moved on') became very negative about her performance:

*(She became) very focused on the six weeks I was away from work as opposed to the rest of the year. My performance she's marked me down on, because she said I wasn't as driven or as committed...it probably would have done an awful lot of damage...I probably would have sought another job, another post, but I wouldn't have been able to continue working for her.*

Female, age group 35-49, in full-time employment

Most working carers found some changes or adjustments in their lives were needed to accommodate both care and work, and only about one in five (21% of 'new carers' and 22% of 'longer-term' carers) said their caring responsibilities 'did not affect their work'. As we show in *Managing Caring and Employment*, Report 2 in the CES series, these were not necessarily a group of working carers with only 'moderate' caring duties; in fact, many were providing 50 or more hours of care per week. The CES study thus drew responses from a group of 'new' carers who reported that they were managing to combine work and care relatively satisfactorily.

It is nevertheless important not to paint too rosy a picture of the situation facing working carers in the

months after caring begins. Responses to the CES survey showed that only one in five 'new' carers (21%) felt they 'had adequate services to enable them to work' (compared with 28% of 'longer-term' carers). Indeed, as discussed more fully in CES Report 2, 46% of all carers working full-time, and 62% of all those working part-time, said they did not have adequate services to enable them to work; a situation which should cause considerable concern to employers, employees and service providers alike. On many of the measures we used (see Figure 1.8 for these), 'longer-term' carers showed greater dissatisfaction with arrangements for accessing and using support services than those new to caring, suggesting that for some the frustrations and difficulties of accessing the help they need increase over time.

One initial set of difficulties faced by the 'new' working carers in the study related to obtaining information. They felt they needed early access to clear, accessible information about their entitlements and options relating to all of the following, and often stressed that the amount and quality of early information they had received had been quite inadequate:

- the state benefits and financial support available to carers and those they support;
- how the assessment process in health and social care works and who will assist them in completing this swiftly and efficiently;
- what services are available in the home or near to where they live, providing safe and reliable alternative care when they are not themselves available – including how much these will cost, who supplies them and how they can be arranged;
- how and in what circumstances they can access respite services and support in 'getting a break' from the combined pressures of work and care, which they may worry will otherwise threaten to overwhelm them;
- their rights and options at work: What steps should they take if they need to take a period of leave, and how will this affect their earnings? Will they be able to reduce their working hours or alter their regular duties at work? How can they agree these? Will it sometimes be possible, perhaps at short notice, to work from home? Will they be

able to have time away from work to accompany the person they care for to hospital or other appointments, and how will this affect their pay or their reputation and standing at work?

- How can they access information and support about coping with work and care in their own specific type of work?

The above list of 'information needs' also indicates the wider range of issues 'new' carers face. Below we outline some of the main points raised in our interviews about assessment of needs, access to services, negotiating packages of care, finding sources of advice and emotional support, and obtaining guidance about job and career options.

A number of interviewees spoke about failures in communication between different departments across the health and social care spectrum, mentioning that this could be a particular problem for those at the beginning of caring, as for this carer supporting her elderly mother:

*It was very unclear who you tell, who you ask for, really. It didn't seem to be particularly good communication between departments. Nobody was unkind, 'Oh no, we can't help you' - they were all falling over themselves to help, but they didn't really know who it was who was supposed to be doing it...as a team, it seems very - it seems like crisis management.*

Female, 35-49 age group, in full-time employment

Some carers spoke of distressing difficulties, at the start of caring, in communicating and obtaining a response:

*I need help, you know. I mean, I get more upset on the phone to them and I've been down to social services, sit down waiting to see somebody, you know, I do, I desperately need help, and especially when [my son] had a problem at home...I'm not asking much, just somebody to come in and help. Because they're professional, and they probably know a bit more than I do. But I don't get any help, I constantly battle with social [services] - I give up, to be honest. I totally give up with social services.*

Female, 35-49 age group, looking for paid work

One male carer in the study was finding his new caring responsibilities very challenging. Divorced with the care of his young child to cope with, he

had recently become the main carer of his elderly father. He was desperate about his situation, and particularly upset about not being able to secure day care support for his father. Feeling increasingly depressed about his own life, he had recently decided the situation could not continue and that his father would have to move to residential care:

*All my life I've been physically active, I've not been one for sitting on my backside. Now, at 38 years old, not getting any younger, I'm contributing nothing to my own life. I've no motivation, no inspiration, no nothing. My life has went down that low that I've got to start getting my own life sorted out- because that just isn't me, this isn't my life. It's just a shit life, it really is, it's a shit existence, so I'm doing something about it.*

Male, 35-49 age group, actively looking for paid work

Initial encounters with the benefits system had also been very difficult experiences for some:

*When we had to go through getting the benefits and all this, it was a horrible experience, absolutely horrible experience...horrendous, I mean, it scars*

*you for life. Because they make you feel so awful and so small, it's just horrendous.*

Female, 50-59 age group, in part-time employment

The bureaucracy associated with making claims and accessing services was sometimes seen as inflexible and inappropriate too:

*...when you fill out the forms, quite often it says main carer, but my husband and I have always shared, you know, in the middle of the night. So I think it's important that the forms reflect that you've got more than one carer quite often.*

Female, 35-49 age group, in part-time employment

When support and services were accessible and appropriate, however, new carers were often keen to acknowledge how much they valued knowing they had somewhere to turn. This help could come from voluntary agencies (see example in Box 1.2) or from social and health services:

*They're there if you need them. I haven't been in a position where I've had to call them as of yet, but they've helped with respite a couple of times. They're there as a back-up. I haven't used it a lot, but that's because I've thought, you know,*

### **Box 1.2 Accessing support with the help of voluntary organisations**

Specialist voluntary organisations had sometimes served as a crucial link between the cared for person, the carer and formal services. Often, 'new' carers in the study had located these voluntary organisations themselves. Clare, now looking after her husband following a car accident, pointed out how her situation improved when by chance she noticed a poster for *Headway* in the hospital. After discovering *Headway*, the situation improved dramatically.

*I got to the point where I really needed to speak to someone because he was doing things out of character and no one had explained to me that this could happen where there had been head injuries.*

*Headway* wrote to their GP and requested that her husband be referred to a specialist service at a hospital in the region. Through this they have become aware of a much broader range of services and therapy; Clare cannot imagine how she would have coped without them.

*When Headway got him referred to the specialist Centre, I wouldn't say it was choice, they then decided he would go. He's had occupational therapy, hydrotherapy, physiotherapy, acupuncture. So he's had a whole range. I think it's excellent. I don't know how I would have managed if they hadn't been there. I can't say enough that's good about Headway. Even now, as my husband's getting better, well, I say getting better - he's as good now as he's ever going to be...and they're still supporting him in everything.*

Clare, 50-59 age group, full time employee

*that's the idea of me staying at home, to do that. The strength is that they build up a rapport and a relationship with you. (Our) GP (has been) superb, I'd put him at the top of the list for who has helped us the most. He's helped us a lot in terms of identifying help and assistance on the social side.*

Male, 35-49 age group, full-time carer

The financial consequences of becoming a carer loom large for some carers right from the outset, too: this is particularly true if the carer feels that sustaining their job alongside the new caring role is going to be difficult, or if an early decision to reduce working hours has to be taken. Many carers also highlighted the 'extra costs' of caring. (The real impact of these usually becomes apparent as the months and years go by, so this aspect, covered in more detail in *Diversity in Caring: towards equality for carers*, Report 3 in the CES series, is mainly considered below in our discussion of 'longer term' caring.)

As we have already seen (Table 1.1), even within two years of becoming a carer, 28% of our respondents reported that, financially, they were 'struggling to make ends meet'. This contrasted with 34% of 'longer-term' carers who said they were in this situation. Among our interviewees, carers who had needed to reduce their working hours to accommodate their caring role were very conscious of the financial impact of this change. A reduced income from employment can quickly come under further pressure through the costs involved in accessing services, as one carer pointed out:

*It costs about £15 a week to take my mother to the day centre, which is 20 miles away.*

These extra costs for the carer often arise because of service limitations. In this case, where the carer is looking after her mother who has come to live with her, there is a nearer day centre, but it has no spaces – 'It was that service or no service'. And the hours when the service is available are also very restrictive:

*The service as it exists at the moment prevents people from working, unless they have extremely flexible employers. There is no reason why they can't have staff there from 8 till 6. Yes, it will cost money, because they are paid on an hourly rate – but who are we running the service for? In a way*

*I have the feeling that the day care facilities are available for the convenience of the staff.*

Female, 60-64 age group, in part-time employment

Even relatively minor adjustments to working hours, made in order to create time to provide care, could cause financial difficulties quite quickly:

*Going down to 4 days, I know it's my decision - but it has stretched me financially. It has made a difference. I don't get any help with that, because my sister's the main carer. It's like it or lump it, isn't it?*

Female, 25-34 age group, in part-time employment

The costs of essential private transport also rapidly mount up, sometimes taking new carers by surprise:

*You've got to have a car. There's no way there's public transport to West Horsley or to the hospital she was in, in Guildford. At one point I was doing 1,400 miles a week.*

Female, 35-49, full time employee

In this case the petrol and parking costs came to £800 a month and at one stage the carer found she was in £6,000 of debt. As she had a full-time job, and her household income was relatively high, she was able to find a way of managing this situation, but this example, relating to caring during a short (6 months) but difficult period during her mother's terminal illness, illustrates some of the unexpected costs of caring.

Becoming a carer, as we have seen, can happen in a wide variety of ways. For those thrust suddenly into caring, the impact on their home and working life, and the pressures on their time, finances and relationships are felt very quickly. For others, where the caring role emerges only gradually, these changes occur more slowly, but are nevertheless keenly felt.

Services – how to find out about them; how to access them; and how to dovetail service provision with the contribution the carer can make (especially when combining work and care) – are crucial for 'new' carers. Those with good support arrangements appreciate them greatly, but very often 'new' carers feel let down and perplexed by what they encounter. These feelings and experiences frequently continue into the longer term, as we show in the next part of this report, dealing with the longer-term impact of caring.

## 2. The longer term impact of caring

When caring roles have become well-established over time (as happens to many, though not all, carers) their impact on the lives of carers and their families can be very significant. Here we explore the experiences of the 1,675 carers in the CES survey who had been caring for 2 years or longer, paying particular attention to those in this group (1,351 carers, over 84% of 'longer-term' carers, and 82% of our entire CES sample) whose caring responsibilities at the time of the survey involved 20 or more hours of care per week.

### **Amount and type of care provided**

We distinguish between those carers with 'moderate' caring responsibilities, and those whose weekly hours of care are 'substantial' (20-49 hours per week) or 'heavy' (50+ hours per week) here because we know from the 2001 Census that there are important differences between carers according to their weekly hours of care, particularly between those who care for less than 20 hours a week and those with more time-consuming caring roles. For example, in the 2001 Census, the impact of caring on carers' health and wellbeing is much more visible among those with 'substantial' and 'heavy' caring responsibilities than it is among those whose caring roles occupy less than 20 hours each week<sup>12</sup>. It was therefore not surprising, in the CES survey data, to find differences between these groups. The new, detailed information in the CES survey reveals for the

first time, however, some features which have not previously been discernible<sup>13</sup>.

In the CES data, 17% of 'longer-term' carers were supporting more than one person. 29% were caring for a sick or disabled child under 20 years old, and 17% were supporting an older child (aged 20+). Over a third (34%) were carers of their spouse or partner, while 24% were providing care for a parent or parent-in-law. 76% of all those who had been caring for 2 years or longer were living with the person they cared for (compared with 66% of 'new' carers). Analysis by the weekly hours of care of the 'longer-term' carers also shows that almost all (90%) of those caring for 50 or more hours per week were living with the person they supported - compared with just under 70% of those whose care responsibilities were 'substantial', and about a third of those with 'moderate' care responsibilities (Figure 1.3). And while almost two-thirds of 'longer term' carers in the 'moderate' care category (less than 20 hours per week) were supporting one person who lived apart from them in a separate household, this was true of only a quarter of those with 'substantial', and fewer than 5% of those with 'heavy', caring roles.

### **Employment and financial circumstances**

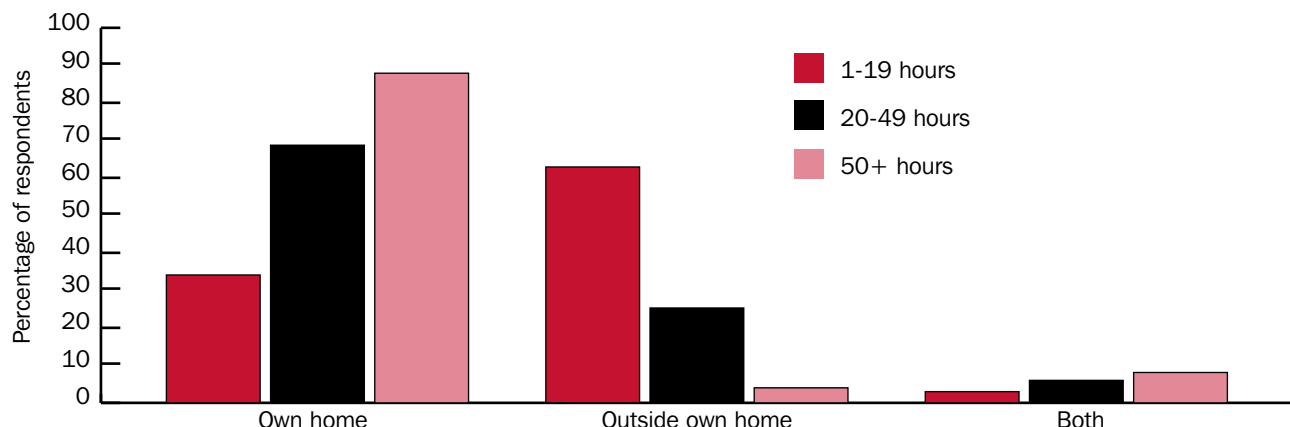
Among 'longer-term carers', there is also a different distribution by weekly hours of caring across 'employment status' categories (Figure 1.4). In the CES survey, well over a third of 'longer-term' carers



**Figure 1.3**

**'Longer-term' carers' living situation, by weekly hours of care provided, carers aged 16-64 only**

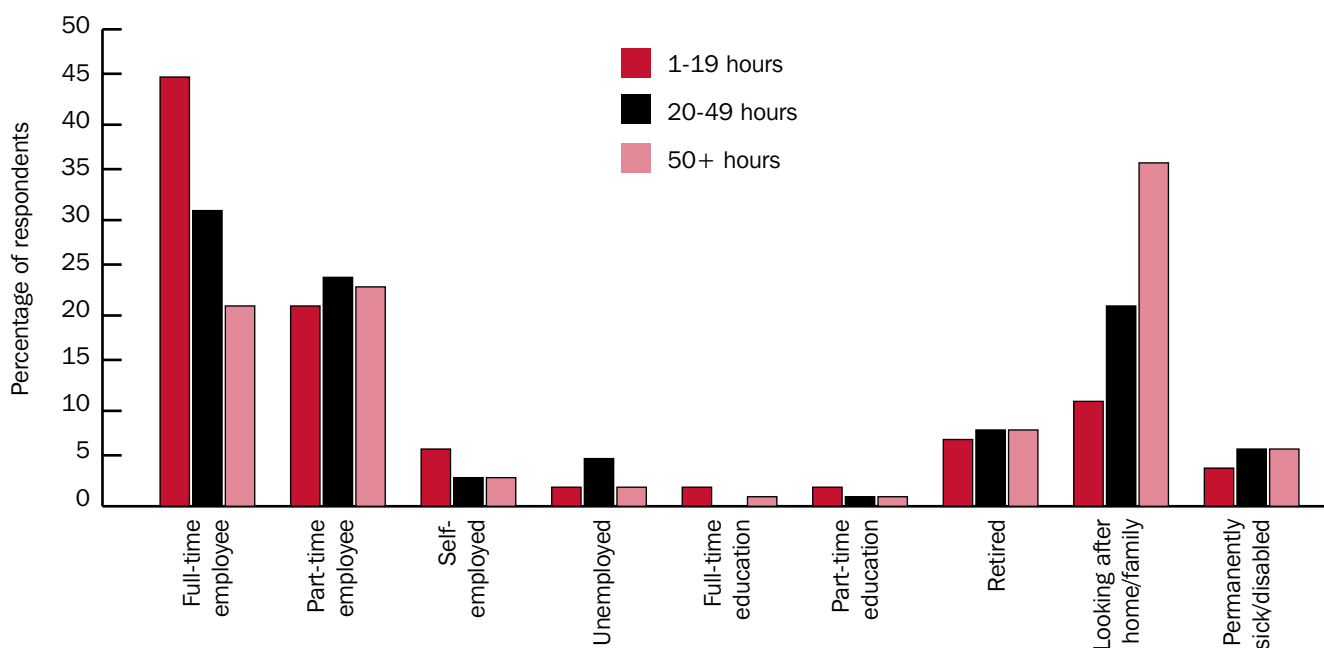
Source: CES Survey, University of Leeds 2007



**Figure 1.4**

**'Longer-term' carers' employment status, by weekly hours of care provided, carers aged 16-64 only**

Source: CES Survey, University of Leeds 2007



in the 'heavy' caring category said that 'looking after their home and family' was their main, full-time role<sup>14</sup>, compared with just 22% of those with 'substantial', and 11% of those with 'moderate' caring commitments. Among the 'longer-term' carers there was also a very striking difference in relation to full-time paid employment: 45% of those with 'moderate', but far fewer among those with 'substantial' (30%) or 'heavy' (20%) caring roles said

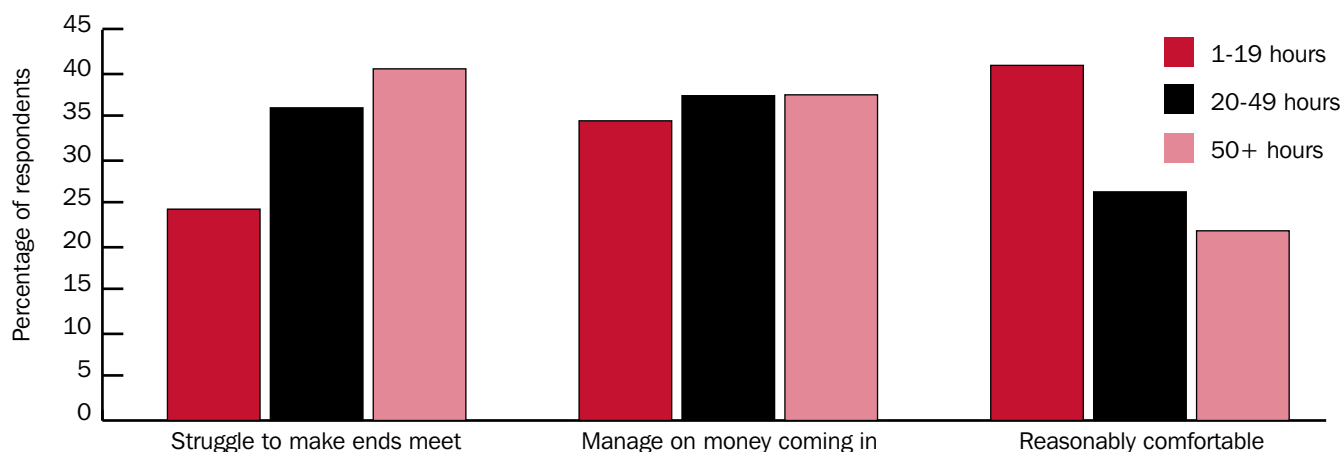
that, at the time of the survey, they were managing to combine care with a full-time job.

Differences between these groups in the other employment status categories were comparatively small, however, with the figures for combining part-time employment and caring around 20% for all three groups, and around 8% of carers, across all three 'hours of care' categories, defining themselves as 'retired'.

**Figure 1.5**

**'Longer-term' carers' financial situation, by weekly hours of care provided, carers aged 16-64 only**

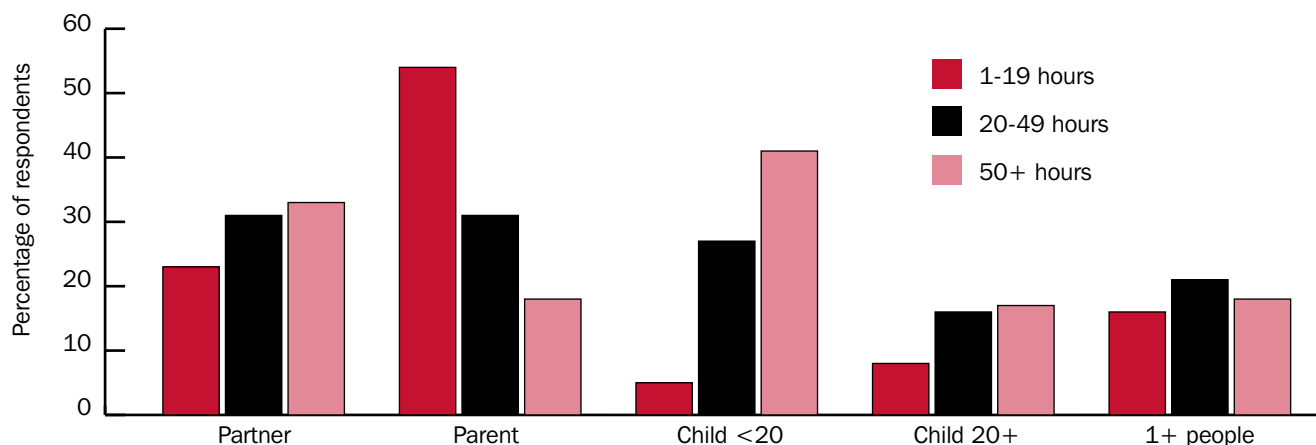
Source: CES Survey, University of Leeds 2007



**Figure 1.6**

**'Longer-term' carers and person cared for, by weekly hours of care provided, carers aged 16-64 only**

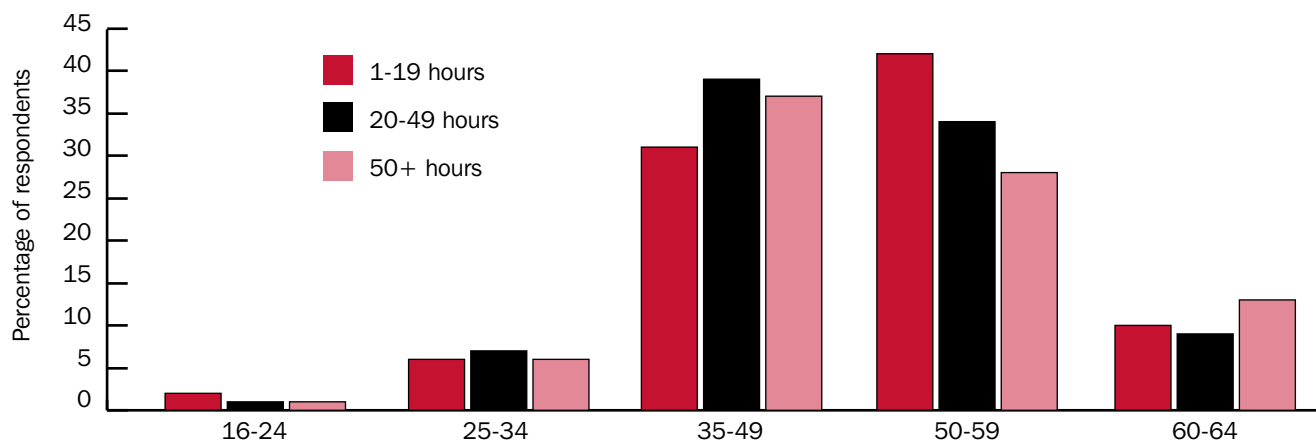
Source: CES Survey, University of Leeds 2007



**Figure 1.7**

**Age of 'longer-term' carers, by weekly hours of care provided, carers aged 16-64 only**

Source: CES Survey, University of Leeds 2007



As noted earlier, among the 'longer-term' carers, 34% (compared with 28% of 'new' carers) were 'struggling to make ends meet'. Most (40%) said they were 'managing' on the money coming in to their household, and only 26% reported that they were 'reasonably comfortable financially'.

There is a clear relationship between the financial circumstances of 'longer-term' carers and their weekly hours of caring (Figure 1.5). This is partly explained by the fact that 'longer-term' carers aged 16-64 who care for 20 or more hours per week are considerably more likely to be out of paid work than carers who make a smaller weekly caring time commitment. Thus while 24% of carers with 'moderate' commitments were struggling to make ends meet, the proportion was much higher for those in the 'substantial' (36%) and 'heavy' (40%) caring categories.

Part of the story here is that carers with 'substantial' and 'heavy' caring roles are often caring for a child, a partner, or for more than one person. A 'moderate' caring commitment is more common among those caring for a parent, who has often been fully independent during most of their adult

life, and whose caring needs have developed rather gradually. Figure 1.6 shows that 54% of carers in the 'moderate' category were supporting a parent, compared with 30% of those with 'substantial' and just 18% of those with 'heavy' roles.

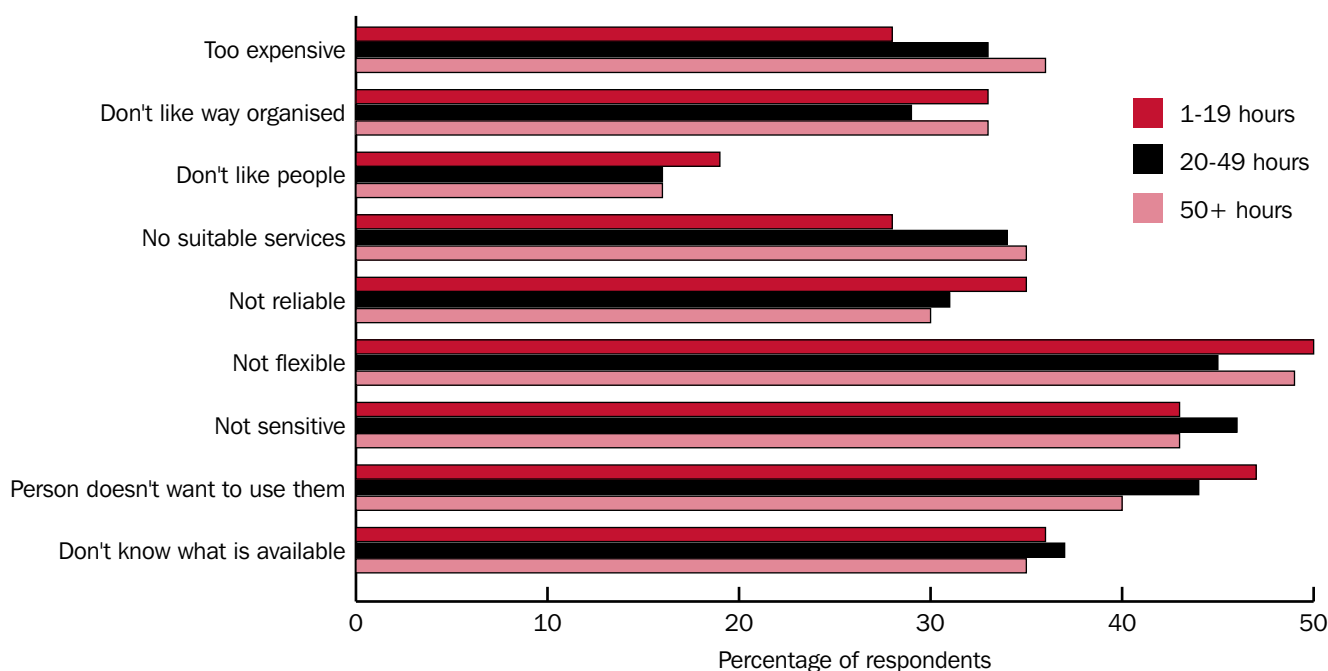
Reflecting this difference, we also find age differences here. Forty-two per cent of 'longer-term' carers who were providing 'moderate' levels of care were in the 50-59 years age group, compared with about 33% of carers in the 'substantial' and 28% in the 'heavy' care categories. By contrast, age 35-49 years is the prime age group for 'longer-term' carers providing 'substantial' or 'heavy' weekly hours of care.

### 'Longer-term' carers and support services

Despite these important differences, among 'longer-term' carers, attitudes to, and perceptions of, formal services vary considerably less by the amount of care provided, as shown in Figure 1.8. 30% of those caring for 20 or more hours per week (and 37% of those with lighter caring responsibilities) were supporting someone who was not receiving any services at all. A very large group of 'longer-term' carers (including some who were, and some who were not caring in a situation where services were

**Figure 1.8**  
**'Longer-term' carers, by limitations on their use of services, carers aged 16-64 only**

Source: CES Survey, University of Leeds 2007



being provided) find that services are not flexible or sensitive enough to meet their needs – and that those they support are reluctant to use services (in the range between 40 and 50 per cent in all cases, irrespective of the hours of care provided). About a third of ‘longer-term’ carers, again in all the ‘hours of care’ categories, also say that their use of services is limited by lack of information or by their reservations about the way services are organised. Carers with ‘substantial’ or ‘heavy’ caring roles are somewhat more likely than those in the ‘moderate’ care group to find services too expensive or to believe no suitable services are available – while it is carers with ‘moderate’ care responsibility who express the greatest reservations about ‘the people who provide services’ – a concern expressed by only a minority of carers in all the groups studied.

### **Pressures and changes in carers’ lives**

Some ‘longer-term’ carers form good relationships with service providers, as indicated in this carer’s comments about caring for her child, who has both physical disabilities and learning difficulties:

*We’ve got to know the people who provide the services over the years, and I feel I have good relationships with all of them. I feel very comfortable if I have a difficulty. I feel I could approach them fairly confidently.*

Female, 50-59 age group, in part-time employment

This is important, as the needs of both the carer and the cared for person usually change and develop over time. Many carers reported difficulties and frustrations in getting the help and services they need, however, and these often had significant implications for their ability, in the longer term, to combine work and care. The CES face-to-face interviews with ‘longer-term’ carers shed further light on this situation; below, using some of the personal testimony of carers themselves, we consider how far, and in which circumstances, caring involves changing and continually dynamic situations in terms of support and service needs, and difficult pressures in the work situation.

For carers who are trying to combine paid work and unpaid care, one of the most stressful and difficult issues is how to deal with unexpected and unpredictable ‘caring crises’ (something we

also discuss in CES Reports 2 and 3). This is a particular issue for those who have to encounter these as part of a ‘longer-term’ caring commitment, and it is important to emphasise that dealing with ‘episodic’ demands for care and with ‘caring crises’ is not the same as merely experiencing a period of ‘adjustment’ to a new caring role.

Carers involved in this type of care – common among those supporting someone with mental health problems such as depression or dementia, for example – often report feeling ‘guilty’ about needing to take time off, or to alter their working hours, and sometimes say their managers and colleagues are unsympathetic, or simply find it hard to understand their situation. One carer explained that, although her employer was ‘very understanding’, and had allowed her to reduce her hours to two days a week, she found it difficult when an appointment for her disabled child clashed with her normal working hours:

*...not under pressure, that’s not really the right word; but I’ve always felt obliged to offer to change my shift, and work another day.*

Female, 35-49 age group, in part-time employment

Another interviewee worried about the way his colleagues were reacting. His wife suffers from chronic asthma and allergies, but when well is able to enjoy social outings with him. He finds it stressful wondering if they think he is exaggerating his caring responsibilities, or taking time off he does not really need:

*If you’ve got a disability, you can see it, but if it’s not ‘in your face’, then people – I think some of them think we’re pulling the wool, like.*

Male, 35-49 age group, in full-time employment

Some types of work responsibility pose particular problems for carers:

*When someone’s away, I’m expected to cover - and then that’s when the problems start. Because if you say you can’t, you know, you’re not being flexible, so it’s not easy.*

Female, 60-64 age group, in part-time employment

‘Longer-term’ carers in the CES study often felt it would have been helpful, in the early days when they were learning about their caring role and the condition of the person they supported, to have

been given better advice, by professionals, about 'what to expect' and how to respond. Later, as they became more confident about 'reading the signs', and of their own ability to anticipate and plan for different situations and risks – in some cases becoming the only real 'expert' on the caring situation in question – their need was not so much for professional advice as for a speedy and flexible response when they asked for additional help. Yet all too often, the assistance they needed had only emerged when a worsening or increasingly stressful situation had turned into a 'full-blown' crisis. Only 30% of 'longer-term' carers in the study reported that their own needs had been formally assessed.

Many carers reported coming to crisis point:

*I'd just got to breaking point, and I'd phoned [social services], and phoned them, and asked, 'Can you just take him out, can someone take him for a couple of hours?' – No. So I got to breaking point, and I phoned them, and I said to them, 'You have two hours', and I said, 'to come up with some sort of thing to help me', I said, 'I'm bringing him down to your office', and I said 'I'm leaving him there because I cannot cope with him any more with no help'. Then, funnily enough, within three days later, I had the pack in the post, saying you have this many hours.*

Female, 35-49 age group, in part-time employment

*Really it's a crisis. They wait for a crisis to happen. Nobody thinks of planning. If you're a carer for a child with learning difficulties, you fight from day one...and really it's the people who make a fuss, like me, who are the people who get results. And the people who can't make a fuss, they just go by the wayside. So I think when I'm doing something, I'm trying to help the other people.*

Female, 60-64, in part-time employment

Another parent/carer, looking after a child with autism, and desperate to hold on to her paid job, was very worried about how long it would be possible to continue combining work and care. In her view, her local authority was doing 'nothing to encourage carers to go to work', despite 'saying that they're entitled to':

*It's just constant battles all the time – and it wears you out mentally, and it wears you out physically.*

*You become ill, you're run down all the time. ... I will one day have to give up, I'll have no choice. To be 36, and not ever work again – what do you do? If you've always worked, to be that young – it's just – you know, it's not for me. If I give up, then autism has completely taken over my life. And that little bit of fight that you have left in you – it's, like, I will NOT allow that to happen.*

Female, 35-49 age group, in part-time employment

The CES survey data in fact showed that among the 'longer-term' carers, more than a quarter (27%) described their own health as 'not good' – compared with 18% of the 'new' carers in the study. This is consistent with other evidence showing a strong association between care, hours of caring, and poor health<sup>15</sup>, a topic discussed in more detail in Report 3 in the CES Series, *Diversity in Caring: towards equality for carers*.

Few carers experience any really long-term stability in the caring role they play, and many, though not all, have to come to terms with the fact that the health of the person they care for is gradually deteriorating. Those caring for someone with a progressive illness, including dementia, are usually well aware that the demands on them as a carer are likely to increase over time. Among our interviewees, a number talked about the way they were preparing themselves for this situation, how they expected it to affect their home and family life, and what it meant for their job or career. The pressures and anxieties uppermost in their minds could be financial, emotional or practical, and in some cases left them wondering just 'how long' they could go on juggling work and care. For some there was never an opportunity for time to themselves, and they were often unable to have even an evening out with a partner, or to get away for an occasional weekend. One carer commented:

*It's just too much hassle to sort of arrange everything. You can't do anything on the spur of the moment.*

Female, 35-49 age group, in part-time employment

The need for everything to be carefully planned, with complicated arrangements to make, was a source of strain, too. These factors took a lot of the fun out of life, and were very much regretted, as in this case where care was being given to an elderly parent:

*We cannot do anything spontaneously. We can't decide to go away for the weekend. Spontaneity's totally gone. And for me personally, and for my husband as well, a lot of the excitement of life has gone really. You have to have everything planned ahead. You can't decide, well, we'll do this now.*

Female, 60-64, in part-time employment

In this type of situation, being able to access respite care or some kind of break was really important. Here the care given was to a disabled child with learning difficulties:

*You know, should a crisis arise, or should you be totally at the end of your tether - that night off - it would be brilliant if (there was) that kind of service. You know, a school with a boarding system.*

Female, 50-59 age group, in part-time employment

The strain of caring day in, day out, gradually took its toll on many carers:

*At first it was okay, but now, as time goes on, [father's] more dependent, and the longer you do it, the more it seems to wear you down, so the more you feel that you need a break from it. It would allow me to be better mentally prepared to do the [training] course and look after Dad – (not just) trudging from one task to the next task, and not any break in between, and it just grinding you down.*

And it could not always be assumed, as this carer discovered, that the wider family would help out<sup>16</sup>:

*We asked my sister for help, and she (would), but her husband turned round and said no...All we wanted was a bit of help, whereby it would give us a weekend away. I find it difficult to get care over the weekend.*

Female, 35-49 age group, in full-time employment

## **Carers' expertise**

'Longer-term' carers, many of whom had long experience of accessing and using formal services to support them and the person they cared for, also spoke about the extent to which, over time, they felt they had become genuinely 'expert' in knowing how to be a carer effectively in their particular set of circumstances. Over the years, many had developed new skills such as advocacy, time management, contingency planning and expertise in a particular

illness or condition. Understandably, some in this group became upset if they felt their intimate knowledge of the person they cared for was being dismissed, ignored or rejected, and particularly in cases where a combination of unpaid care and formal services was involved, were keen to be treated as 'equal partners' in the delivery of the overall care package. Their frustrations could spill over if they felt they were not being treated with respect and consideration – although conversely, where combinations of care arrangements were well designed and working well, they could also be full of praise for those involved. (The way some local authorities are trying to involve carers, and to work with them as partners, recognising their expertise, are reported in CES Report 4, *Carers and Services in their local context*.)

Thinking back over her recent experiences, one carer, a mother with very heavy care responsibilities for her profoundly disabled 19-year-old son, explained how she had learned to 'push' for the support she needed:

*When I was trying to tell them what I needed, they were trying to give me something else. They weren't saying 'Well, she's the carer; she's got him 24/7'. I took what I could get, and then worked on it from there. When I actually got it, I pushed for what I really wanted. I had to do it bit by bit. After some pushing and pushing, it got easier – because I kept on pushing. You see, to them, (after 15 years) I was still coping.*

Female, 35-49 age group, full-time carer

Others emphasised that they only sought support when genuinely desperate for help. This carer, supporting an elderly parent who was living with her, often found:

*I don't know, I just sort of plod on, and I don't really ask for anything. I always have to be the one to instigate meetings and things, rather than them getting in contact with me. If I don't get in contact with them, then - you know, (they think) everything's going quietly, so just leave it, get on with it, sort of thing. I'm usually getting close to the end of my tether before I ring them.*

Female, 35-49 age group, in part-time employment

Some were simply uncomfortable asking for help,

and felt they were left to cope very much alone as a result, as in this case of a woman combining her part-time job with the care of her disabled partner:

*If you want anything doing, you've got to shout very loud, and I've never been one of them.*

Female, 50-59 age group, in part-time employment

The full impact of longer-term caring on carers' health, financial situation and ability to work is explored in detail in two of our other reports in the CES Series, *Managing Caring and Employment*, and *Diversity in Caring: towards equality for carers*. In our group of 'longer-term' carers, 27% reported that their health was 'not good', 34% said that they were 'struggling to make ends meet', and over 59% identified at least one service not currently received which they would have liked to have.

So far we have considered the situations of 'new' carers and of those who have been caring in the longer term. We turn now to the 'end' of caring, a transition in the experience of caring to which some had given much thought. Caring can end abruptly, for example if the cared for person dies suddenly, but caring at home can also end in many other ways, and does not always mean the end of all the carer's support. These issues are discussed in the next, short, section of this report, 'as caring ends'.

## 3. As caring ends

Often, the end of caring at home comes when the person cared for dies or becomes too ill or disabled to be supported in the home setting. In other cases, care has to end, or the time and effort committed to it has to be reduced, when the carer finds there is unsustainable tension between work and care, or too much personal strain, making the carer ill, or perhaps creating difficulties between family members. Caring can also end in more positive circumstances, when a cared person recovers or becomes able to live independently.

When such developments occur, the care provided sometimes does not really 'end' but changes, so that the tasks performed and the time spent become different, and a new balance is struck between unpaid and paid care. This may be a desirable outcome welcomed by all concerned – or it may be the unhappy conclusion to years of stress, frustration and exhaustion.

### **Carers' experiences and perceptions**

In this final section of the report we briefly explore what the CES study can tell us about carers' experiences and perceptions at the end of caring. It draws on carers' comments about coming to terms with transferring the person they have cared for to residential care or supported living, or preparing for the time when this will happen. We have limited material in our study, of those currently involved in caring, about adjusting to the end of caring after

bereavement. Our main focus here is on how the services available to carers going through these changes can help or hinder them, and on their views about how they could be improved.

Because caring can end in so many different ways, it is not appropriate to generalise about the detailed support and services carers need at this time, or about the impact the end of care will have on their working lives. Varying according to circumstances, carers experience and see the ending of care in a range of different ways. Here we distinguish between those for whom changes in the caring role arise in three types of situation: when the cared for person moves into independent/supported living; when care at home ends during or at the end of a terminal illness or when the cared for person dies; and when a cared for person moves into residential care, often because their needs can no longer be safely met by the carer living with them at home.

Although our qualitative sample was quite large (134 carers), only a very small number of those we interviewed had reached the 'end of care at home' stage, so we do not have personal testimony relating to all of these situations. Nor can we explore the psychological dimensions of these different 'end of caring at home' scenarios in a study of the kind undertaken here. Some of carers' changing needs in relation to supporting services were highlighted in our data, however, and it is these we emphasise here.



## Moving to independent living

A move into independent/supported living is often interpreted favourably by the carer, and seen as a positive development. Frequently this outcome is welcomed by both the person cared for (often a disabled child reaching adulthood) and the carer, and represents a shift to independent living. Carers in this situation are often keen to make plans in advance to secure the best outcome:

*That's why we're getting specialist services involved, because when she becomes 16, I don't want the authorities making decisions for her, as previously happened with the local authority. So now is the time to start planning, which we're doing, and we want to be part of that future for her.*

Female, 35-49 age group, in part-time employment

Such developments usually involve a change in, rather than the end of, the carer's role (see Box 1.3.) Many carers wish to resume paid work or to take up training opportunities at this stage, with a view to returning to work, and many need

support in taking this step, especially if they have been full-time carers for many years, or if their caring role is continuing, though changed. Visits, emotional support, advice and companionship are all likely to continue to play an important part in the carer's changed situation. It may also be a time when emotional support is needed, and when the consideration and understanding of employers and work colleagues is particularly valued. Some of the ways local agencies and projects have been developing services to meet these needs are discussed in CES Reports 4 and 5.

## Into residential care

For some carers, however, residential care becomes the only viable option when the care needs of the person they support increase. (Older carers, who were not the focus of the CES study, also frequently find that their own failing health and strength makes continuing to care at home impossible.) A move to residential care does not necessarily mean that caring comes to an end, of course, as we have

### Box 1.3 Caring when the person cared for moves away from home

Alice, in her 50s, had been the full-time carer of her 17 year old daughter with MS for some years. Recently her daughter had moved to a residential college several hundred miles away from home, so Alice's day to day caring responsibilities now continued out of term-time only. She had not felt well supported as she made arrangements for this change, noting particularly the lack of support from her social worker in selecting a suitable institution:

*She didn't help at all towards the college. It was all my doing. I had to go around looking at different colleges, looked on the internet first, and then went to visit, and fought for her to go there. You have to fight. They go for the cheapest option - the local council, education, or whatever. They always go for the cheapest option, and you've got to prove - you've got to do your homework before you ask for anything. You've got to prove why it's a better option.*

With other caring responsibilities towards her mother, and in poor health herself, suffering from ME, she continues to receive support with her daughter's care in holiday periods, but she feels the home care service is limited:

*When she is home I get 6 hours a day, but that goes down to 2 hours over Christmas and New Year. That's because they won't give more than personal care, even though they say I need the care during normal days. Between Christmas and New Year you're only allowed 2 hours in the day, one hour in the morning, one hour in the evening.*

She is looking forward to having more time to herself now that her daughter is in college, and is considering re-entering employment – but as she has been out of work for 16 years, and has health problems herself, she knows this will be difficult.

already seen above (on page 9). Carers in this situation still face time pressures and significant costs, often alongside emotional strain and new worries and anxieties about the cared for person, even though the shift to residential care is for that person's own welfare. As one carer put it, in relation to his elderly mother:

*I'm sure I couldn't manage at home. I mean, the will is there, but I don't think I could provide the level of safety that she needs.*

Male, 50-59 age group, in full-time employment

### **Preparing for the future**

Some carers of disabled children spoke at length about their concerns for their child's welfare after their own death or if they ever became incapable of providing the care they needed. Again, we know that these concerns often become even more prominent for older parent carers, who were not included in this study<sup>17</sup>. Some of those we spoke to felt disappointed by official reactions to the plans they wished to make in advance:

*If anything happens to myself and my husband, [our daughter] would be slotted into anywhere where there's a vacancy in a community, and that could be people with mental health problems, it could, I don't know, be schizophrenics – all sorts of people, you know. There could be older people, and we didn't want this. So we dared to ask whether we could have a house, and everyone threw up their hands in horror.*

Female, 60-64 age group, in part time employment

As we have seen in this report, carers go through many stages and transitions, with the 'end of caring' one part of an inevitably dynamic process. Becoming a carer, developing experience and expertise in a caring role, and accepting that caring comes to an end are all important elements in carers' lives. Considering them, as we have done here, helps us to understand that caring is a normal and important part of life, as many of the carers we interviewed pointed out.

# Conclusions

Giving and receiving care is an essential part of each person's humanity and crucial for the wellbeing of the overall social fabric. Yet all too often, as we have seen, carers feel unsupported, with their needs unrecognised and their contribution easily taken for granted. In this report, we have looked at different stages and transitions in the experiences of carers of working age. We have focused particular attention on those who are relatively 'new' to caring, and on those who have become 'longer-term' carers. We have also briefly considered some of the ways in which caring at home comes to an end, and some of the needs which carers have at this time.

From our analysis (which should be read alongside the other reports in the CES Series) we conclude that there is a need for significant change in the way carers of working age are supported. Most carers reported that, when they were new to caring, the initial information they were given or were able to find was inadequate. Details of their needs at this stage were emphasised in the report (see page 11). Carers also found that assessment processes were frequently cumbersome and slow, and that agencies often seemed poorly equipped to help them as their needs developed and changed. A large number of carers were supporting someone whose needs had not been assessed, and only a minority had themselves had a carer's assessment.

This situation means that carers' right to combine work and care is not yet well supported; and for

those who drop out of work to care (discussed in more detail elsewhere in the other CES reports) finding the support they need to return to work is often even more difficult. Those who were combining work and care at the time of the study reported varied experiences with their employers, managers and colleagues. In the best cases, employers were very considerate and understanding and giving carers the flexibility they needed, but a lack of support at work was a common experience too. Carers emphasised that even where services were available to support them, there were a range of issues – such as hours of opening, distance from their home, and time and cost involved in making necessary transport arrangements – which meant they did not have the flexibility and responsiveness they needed. A common concern was that services were hard to find out about, and that when they could be located they were not suitable in their specific situation, or flexible enough to meet their particular needs.

As found in previous research (Stiell et al 2006)<sup>18</sup> carers often feel it is important to maintain their other identities when they become carers, and worry about the way caring is impacting on their other family relationships, on their social and leisure activities (which has implications for their health and wellbeing), and on their ability to hold on to their job or career, and to the income, social contacts and mental stimulation which they get from paid work. There is scant evidence in the CES study that

carers, even those who are the most committed to caring, want to ‘disappear’ into a ‘hidden world of caring’. Rather, many feel that work is an important psychological ‘lifeline’ for them, besides being crucial for their household finances and a way of getting a break from the physical demands of caring. Most importantly, data in this study confirms that for many carers, paid employment is part of their normal life – and something from which most, including both the men and the women in our study, did not want to be excluded.

The carers who were interviewed for this study often took pride in the skills they had acquired as they had moved through their experience of caring, and wanted these to be recognised. New policy developments (described in CES Report 4) increasingly make reference to ‘expert’ carers – but it is not yet clear what the implications of recognising carer expertise will be for paid care workers and other professionals providing support for carers or assisting them in accessing services. Carers noted that at the outset of caring, they needed help in quickly developing the skills they need, and in finding information about their specific caring situation; but they also stressed that they wished to be treated with respect in relation to the caring contribution they made, and that as caring progressed, they gained detailed knowledge about the needs of the person they supported which made it essential they be treated as equal partners in the provision of care.

The significance of the findings presented in this report for policymakers, service providers and commissioners, employers, managers and others, is discussed in detail in Report 6 in the CES Series, *Carers, Employment and Services: time for a new social contract?* There, we highlight the urgent need for a major shift in the way caring is perceived throughout society. The shift needed involves radical new thinking about the value of care and caring in society, and will mean major changes in the way carers are supported, recognised and consulted. In the future, it is essential that the contribution carers make, not only to the life of their own families, but also to the wellbeing of the wider community, is appropriately recognised. New commitments will need to be made by all agencies to ensure that carers are integrated into society,

rather than isolated or excluded from it, and that their caring can be undertaken as part of normal life, without compromising their health, finances, jobs or careers. These issues are fully considered in CES Report 6, which also contains a full set of policy recommendations based on the evidence produced in the Carers, Employment and Services study and on the learning achieved through the Action for Carers and Employment Partnership.

## Appendix 1 Research Methods

The Carers, Employment and Services (CES) study (2006-7) was directed by Prof. Sue Yeandle and based at the University of Leeds. Here we outline the methods used in collecting data for this report (CES Report No. 1). Fully described in CES Report No. 6, they included:

- A national survey of carers (1,909 responses), targeting carers of working age.
- In-depth interviews with carers in ten selected localities in England, Wales and Scotland.
- Interviews with 'key informants' in the selected localities.
- Documentary analysis of publicly available sources and other relevant materials.
- Detailed statistical analysis of the 2001 Census.

### The CES Survey

The survey questionnaire was specially designed for the project and tested in a range of pilots. It was distributed to respondents in two formats, a postal (paper) and an electronic version, and collected information about carers' personal/demographic characteristics, their caring responsibilities and the services they were accessing, their employment and financial situation, and their perceptions and attitudes. In the ten selected localities (which targeted both urban and rural carers, White and Ethnic Minority carers; and carers in affluent and deprived areas), the questionnaire was distributed via major employers, carers' organisations and other voluntary groups, social care and health services, and at relevant events such as conferences on carers' issues. The questionnaire was also made available on the websites of a number of relevant national organisations, and some employers distributed it electronically outside the target localities. Our aim was to access carers of working age, with a special focus on those who were in employment, wanting to work alongside their caring role, or had given up work to care. All questionnaire responses were entered in an electronic database and subjected to detailed analysis.

### In-depth interviews in the ten localities

Researchers selected 134 interviewees on the basis of information supplied in the questionnaires, attempting to achieve a balance in each area among various caring situations. Contact was made with carers who had given consent to further involvement in the study, and an appointment booked by telephone; interviews took place either in the interviewee's home or at their workplace. For each interview, anonymity was guaranteed and the purpose of the study explained; interviews were tape-recorded with consent. The interview schedule was structured to capture the carer's experience of social and other services in relation to their employment situation, including the strengths and weaknesses of the existing system, their employer's attitude to working carers, and perceptions of ideal services; there was also flexibility for the interviewee to focus on issues specific to their own situation. The interview material was transcribed by the interviewer, using a template which focused on key issues relating to the project. Field-notes were included as well as verbatim quotations to capture interviewees' direct experiences of caring, and the completed templates were then subjected to a thematic analysis.

## Notes

- <sup>1</sup> Many parent/carers of sick or disabled children nevertheless also have one or more dependent children who are unaffected by their own illness or disability.
- <sup>2</sup> A full description of the study methodology is available in Report 6. Appendix 1 summarises the main elements of the study relevant to the analysis presented here.
- <sup>3</sup> The 10 localities selected were all areas where a single local authority had responsibility for the provision of social care services, and included: Hertfordshire; West Sussex; Southwark, Leeds, Sheffield, Sandwell, Falkirk, East Ayrshire, Anglesey and Swansea. All interviewees lived in these areas, although some survey respondents lived elsewhere in Great Britain.
- <sup>4</sup> The question used in the 2001 Census was: *'Do you look after or give any help or support to family members, friends or neighbours or others because of: long-term physical or mental ill-health or disability or problems related to old age?'*
- <sup>5</sup> The CES survey targeted carers of working age. A small number of respondents under 16 have been excluded from the analysis presented here. 244 respondents (13%) were aged 65 or older, among whom 16 were gainfully employed. Except where indicated, this small group of older carers has been included in our analysis.
- <sup>6</sup> Figures for men and women do not add to 214 due to a few respondents who did not answer the question about their sex.
- <sup>7</sup> Throughout the CES Series of reports, we describe the caring responsibilities of those who care for 1-19 hours per week as 'moderate'; of those who care for 20-49 hours per week as 'significant'; and of those who care for 50 or more hours per week as 'heavy'.
- <sup>8</sup> Some of the material from our interviews quoted here is from carers who, when interviewed, had been caring for more than two years, but in all cases it relates to their early experience of 'becoming a carer', in the first two years of care responsibility.
- <sup>9</sup> Finch, J and Mason, J (1993) *Negotiating Family Responsibilities* London: Routledge.
- <sup>10</sup> Yeandle, S, Bennett, C, Buckner, L, Shipton, L and Suokas, A (2006) *Who Cares Wins: the social and business benefits of supporting working carers* London: Carers UK
- <sup>11</sup> Agreeing with the statement, *'My employer is carer-friendly and I feel supported at work when my caring responsibilities affect my job'*.
- <sup>12</sup> Buckner, L and Yeandle, S (2006) *Who Cares Wins: Statistical Analysis* London: Carers UK. Also noted in Arksey, H, Kemp, P, Glendinning, C, Kotchetkova, I and Tozer, R (2005) *Carers' aspirations and decisions around work and retirement* Leeds: Department for Work and Pensions Research Report No. 290.
- <sup>13</sup> The 2001 Census did not collect information about carers' finances, the person cared for, co-residence with the carer, use of services or any attitudinal data.
- <sup>14</sup> This designation is treated as 'economically inactive' in all official labour force statistics.
- <sup>15</sup> Maher, J and Green, H (2002) *Carers 2000* London: The Stationery Office; Buckner, L and Yeandle, S (2006) *op. cit.*
- <sup>16</sup> In CES Report 2, *Managing Caring and Employment*, we show that about two thirds of working carers rely on support from family and friends to enable them to work.
- <sup>17</sup> Arksey, H, Beresford, B, Glendinning, C, Greco, V and Sloper, P (2007) *Outcomes for parents with disabled children and carers of disabled or older adults: Similarities, differences and the implications for assessment practice*, Social Policy Research Unit, University of York, York.
- <sup>18</sup> Stiell, B Shipton, L and Yeandle, S (2006) *Caring for Sick or Disabled Children: parents' experiences of combining work and care* London: Carers UK.



## Finding out more

Carers UK improves carers' lives through information provision, research and campaigning. This research was commissioned by Carers UK on behalf of the ACE National partnership, and part-funded under the European Social Fund's EQUAL Community Initiative Programme. To find out more about Carers UK, contact:

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